Flourishing at the margins: an exploration of deaf and hard-of-hearing women's stories of their intimate lives in Ireland

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Declaration

I, the Candidate, certify that this thesis is all my own work and that I have not obtained a degree in this University or elsewhere on the basis of any of this work.

Signature: ___________________________________

Date: 26.07.19

Chapter 1: Introduction

Chapter 2: Context setting and problematising through the WPR approach

Chapter 3: Literature review and conceptual framework

Part A: Literature Review

Part B: Conceptual Framework

Part C: Theorising Intimate Citizenship

Chapter 4: Methodology

Chapter 5: Intimate lives of young deaf people

Chapter six: Negotiating intimacies

Chapter 7: Intimate troubles, public issues; access to sexual and reproductive healthcare and information

Chapter 8: The flourishing deaf intimate citizen: DEAF-GAIN and social capital

9: Bringing it all together; the story of flourishing

Appendices

List of figures

List of tables

ACRONYMS

ASL – American Sign Language

BSL – British Sign Language

CEDAW - Convention on the Elimination of all Forms of Discrimination Against Women

CI – Cochlear implant

CIDP – Catholic Institute for Deaf People

D/dhh – Deaf/deaf and hard-of-hearing

DAPPSS – Department of Applied Social Studies

DVI – Deaf Village Ireland

FDS – Feminist Disability Studies

HI – Healthy Ireland

HoH – Hard of Hearing

HSE – Health Service Executive

IDRN – Irish Deaf Research Network

IDYA – Irish Deaf Youth Association

ISL – Irish Sign Language

MU – Maynooth University

NDWI – National Deaf Women of Ireland

RSE – Relationships and Sexuality Education

SPHE - Social and Personal Health Education

SHR – Sexual health and reproductive

STI – Sexually Transmitted Infection

UCC – Unrecognised Cultural Currency

CRPD – Convention on the Rights of Persons with Disabilities

DEDICATION

This thesis is dedicated to Frank Meehan, my dad (1947 – 2012),

and Gerry Byrne, my father-in-law (1955 – 2018).

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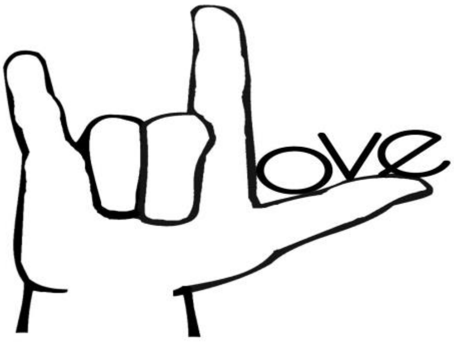

ABSTRACT

This research is an exploratory, qualitative study that advances knowledge on the intimate lives of deaf women in Ireland.

It asks, how do deaf women experience and understand their intimate lives? Additionally, how are deaf women's intimate lives contoured, what are the effects of this and how can we problematise this? I ask how we can reimagine new worlds where all deaf women flourish in their intimate lives and intimate citizenship - what are the 'radical possibilities'?

Through a critical analysis I argue that deaf women are positioned through an audist/ableist lens as 'vulnerable' at discursive and policy level. I contend this is grounded in hegemonic notions of deaf women's bodies as deviating from the 'norm'. I explore the opportunities for troubling these understandings in discourse and policy through deaf women's own embodied knowledge and subjective experiences.

As a deaf woman and researcher, I valued starting with the stories of other deaf women which were collected through twenty-nine one-to-one, in-depth interviews. I applied narrative thematic analysis to the data to centre deaf women's insights.

The findings from my research provide new knowledge and thinking on how deaf women learn and do sexuality, negotiate their intimate lives, as well as deaf intercorporeal encounters, and through this considers the role of 'deaf social capital' and 'DEAF-GAIN' (Bauman and Murray, 2014) in these spaces of resistance. This serves to highlight the collective and solidaristic aspects of flourishing. My research identifies new pathways towards flourishing for deaf women and how we might understand this in relation to intimate citizenship. Taken together the narratives tell a story of flourishing because of, not despite, being deaf.

In this way my research reimagines 'ways of knowing' and promoting deaf women's intimate lives to inform theory, policy and practice responses through deaf women's own knowledge and experiences.

Chapter 1: Introduction

1. Introduction

> "…The margin is more than a site of deprivation, it is also the site of radical possibility, a space of resistance…a site one stays in, clings to even, because it nourishes one's capacity to resist. It offers to one the possibility of radical perspective from which to see and create, to imagine alternatives, new worlds"
>
> (bell hooks, 1989: 20).

This study explores the lived intimate experiences of twenty-nine deaf and hard-of-hearing women in Ireland[1]. As a traditionally 'marginalised' group in Ireland, we know relatively little about the lived lives of deaf women. Occupying "a specific site of exclusion" (Goodley, 2017:45), the intimate lives of deaf women remain at the periphery. As a deaf woman, I was motivated by the lack of knowledge on deaf women's lives and I was inspired by the work of bell hooks (1989) to look to perspectives 'from the margins'. What has emerged is a story of how the margin can become a space where deaf women resist disabling and victimising discourses and from where their stories of flourishing intimate lives present radical new perspectives.

My research asks the questions;

- How do deaf women experience and understand their intimate lives?
- How are deaf women's intimate lives contoured and what are the effects of this?

I explore these questions through the narratives of deaf women as well as by examining and 'problematising' (Bacchi, 2009; Foucault, 1980) key factors contouring deaf women's intimate lives. This research critically advances knowledge on deaf women's intimate lives, as well as women's lives more generally, in Ireland. It provides new knowledge and thinking on how deaf women learn and do sexuality and negotiate their

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[1] Following language choices of this research I largely use the encompassing term 'deaf women' hereafter. Language politics in Deaf Studies regarding this terminology is explained further on in this chapter.

intimate lives, as well as deaf intercorporeal encounters, and through this considers the role of ‘deaf social capital’ and ‘DEAF-GAIN’ (Bauman and Murray, 2014) in these spaces of resistance. In this way my research reimagines ‘ways of knowing’ deaf women’s intimate lives to inform theory, policy and practice through deaf women’s own embodied knowledge and subjective experiences. Taken together, the narratives of deaf women’s intimate lives in this study tell a story of flourishing because of, not despite being deaf. From here I ask how can we create conditions for positive sustainable change through practice and policy where all deaf women have opportunities to flourish in their intimate lives?

1.2 Reimagining ways of framing deaf women’s intimate lives; the flourishing framework

I begin this task through a deliberate use of positive language and frameworks in this research (i.e.) ‘flourishing’. Deaf scholars have recently begun to shift their language and lens towards the value and positive attributes of being deaf [see ‘deaf value’ (Friedner, 2015) and ‘deaf gain’ (Bauman and Murray, 2009)]. I contend that this is an important ‘turn’. As Kennedy (1999: 238) notes, “language can be used to broaden horizons, to deconstruct structures, to provide and introduce alternatives…”. I use this deliberate approach to challenge ways of perceiving deaf women and broaden horizons to seek out alternatives.

Flourishing emerged as a core concept of this research. Through my initial, informal conversations with deaf women from the outset of my research, through to the narratives of my research participants, the notion of positive intimate lives was reiterated again and again. Confronting the manner in which knowledge on deafness and ‘deficit’ (Joharchi and Clark, 2014) is often uncritically reproduced when we begin by asking ‘what is the problem?’, I drew instead on ideas of flourishing as a positive framework to examine ‘what is working’ and ‘what is going well’, to see how we can reap more of this (Cherkowski and Walker, 2013). Flourishing is also conceived of as the goal of achieving a high-level of intimate well-being, thriving and fulfilment at all levels of intimate life. I argue that deaf women harness a positive sense of their deaf identity and relational autonomy in the form of embodied social capital, to resist and navigate contours of inequality and to generate meaningful access to intimate citizenship. These stories reveal flourishing as an inter-relational experience. It requires connection, drawing on relationships at the margins and across collective spaces. Thus, my research illuminates the solidaristic dimension to stories of flourishing.

1.3 Research overview

Drawing on a social constructionist perspective (Berger and Luckmann, 1991) this research uses an innovative, inclusive methodology to develop a deeper, critical understanding of deaf women's intimate lives. From a theoretical perspective, this study is interested in the intersection between deafness, gender and sexuality (Crenshaw, 1991, 1997).

Using a qualitative approach that blends deaf feminist standpoint epistemology with aspects of narrative inquiry, such as privileging story-telling and relational engagement (Kim, 2016) I explore intimate stories with twenty-nine deaf women through the intersectional lens of deafness, gender and sexuality (Crenshaw, 1991, 1997). In applying this approach, I aim to contribute to "the formation of counter-hegemonic cultural practice" by "identifying spaces" where reimagining and creating alternative knowledge can begin (hooks, 1989: 20). Participants' powerful, rich narratives are centred, thus foregrounding the lived voices and stories of deaf women. Through this, dominant ways of situating and problematising the lives of deaf women are dismantled and displaced (Bacchi, 2009).

The specific methods used are in-depth interviews with twenty-nine deaf women and semi-structured interviews with nine key informants as a scoping exercise. Participants were recruited through purposive sampling and snowball and online recruitment strategies were used to assist this. Interviews were held through either Irish Sign Language (ISL) or English and then transcribed. A narrative thematic analysis approach is used to analyse interviews. During this process stories were restoried throughout the analysis chapters following a chronological sequence. This is discussed in the methodology chapter.

As a community worker and a deaf woman, I prioritise starting with deaf women's stories of everyday life. Traditionally, deaf women's narratives and lenses have been neglected nationally and internationally. Coogan and O' Leary note, "the lack of extensive insights into the societal and cultural lives of Irish Deaf women" (2018: 2). As Ladd (2003) points out, there are many studies on sign language use, but far fewer regarding the cultural lives of deaf people. Thus, we have a limited understanding of deaf lives. Additionally, deaf communities have been subjected to traditional, oppressive ways of 'doing research' (Harris et al., 2009).

The narratives of deaf women are located within a critical review of the evidence base considering some of the key factors contouring deaf women's intimate lives. I developed a critical analysis of policy and socio-cultural meanings and contexts contouring deaf women's intimate lives by utilising Bacchi's (2009) 'What's the Problem Represented to be?' (WPR) approach. The WPR approach facilitates critical interrogation of policies to uncover what Bacchi (2009) terms 'implicit or explicit representations 'of 'problem representations'. In using this approach I uncover how conceptualisations of and assumptions of 'vulnerability' and the normative body are constructed and embedded in sexuality-related policy and discourses. I argue that deaf women are positioned as vulnerable and 'deviating' from the normative body. I contend that in situating deaf women in such ways the present policy-making process contours deaf women's lives in particular ways. This is further outlined in chapter two. My research calls for a new way of problematising ideas around deaf women, and women and sexuality more broadly, in Irish social policies.

By exploring and embracing deaf ways of knowing (West, 2013), and doing research that is not objective, but rather is inherently political (Baker et al., 2004), I challenge normative ways of perceiving and locating deaf women at the level of both policy and theory.

Participants highlight audist/ableist[2] inequalities that contour and shape their lived sexuality-related experiences. Material inequalities, along with inequalities of

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[2] I go into further detail in Chapter 3 on the concepts of audism/ableism. Audism is defined as "appear[ing] in the form of people who continually judge deaf people's intelligence and success on the basis of their ability in the language of the hearing culture. It appears when the assumption is made that the deaf person's happiness depends on acquiring fluency in the language of the hearing culture" (Humphries, cited in Bauman, 2004: 240). Ableism is distinguished (Campbell, 2009: 5) as; "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal

recognition, are highlighted (Baker et al., 2004). Simultaneously, participants' narratives contrast with dominant audist/ableist social constructions and reflect a reality of deaf women who are flourishing and empowered in their capacities and agency, living rich, positive intimate lives. Through this, a 'vulnerability' discourse (Brown, 2012) is rejected and previously obscured experiences are illuminated. I address these points throughout the thesis. The chart below illustrates the research steps and knowledge contributions made throughout the thesis;

Figure 1: Roadmap for the research

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standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is then cast as a diminished state of being human".

1.4 Research significance and rationale

Drawing on hooks' (1989: 20) call to reimagine, 'from the margins, from spaces of resistance', I seek to highlight deaf women's narratives of flourishing and through "reimagining", contribute new ways of knowing deaf women's lived experiences (Baker et al., 2004). This research is significant, first, in terms of its knowledge contribution. It is the first piece of research to explore this specific topic in Ireland with deaf women. The findings that have emerged are novel because of how this research was operationalised (through a blended approach that centered a deaf feminist standpoint, a deaf framework and prioritising stories of deaf women), the ontological/epistemological stance it is grounded in (deaf feminist standpoint) and how I situated myself as the researcher (a young deaf woman). Thus, my research rationale is multi-faceted by seeking to; identify intellectual and policy gaps, address a key area of social justice by challenging the misrecognition (Fraser, 2004) of deaf women and to contribute to transformative social change through applied research with deaf women.

Deaf women should experience good access to sexuality-related services and information. However, there is evidence to suggest that this is not the case in the Irish context (Coogan and O' Leary, 2018; Steinberg, 2006; Begley et al., 2009; Leeson et al., 2014; CIB, 2017). Additionally, there is limited knowledge of how socio-cultural-historical processes interact to shape and contour deaf women's intimate lives in Ireland (Coogan and O' Leary, 2018). This research seeks to understand how these experiences are shaped and to examine the context within which these experiences take place. I do so by focusing upon the subjective experiences, voices and stories of deaf women in order to reimagine new ways forward and "alternatives, new worlds" (hooks, 1989: 20).

I also argue that this knowledge gap has influenced Irish sexuality-related policy responses in the sense that deaf women are overlooked and rarely mentioned in policy[3]. Where deaf women are mentioned they are constructed as 'vulnerable'. Available sexuality-related information relating to deaf women is largely derived from the US and generally focuses on "myths, misunderstandings, and problems related to sexual health and behaviour" (Jorharchi and Clark, 2014: 1536). In the absence of robust Irish based

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[3] There is no specific policy in the Republic of Ireland addressing the sexuality-related needs of deaf women.

research, explicit theorising at the intersection of deafness, gender and sexuality in Ireland remains absent. This research addresses this gap by making critical connections between gender, disability and ideologies of normativity.

1.5 Research background; locating deaf women's lives in Ireland

Deaf groups put the number of deaf ISL users at 5,000 (Conama, 2018b) or 6,500 (Leeson and Saeed, 2012)[4]. Profile 9 in Census 2016[5] found that 103, 676 people have a "hearing related disability" and of this cohort 49, 330 are women. We have only a broad understanding of deaf women, by which I mean there is no disaggregated data available regarding how many deaf women use ISL for example. As Kennedy (1999: 238) notes, social policy commonly uses language "which aggregates people". I agree with Baker et al., (2004) who contend that groups must be disaggregated to ensure we do not homogenise groups when addressing group inequalities.

Along with this gap in census data, we know little about deaf women's lives in Ireland in general. Some research explores the gendering of ISL (LeMaster and O'Dywer, 1991; LeMaster 2003) and the lives of deaf girls attending St Mary's School for Deaf Girls from 1846 – 2016 (O' Leary and Jones eds., 2017; O' Connell, 2017). There is also some exploring the inequalities deaf women experience in maternity care (Begley et al., 2009; Steinberg, 2006; Doyle et al., 1986). Additionally, Coogan and O' Leary (2018) explored a number of themes relevant to 301 Irish deaf women such as education, jobs, technology and access to maternity services.

These pieces serve to indicate mixed experiences and that engaging with the maternity care system is difficult and unequal for deaf women. Communication is frequently challenging. "As a result, women are more inclined to avoid health services and not attend for appointments, rather than deal with the embarrassment and frustration that can develop from such challenges" (Begley et al., 2009: 78). Other barriers named are named as lack of access to interpreters[6]; being inappropriately encouraged to use family members when communicating with healthcare professionals and over reliance on

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[4] According to Census 2011, there were 1,077 deaf ISL users in Ireland (CSO, 2012)

[5] Census 2016 – Profile 9: Health, Disability and Carers in Ireland

[6] In this research 'interpreters' always refers to Irish Sign Language (ISL) interpreters

written information which may be difficult for women for whom ISL is their first language. Deaf women may have difficulty with the English vocabulary being used as their first language may be ISL and their English literacy may be low (Begley et al., 2009). This literature raises a number of pertinent points for sexuality-related services and information and has informed the research motivation and rationale.

Regarding limited sexuality-disability research, Shakespeare (2000) and others (Goodley, 2017) suggest it was not prioritised with the same urgency as public issues, such as employment or housing. They explain it was not clear how policy could play a transformative role in respect of disabled people's private sexual lives. Secondly, Shakespeare thinks it was an area of "distress and exclusion and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded" (2000: 160).

The reason Deaf Studies has neglected this topic is unclear. Research seems stagnant – "it appears as if the sources and completeness of deaf related sexuality information have not changed over the decades" (Schirmer, 2001; 162 cited in Job, 2004: 264). Mauldin and Fannon (2017) find that deafness is frequently conceived of as a 'deficit' and 'problem'. From this, it could be inferred that, considering that deafness was imagined as a differential embodiment, the area of deaf people and sexuality was overlooked as it did not fit with normative expectations of communication and bodies. Finally, because of educational and language obstacles we are only now starting to see an increase in deaf academics (Kusters et al., 2017). Thus, more research relevant to deaf people's lives has been broached.

Broader disability-related research suggests it is common for many disabled people to have less experience with romantic partners and sexual activity (Shakespeare et al., 1996). This research has generally only included participants with physical or visual disabilities (Retnik, 2017). This can often be related to a researcher's failure to make the study inclusive by meeting deaf people's language requirements. Retznik et al., (2017: 1) explored the relationship experiences of young adults with visual, hearing or physical disability. Their findings were that deaf participants "had the most relationships and experienced their first sexual intercourse earliest" and did not see being deaf as impacting on their romantic relationships in contrast to other participants with a different disability. The authors (2017) suggest that this is possibly because being deaf is seen as less stigmatising than a physical or visual disability. They also suggest it could be connected to differences in mobility access and independence. Young deaf people might have more access to both than a person with a visual or physical disability. This means they have more opportunity to initiate romantic relationships. Young deaf people may also socialise with other young deaf people frequently because of their educational links in a deaf school. Thus, they may have more access to a bigger social network in which to find romantic relationships.

How deafness and sexuality-related experiences and outcomes are shaped are influenced by multiple forces – ideological, cultural, linguistic, social and environmental. These forces hold material effects and need to be examined for their implications.

1.6 Advancing ways of knowing deaf women's intimate lives

Within academic research, deaf women are often problematised in terms of individualised ‘deficits', for example, lack of knowledge about sexual health (Wakeland et al., 2017; Heiman et al., 2015). As Block et al., (2012: 164) explain, this is not unusual as disability and sexuality focused research tends to be dominated by four key approaches, that:

1) Perceives disabled people's sexuality as an individual problem to be solved;
2) Explicitly or implicitly is concerned with treatment objectives;
3) Focuses on how individuals stack up on a scale of sexual functioning; and
4) Views disabled sex in terms of physiological, psychological, social and relational norms derived from research with nondisabled people.

This is the dominant discourse I speak of challenging through locating insights of deaf women at the margins and presenting a new way of perceiving and reimagining deafness and sexuality. As referred to at the beginning of this chapter, occupying “a specific site of exclusion” (Goodley, 2017:45), disabled women's subjective interpretations of their intimate lives remain on the periphery rather than at the centre of current analyses on gender and sexuality. Disabled feminists (Morris, 1996; Finger,

1992) have resisted this exclusion through highlighting lack of attention from and invisibility in feminist and disability movements. They argue that sexuality has been dominated by normative, ableist discourses. As a result, disabled people have been "positioned largely as asexual [and] assumed to lack the capabilities and capacities to embody sexuality, sensuality, expression and desire" (Liddiard, 2018: 1).

For deaf women this absence is compounded at the intersection of deafness, gender and sexuality (Jorharci and Clark, 2014). This insight chimes with Baker et als'., (2004) equality framework illuminating how inequality is experienced in private spheres of life also. Economic and political systems are not the only ways in which inequality is perpetuated – it is also perpetuated through cultural and affective systems. The cultural system encompasses the "production and transmission" (2004: 59) of practices and is a key mechanism by which social structures built around differences of appearance and disabilism are reinforced. The affective system is "concerned with providing and sustaining relationships of love, care and solidarity" (60). The relationship between the two systems can be seen where disabled people's bodies are positioned as less valued in sexual and reproductive terms, which can shape access to loving and caring relationships. All systems are important and inter-related, however, as the authors note, different social systems can result in different inequalities for different groups. In this research the cultural and affective system are taken as most relevant to inequalities encountered in intimate lives of deaf women.

Research at this intersection also engenders critique for a focus upon what is 'problematic', how deaf or disabled people are 'vulnerable' and seeking ways of 'solving barriers' (Block et al., 2012). Consideration of the positive aspects of deaf and disabled sexuality is seriously lacking in contemporary research and popular discourse (Block et al., 2012). The view that particular inequalities occur because of inherent 'vulnerability' (Brown, 2015) – that issues present are connected to an individual's disabled embodiment - rather than to wider structural inequalities in terms of gender and disability is constituted in this way. This neglects to address causes of inequality effectively through failing to subject structural practices to scrutiny and failure to recognise that inequalities are reproduced by and through social systems (Baker et al., 2004; Lister, 2010). Simultaneously, it ignores the vulnerability of *all* embodied human subjects (Lynch, 2010).

Agreeing with Lister (2010), Shakespeare posits such assumptions and discourse about disabled people have material effects. He (2018: 46) notes, disabled people attract pity and sympathy because people often objectively assume that ‘it must be terrible’ to have a disability. Shakespeare responds that disabled people are thriving and, based on the available evidence, the majority of disabled people agree that the quality of their lives is very good. Noting the strong difference between objective and subjective status, Shakespeare suggests that human flourishing “*is possible,* even if you lack a major sense, or you can’t walk or you’re totally physically dependant on others” (46). Reflecting Shakespeare’s insights, my research findings suggest that deaf women are strong, empowered and *flourishing* agentic sexual beings. Revealing this has been a powerful research motivation.

1.7 Research motivation

The gap in academic knowledge, lack of deaf inclusive policy, as well as a desire to challenge dominant constructions of deafness and sexuality, comprised my research motivation. Alongside this, I was motivated by my personal background and tacit knowledge as a deaf woman and my professional background as a community worker which in turn influenced this research design. My personal experiences and my professional and educational experiences as a community worker are bound together and have been formative in shaping who I am, the values and beliefs I bring to this research and how I do this research. Undertaking an exploratory study of deaf women’s intimate lives means that it is essential that I acknowledge the ways in which this research is rooted in my own biography and that I maintain a reflexive approach throughout.

I am a deaf woman who grew up in a hearing family. Until roughly my mid-twenties, I had only hearing friends and, in hindsight, was surrounded by hearing ways of being and seeing the world. I rejected what I negatively perceived as deaf ways of being in the world by refusing to learn ISL and/or to engage with deaf groups. I sought to ‘fit in’, and to pass for what I identified as ‘normal’ - hearing - by hiding my deaf embodiment through concealing my hearing aids, working on my voice and concentrating hard on hearing conversations. In this way, I drew on my ‘bridging’ social capital (Putnam, 1993) of how to present and pass as hearing. I was not always successful at this.

These experiences formed a starting point for this research as I sought to inquire into how other deaf women related or did not relate to these experiences – where were points of convergence and divergence and in what ways were their deaf identities bound up with their intimate experiences? For example, as a deaf person, it is not natural for me to use voice tone to express myself. Facial and body gestures are my natural way of expressing – which does not fit in with a hearing way of expressing. My way of being in this sense elicited frustrated responses from some hearing people, including one hearing friend who expressed annoyance by exclaiming ‘God, don’t cry about it!’ if I expressed frustration or worry through facial gestures. They also concluded that I would not be destined to be single forever as I was pretty, so potential partners would overlook my being deaf. I was concerned that I had to present myself differently, as well as ‘be pretty’.

An ex-boyfriend in my early-20’s told me his friends were ‘taking the piss out of him’ for going out with a deaf girl, which was one of the first times I became aware of my being deaf as a potential issue for a boyfriend. From this it became something I worried about and I became more aware being deaf was bound up with my intimate life. Another friend remarked she did not even see me as deaf – it was not an issue for her. I wondered if my being deaf was something was that people choose to benevolently overlook. While I do not think anyone was ill meaning, these types of occurrences all signalled I should attain and perform gendered, aesthetic, heteronormative standards and that my deaf-self or subjectivity had to be presented in particular ways to be accepted, have friendships and have relationships in the hearing world. It also was not recognised as actually a valued part of my embodiment.

I share these stories here as these are the kind of personal experiences I shared and swapped with participants in our intimate co-construction of knowledge. Another example is that I met my hearing partner through online dating, and this was another topic I explored with participants in the research. I wondered about how best to disclose my deaf embodiment to him and I wondered if other deaf women had a similar experience.

These stories I share are not hard memories but an insight into how I formed my awareness of how deafness, and I by extension, may be perceived. This awareness of intimate audism formed a starting point and research motivation, guided my questions and my interactions with other participants.

Along with this personal motivation, in 2012 I began a community work placement in Deaf Village Ireland (DVI)[7] in Dublin as part of a professional Master’s degree in Community and Youth Work. I was based in Chime[8] and worked across a number of areas relevant to my professional development as a community worker and researcher. I began to spend more time with other deaf people and professionals and had a number of conversations with service providers I was working alongside. One provider discussed the challenge of how to approach the topic of menopause with a deaf woman with an intellectual disability and the struggle for appropriate materials to assist this. Another researcher shared her insight into the lack of conversation around sexual and reproductive issues with deaf adults with intellectual disabilities (Mathews, 2015). I also had conversations with other young deaf women I knew who expressed that this topic was of interest and they shared their insights with me. I began to question the lack of research and attention to the deaf women and sexuality. These conversations and my own informal research acted to raise my consciousness and analysis of broader structural issues contouring my own and other deaf women’s experiences. This highlighted the need to specifically seek the views of deaf women on their broader intimate experiences in Ireland, as well as to examine the broader structural dimensions impacting this issue.

During this time, I honed my critical professional skills of working with and alongside deaf people and built my personal and professional relationships with other deaf people and organisations. Through my research at the time I fostered key values and principles as a community worker researcher with an emphasis on knowledge production for inclusivity, empowerment and social change. Later I joined the Irish Deaf Youth

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[7] Deaf Village Ireland is a complex in Cabra, Dublin where a number of deaf organisations and groups are based and provide a range of facilities and services to deaf people.
[8] At the time Chime was known as DeafHear but has recently changed its name.

Association (IDYA)[9] board and through this co-facilitated a three-week workshop on healthy relationships and sexual health with young deaf women. Learning from this further fuelled my professional motivation for this research topic. Through the placement and my role sitting on the boards of two deaf organisations; IDYA and Catholic Institute for Deaf People (CIDP)[10] I further built my professional network and a strong foundation from which to develop this research and make significant contributions. I began having more discussions about this research topic with other adult deaf women I know. As a community worker I prize learning through consciousness raising developed through informal processes of dialogue (Freire, 1970). Informal dialogue for me is powerful and provided key insight into the appetite that was present for this research topic. For example, on one occasion I went to a deaf play and three deaf women called me over to ask me about my research. They proceeded to talk about their experiences of breastfeeding which was deeply interesting and informative. They were interested in learning more about other women through this research. Following my presentation at the 2018 Irish Deaf Research Network Conference two deaf women approached me to request that I travel to their deaf club to present my research findings when completed. On that day another deaf woman stated how excited she was to hear the findings. This expresses that this research touches on something of interest and meaning to a lot of deaf women in Ireland. I feel this thesis is the beginning of something meaningful.

Additionally, during the time that I was carrying out informal research with a view to beginning this PhD, the National Sexual Health Strategy 2015-2020 (DoH, 2015) was developed. I was cognisant of the absence of deaf women in this strategy – there was no reference to deaf women in this strategy at all. I aimed to carry out and complete this research in time to make a new and substantial contribution under key recommendations laid out in the strategy and contribute to the new strategy beginning from 2019, as well as other relevant strategies such as the National Women's Health Strategy for 2020 to 2030 that came on stream. The National Sexual Health Strategy outlines an overarching goal as the need to generate an evidence base of sexual health information to inform policy, practice and service planning, with the aim of improving the health of the

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[9] IDYA is the acronym for Irish Deaf Youth Association. IDYA is a deaf organisation based in Dublin that supports young deaf people aged eight years old up to thirty-five.

[10] The Catholic Institute for Deaf People is a non-profit organisation supporting deaf people in the area of education, care and pastoral work.

population. Section 3 elaborates on this goal under 3:16 where it commits to developing an evidence-informed response to ‘targeting’ those most at risk of negative sexual health outcomes. They name ‘at-risk and vulnerable’ groups (DoH, 2015: 64) under this.

With support from other community work practitioners and colleagues in the Department of Applied Social Studies (DAPSS) I applied for the John and Pat Hume Scholarship in Maynooth University (MU) and was successful. I had developed strong relationships with DAPPS colleagues and was deeply aligned to the core values and mission statement of DAPPS, that is to:

> Promote human rights, social justice and equality, nationally and internationally, through excellence and innovation in education, research and public engagement that contribute to the development of the social professions and applied social sciences (DAPSS, 2018: para 1).

DAPPS has a renowned reputation for excellence in Social Policy studies and in shaping policy in its fields through making extensive contributions to human rights, social justice and equality, nationally and internationally. Furthermore, my supervisor, Kathryn McGarry, has extensive experience in advocacy and research with marginalised women, particularly sex workers, which bears much relevance to my research. She privileges an applied and participatory approach to research and making connections to and informing policy. While our professional backgrounds diverge, we share a commitment to principles of social justice and embedding these in research practice. Experience in guiding research aiming to realise the achievement of social justice on a practical and sustainable level is relevant to a goal of this research; to contribute to transformative social change in relation to sexuality-related inequalities encountered by deaf women. All these elements together comprised my motivation to undertake this research.

1.8 Language politics

Mathews (2017: 5) reflects that what is meant by the term ‘deaf’ is deeply contested and terms used “are not neutral, but rather are laden with political meaning”. It is a debate that draws on issues of language, culture and community. Deaf academia has leaned towards making a distinction between, "*deaf* (spelt with a lower-case *d)* and D*eaf* (upper-case D) to clarify between medical and social discourses of d/Deafness, respectively" (Mathews, 2017: 5). Generally, 'deaf' (with small d) has been applied to signal audiological status and being a non-signing person and 'Deaf' (with capital d) to signal membership in the Deaf Community and being a signing person. However, deaf academics, Kusters et al., (2017: 13), note a reducing trend in the use of these terms in "recognition of increasing diversity in deaf worlds" with the trend moving towards simply 'deaf'. 'd/Deaf' suggests a binary between 'two groups' which has led to marginalisation of particular groups under the 'deaf umbrella'. Along with this it promotes a problematic, essentialist categorisation of deaf people. Increasingly research from Deaf Studies[11] has come to recognise the presence of multiple, fluid social locations in relation to deaf identities, language and modality use. To capture all of this within 'd/Deaf' is not possible. Additionally, there are problematic associations with the application of 'Deaf' or 'deaf' to people who may not relate to the words. Kusters et al., (2017) propose that it is more helpful to situate 'deaf' as a base term that encompasses the locations of all deaf people and to which other dimensions can be teased out such as 'deaf signer', 'use of speech', 'cochlear implant user' and so on.

In terms of self-identification, participants oscillated between a strong emphasis on 'Deaf' (to indicate ISL user and heavily involved in the deaf community), 'deaf' (to indicate using both English and ISL and from a hearing background) and 'hard-of-hearing' (to indicate using spoken English as their predominant language and being less involved in the deaf community). I chose to follow participants' lead by using their terminology and use the terms 'deaf' or 'hard-of-hearing' where relevant. Likewise, I also use 'deaf embodiment' as concerns of language and community were not to the fore of all narratives. Rather narratives emphasised how it felt to occupy a deaf body that others perceived or treated as deviating from the norm.

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[11] Deaf Studies' refers to the academic and activist discipline that emerged in the United States in the 1970's (Friedner, 2017). This interdisciplinary academic field first emerged around convictions of sign languages being languages like any other and a concern with exploring deaf culture and deaf identity (Bauman and Murray, 2010).

1.9 Research aims and objectives

The overall aim of this exploratory study is firstly, to understand the subjective intimate experiences and worlds of deaf women in Ireland and secondly, how can we create sustainable conditions that advance deaf women's opportunities for flourishing in intimate life.

This research seeks to make a contribution to knowledge in doing so. The central guiding questions of this research are:

- How do deaf women experience and understand their intimate lives?
- How are deaf women's intimate lives contoured and what are the effects of this?

With this in mind I operationalised my research through the following objectives:

- To explore the experiences and perspectives of deaf women through their narratives of their intimate lives.
- Through this exploratory study, examine and understand how the intimate lives of deaf women are contoured (the lived realities of their intimate citizenship) in different ways and different contexts.
- To establish how to foster, sustain and normalise opportunities for deaf women's flourishing in intimate life.

1.10 Chapter overview

This research is organised into eight chapters.

Chapter one has introduced the aims and objectives of this study.

In chapter two Bacchi's (2009) WPR framework is outlined and used to develop the research rationale and broader context this study is situated within.

Chapter three takes a detailed three-pronged approach towards understanding and contextualising the intimate experiences of deaf women by critically engaging the relevant key empirical, conceptual and theoretical literature.

Chapter four addresses the research design, methodology and methods guiding this research. I ground this research in its philosophical underpinnings. Detailed information about sampling, analysis and ethical considerations are also set out here.

Findings from this study are presented in chapters five through eight. Chapter five describes the narratives of deaf women in relation to ‘learning and doing’ sexuality during adolescence and young adulthood. Chapter six explores the intimate lives of deaf women to ascertain how this intertwines with their sexual subjectivities and how they negotiate their intimate citizenship in different contexts. Chapter seven explores the wider factors mediating deaf women’s intimate citizenship and access to sexual health services and information of deaf women in Ireland.

Building on the findings, chapter eight provides a focused discussion of what contours the positive embodiment of deaf women and how they mitigate structural inequalities.

Chapter nine presents a conclusion to the research and draws together the story which emerged. It considers the contribution of my study to knowledge, policy and practice to support deaf women’s intimate lives, as well as the potential of my findings for informing the wider policy agenda for women in Ireland.

Chapter 2: Context setting and problematising through the WPR approach

2. Introduction

This chapter has two overarching aims. Firstly, to present the policy and socio-historical-cultural context in which the intimate lives of deaf women in Ireland are situated and shaped by. Secondly, to unpack and begin problematising how deaf women are positioned at policy and discursive level. I adopt and adapt Bacchi's (2009) analytical framework, 'what's the problem represented to be' (hereafter WPR approach) to do so. The WPR approach offers a framework to explore the historical, ideological, legal and policy context within which to locate the intimate lives of the research participants. It facilitates critical interrogation of public policies and considers "the process of problematisation in research, policy and practical applications, as well as the impact of that problematising process" (Bletsas and Bleasley, 2012: 2). I harness this framework to address a key objective of this research, which is to scrutinise how normative sexuality and deaf women are constructed and represented within policy. This is carried out in order to explore the discursive implications of how deaf women are understood for their intimate lives. Using this approach reveals and problematises the normative, ableist construction of deaf women as 'vulnerable' at discursive and policy level in Ireland.

The following chapter provides a brief overview of the WPR approach[12], its theoretical influence and a discussion of the six questions contained in the framework and used within this thesis. As the chapter and thesis progresses, the WPR framework is used to interrogate how the normative construction of sexuality has come about and how 'problematisations' linked with deaf women and sexual well-being are framed across particular policies. This framework is also used to provide context setting for this research, addressing conceptualisations of deafness, disability, gender and sexuality in Ireland.

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[12] Further in depth explanation of the WPR framework is contained within appendix 2.

2.1 Theoretical underpinnings of WPR

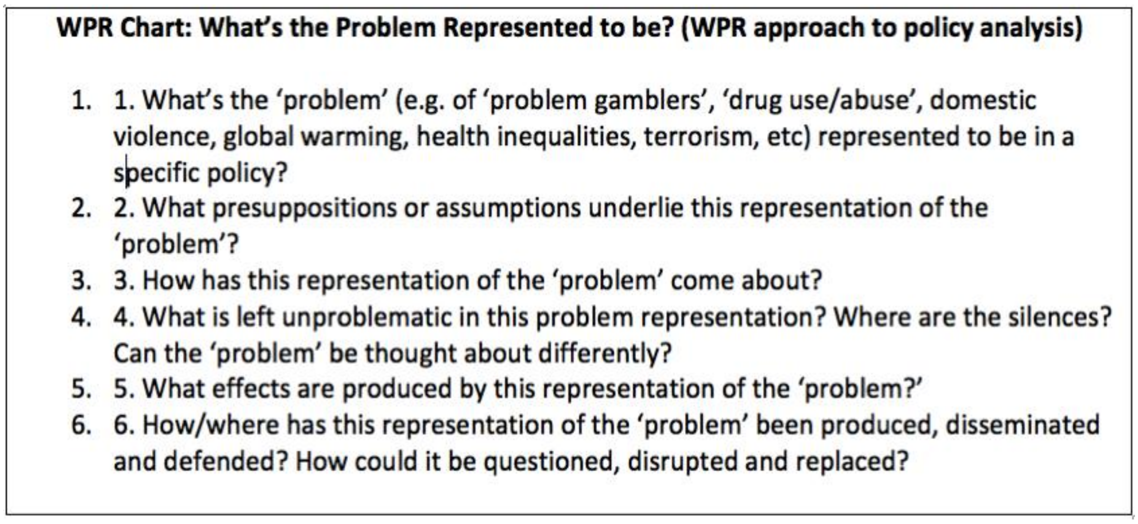
Bacchi's WPR approach, grounded in a feminist understanding, contends that lived lives are affected by discourses which produce particular representations of a 'problem'. It asserts that people are "governed, not through policies, but through problematisations – how 'problems are constituted'" (Bletsas and Beasley, 2012: 22). This Foucault-influenced mode of problematisation offers a way to dismantle 'established, unexamined' ways of thinking and assumes that there "are ways of thinking that emerge from practices" (Bacchi, 2009: 4). The 'taken for grantedness' of meanings and objects of knowledge, such as sexuality, is interrogated and the social and political practices involved in constructing it as an object for thought and knowledge as 'true' are revealed (Bacchi and Rönnblam, 2014). Deaf people often problematise ideas about deafness by contesting the idea that they are disabled and contending that they are part of a cultural and linguistic minority. Similarly, I trouble and problematise how deaf women are constructed as vulnerable in policy, in contrast to their lived experiences.

Power is crucial in knowledge production. Foucault (1980) uses the term power/knowledge to express that power is constituted through the production of acceptable forms of knowledge. Knowledge production requires power and exercises power by shaping people's lives. Power is exercised through relations between subjects and reinforced through knowledge disseminated from institutions such as education and medical experts (Bacchi and Rönnblam, 2014). Foucault (1990) contributes to sexuality work as he offers a useful approach for considering "how personal lives are constituted in the sexuality discourses which inform social policy and practice" (Carabine, 2009: 30). Using this perspective, the social knowledges underpinning knowledge construction and practices in relation to deaf women's sexuality and intimate experiences are considered, as well as "suggest(ing) that policies, through the subject positions they create, shape our subjectivities (to an extent)" (Bacchi, 2009: 6). This understanding allows for an exploration of how deaf women's sexuality is discursively constructed, the boundaries created by the representation of deaf women, what is silenced, and what is invisible and visible.

2.2 The WPR Approach

Bacchi (2009) describes public policy making as a process typically viewed as an improvement exercise that, ‘fixes a problem’. This presumed ‘problem’ may or may not be given explicit mention in government policies and often is not. Bacchi contends that there is a need to make perceived (implicit and explicit) ‘problem(s)’ within policy explicit and to do so through a process of methodically ‘problematising’ to inquire into assumptions underpinning policy. Problematising emphasises problem *questioning*, as opposed to solving, and considers how knowledge is developed – the discourse of how something is seen, spoken of and its effects. Discourses are meaning systems, established in the ways that language is used and are productive. They have material effects, produce subject positions and can assist in producing and maintaining inequalities (Carabine, 2009). We engage with discourses to transform them, reconstitute new ones, to take up subject positions or refuse them, as deaf people reject pathological views of deafness. If certain subject positions are taken up, this means taking on ways of thinking about oneself, also understood as internalising ideas (Bacchi, 2009). Deaf people may internalise ideas about ability to hear as the normal standard to attain and deafness being less acceptable than this.

Bacchi sets out six questions to be applied to systematically delve into a deeper understanding of policy. Figure 2 sets out these questions;[13]



WPR Chart: What’s the Problem Represented to be? (WPR approach to policy analysis)

1. 1. What’s the ‘problem’ (e.g. of ‘problem gamblers’, ‘drug use/abuse’, domestic violence, global warming, health inequalities, terrorism, etc) represented to be in a specific policy?
2. 2. What presuppositions or assumptions underlie this representation of the ‘problem’?
3. 3. How has this representation of the ‘problem’ come about?
4. 4. What is left unproblematic in this problem representation? Where are the silences? Can the ‘problem’ be thought about differently?
5. 5. What effects are produced by this representation of the ‘problem?’
6. 6. How/where has this representation of the ‘problem’ been produced, disseminated and defended? How could it be questioned, disrupted and replaced?

Figure 2: WPR Chart[14]

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[13] These questions are further outlined in appendix 2.

This process analyses policy with the aim of understanding how a problem is characterised and an issue understood. Policies effectively are problematisations, which is why we interrogate them for problematisations within. Policies relevant to deaf women and sexual health have been selected for analysis in this research. The critical analysis of these policies revealed the predominant problem representation in relation to deaf women is ‘vulnerability’. Next, I apply Bacchi’s WPR approach to draw this out.

2.3 What’s the ‘problem’ represented to be in a specific policy?

In relation to question one, I have not carried out a meta-analysis. I examine key policies as they relate to the research aims as a tentative exercise to reveal problematisations within them. The WPR method is not used in a ‘conventional way’ to analyse one specific policy. I have adapted it to consider the location and understanding of deaf women across a few policies related to sexual wellbeing. No social policies have been developed specifically regarding deaf women. Additionally, there is little representation of issues concerning deaf women across policies. Deaf women are often an invisible group subsumed within the overarching disability category. Thus, I draw on wider social policy developments in relation to women and disabled people to situate and frame deaf women’s intimate experiences in Ireland. Disabled women have traditionally been neglected within feminist research and we lack a gendered perspective in disability research (NDA, 2006: 5).

This section gives a short overview of influential policy at national level before problematising specific relevant national policy relating to deaf women and sexuality-related issues and the research objectives. It is important to also mention that, as an EU member state, Ireland’s policy making process is bound up with EU influence. The rights of disabled people and women have been largely advanced through EU level directives and the commitments of the Irish government to implement UN conventions that seek to protect the rights of women and disabled people[15].

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[14] Adapted from Bacchi (2009).

[15] At European level the current strategy statement of the European Commission is the Strategic Statement for Gender Equality 2016-2019. Internationally, the 1995 UN Fourth World Conference on Women: Beijing Platform for Action has set out an agenda for achieving gender equality and the Transforming our World: the 2030 Agenda for Sustainable Development sets out 17 sustainable

2.3.1 National policy

At national level multiple statutes of equality legislation exist in relation to disability: the Disability Act 2005; Disability (Miscellaneous Provisions) Bill 2016; Equal Status Acts 2000 – 2015; Education for Persons with Special Educational Needs Act (2004), Citizens Information Act 2007 and Irish Human Rights and Equality Commission Act 2014 – Section 42. These legislative pieces underpin various policy objectives set out in strategies, such as the National Disability Inclusion Strategy 2017 – 2021 and the HSE Service Plan (2018c), strategies which aim to ensure disabled people are supported to live independent lives where they can participate in society and achieve their potential (CIB, 2018).

2.3.2 Irish Sign Language Act 2017

Prior to the ISL Act 2017, ISL had no official status in Ireland. For the first time this Act gives ISL formal recognition as an official language of Ireland. It "contain(s) eleven clauses covering the recognition of ISL and the right to use it, ISL users' statutory rights to access public services, the setting up of an accreditation and registration scheme for ISL interpreters, and vague references to children's rights in education"[16] (Conama, 2018b:7). Conama notes that 'access' is not explicitly defined within the Act but asserts it can be assumed that it relates to ISL interpreting services. He notes that the final version is generally viewed by deaf campaigners as "imperfect" (2018b: 8) but a necessary compromise in order to ensure the Act was finally passed. Under the Act,

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development goals with 169 targets that are relevant to achieving gender equality and universal access to sexual and reproductive health and rights.

Ireland is also party to the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (Dept of Justice and Equality, 2017). The United Nations Convention on the Rights of People with Disabilities (UNCRPD) is a broad, legally binding international treaty that defines disabled people as rights' holders (Conroy, 2018). It does not confer new rights but reinforces existing ones. Countries that have ratified this treaty must follow UNCRPD obligations and mainstream disability rights throughout legislation and policy (Conroy, 2018). Ireland ratified UNCRPD in April, 2018 (CIB, 2018). At this time the Optional Protocol to the UNCRPD – a crucial mechanism allowing individuals to bring complaints against Ireland at the UNCRPD Committee – was not ratified, with a statement it will be ratified at a later date. The European Disability Strategy 2010-2020 (EDS) is the main instrument building on UNCRPD through setting out a comprehensive framework for implementing UNCRPD at EU level. The strategy aims to empower disabled people to access their rights to participate and be included as EU citizens by removing socially created barriers within Europe.

[16] Additional clauses in the Bill include the use of ISL in "legal proceedings, with the provision of access to civil cases an especially important change. The most useful part of the Act is the review of the Act in 2020 and every five years subsequently" (Conama, 2018b: 7).

State bodies are obligated to provide free interpreters to a deaf ISL user using their services. They are also required to prepare and implement ISL action plans. This ensures that ISL users will not be forced to depend on their second language, English, when accessing public services and information, as has been the case up till now.

At this juncture it is difficult to develop an analysis of the Act or its implications. However, it is possible to problematise the politics of the development of this Act. The Irish Deaf community have been campaigning for official recognition of ISL since the early 1990's. A number of official attempts to have ISL recognised were unsuccessful with little clear reasons given for previous rejections (Conama, 2018a). Conama (2018b) notes that the original version of the Bill developed in 2011 contained more than 30 clauses and the ISL Act passed in 2017 contains 11 clauses[17]. He explains that decisions about the Act were made "without being cleared with the Irish Deaf Society (IDS)[18] and its legal expert" (2018b: 7) and the campaign group had "no real option" but to accept amendments in order for the Bill to pass. Consequentially campaigners had to accept an "imperfect Act". Important for this research is that here we see deaf people, who should have been considered as 'experts' on their own language and access requirements, being overlooked and misrepresented. Deaf people were required to submit to hegemonic understandings of what should be in this Act, rather than the Act being guided by work done by a cross community group of deaf representatives. Conama (2018b) cites Conama and O'Donnell (2001) to note that typically deaf people have been excluded from policy-making structures where they could give an 'insider view' of deafness. The development of the 2017 Act was a missed opportunity to rectify this injustice.

Finally, it is pertinent to note that, while this Act is very important for the status of ISL, it may not be perceived as useful by all deaf people in Ireland in practical terms, as not

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[17] Conama notes that the 2011 proposal also included also "the establishment of statutory targets regarding the accessibility of television programming and regulation of ISL interpreters, Deaf interpreters and ISL teachers with the establishment of an Irish Sign Language Council to ensure standards for interpreting and teaching ISL. Furthermore, it included a legal requirement to provide ISL classes for parents of Deaf children, and provisions to make sign language interpreting services, when accessing public services, available free of charge for the users of ISL" (2018b: 6).

[18] The Irish Deaf Society (IDS) initially set up the campaign for the recognition of ISL and facilitated the cross community group of deaf national organisations (Conama, 2018b).

all deaf people use ISL. However, it sets up structures that may encourage mainstreamed[19] deaf people to learn and use ISL and therefore holds potential.

2.3.3 Healthy Ireland (HI) Strategy

The HI Strategy sets out the Irish government's commitments towards addressing health inequalities. The framework states that it recognises that health inequalities are contingent on environmental factors[20] as well as individual. A broad-based policy and whole system approach that reaches beyond government to include a wide network of public and private stakeholders is advocated to encompass and gain insights into the societal aspects of health and put health on the agenda for relevant policy areas. The vision is outlined as; "where everyone can enjoy physical and mental health and wellbeing to their full potential" (2013: 5). The broader HI framework aims to address these factors and amongst other policies[21], to harness the National Sexual Health Strategy 2015 – 2020 to support these aims.

Important for this research is how the concept of vulnerability, in relation to disability, is developed and carried into subsequent strategies. Disability is not clearly defined but seems to be conflated with ill health - "when a person experiences health problems, suffers illness or has a disability" (2013: 6). It is important to recognise that disability is not just a health or welfare issue – it is also a civil and human rights issue.

Within the strategy, actions are grouped under six themes. Under theme three, 'empowering people and communities', the strategy focuses upon ways that people and communities can be empowered to take responsibility for their own health and wellbeing. It notes that this requires considerations for 'vulnerable groups' and for the 'general population' (2013). Disabled people are designated as one of these 'vulnerable groups'. This theme discusses the importance of communities building awareness of and action on the challenges that affect health and wellbeing in their own communities, which needs to be balanced with provisions influencing the choices that people have such as regulatory and legislative options. For instance, Action 3.8 under Theme Three

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[19] 'Mainstreamed deaf people' refers to deaf people who did not attend a deaf school but rather attend a school in their community – a mainstream school.

[20] These are named as socio-economic status, level of education, housing and employment.

[21] Obesity Policy and Tobacco Free Ireland.

outlines that, to meet the health and wellbeing of communities, health literacy must be addressed in developing future policy, educational and information interventions. Other actions outline the need to support children, young people and older people. There is no further specific mention of who within the 'vulnerable groups' will receive targeted interventions or what mechanisms should be implemented to improve health literacy or participation in decision making at community level for health and wellbeing.

This categorisation puts the notion of vulnerability at the core of the framework shaping subsequent actions or 'interventions'. It does not interrogate the concept of vulnerability and the way in which 'vulnerability' is produced and experienced, instead promoting an approach that suggests vulnerability is something innate in deaf people and other such 'at risk groups'. I consider the National Sexual Health Strategy in this context as it has been developed under the broader HI framework.

2.3.4 National Sexual Health Strategy

The National Sexual Health Strategy 2015-2020 (Government of Ireland, 2015) is a strategic framework set out to address sexual health and wellbeing in Ireland. It is the first national framework in Ireland for sexual health and wellbeing and was set up to establish a clear framework for responding to sexual health needs in Ireland. The strategy has three goals:

- To ensure that everyone has access to appropriate sexual health education and information;
- To ensure that high quality sexual health services are available and affordable;
- And ensure that good quality data is available to guide the service.

One recommendation under 'sexual health promotion, education and prevention' refers to interventions for 'at risk' or 'vulnerable' groups (2015: 19). 'Vulnerable groups' are described as requiring "targeted support to improve their sexual health and wellbeing". Such groups are outlined as including; "people with a migrant background, people with an intellectual disability, and young people in care" (2015: 31) as well as "people with disabilities or mental health problems" (2015: 39). While deaf people are not named specifically, the perception of the vulnerability of disabled people provides insight into how deaf people might be perceived. The term ‘vulnerability’ is used unproblematically, without clear explanation of its meaning.

A description of the wider systemic barriers that have been found to contribute to the experiences of ‘vulnerable groups’ in relation to sexual health information and services is included. There is overlap regarding sexual health information and service experiences of deaf people, such as language and communication issues and costs. Thus, it could be inferred that deaf people are likely to be perceived as a vulnerable group and require ‘targeted interventions’ also. It seems this approach regards ‘identifying’, ‘targeting’ and ‘intervention’ as the priority. In other words, it prioritises imposed solutions upon groups that are perceived of as in need of ‘intervention’. This is the focus, as opposed to paying attention to the wider structural context creating systems of inequality and developing accessible, inclusive systems in recognition of this.

The group driving development of the strategy established four sub-groups[22]. Membership of these various sub-groups and the Strategy Group was drawn from a wide array of governmental and community organisation interests that have experience in the area of sexual health policy and service delivery[23]. There is no mention of representation from a deaf led organisation. As noted in the HI Framework, an intersectoral working strategy is critical in order to address the four broad interlinked policy goals put in place under the HI framework. I suggest the Sexual Health Strategy needed to include and represent the needs of deaf people in Ireland.

2.3.5 National Strategy for Women and Girls 2017 – 2020

This strategy sets out a framework “through which the Government will pursue actions to advance the rights of women and girls and to enable their full participation in Irish society” (2017: 7). Important for this research is objective two, ‘advance the physical

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[22] Education and Prevention working group; the Health Intelligence working group; the Sexual Health Services working group and the National Sexual Strategy writing group.

[23] The Department of Health; the Health Service Executive; Irish Association of Nurse and Midwife Managers; Department of Education and Skills and others; major regional hospitals; and the Social Inclusion Unit. Community organisations were comprised of; BeLonG To; Dublin AIDS Alliance/Gay Health Network; Squashy Couch; Dublin Well Woman; Gay and Lesbian Equality Network; One Family; Irish Family Planning Association; Treoir; Positive Now and others.

and mental health and wellbeing of women and girls'. Action 2.20 notes the need to generate data through research on maternity services and supports for women with disabilities during and post pregnancy. Overall, disabled women are not explicitly visible - a general trend within gender equality discourse. There is a significant knowledge gap in terms of disability and gender disaggregated data, necessary to inform policy making. It appears the opportunity to rectify this perpetuated invisibility was missed in this strategy. The strategy is referred to as a live document thus there is potential for greater visibility in updating the strategy. In addition, concerns have been raised regarding the short duration of the strategy and what can be achieved within this time frame – particularly without the existence of measurable and time bound objectives (IPH, 2017).

2.3.6 National Maternity Strategy 2016 – 2026

Ireland's first national maternity strategy sets out to restore confidence in and address shortcomings in a system that has been found severely lacking for pregnant women in Ireland. The strategy notes that it is "…focused on and responsive to, women and their individual needs" and the vision is an Ireland where; "women and babies have access to safe, high quality care in a setting that is most appropriate to their needs" (DoH, 2016: 4). There is little specific mention of disability and thus here we see a crucial gap. The strategy has been criticised for continuing to promote an outdated biomedical model that divides women into three risk groups – low, high and medium and fails to increase choice for women in the latter two groups and thus is not fully women centred (AIMS, 2016).

The Institute for Public Health prepared the consultation report for this strategy and sets out responses to question 27, 'What are the key considerations when designing how maternity services are provided (a model of maternity care)?'. Responses gathered under the heading 'Accessible and Equal', outline the need for "equality of access and outcomes for vulnerable or socially excluded women including those with disabilities…". Respondents noted that the principle of equality for all needs should be encompassed within the new model of care. Chime[24] were one of the respondent organisations and while groups such as Travellers and migrants are mentioned there is

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[24] DeafHear has recently rebranded to Chime and submitted under the previous branding.

no specific mention of deaf or disabled women within the consultation report apart from the aforementioned section.

Two focus groups are referred to as being held as part of the consultation for the strategy. It notes that these focus groups targeted representatives from ‘vulnerable groups’ (Keilthy et al., 2015) and “included…women and family groups, pregnancy related advice and support groups, domestic violence support groups, women who experienced a loss, and Migrant, Traveller and Roma populations (Keilthy et al., 2015: 98). Disabled women are not mentioned; thus, we see silences again. I contend that if they had been consulted with it is likely the needs of deaf women would have been considered under the ‘vulnerable’ heading also. It appears that the strategy promotes a normative understanding of pregnant bodies with little attention to the needs of diverse pregnant women. Empirical evidence from past research (Begley et al., 2009) has suggested that when disabled women access maternity care they are perceived as asexual and marginalised. This strategy does not appear to do anything to challenge this.

2.3.7 Breastfeeding in a Healthy Ireland: HSE Breastfeeding Action Plan 2016 – 2021

There is considerable emphasis about the need to improve breastfeeding supports and breastfeeding rates across a number of national policy framework documents under the Healthy Ireland strategy. Lack of breastfeeding support and the need to implement the HSE Breastfeeding Action Plan was a key theme in the National Maternity Strategy consultation report prepared by the Institute of Public Health. Respondents noted that they felt they lacked support within the hospital, community and home setting. The feedback under this section was general and did not refer to any specific communication, linguistic or other issues that women may encounter in relation to breastfeeding apart from tongue tie. Within section three in the report it is noted that there is a need to make information accessible in clear formats for women who have sensory or literacy issues. The National Maternity Strategy report notes that Ireland “compares poorly to other European countries in relation to breastfeeding, despite the recognised importance of breastfeeding for mothers and babies” (2016; 41) and that women reported receiving poor quality and inconsistent information on breastfeeding as well as “limited support on postnatal wards with little or no access to lactation consultants” (2016; 57). However, there is no specific acknowledgement of the intersectional needs of breastfeeding women within the consultation report or the maternity strategy. It is crucial to take an intersectional approach to understanding both the needs of pregnant women and new mothers in order to ensure best outcomes for women who choose to breastfeed.

This tentative WPR exercise carried out with key relevant policies reveals much in terms of the silences, the gaps and the construction of deaf women under general categories of ‘vulnerable’. The next step teases out this underlying assumption. There are limitations associated with this approach as Clarke (2019) considers. He notes that this approach is effective at uncovering how problematisations are connected to embedded discourses. However, this approach is less effective at uncovering, in a practical way, how this happened or when it happened. “It does not exhaust the conditions that shape this process” (2019:190) and this is a limitation I have encountered within my use of the WPR analysis which is particularly noted under section 2.5, ‘how has this representation come about?’.

2.3 What presuppositions or assumptions underlie this representation of the problem?

Step two interrogates ideas around the problem representation. Assumptions are our unquestioned knowledge that can perpetuate harmful misperceptions and constitute problems in particular ways. I interrogate and deconstruct how deaf and disabled women and ‘the problem’ are represented across policy relevant to sexuality which underpins and shapes the approach to ‘the problem’. I argue that there is an implicit assumption and suggestion within policies that the ‘vulnerability’ of disabled and deaf women explains their sexuality-related experiences. This misleading problematisation distracts from the need to interrogate assumptions within policies and for policy makers to devise better strategies that address wider structural inequalities contouring the intimate experiences of deaf women.

2.4.1 Problematising Vulnerability

Munro and Scoular (2012: 190) note that within broader contemporary social policy making, “there has been an exponential rise in the discursive emphasis placed upon the condition and experience of vulnerability by law – and policy-makers”. Irish policies related to sexual health have not been immune to this, nor has traditional discourse surrounding disabled or deaf people. It is a prominent concept in both.

Theorists (Beckett, 2006; Brown et al., 2017; Munro and Scoular, 2012; Taylor, 2017) highlight that we are living in a ‘vulnerability zeitgeist’ (Brown, 2015) and the concept has become increasingly embedded in and influential across social policy responses and socio-political discourses. It has yet to receive sustained critical interrogation into its multiple, malleable meanings and practice implications. Thus, different explanations and vague understandings of the concept exist. Brown et al., (2017: 2) note despite this, “its use is often normative, implying deviation from usually undefined standards of life or behaviour, and supporting powerful moral and ethical projects”. Their review indicates that the term appears in three main forms: “as a policy and practice mechanism…as a cultural trope or way of thinking about the problems of life…and as a more robust concept to facilitate social and political research and analysis” (2017: 4). As a concept it is linked with many strands of thinking about citizenship and the state/individual relationship (Brown, 2015).

Brown (2012) proposes that the concept may initially appear favourable to disadvantaged groups. Groups such as “women, children…and individuals with disabilities” are often labelled as ‘vulnerable’ (Satz, 2015: 185). Brown contends that it seems apparent that the label confers a special exemption on groups or individuals, generating a sense that they are victims of their (negative) circumstance and as such should not be implicated in this but rather viewed in this way. The danger with this conception is that the label is often unproblematically applied to groups without their consent (Taylor, 2017). Consequently, it often constructs a perception that vulnerability is an innate characteristic of a person meaning they require protection (Dunn et al., 2008; Hollomotz, 2012). This sparks attention towards issues such as ‘deservingness, agency and social control’ (Brown, 2015). Taylor (2017) states that this discourse exerts a misleading perception that ‘vulnerable people’ are not rational agents who possess rights, agency and autonomy. In relation to sexuality and disability I find the connotations of vulnerability crucial. Weeks (2007: 126) reminds us that “the languages of sexuality shape the way we see the body and its potentialities”. Connotations of vulnerability direct particular understandings of the body and its possibilities and to my mind close off possibilities.

Hollomotz (2012) contends that the protective discourse attached to vulnerability is a double-edged sword. By creating a situation of dependency out of protection concerns, the greater the potential for exploitation. Furthermore, it has given rise to ‘new forms of state surveillance’, developed to protect ‘vulnerable people’, for example, criminal record checks (McLaughlin, 2017). Munro and Scoular (2012) contend this strategy asserts a direct relationship between ‘vulnerability’ and ‘risk’ and positions certain groups as ‘risk managers’, supporting the extension of state intervention into people’s lives. The approach then fails to be helpful as it focuses analysis upon the individual’s ‘inherent’ vulnerability, as opposed to how overarching structures and unequal treatment of groups create situations of ‘vulnerability’ (Hollomotz, 2009; Brown, 2015).

Challenging this discourse is difficult for groups such as disabled people when faced with the reality of meeting day-to-day needs. It is suggested that the construction of disabled people as ‘vulnerable’ is potentially the most embedded across public policy (Taylor, 2017). It could be argued that disabled people are often compelled to draw on this language and play the part of a vulnerable person (Hollomotz, 2012) to compel response from the state and access much needed services and supports (Taylor, 2017; Munro and Scoular, 2012). Disabled people have challenged this view, maintaining that the suggestion that vulnerability is an innate trait located in certain bodies fails to take into account society’s role in constructing situations of vulnerability (Oliver and Sapey, 2006). The concept has received attention from some disability theorists in this respect.

Others have suggested (Beckett, 2006), that vulnerability is a marker of human beings, an inevitable state of being that *all* people have in common (Lynch, 2010) and “that some individuals may (or may not) experience vulnerability more acutely than others” (Satz, 2015: 185). Satz (2015) elucidates that the concept in itself is not something to be viewed within a negative framework, but because it is so often applied to particular groups in a way that promotes pity, a negative light is cast upon it. Its use should not be completely decried. Some argue it can be and has been helpfully wielded to secure greater access to social protections and services (Brown, 2015; McLaughlin, 2017). Some commentators seek to promote the concept of ‘universal vulnerability’ – all people are vulnerable (Butler, 2004b; Fineman, 2008). If this universal nature is recognised, we can develop appropriate social services. However, concern lies with the need for its implications when used without conscious care and whether it can act in harmful, regulatory ways (Brown et al., 2017).

This research raises questions in relation to the concepts of ‘vulnerability’ and ‘intimate citizenship’. Brown (2015: 1) writes that those labelled as vulnerable “may be resistant to being classified in this way”. They might disrupt and displace problem representations and reimagine new ways of knowing. Bacchi (2009) writes that the goal is to intervene to challenge deleterious problem representations and suggest ways of re-thinking. Key to this research was how participants’ narratives present an opportunity to disrupt and reimagine. I asked some participants their feelings about the word ‘vulnerable’ and received vehement responses that the descriptor was not relevant to them as they understood its meaning. This suggested that it is an ‘imposed word’ (Brown, 2015) and raised opportunities for displacement – for replacing this discourse with another; flourishing. This research presents a disruption and displacement of ideas of vulnerability with ideas of flourishing.

As a strategy, designating certain groups as vulnerable has developed in popularity. It is an important concept to define and the meanings in place should be considered to ensure that deaf women are not positioned as vulnerable victims, as this is certainly contrary to their lived experience. Deaf women are not “always and inevitably vulnerable” (Brown, 2015: 67). Their narratives are an important challenge to the traditional, overarching construction of disabled and deaf people as vulnerable. Any concern with vulnerability must be treated very carefully as it can put “solidaristic approaches” in jeopardy or “oversimplify complex social phenomena” (Brown, 2015: 67). As evident throughout the exploration of policies there is mention of deaf women as vulnerable. However, there is little explanation as to what this actually means.

I now proceed towards addressing how the problematisation of vulnerability has come about and its effects. This is a challenging task given, as noted earlier, that how vulnerability is conceptualised is frequently not drawn out within the policy literature. Within policies analysed earlier it is not clear what vulnerability means. There is no reflection on this. However, through examining discourse within the policy - only certain groups who habitually experience marginalisation are referred to as vulnerable. Thus, it can be inferred that the concept is used and meant in a particular way and attached to particular categories or groups. It is engaged in a process of meaning making. At this juncture an understanding of the socio-historical context in which constructions of disability and state responses to and treatment of gender, disability and deaf people have evolved is helpful to respond to the third WPR question.

2.5 How has this representation of the problem come about?

Here Bacchi directs us to interrogate non-discursive practices to understand how a 'problem representation' has been constructed, 'come about', over time. It is useful to consider at this point, the complexities and nuances of how the Irish state has conceptualised and responded to disabled and deaf women and sexuality, and how this is embedded in socio-cultural and historical processes. In a limited way this draws on a Foucauldian genealogical approach – (to carry out an in-depth genealogical approach is beyond the scope of this research) (Bacchi, 2009). Nevertheless, it is possible to draw together an overview interrogation, which has already been touched on in the previous sections.

2.5.1 Conceptualisations of disability and deafness in contemporary Ireland

McDonnell (2007) writes that the relationship between disability and society in contemporary Ireland has undergone a transformative change and understanding this transformation "requires an exploration of what we might call the deep structures of the relationship between disability and society – the prevailing and often taken-for-granted beliefs, ideas and values which shape that relationship" (McDonnell, 2016: 778). This relationship is bound up with the historical legacy of "nineteenth century charity and containment", which is woven through newer ideas in relation to human rights and evident in the lack of full citizenship and rights for disabled people (Conroy, 2018: 1). While disabled people in contemporary Ireland remain marginalised and disabled people still "have not been allowed to emerge from the margins of society" (Conroy, 2018: 3) disabled people have witnessed positive, rights-based change in "fields as varied as legislation, education…and even in the meaning of disability itself" (2018: 1).

Regarding the situation of deaf people - the ISL Act was written into legislation in 2017. This Act finally gave deaf people the right to access public services and information in their own language, as discussed earlier. This process challenged language ideology in relation to signed language (Conama, 2018a). The Act however, is regarded as “imperfect”, and thus the rights of deaf citizens remain to be fully realised. As Conroy (2018) contends, disability rights are among the last of the civil rights to be extended in Ireland. She asserts that it is crucial we examine ideas, values and structures of what has gone before to propose where we must go.

Changes in the relationship between disability and society are linked to broader changes post WWII whereupon greater understanding of the rights of minorities and protections began to emerge alongside a surge of civil rights, women’s social movements and the emergence of the welfare state (McDonnell, 2016). Disabled people in Ireland have historically been subject to processes of domination, institutionalisation, segregation and lack of recognition of their rights (Conroy, 2018). Ideology has been a powerful force with the two ideologies of normalisation and rights being most influential in recent times, underpinning much policy development (McDonnell, 2016). Normalisation grew in influence following WWII with increased resistance to the practices of segregation and institutionalisation and as the medicalisation of disability also increased. “Rather than being locked away, children and adults with disabilities were to be normalised out of their differences” (Conroy, 2018: 6).

While this is not the singular ideological influence on Irish policy making it bears the most relevance to policy making concerning deaf people. Normalisation promoted a critique of existing practices, arguing that disabled people had the right to participate in mainstream society as equals with non-disabled people. Such discourse was predominantly located amongst professionals with no lived experience of disability. As an ideology it is paternalistic and places a high value on the diminution of difference. “It is also a ‘norm’ individuals are expected to aim for...against which all are evaluated…” (Carabine, 2009: 37). It is recognised as attempting to address issues of disempowerment and discrimination and so targets segregation and institutionalisation. This ideological lens perceived deaf and disabled people as ‘vulnerable’, ‘dependent’ and in need of professional intervention and supports decided by and implemented by professionals. McDonnell points out (2016), this ideology has a longer, more deeply entrenched history for Deaf communities than for disability. This becomes evident through a short overview of significant events relating to deaf history and education in Ireland.

Education of deaf people has been deeply influenced by mainstreaming philosophy which has its roots in normalisation ideology and became the dominant practice in deaf education in Ireland from the 1970's onwards (Crean, 1997; McDonnell, 2016; Mathews, 2017). The school for deaf girls[25] and boys[26] established by CIDP[27] followed the pedagogic approach of using sign language to teach deaf children[28]. The schools initially taught children through ISL for the first one hundred years following establishment and followed the approach typical of the nineteenth century which was to segregate and contain those who were different into large, removed institutions (Walsh, 2003). Children were often separated from their parents and sent into residential schools (Conroy, 2018). This was a crucial development for policy and society – the view that disabled people were different and subject to personal deficit formed. Disabled people were contained and segregated into institutions and "began to suffer a particular form of social control….they became invisible and in terms of public policy – forgotten" (Conroy, 2018: 6).

Deaf educational policy changed following the 1880 International Congress for the Education for the Deaf in Italy which promoted prohibiting the use of sign language in deaf education (O'Connell and Deegan, 2015). Sign language became marginalised and replaced with a policy of Oralism, an approach that emphasised the importance of spoken-language communication, despite warnings of the abysmal outcomes this would have for deaf children's education. Oralism was difficult for many deaf children. LeMaster (2003: 162) describes it as a policy that required deaf children to "mask their deafness" and attempt to pass as a hearing person. From this time onwards, focus

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[25] The school for deaf girls was named St Mary's School for Deaf Girls and established under the management of the Dominican Sisters Order in 1846 in Cabra, Dublin.

[26] The school for deaf boys was named St Joseph's School for Deaf Boys and established under the management of the Christian Brothers in 1857 in Cabra, Dublin.

[27] CIDP is the acronym for the Catholic Institute for Deaf People

[28] Deaf education in Ireland has its roots in the educational work of abbe de l'Epee in France. This educational approach developed by the philanthropic educator focused upon educating and learning through sign language – not spoken language (O' Connell and Deegan, 2015; McDonnell, 2016). This ground-breaking approach made education accessible to deaf people.

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switched from educating deaf children through ISL to the acquisition of speech. The construction of and ideologies of deafness and ISL as a ‘deficiency’, in need of correction can be traced from these developments (LeMaster, 2003). The switch in ideologies placed onus on the deaf child or person to adjust themselves and their natural method of communication, rather than on the hearing world to construct and adjust itself to the deaf person. While LeMaster is contested on this point (2003) she contends that this new discourse that rejected deafness and ISL as a normal state of being, resulted in deaf people also moving away from internalising the view that deafness was normal and acceptable.

This approach has been deigned harmful on multiple levels – “it does not recognise the cultural or linguistic standing of Deaf communities and its primary aim is the assimilation of Deaf children into hearing society” (McDonnell, 2016: 781). McDonnell writes that this approach continued to be embedded in policy development – referring to the Education Act (Ireland 1998a) which overlooks the central role of ISL and its importance in supporting access to education for deaf children, rather referring to it as a support service. Ultimately, the harm of normalisation is contained within its emphasis upon assimilation and its failure to embrace diversity. With the passing of the ISL Act (2017) we are witnessing a challenge to normalisation ideology. However, referring back to the notion of vulnerability, it is also possible to make links between normalisation ideology and present-day policies to see that normalisation remains embedded in the heart of Irish social policy making, framing widespread assumptions of deaf and disabled people as ‘vulnerable’, and in ‘need of targeted interventions’.

Along with this consideration of normalisation and deaf people - it is helpful to consider gender and sexuality in contemporary Ireland and how disabled people and women who did not fit into normative ways of being sexual were seen as deviant and subjected to methods of containment and marginalisation.

2.5.2 Gender and sexuality in contemporary Ireland

The Church and State have played a predominant role in shaping sexual and reproductive lives and women’s bodies in Ireland since the foundation of the Irish state in 1922. Bacik (2013) has highlighted the importance of the Charitable Bequests Act of

1844 which gave the Church institutional and societal power over schools, hospitals and social services in Ireland. As Ireland's fledging nation-state developed, strategic co-operation between the Church and State also grew and both became 'self-appointed guardians' of Irish citizens' morality and reinforcers of a conservative patriarchal Catholic hegemonic gender order (Garrett, 2016; Smith, 2007). This collusion and their response to women's rights following Irish independence was in contradiction to the expectations of Irish women prior to independence. Women played a prominent role in the struggle for independence and expected their contemporary conception of gender ideologies to be realised and reflected in subsequent legislation and public life (Valiulis, 1995; Garrett, 2016).

Fischer (2016) contends that the project of the national imaginary that emerged at this time was linked to efforts to distinguish the postcolonial Irish identity from British identity. This new vision championed key features of Irish national identity – "purity, chastity and virtue" - values advanced through authoritarian Catholic social teaching and "instituted a regime of inward-looking repressiveness" (2016: 822). For moral purity, read what was in practice sexual purity, "enacted and problematized through women's bodies" (Fischer, 2016: 822). This project designated women's bodies as the instruments through which Gaelic moral purity would be enacted whilst also being sites for purity to be enacted upon and simultaneously upheld as symbolic representations of Irish purity. The ideal identity of Irish women became constructed as virgin/wife/mother (Kennedy, 1999) and thus began a process of gendered containment that remained the most prevalent societal structure until the 1970's (Valiulus, 1995; Bacik, 2007), a structure that perceived sexual transgressions as "especially significant" (Garrett, 2016: 711). Legislation enacted had profound effects, restricting the role of, and physical presence of women, in the public sphere while simultaneously designating women's place as within the parameters of the (marital) home (Crowley and Kitchin, 2008; Kennedy, 1999). This new moral order was held with grave prestige, such that any potential or actual sexual transgression by women was identified as not only deviant behaviour but also a fundamental threat to the new national identity. Thus 'unmarried mothers' and their 'illegitimate children' became symbolic of the danger of those who dared to violated Irish morality and a core concern of welfare policies (Luddy, 2011). Seen as a threat to the purity of the new Irish nation state, such transgressors were subject to the ramifications of "shame, betrayal and exile" (Smith, 2007: 1).

Co-operation between Church and State led to the enactment of a considerable bedrock of legislation that effectively established Ireland’s ensuing containment culture and further constrained women’s rights (Smith, 2007). This phenomenon, termed the ‘architecture of containment’ (Smith, 2007: 2) was most evident in the institutions of “industrial and reformatory schools, mother and baby homes, adoption agencies, and Magdalen asylums among others” as well as the legislative, public and official discourse that framed them. At this time several commissions were occupied with examining social and moral issues prevalent in Ireland, which Crowley and Kitchin (2008) identify as contributing towards an intensified ‘disciplining regime’ and greater ‘institutionalised power’. Additional legislative pieces were introduced, drawing on Commission recommendations, which gave the states and its bodies further powers of intervention into citizens sexual lives and thus constructed a particular moral landscape in Ireland (Crowley and Kitchin, 2008: 355). This moral landscape led to the development of the network of powerful institutions named above - sites that women (and children) were physically contained in. These functioned to increasingly pathologise and institutionalise women, which, as Fischer (2016) contends, was part of the larger politics of shame leading to the changing “sexual landscape of Ireland” (Crowley and Kitchin, 2008: 355).

This is evident in the influential Commission on the Relief of the Poor (1927) report – a document which played an instrumental role in the containment of perceived ‘deviant’ women by performing a dividing practice where “‘two classes’ of ‘unmarried mothers’ were delineated: ‘those who may be amenable to reform’ and ‘the less hopeful cases’ ” (Commission on the Relief of the Poor, 1927: 68, cited in Garrett, 2016: 714). Mothers who were ‘first offenders’ were treated differently to mothers who had ‘fallen pregnant’ a second or more time outside of marriage. Containment or ‘detainment’ was advocated for the latter group of a period of up to two years through confinement to a Magdalene laundry, as opposed to a mother and baby home for a shorter amount of time (Fischer, 2016). These institutions have been identified as carrying out systematic human rights violations against what is estimated to be 10,000 women[29] in the period before and after the foundation of the Irish state.

The Church's influence was challenged and disrupted by feminists and civil rights activists from the 1970's onwards and women became increasingly visible in the public sphere with considerable socio-political advances also being made. The Irish women's movement mobilised and influenced social policy placing the issue of women and sexuality in the public realm and addressed issues such as; protection from male violence, legalising the sale of contraceptives and equal pay, amongst other issues (Kennedy, 1999; Galligan, 1998). A number of women's organisations urged the government to set up a Commission on the Status of Women which sparked later progressive legislative reform in relation to women's rights (Smyth, 1988). The 1980's onwards witnessed greater focus on sexuality and sexual politics (Smyth, 1988). Mary Robinson became President, divorce was made legal, more substantial workplace equality legislation was passed under EU influence and women continued to enter the labour force in larger numbers with more women also remaining in employment after marriage and while raising a family (Bacik, 2007; Kennedy, 1999, 2004).

During this time women were still subjected to "social, psychic and moral battering(s)" (Smyth, 1988: 341) from 15 year old Ann Lovett dying on her own in a Catholic grotto after giving birth to a stillborn child, to Eileen Flynn losing her job as a teacher for having a child outside of marriage and living with a married man and Sheila Hodgers dying in agony having given birth to a child while battling cancer. Each issue was extremely bitterly fought as can be seen in relation to the issue of rape and sexual assault law reform – a hard won battle with marital rape being criminalised only in 1990 (Ferriter, 2012).

While the Church's discursive and legislative influence over morality and sexuality (Inglis and MacKeogh, 2012) has waned, many services - particularly in the areas of

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[29] The State's report, Magdalen Commission Report, estimates that approximately 10,000 women entered a Magdalene Laundry from the foundation of the State in 1922 until the closure of the last Laundry in 1996 (DJE, 2009: I).

health and education - still remain under disproportionate control of the Church and it continues to have some hold on the sexual politics of contemporary Ireland. In 1983 a referendum made abortion unconstitutional through the 8th Amendment and the lives of women and children equal in Ireland (Bacik, 2007). The amendment was overturned in 2018, ending with one in three voters voting to repeal the 8th Amendment. Until this, women who had unwanted pregnancies were subjected to social and legal sanction and forced into illegally securing abortion pills online or leaving the country to access an abortion, thereby exporting the healthcare 'problem'.

Albeit advances have been made, women in Ireland continue to experience gender inequality and fight to advance their bodily integrity, freedom and equal treatment in the areas of reproductive health, sexual well-being, bodily autonomy and relationships, amongst other related areas. This is seen most recently in a major failure in cervical cancer screening resulting in a case where 221 women had not been told they had inaccurate smear test results, contrary to the HSE open disclosure policy. An audit revealed that 208 women had originally been given an all clear, false result. 162 women were not informed of their test result and at this time 17 have since died with others receiving a terminal diagnosis (Carswell, 2018). We are still living in tumultuous times for feminists where many continue to take solidaristic actions with the aim of challenging ongoing harmful effects of sexism and misogyny – evidenced in the larger context of responses to #MeToo movement which emerged in late 2017. Closer to home recent events such as the Belfast rape trial and response #IBelieveHer have sparked heated debates across Ireland about misogynistic attitudes towards victims of sexual assault, as well as the lack of accountability faced by perpetrators.

2.5.3 Current policy and legislative considerations

At policy and legislative level, a review of the Relationships and Sexuality Education (RSE) curriculum began in 2018. One way young people commonly access sexuality-related information is through the RSE curriculum, introduced into Irish schools in 1997. This programme evolved out of a particular socio-historical context associated with a number of events during the 1980's and early 1990's, such as the death of Ann Lovett and the rising challenge of HIV/AIDS, along with greater attention to public health. This sparked pressure for a formal school based sexual education programme

(Ferriter, 2012). Prior to this, sex education was primarily delivered by individual teachers within a Catholic moral framework that prioritised the discussion of sex as taking place within the context of heterosexual marriage and for the purpose of procreation (Kiely, 2014). It was argued that such education should only be delivered to young people in their teens. Kiely (2014: 301) describes sex instruction given in the 1960's as one that "according to many testimonies, left a damaging legacy. It was shrouded in mystery, made strong associations between sex and sin and put the responsibility squarely on women to be the enforcers of Catholic morality". When the RSE programme was introduced it was considered controversial and a number of clauses were attached to it; teachers who objected to delivering the programme could be exempt, children whose parents who objected could be exempt and finally while the programme was a compulsory element of the SPHE (Social and Personal Health Education) programme, the content was not prescriptive or compulsory and could be decided by the school community and thus adapted to their individual, religious ethos (Kiely, 2014). As Kiely notes, this effectively means that "students in Ireland do not have equal opportunities in their sex education learning" (307).

Other key developments include the introduction of Provision of Objective Sex Education Bill which is currently before the Oireachtas. In addition, policy actions such as the National Sexual Health Strategy of 2015 – 2020 and the National Strategy for Women and Girls 2017-2020 have been introduced.

This is the wider socio-political context in which this research is situated, and the intimate lives of deaf women are lived in. What is crucial is that the stories of deaf and disabled women are also spoken of and included in this context – which this research seeks to do so. Deaf and disabled women's needs have often been an afterthought or added in. This is changing as we can see with the strong voices of and representation of deaf and disabled women during the Repeal the 8th campaign (Edwards, 2018) and groups such as Disabled Women Ireland emerging in 2018. I argue that this approach must not continue to be novel - we must disability mainstream our feminist movements, research methodologies and policy developments to ensure that deaf and disabled women stand alongside hearing and non-disabled women and their stories are equally recognised and held with the same import.

2.6 What is left unproblematic in this problem representation?

In question four Bacchi directs us to consider, ‘what is left unproblematic in this problem representation? Where are the silences? Can the ‘problem’ be thought about differently?’. The task is to consider gaps, limits, the failure to problematise and highlight conditions by which “particular problem representations…take shape and…assume dominance, whilst others are silenced” (2009: 14). There is a dearth of deaf women’s representation, and little apparent participation of deaf representatives during the consultation period of the policies analysed earlier. This is not to suggest deaf groups have been deliberately excluded, but without conscious effort to engender deaf participation and representation the needs and interests of deaf women remain silenced or perceived as non-normative within the policy making process and a challenge to these ingrained views is lacking.

Shildrick contends that a major difficulty within the policy making process is “the widespread use of the reductive term ‘the disabled’ which encourages planners and lay people alike to lump a large variety of disabling conditions into a single category which denies the individuality of each person’s life” (2009: 124). This is a core practice across policy, contributing to misrepresentation of deaf women’s needs and lives. As Shildrick elaborates, this does not construct greater understanding of differences between a deaf person and someone with mobility issues. Thus, she highlights a significant practice contributing to how this problem representation of deaf women as vulnerable has come about. Moreover, where policy pays little attention to or has little to say regarding disabled or deaf women’s sexuality, it plays a significant part in constructing how disabled sexuality is thought about and puts down shutters to thinking about ‘normative sexuality’ differently. This has implications for how groups are responded to and promotes a ‘one size fits all’ approach. In its absence it is evident that deaf sexuality is not conceived of as an issue requiring policy attention. Thus, it is misrecognised (Fraser, 2004), and this says something powerful about what is considered to be ‘normative sexuality’ or who is considered to be ‘normatively sexual’ within national policy. I have discussed the census data in section 1.4. This data does not disaggregate deaf women who use English or ISL as their first language. Invisibility in data or statistics is often reflected by invisibility in policy. Fraser (2004) discusses this misrecognition as a harm that also impacts upon redistribution of resources, rights and entitlements.

From analysis thus far it is evident that deaf women are often subsumed within the general term ‘disability’ or represented as ‘vulnerable’ and thus at risk of their particular lived experiences and requirements being overlooked or misunderstood through this lack of/mis-representation. Women’s health status and life expectancy have improved in the past two decades as NWCI[30] (2017) details. However, as NWCI (2017: 6) maintains, there is a need for the differentiated health needs of women to be addressed - “the different experience of health between women and men remains absent from general health policy and service development and is most often confined to women only-illness”. At present no comprehensive national strategy on women’s health is in existence in Ireland. Additionally, nothing specific in relation to deaf women exists, instead being commonly conflated into research considering disabled people without regard to gender disaggregation or needs in terms of distinct impairments.

It is crucial to take a gendered approach to health in order to address health inequalities between different sub-populations of women and to meet Ireland’s international, EU human rights policy commitments, as well as domestic policy commitments (NWCI, 2017). Access to Irish sexual and reproductive health resources for deaf women is incrementally improving. A positive development is the response of Women’s Aid[31] to deaf women. Their website provides information on domestic abuse through ISL videos. Deaf women can avail of a text service to contact the agency and they will organise an interpreter of the woman’s choice. However, evidence from this research and elsewhere (Coogan and O’Leary, 2018; Steinberg, 2006; Begley et al., 2009; Leeson et al., 2014; CIB, 2017) indicates that there is still much to be done. In order to rectify lack of/mis-representation, deaf women must participate in, and be named in policy making, as well as have their discourse privileged. From this starting point deaf women can define and more accurately shape the concepts and problematisations that affect their lived lives and challenge experiences of exclusion and marginalisation.

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[30] NWCI is the National Women’s Council of Ireland – the leading national women’s organisation in Ireland.

[31] Women’s Aid is a domestic violence service in Ireland

2.7 What effects are produced by this representation of the “problem”?

Question five probes effects produced by this problem representation. Thus far, it is a way of coming to understand what the problematisation is reflective and constitutive of, opening up new ways of thinking about this and understanding that policy making is not a neutral process. Continuing analysis from this point considers how policy has consequences and might benefit “some and harm(ing) others, and what can be done about this” (Bacchi, 2009: 15). This brings attention to three effects of problem representation; discursive, subjectification and lived effects.

Bacchi (2009) explains that exploring ‘discursive effects’ questions how discourses used within policy direct us to think in certain ways and in doing so close off other ways of conceiving of issues. The conflated term ‘disabled people’ can promote the misperception that all disabled people’s needs are similar and can be addressed under the same model. It distracts from focusing upon how policies should be developed from a different starting point. The starting point should be the diversity of ‘women’, ‘pregnant bodies’, and ‘sexuality’ as opposed to an approach that ‘adds in’ cases that deviate from the ‘norm’. Deaf women should be recognised as women, mothers or sexual beings with different communication needs and cultural and linguistic identities. They should be represented as such within policies, not within an overarching ‘vulnerable’ or disabled category that misrepresents many deaf women.

‘Subjectification effects’ considers how people are positioned within policies through discourse used. This process can impact upon the subject, constructing how they might think about themselves and the world and can produce dividing practices (Bacchi, 2009) for example, vulnerable/not vulnerable, deaf/hearing. Representations of ‘problems’ “usually have built into them suggestions about who is responsible for the ‘problem’ (2009: 17). By designating persons as vulnerable, the ‘problem’ is located within their ‘inherent vulnerability’. It is difficult to ascertain how the majority of deaf people might feel about being referred to as vulnerable. Some participants in this research have identified it as an offensive term and dislike its application to them as individuals or a group member.

Regarding ‘lived effects’, Bacchi (2009: 17) refers to this as “the material impact of problem representations”. One form of lived effects can be conceived of as discrimination. Discriminatory attitudes can form a substantial part of the disabled person’s experiences. Disabled people are more likely to experience discrimination than a non-disabled person with on average, 15% of disabled people more likely to experience discrimination in comparison to 11% of non-disabled people (Banks et al., 2018: ix).

The National Survey of Public Attitudes to Disability in Ireland (NDA, 2017) found that public attitudes to disability and relationships have improved (NDA, 2006, 2011, 2017). Latest findings (NDA, 2017) revealed members of the public agree that disabled people have the same right to fulfilment through sexual relationships as everyone else. Agreement increased for people with vision or hearing disabilities (77% to 90%) and physical disabilities (76% to 88%) compared to 2011.

Researchers (Banks et al., 2018) who examined the relationship between discrimination and disabled people in Ireland report that there has been a fall in reported discrimination by disabled people since 2004. However, they also find that of 2014, disabled people were still 50% more likely to experience discrimination than a non-disabled person (2014: 8)[32]. Thus, while attitudes may be documented as improving, Banks et al., (2018) raise questions as to how substantial this change is if discrimination at this rate still occurs. Discriminatory attitudes can influence the internalisation of negative ideas and contribute towards ways of thinking and being that subject. Another form is the materiality awarded to dominant ways of knowing deaf women which has lived effects in the manifestation of this perception within institutions and policies.

Finally, deaf people have been marginalised because ISL has not been regarded or constructed as a language with equal importance to spoken English and thus deaf ISL signers have experienced effects of exclusion when accessing services and information (CIB, 2017). Within the following chapters I further address question five of the WPR through the empirical evidence discussed in the analysis chapters.

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[32] Disabled people were most likely to report discrimination when accessing health services with 19% of reports of discrimination by disabled people relating to this. In addition the report found that discrimination in public services (education, health, transport and other public services) was nearly three times higher for disabled people than those without.

2.8 How and where has this representation of the "problem" been produced, disseminated and defended?

In question six, Bacchi (2009) asks 'how/where is this representation of the 'problem' produced, disseminated and defended? How could it be questioned, disrupted and replaced?'. What practices perpetuate particular problem representations and how do these representations continue to reach groups and become 'knowledge?'. Thus far, my tentative WPR policy analysis has revealed much in terms of a tendency of policy to start from normative assumptions of sexuality and disabled bodies that promote normative ways of thinking and problem representation. I contend that this impacts upon the policy making process, resulting in policies performing a 'normalizing role' (Carabine, 2009). Regarding 'how could it be questioned, disrupted and replaced?', I set out to address this and question five and six by engaging with the narratives of research participants. These narratives disrupt and displace the normative construction of deaf women's sexuality and explore where radical possibilities lie, as identified from the spaces of resistance. As such I draw on Bacchi's (2009) notions of disruption and displacement and bell's (1989) notions of resistance and reimagining. Normative frameworks, along with the 'vulnerable' narrative elucidated in this chapter, are disrupted and displaced. They are then reimagined through framings of 'flourishing deaf women' by presenting narratives of deaf women's subjective and lived intimate experiences.

2.9 Conclusion

This chapter has used Bacchi's (2009) WPR approach to outline relevant contextual information within which this research is situated. I have discussed how deaf and gendered bodies are conceptualised and responded to by the state. I have also set out a methodology for examining how deaf women are currently located at discursive and policy level in Ireland. The next chapter addresses the empirical, conceptual and theoretical framework structuring this research.

Chapter 3: Literature review and conceptual framework

Part A: Literature Review

3. Introduction

> "Frameworks and theories are, in my view, meant to assist and develop our thinking, not restrict it"
>
> (Corker, 1998: 9).

In this chapter I draw on knowledge and theoretical understandings from different disciplinary fields such as sexuality studies, feminist disability studies, deaf studies, citizenship literature and others, with a focus on exploring and understanding how deaf women's intimate experiences are constructed. As outlined, limited empirical evidence on deaf sexuality through a critical deaf epistemological lens exists. Thus, this research makes a new contribution in this vein. In section 1.2 I noted the recent shift by Deaf scholars towards the value and positive attributes of being deaf. I extend this to encompass deafness and sexuality. This study works to trouble dominant ableist, normative constructions of deaf sexuality and contribute new ways of knowing deaf intimate lives.

A range of theories and concepts inform my research which Corker and Shakespeare (2002) label as a 'toolbox approach'. I take a three-pronged approach towards this chapter to provide a framework for understanding the exploration of deaf women's experiences of intimate citizenship. I begin by first drawing out empirical literature related to deaf and sexuality-related research in Ireland, as well as internationally. Within the second prong, I discuss core concepts, discourses, and critical scholarly work at the intersection of disability, deafness, sexuality and gender, and in the third prong I set out key theorising underpinning intimate citizenship.

I take a 'funnelling' approach towards presenting the literature and conceptual framework, starting quite broadly and then narrowing down to core concepts. I use theories as and when they are helpful to me following Hughes, Goodley and Davis (2012) suggestion to 'plunder theories unapologetically'. Liddiard (2018: 15) writes that “theory and theorising, quite rightly, can be messy jobs”. In her writing she states she has created “a right mess” applying multiple theories to understand and explore disabled peoples’ intimate lives, an approach which she regards as embodying critical disability studies. I follow the suggestion of the disability theorists cited above to draw from a ‘theoretical toolbox’ in order to carry out sense-making in my research, to develop a critique of the present and reimagine an alternative vision of the future. As such this chapter and thesis is not a neat ordering, instead reflecting “the contradictory messiness of human life, such that no category system can ever do it justice” (Plummer, 2011: 205).

3.1 Locating sexuality-related experiences in Ireland

Drawing on feminist conceptualisations, this research worked from the starting point that sexuality is a significant, multi-dimensional facet of the human experience throughout the life course. Sexuality is more than sexual identity and having sex, it is about affective attachments (Baker et al., 2004), personal relationships, how people are or are not considered sexual by others and by themselves (Jackson and Scott, 2010). Understanding factors shaping the wider experience of intimate lives is important to ascertain how flourishing in intimate life might be established and maintained and how the cultural and affective system plays a role in this (Baker et al., 2004).

Research available exploring sexuality and sexual health in Ireland is not extensive at academic or policy level. Relevant research is primarily from literature published under the HSE Sexual Health and Crisis Pregnancy Agency with significant investment towards three nationally representative reports on sexual health in the general population carried out between 2003 and 2010. However, as a recent HSE report (2018a) comments, these findings are not new and thus may not be reflective of the current situation. There is little information available on the sexual behaviour of young people (Young et al., 2018) or sex education in Ireland (Sherlock, 2012). Additionally, there is no specific sexual health and sexuality-related information in relation to deaf young people and adults available. Thus, research referred to is primarily drawn from an international base to contextualise the research analysis. I first outline what we know about the sexual health knowledge of young and older Irish people and deaf people. I then consider the wider informal and formal factors shaping this and along the way outline what is specific to deaf people's experiences.

3.1.1 Sexual health and sexuality-related knowledge in Ireland

Sexual health is shaped by "a range of socio-cultural, psychological, physical, cognitive, religious, legal, economic and political factors, a number of which adults and young people have no control over" (Young et al., 2018: 15).The authors (2018) collected nationally representative data from 4494 young people in Ireland aged 15 -18 years old to examine sexual health behaviour and the context in which this behaviour occurs. This survey does not examine access to sexual health related information. Findings reflect that 25.7% of boys and 21.2% of girls were sexually initiated and unprotected sex at last intercourse was reported by 10.5% of boys and 6.8% of girls. The latest HSE (2018a) sexual health report notes that initiation of heterosexual sexual activity trends has remained stable at eighteen years old between 2003 and 2010. Given the time lag these statistics may not be representative of the current situation.

Hyde and Howlett (2004) note that young people highlighted gaps in their knowledge on sexually transmitted infections (STI's). Recent research (HSE, 2018a) notes that STI's are on the rise in Ireland and that there is a concentration amongst two groups with young people having had the most notifications in 2016[33]. This is concerning, indicating nothing substantial has been done to address the 2004 findings. Ireland's 2016 HIV notification rate at 10.7% per 100,000 of population is higher than findings from the EU and EEA area rate of 5.9% per 100,000 (HSE, 2018a). Other commonly reported STI's are chlamydia, gonorrhoea, early infectious syphilis and genital herpes. Regarding knowledge about these STI's, the HSE (2018a) report references findings from a 2006 nationally representative general population study – the majority of women (74%) had heard of chlamydia with correct knowledge about it highest among young people (18-24) and women as well as other groups[34] (HSE, 2018a). 85% of survey participants expressed accurate knowledge in relation to HIV. A 2017 report with 1,000 people found good knowledge of HIV (HSE, 2018a). No information is given in this

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[33] The second group noted in this report is MSM (men who have sex with men).

[34] Other groups identified are those with a self-reported diagnosis of chlamydia, men self-identifying as homosexual, those with higher levels of educational attainment, those from higher social classes and those living in urban areas.

report about knowledge on other STI's (HSE, 2018a). The 2006 report notes that a higher level of education was a determinant of knowledge, as well higher social-class positions and this highlights "the importance of socio-economic inequalities in shaping outcomes" (119). They note that the reasons for the knowledge differential across groups are complex and not clear at time of reporting.

While the recent HI survey (2016) findings note that one quarter of the population reported using a condom, with one of the highest rates of condom usage being among young people aged 17-24 (61%), the 2004 (Hyde and Howlett) national survey report notes that young people had limited accurate general contraceptive knowledge. Young women in the 2004 report who used the contraceptive pill had often been prescribed the pill for period management. Young women in an urban environment reported less problematic access than young women in rural areas to family planning clinics. Rurally based young women reported feeling concerned that their parents may find out information from the local G.P. The HSE (2018a) report notes that the general population are knowledgeable about emergency contraception availability but are not informed about the effective timing window, with women and young people being most likely to have correct information. Interestingly, the 2018a report named 'cost, stigma and embarrassment' as 'access issues affecting contraception use and efficiency'. There is no specific attention to language, literacy, disability accessibility or the intersectional experience of disabled people across this report or other publications available on the 'sexualwellbeing.ie'[35] website.

International studies suggest a disparity between deaf and hearing people in relation to HIV/AIDS knowledge with a higher knowledge deficit amongst young deaf people and college students (Goldstein et al., 2010; Bat-Chava et al., 2005). Moinester et al., (2008), exploring HIV/AIDS risk, assert that young deaf people in the U.S. are at higher risk of contracting HIV/AIDS due to little formal sex education in deaf schools and barriers posed by the reliance of health campaigns on auditory technologies. Heuttel and Rothstein (2001) echo this, arguing that deaf people possess less knowledge due to communication barriers. However, Moinseter et al., (2008) could not find accurate

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[35] This website is an online sexual health resource for parents, professionals and others, run by the main statutory funded national programme for sexual health and crisis pregnancy – the HSE Sexual Health and Crisis Pregnancy Programme.

numerical data highlighting the prevalence of HIV/AIDS amongst deaf people despite a number of studies suggesting that HIV/AIDS runs higher among deaf people. Other research (Doyle, 1995; Joseph et al., 1995) found low consistent condom use among deaf college students and a high reliance on withdrawal (34 – 50%). A more recent study (Goldstein et al., 2010) reinforced these findings noting low levels of HIV knowledge among a sample of 700 deaf adolescents. Heiman et al., (2015) compared findings from 282 U.S. based deaf participants with a general population group. They found that deaf respondents in their research self-reported higher levels of sexual partners over the past year compared to the general population. They also found condom use was higher among deaf respondents, challenging the evidence cited above. However, this may not represent consistent condom use. They conclude that “deaf individuals have a sexual health risk profile that is distinct from that of the general population” (2015: 579).

While quantitative data cannot highlight the full complexity of this experience it is useful to begin with this to gather a sense of the issue before branching into contributing factors. It is also important to note that many of the cited pieces carried out research through written English and as Goldstein et al., (2010: 534) warn; “this is not an optimal method of surveying deaf adolescents whose primary language is ASL [American Sign Language]”.

3.1.2 Informal opportunities for building sexual knowledge

Hyde and Howlett (2004) explore 226 Irish post-primary students’ views on sexuality, sex education and influencing sexual socialisation factors. Key findings indicate that many young people do not discuss sex with their parents and implicitly and explicitly receive mixed messages from their parents about sex. Their research finds gendered messaging prevalent with parents frequently drawing on heteronormative ‘protective discourses’ to regulate female sexuality to keep young women safe from pregnancy and the ‘danger of men’. They note that the minority that did engage in discussion with their parents were primarily girls with their mothers. Mothers emerged as most likely to take responsibility for sex education. They also discuss that young women stated their sexual behaviour was more subject to policing by their parents in comparison to young men.

Analysis by Kelleher et al., (2013) draws on best international evidence which suggests that parents play an important role in this learning and should be involved in their children's sex education from a young age. Thus, research demonstrates that parents' influence is key to a young person's emotional and sexual development but that many young people do not discuss sex or relationships with their parents, even if encouraged (Hyde et al., 2009; Kelleher, et al., 2013). The HSE (2004) report comments that studies find that good communication with parents about relationships and sex has been linked with better use of contraception at first sex and a lower likelihood that the young person will have sex before seventeen years.

Other informal channels by which young non-deaf people learn about sex include friends and the media. In the Hyde and Howlett (2004) report young people, particularly young women, more commonly cited learning from and talking about sex with their friends than parents. However, information from friends was also regarded as less reliable than that from parents or teachers. Furthermore, young women were subject to regulatory practices by friends through shaming practices if their sexual behaviour was considered to diverge from normative gendered sexual scripts. Young women also reported that they sought information through print media such as teenage magazines which provided information in a less morally loaded way. From this research the authors identify that young people were subject to two prevalent discourses from these spaces; discourse of sex as male driven and discourse of sex as mediated with emotion (2004: 49).

Little information exists on young deaf people's sexuality-related experiences. While existing deaf-related studies do not often specifically reflect on sexual health, they indicate that young deaf people face difficulties when accessing general health information such as; "peer misinformation, inadequate school instruction, parental reluctance to provide health education and insufficient opportunities to acquire reliable information" (Berman et al., 2013; Bisol et al., 2008; Job, 2004; Smith et al., 2012: 42). In relation to deaf individuals, Hauser et al., (2010) refer to Swartz (1993) who found that only 2.9% of deaf individuals learned about sex from their mother in contrast to 23% of hearing individuals. This complex issue is compounded by communication barriers. If the parent lacks ISL fluency or does not possess a sexuality-related sign vocabulary, complicated relationships and sexuality conversations can become problematic and young deaf people may miss out on support and incidental learning (Hauser et al., 2010). Mathews (2015) comments that up until relatively recently in Ireland parents were not expressly encouraged to learn ISL and it is still debatable as to what degree supports are provided to parents learning ISL (2015: 4). As over 95% of deaf individuals are born into a hearing family who often have no experience with how deaf people live and learn, this can create barriers for deaf people from a young age (Hauser et al., 2010). Other research emphasises reliance by deaf students on friends for information, followed by media (Doyle, 1995; Heuttel and Rothestein, 2001).

The loss of incidental learning and informal access to knowledge presents an additional barrier regarding informal relationship and sexuality-related learning for deaf people. For example, when hearing individuals converse with each other at the dinner table, if the deaf individual is not fully involved, incidental learning is lost (Hauser et al., 2010). “Deaf children who do not have full access to everyday communication often do not see how adults express their thoughts and feelings, how they negotiate disagreements…” (Hauser et al., 2010: 488). This can have negative repercussions (Hauser et al., 2010). The lack of access to informal information about family health can lead to, for example, the knock-on effect of a deaf individual failing to be aware of what family history they need to provide to their doctor to ensure a full health screening. In addition, Mayer (2007) highlights literacy issues with findings that 50% of deaf students leave school with a fourth-grade reading level or less and 30% are illiterate when leaving school (Traxler, 2000). This has repercussions for deaf individuals with weaker literacy when researching information on the Internet or breaking down complex written information distributed by sexual health services.

Deafax, a deaf UK based organisation, carried out small scale research with deaf people (2014) on relationships and sex. 65% surveyed report receiving inaccessible sex education. Deafax noted that that deafness and sexual health is still an overlooked area. Sexual health messages that reach the hearing population are likely to be inaccessible to some deaf people. One reason for this is that deaf people may have difficulty understanding the material as their English literacy may be low. In addition, they may have difficulty in understanding new health/medical terminology that they have not encountered before (Smith et al., 2012). Additional issues are that sexual health education materials are often developed for a hearing audience as Goldstein et al.,

(2010) point out, whereby materials are disseminated through television, radio, and print media. “The messages provided through these media are not readily available to deaf individuals owing to inability to hear spoken English, low English literacy levels and the need for simplified captions” (525). This combination of factors can serve to heighten the risk for misinformation (Heiman et al., 2015).

3.1.3 Formal opportunities for sexual knowledge building

The RSE curriculum is another way young people commonly access information. Hyde and Howlett’s (2004: 9) research find that sex education in schools varies with participants reporting “factors associated with teachers and pupils, and prevailing ideologies about sex creating difficulties with its delivery”. Relevant information often came after young people had started to informally learn about sex, which respondents felt was too late. Additionally, key topics such as STI information were not covered. This issue was framed through young people expressing that they felt unsupported during a critical time in their life (2004). The authors (2004) suggest that the RSE programme and training of staff delivering sex education should be improved. They note that (2004: 12) “learning about sex and relationships is important for young people in order to ensure that they are comfortable with their sexuality, that they possess the skills necessary to negotiate sexual situations and that they are able to avoid the unwanted consequences of sex”. As their review ascertains, sex education programmes are vulnerable to critique, with research by Holland et al., (1998) finding that sex education aimed towards young women often contained a “protective discourse” centring on the dangers of sex and the vulnerability of young women (Kiely, 2006) what Fine (1988) refers to as the ‘missing discourse of desire’. We do not currently have insight into the RSE programme from deaf or disabled young people’s perspective.

The Irish Study of Sexual Health and Relationships (ISSHR) (Layte et al., 2006) was carried out with 7,441 adults aged 18-64. This finds that 72% of adults have received some sex education, increasing as age decreases, which is linked to the RSE programme only being introduced into schools in 1997, as well as more liberal attitudes developing around sex education at home and school over the past decades (McBride et al., 2010; Layte et al., 2006). 50% of adults in the ICCP (2010) research reported that they learned about sex at school only, 8% at home only and 32% from both. This also reveals that adults who have received sex education are twice as likely to use contraception when having sex for the first time. Interestingly, neither report explored women's experiences with onset of menarche.

Similar findings emerge in Leane's (2014: 28) research with 21 women born in Ireland between 1914 and 1955. She notes when growing up, "…women were denied explicit information about sexual matters. A lack of concrete knowledge about menstruation, copulation, conception and pregnancy was reported by all but two of the 21 women interviewed". Parents frequently avoided sexual topics and the participants learned about sexuality-related topics through informal sources such as friends or work colleagues. Her participants were subject to gendered, protective discourses promoting modesty with any discussion of sex presented through a framework of sin and risk.

There is limited knowledge of young deaf people's experiences of sexual knowledge building in either mainstream or deaf schools. The 2014 Deafax survey finds that sexual health information in school was not always accessible to deaf pupils. For example, they were shown videos without subtitles, resources had words they did not understand and there was a lack of visual information. Getch et al., (2001) in the U.S. finds that few teachers feel equipped to teach and communicate on sexuality issues, many feel unsure how to use appropriate sexual signs and do not have suitable materials (see also Suter et al., 2009). Suter et al., (2012) explore the views of young deaf people on school and home sex and relationships education (SRE). Surprisingly, in the context of findings from wider literature, young deaf people in their survey report a higher level of school SRE satisfaction than hearing young people. The authors conclude that there is still scope for improving SRE provision and a clear need to address the requirements of deaf pupils when designing lessons.

Mathews (2015) explored the gains and gaps in the life skills of Irish deaf vulnerable adults following a residential life skills programme. Health and pregnancy, parenting and childcare were documented as two areas amongst four where gaps remained[36]. Sexuality, sexual health, reproduction, contraception and childbearing were noted as concerns. Parents and staff expressed a lack of certainty concerning what knowledge the

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[36] Housing (knowledge of renters' rights and obligations)and legal knowledge (rights when arrested, function of a lawyer) were identified as the other two (2013: 11).

programme participants had about relationships and sexuality. Mathews concludes that "this gap in their knowledge leaves (participants) particularly vulnerable and should be addressed with a degree of urgency" (2015: 12).

Thus, we have a significant knowledge gap on the sexuality-related experiences and views of disabled and deaf people in Ireland. Therefore, I look internationally to build up a picture of the sexuality-related experiences of deaf people.

3.2 Research at the intersection of deafness, sexuality and gender

It has been argued that disabled women are frequently invisible within sexuality research due to the misleading societal belief that disabled people are either asexual beings, or unable to take part in sex as a consequence of their disability (Anderson and Kitchin, 2000). I argue that this insight has bearing for research related to deaf women and sexuality also.

Research exploring deaf women and sexuality typically emerges from a U.S. context. There is limited research from the global south, some of which is included here. An overview indicates that much of the published peer reviewed research has followed a 'deficit' approach with a prevalence of particular topics such as 'victimisation' or 'risks' for deaf women relating to sexual assault/intimate partner violence[37]. Other areas include sexual health behaviours of deaf people (Heiman et al., 2015), assessing sex knowledge and education gaps, needs and support[38] and HIV and AIDS related research[39]. My review indicates that, to date, research exploring gender, sexuality and deafness predominantly employs a victimisation/deficit/risk/vulnerability framework, reinforcing Joharchi and Clark's contention (2014: 1536) that "our understanding of sexuality in Deaf individuals is almost non-existent" and "available information focuses on myths, misunderstandings, and problems related to sexual health and behaviour". Furthermore, there is little research explicitly seeking the views of deaf women on their experiences.

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[37] See Wakeland et al., 2017; Ballan et al., 2017; Opshal and Pick, 2017; Elliot and Pick, 2015; Williams and Porter, 2014; Anderson and Pezzarossi, 2012; Anderson et al., 2011; Obinna et al, 2005.

[38] See Suter et al., 2012; Mprah, 2013; Job, 2004; Gabriel and Getch, 2001; Getch et al., 2001; Joseph et al., 1995; Gannon, 1998; Swartz, 1993; Fitzgerald and Fitzgerald, 1978.

[39] See Groce et al., 2007; Taegtmeyer et al ., 2009; Bisol et al., 2008; Bat-Chava et al., 2005; Osowole and Oladepo, 2000; Peinkofer, 1994; Kennedy and Buchholz, 1995; Doyle, 1995.

Until recently, dominant thinking focused upon deaf people as having insufficient sexual health knowledge relative to hearing peers; “children and youth who are deaf typically lack knowledge regarding human anatomy, birth control, sexually transmitted diseases (STD’s), emotions, responsibilities in relationships, and how to avoid contracting HIV/AIDS” (Getch et al., 2001: 402). Some research indicates that “rates of psychological, physical and sexual intimate partner violence against Deaf college and community women are nearly double compared with their hearing counterparts” (Anderson and Pezzarossi, 2012: 411). It is challenging to find empirical information that disaggregates information on the basis of gender and deafness outside of intimate partner violence (Kelly, 2008; Brueggemann and Burch, 2006). The ‘problems’ and ‘deficits’ orientated evidence (Joharchi and Clark, 2014) highlights the lack of available research in general and the dominant construction of deaf women’s sexuality. This has implications for how the sexuality of deaf women is perceived and responded to at policy and discursive level.

Two exceptions I discovered through extensive qualitative literature searching are Joharchi and Clark (2014) who use a model of generativity (described as success/feeling of accomplishment) to explore positive aspects of older deaf women’s sexuality satisfaction and well-being; and an MA thesis by Prior (2015) exploring deaf women’s sexuality experiences and knowledge in New Zealand. These were inspiring, troubling my lens of ‘deficit and vulnerability’ and demonstrating a new way of thinking about and approaching deafness and sexuality.

3.2.1 Myths and misconceptions

In the context of this empirical vacuum and the medicalisation of disabled people’s lives and bodies, myths and stereotypes of disability and sexuality abound. Within an audist/ableist culture these myths take on momentum and encompass a range of assumptions including that all disabled people are asexual (lacking any sexual feeling or desire) or paradoxically that all disabled people are hypersexual (Anderson and Kitchin, 2000). Such myths were found to be held in relation to deaf people also (Job, 2004). These myths and stereotypes have been documented as contributing to the continued marginalisation of disabled people within the sexual politics arena (Morris 1991; Shakespeare et al., 1996) and reinforcing barriers.

Myths noted in relation to sexuality and disability (Irish Family Planning Clinic (IFPA) 2007: 6) are;

- All disabled people are heterosexual
- All disabled people are asexual or hypersexual
- Information and education about sex will encourage 'inappropriate' sexual behaviour
- Intellectually disabled people are incapable of understanding sexuality
- Physically disabled people are unable to have sex
- Disabled people cannot / should not be parents
- Disabled people should be grateful for any type of relationship

Similar myths colour disabled women's experiences. Such myths found are that; disabled women are asexual, disabled women who are not married do not have sex and cannot be mothers; if a mother becomes disabled, her children are not getting a 'real' mother; in relationships, the non-disabled person manages the relationship; disabled women should be grateful for a sexual relationship; disabled women are too fragile for vigorous sexual activity; all disabled women are heterosexual (O'Toole and Bregante, 1992).

The combination of these myths with structural inequalities holds deeper challenges– whereby disabled women might internalise these ideas, prevent themselves from engaging in romantic relationships or seek to pass as non-disabled (O'Toole and Bregante, 1992). Tilley (1996) reports that the further danger is the consequence that disabled women are often less likely to have sex education classes or to have received basic sexual health such as cervical screening[40]. The IFPA (2007: 2) stresses that without access to sexual health services and information disabled women are vulnerable to "unplanned pregnancy, poor self-image, possible fertility problems, STI's, sexual violence and dissatisfaction with relationships and sex".

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[40] The CervicalCheck programme in Ireland provides free cervical screening (also known as pap smears) to women aged 25 – 60. This screening is a way of testing for abnormal cells in the cervix (neck of the womb) which if not detected and treated could develop into cervical cancer (HSE, 2018b).

Job (2004) finds ‘mythconceptions’ also apply to deaf individuals and details them as being that;

- Deaf individuals are eternal children and asexual
- Deaf individuals need to live in environments that restrict and inhibit their sexuality, to protect themselves and others
- Deaf individuals should not be provided with sex education, as it will only encourage inappropriate behaviour
- Deaf individuals should be sterilised because they will give birth to children who are also disabled
- Deaf individuals are sexually different from other people and more likely to develop diverse, unusual or deviant sexual behaviour
- Deaf individuals are oversexed, promiscuous, sexually indiscriminate, and dangerous and you have to watch your children around them
- Deaf individuals cannot benefit from sexual counselling or treatment

These myths are assumptions that become problematisations embedded in policy (Bacchi, 2009) and that have materiality in relation to governing of bodies. As Jorachi and Clark (2014: 1537) note, these ideas have evolved, were explicit in the past and may still be implicit today. They warn that we must be cognisant that these myths “influence us, limit our approaches and understanding of Deaf sexuality and leave us without an understanding of Deaf sexuality”.

3.3 Deaf women and sexuality - the Irish context

While the right to equitable access to health is enshrined within national and international legislative frameworks, it is also documented within the limited literature that many deaf people are frequently denied equitable access to health services (CIB, 2017). This has meant healthcare engagement is often a difficult experience for deaf women (Conama and Grehan, 2002; Steinberg, 2006; O’Connor et al., 2006). Moreover, disparities in healthcare access and tensions between the medical and social model[41] understanding of disability have been identified as leading to unequal health outcomes for deaf people.

Lloyd (1992) cited in O'Connor et al., (2006) found that disabled women identified sexuality and reproduction as primary sites of discrimination. Steinberg's research (2006) exploring how deaf mothers in Ireland negotiate access to maternity care and the inequities faced, notes little systemic change since other similar Irish research twenty years previously (Doyle et al., 1985). Steinberg (2006: 250) notes that the challenge for deaf women lies in negotiating their own "self-identity as a healthy Deaf individual and the medical system's view of them as disabled". This speaks to the crux of my own research also. Deaf women have grappled with medical authority over their bodies in many contexts, through occupying both a deaf body and a female body.

Begley et al., (2009) carried out an extensive Irish study examining policies governing procedure and practice in service provision during pregnancy, childbirth and early motherhood. 123 policies relating to disability, women's health and provision of health and/or maternity services and care, were examined. Of these, three considered the needs of women with disabilities during maternity care and all three were from the UK context[42]. This showed mixed experiences for deaf women (Begley et al., 2009) and raised points pertinent to this research – discussed in section 1.3. There are a number of factors contributing to these structural and institutional inequalities. In light of this it is worth considering what ideological and social factors contribute to shaping these inequalities.

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[41] The social model and medical model of disability are the two most commonly cited 'models' of disability. The medical model is understood as viewing disability as a problem natural and inherent in the body or mind of an individual person and should be responded to by being 'fixed', 'cured' or 'protected'. The social model argues that disability is caused by the way society is organised and that social barriers and structures must be challenged and removed to tackle disability (Shakespeare, 2014; Thomas, 2006).

[42] Anecdotal evidence suggests the situation remains much the same. Sarah-June O' Regan, a deaf Irish mother who uses a cochlear implant (CI) and identifies ISL as her first language, spoke on the Late Late Show in March 2017, as well as in a 2017 RTE 1 documentary 'Deafening', about her experiences of maternity care in the labour room in 2016. Sarah-June's request to wear her cochlear implant was ignored during her labour thus meaning she was denied the profound opportunity to hear the first cries of her twins being born. Alongside this, a barrier placed at the top half of her body prevented her from seeing the doctors or any other labour room information during the C-section - thus denying a deaf woman who exists primarily in the visual world, particularly without their CI, any insight into what was happening in the labour room. This meant an Irish Sign Language interpreter had to be brought into the room and be present at what is a private, sensitive time for many people. While some deaf women may have no issue with an interpreter being present, others prefer to manage the labour themselves without an interpreter.

Part B: Conceptual Framework

3.4 Introduction

The previous section provided a critical review of key empirical literature to contextualise deaf women's intimate experiences. This section identifies and problematises key concepts, discourses and critical scholarly work at the intersection of disability, deafness, sexuality and gender. As noted, there is limited deaf related academic scholarship and thus I draw more on literature considering disability and sexuality.

3.5 Feminist disability studies (FDS)

> "We need a feminist theory of disability…because the oppression of disabled people is closely linked to the cultural oppression of the body. Disability is not a biological given; like gender it is socially constructed from biological reality"
>
> (Wendell, 1989: 104).

FDS takes an intersectional approach to understanding how disability is bound up with other categories of identity; gender, sexuality, class (Garland-Thomson, 2011). As Shuttleworth (2007a) and others (Finger, 1992; Shakespeare et al., 1996) have agreed, the intersection of disability and sexuality fell under the radar in agitation for rights for disabled people for a long time. Disabled feminists called attention to issues faced by disabled women (Fine and Asch, 1988; Morris, 1996; Thomas, 1999; Waxman and Finger, 1989; Zitzelsberger, 2005) and shared feelings of being unseen in regard to their lives, experiences, bodies, capacities and desires. Issues of interest to disabled women (reproduction, motherhood, sexuality and gender) were ignored in pursuit of issues deemed to be connected with the public sphere. It is argued that this exclusion remained unheard until recently (Lloyd, 2001) with the consequence that the body, impairment and subjectivity was omitted in both disability and feminist writing. In response feminist disability and critical disability research has worked to challenge dominant constructs of embodiment, disability and sexuality – constructs rooted in sexism, ableism, ageism and heteronormativity (Campbell, 2017).

Within disability literature it is acknowledged that disabled people have “rarely (been) regarded as either desiring subjects or objects of desire”, rather being “depicted in terms of either tragic deficiency or freakish excess” (Mollow and McRuer, 2012: 1) - views connected to the myths detailed earlier (Morris, 1991). Furthering points noted in the previous section, as a consequence, disabled people’s sexuality has historically been overlooked, their basic human rights in relation to sexuality have been ignored, sexual expression has been denied, access to sexual services has been limited and their participation in society has been marginalised (Peta, 2017; Bonnie, 2014; Cheng, 2009; Anderson and Kitchin, 2000).

Disabled people have experienced a lack of sexual autonomy, infringements on their sexual relationships and legal and constitutional forces that disrupt their ability to live their sexuality to full capacity (Siebers, 2012). As Cheng (2009: 114) identifies, as a consequence of such oppressive attitudes “disabled people of all genders may find that they have fewer opportunities for love, relationships and even parenting”. Additionally, as a consequence of this ubiquitous denial of their sexuality and of cultural notions of beauty and the abled body many disabled people have internalised ableist notions of sexuality and disability and express feelings of pain and psychological struggle in relation to their own sexuality (Rembis, 2009). “For women, disability often means exclusion from a life of femininity, partnership, active sexuality and denial of opportunities for motherhood” (Addlakha et al., 2017: 4).

However, increasingly academics and activists highlight and address the embodied inequalities that disabled people face whilst also identifying the pleasures, positive sexual self-identification, desires and practices of disabled people’s sexual lives (Shakespeare and Richardson, 2018; Liddiard, 2018; Kulick and Rydström, 2015; Shakespeare, 2014; Mollow and McRuer, 2012). The medical perspective alone views a person with impairment as belonging to a category, “displacing them as subjects” (Shakespeare et al., 1996: 3) and often reduces people to dysfunction or ‘deficit’ (Rembis, 2009). It is crucial to understand gender, disability and sexuality as lived, embodied experiences that are “constitutive features of the ways in which our fully integrated selves are…lived and known” (Hall, 2015: 89) and moreover disabled people must be recognised as the experts in their own lives. It is also crucial to address ‘the missing discourse of pleasure and desire’ a common occurrence at the intersection of sexuality and disability (Tepper, 2000) to avoid perpetuating the false asexual notion attributed to disabled women as well to as tackle embedded inequalities.

3.5.1 Applying concepts from an FDS framework

Through emphasising the feminist motto, ‘the personal is political’ (Kennedy, 1999) feminist writers challenge the narrow focus of the social model of disability on physical and social barriers. The social model emerged from Union of Physically Impaired Against Segregation activists who argued “it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (UPIAS, 1976: 3 cited in Shakespeare, 2014: 12). More recent critical FDS work developed an understanding of the gendered experiences and impacts of disabilism and “how the social forces that construct and give shape to gender and disability are closely intermeshed” (Thomas, 2006: 178).

Furthermore, feminist researchers contend that the disability/impairment binary reinforced the putative disembodied public/private dichotomy that feminist work revealed by interrogating the claim that disability was public and impairment was private (Bê, 2012). This contributed towards societal perceptions of disabled sexuality and disabled people’s “lack of sexual culture” (Siebers, 2012) as well as the further exclusion of disabled women from the public sphere by ignoring the topic of sexuality (Shildrick, 2007). The FDS approach brings a new focus to disability and in turn assists an “analytical focus on the intersection of disability with other social identity categories, currently missing from much disability and sexuality research” (Liddiard, 2018: 12) as well as developing ideas on psycho-emotional disabilism and embodiment.

3.5.2 Psycho-emotional disabilism

Thomas defines psycho-emotional disabilism as a process by which oppressive words and actions can impact upon disabled people’s emotional wellbeing (Thomas, 2007). She extends her theorising on disabilism to being “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (2007: 73).

This concept ties into the feminist deconstruction of the public/private divide and the 'personal in political', by offering a nuanced understanding of how oppression can be experienced on an emotional and psychological level, as opposed to just public and outside the body (Thomas, 2007; Reeve, 2014). Psycho-emotional disabilism "is a form of disabilism that works with and upon gendered realities…and frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden" (Thomas, 2007: 182).

It draws on an understanding of disabilism as a social oppression, comparable to that of racism or sexism and recognises the presence of both structural disabilism (barriers to doing) and emotional disabilism (barriers to being) (Reeve, 2014: 123). This occurs when disabled people must manage behaviours and attitudes they encounter in interpersonal interactions and relationships that work to devalue or undermine an individual's self-esteem, confidence and self-worth. One example is, "being denied access to family planning services because of assumptions about disabled people as asexual and undesirable" (Reeve, 2014: 123). There are direct and indirect forms of psycho-emotional disabilism (Reeve, 2014) with direct forms being conveyed in ways such as stares, words, or actions – for example, hearing people staring at deaf people signing or a hearing person dismissing a deaf person's request to repeat what they said. Actions and words can be equally harmful such as treating a deaf person dismissively or asking rude questions. These forms of interaction can be experienced as pathologizing and a disabled person may seek to practice emotional work to manage this by avoiding an interaction or engaging with people in particular ways to educate them or by passing as 'normal' (Reeve, 2014).

Reeve (2002) explains that psycho-emotional reactions can manifest differently, for example as; frustration, shame, humiliation, upset or pain - and are a response to structural and attitudinal barriers. Reactions can also be internalised differentially, such as internalising the belief that one does not have the right to be a sexual person (Reeve, 2002: 495). Reeve draws on work by Campbell (2009) who suggests that internalised disabilism can be witnessed in the ways disabled people take on ableist norms or attempt to 'pass' as non-disabled. Thomas (2007) asserts that while it is difficult, it is possible to resist this through accessing collective support. Reeve (2002) adds that psycho-emotional disabilism does not play out identically for all disabled people as not all disabled people are the same, and their access to community supports differs.

From this we can understand indirect emotional impacts of structural discrimination, described as knowing one is ‘out of place’[43] (Reeve, 2014). Structural discrimination takes varying forms from inaccessible audio information, to no interpreter being provided. The way in which reasonable adjustments are provided can also be harmful emotionally if provided in a way that disregards a disabled person’s dignity, such as accessing a building by going in the back way behind bins. For a deaf person this might present as a hearing person writing short, brief notes that lacks relevant information which causes feelings of frustration through being denied full, in-depth information. It is a complicated, nuanced experience that can be mediated by a number of factors, such as cumulative occurrences (Reeve, 2014). This form of disabilism is harder to tackle than physical, infrastructural forms which can be addressed through policy and legislation more easily (Reeve, 2014).

Linked with this are the notions of carrying out gendered, emotional work (Hochschild, 1983) which Wong (2000) contends disabled women carry out when dealing with barriers in sexual and reproductive healthcare. Liddiard (2014, 2018) has explored disabled people’s experiences of intimate relationships and argues that her informants emotional and gendered work of manging their own feelings and others constituted a form of psycho-emotional disabilism. She articulates that women have primarily been found to carry out the labour of emotional work in relationships. Male participants in her research also encounter emotional work which is shaped by “a gendered sexual culture that privileges hegemonic masculinities” (2018: 84). For example, male participants stayed in relationships with women they did not love because they feared never finding another partner or overlooked cheating by their partner. Other forms of work she discusses is teaching partners how to care for physical needs, which also requires emotional management. In this research it could be understood as teaching

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[43] This is when being out of place is felt on more than a material level – when the hearing loop or subtitles in the cinema are not working the deaf person is not just excluded from the film, they can feel frustrated and upset that they have wasted time travelling to a film, paid for tickets and now they cannot enjoy a film that they were looking forward to and they are excluded in a way that other hearing people at the same film are not.

partners how to communicate effectively and emotionally managing any frustration or requirements for patience that ensue.

3.5.3 Embodiment

Disabled feminists interrogated the social model and argued that it was problematic for ignoring the role that 'bodies and brains' played in disability (Shakespeare, 2014). They contended that its rigid impairment/disability distinction whereby 'impairment' is defined in individual and biological terms and 'disability' social terms (Shakespeare, 2014) played a role in this. A parallel can be drawn here with the sex/gender distinction whereby impairment is to sex, as disability is to gender. Disabled feminists began to problematise this distinction by arguing that the experiences of impairment, subjective experiences and the reality of the material body were being written out (Liddiard, 2018) and in fact, private and intimate lives are deeply important aspects of the experience of disability (Bê, 2012). While we know something of public experiences (education, language and access to health care) of deaf women we know little about private, embodied and subjective experiences.

> "Embodiment is a way of thinking about bodily experience that is not engaged solely with recovering the historical mistreatment of disabled people. Rather, it includes pleasures, pains, suffering, sensorial and sensual engagements with the world, vulnerabilities, capabilities and constraints as they arise within specific times and places"
>
> (Wilkerson, 2015: 67).

This approach recognises the importance of the body in everything we do, the social meaning that is attached to the body and how the body is experienced relationally, physically and socially and that this is deeply intertwined with one's sense of self (identity and subjectivity). The body is not just a material object, but also a social entity from which we 'perceive and experience the world' (Tolman et al., 2014).

Tolman et al., (2014: 761) further describe embodiment ideas as emanating from the work of Merleau-Ponty (1962) to explain that the experience of the body in the world is a 'genuine experience' of the body in itself. It cannot be reduced to a rational - confined to mind -understanding or experience. Our bodies also feel, are aware, have sensations, “it is a form of subjectivity, manifested bodily” (Wilkerson, 2015: 68) named as lived embodiment that consists of intersectional experiences tied to identity. This approach usefully critiques, and challenges disembodied ideas underpinning liberal individualism – that of the “normative, able-bodied, white, bourgeois, heterosexual man” (Wilkerson, 2015: 68). It promotes the idea of intercorporeality, that embodiment is never individual but interdependent and contoured by our engagement with other bodies. Furthermore, it insists that bodies are deaf, gendered, disabled and that embodiment is not fixed. It is a process, a ‘doing’. Drawing on ideas of embodiment allows me to explore how sexual subjectivities are produced, how these intertwine with deaf identity and how a deaf gendered identity is embodied.

3.6 Building an intersectional approach: FDS and Deaf Studies

Intersectionality, a term coined by Crenshaw (1989), examines and explains overlapping and interconnecting systems of oppression, processes of oppression and relationships between and within social groups that can lead to multiple inequalities. This non-hierarchical concept was first developed by black feminists to challenge gender as the sole category of analysis in feminism and explain inequalities experienced by working class black women. It has been developed and expanded to examine other areas of marginality and identity beyond the gender-race-class triumvirate. FDS academics (Meekosha, 2007; Garland-Thomson, 2011) criticise feminist studies for failing to widely include disability when theorising, despite intersectionality approaches being widely used in feminist work.

More research explicitly using an intersectional lens exists in the FDS arena and as Campbell (2017: 4) identifies, the intersectional lens is;

> “of particular value to disability-sexuality research because it presents scholars with a means to further examine disability and sexuality in relation to social identities and experiences such as race, religion, ethnicity, age, socioeconomic status, gender and sexual orientation”.

As an example, it can be used to examine the fact that deaf and disabled women experience higher rates of violence than non-disabled women and may experience this differentially (Anderson and Leigh, 2010; Conejo, 2013). Incorporating a critical intersectional lens is crucial not only for an intersectional understanding of deafness, gender and sexuality in relation to other social identities and the wider context but also for strategically identifying how social change and social justice can be achieved (Baker et al., 2004).

Recent deaf studies' research shows better recognition of the need to prioritise an intersectional lens to consider the complex ways in which "ethnicity, gender, sexual orientation, class, family and nationality shape the experience of being deaf" (Kusters et al., 2017: 11) and particularly how these mutually intersect to shape everyday experiences (Mauldin and Fannon, 2016; Friedner, 2014; Valentine, 2007). Valentine and Skelton (2003) point out that deaf people with other disabilities have had to fight to get their needs met within deaf communities, thus an intersectional lens is crucial. There is minimal research considering the intersectional sexuality-related experiences of deaf women in Ireland, and so seeking to address this knowledge deficit I draw on Meekosha (2007: 163) who advocates that "if gendered, racialised and disabled bodies are all part of a broader process of exclusion (where all bodies are patterned by each of these parameters); strategies for inclusion must similarly be integrated".

3.7 Weaving deaf studies and disability studies together

Traditionally, tension has existed between Deaf and Disability Studies (Corker, 2002) described as "(e)strange(d) bedfellows largely as a result of deaf studies scholars' and deaf lay people's uneasy relationship with the category of disability" (Friedner, 2017: 129). Historically, Deaf Studies has stressed the sharp distinction between the two. Padden (2005) locates this by explaining that for a long time deaf people viewed themselves as segregated from non-deaf people by virtue of attending separate deaf schools and sharing a separate collective cultural and linguistic life. Deaf history and culture developed through the lens of segregation. Deaf people thereby situated their arguments for discipline segregation in the collective identity of deaf people being different to the political interests of the disability movement (King Jordan, 2005). Thus, the disciplines developed divergent interests and viewpoints. I do not contest the validity of the deaf experience or the need for the separate existence of Deaf or Disability Studies. However, I think, given the strong overlaps between the two, the constructed nature of deafness and disability and the "commonality of experience and philosophy" (Robinson and Adam, 2003: 2) that both have insights and ways forward to offer each other.

Deaf academic, Friedner (2017) notes that recent Disability Studies' intellectual trends are worthy of consideration. "The concept of disability is a function of the concept of normalcy" (Davis, 1995: 2). In distinguishing how bodies deviate from this norm, normalisation operates to set a standard of how people should look and how bodies should perform. This concept can also be applied to diversity in language modality, speech, and sexuality. Individuals who sign, deviate from the spoken modality and those whose bodies do not perform to particular aesthetic standards are not sexual.

This links with Foucault's understanding of biopower and disciplinary power (1991) over and on bodies. He regarded disciplinary power as functioning through techniques of surveillance that authoritive figures such as schoolteachers and doctors have a key role in operating (McDonnell, 2007) and through norms that determine particular bodies as acceptable and others as abject (Tolman et al., 2014). Biopower is power over life and can be experienced individually and at group level (Taylor, 2017). Disciplinary practices are productive - concerned with shaping and normalising individuals to encourage homogeneity. Those who deviate are abnormal and will be adjusted through corrective measures (Lilja and Vinthagen, 2014). Biopower focuses on regulation through monitoring, organising and controlling populations and working to manage large demographic groups (Taylor, 2017). It works differently to disciplinary power – rather working through the state and governmentality strategies such as standards of living and health. Through power exerted through norms and practices bodies are coerced and regulated into behaving in particular ways and "we come to internalise these norms or discourses and embody them" (Tolman et al., 2014: 761).

Foucault also argued that that power through discourses was productive of subject positions and how bodies are experienced – subjectivity (Carabine, 2009). This developed an understanding of bodies as not just material, biological things but also social, contoured through social processes. Also important is Foucault's theorisation of the development of knowledge about sexuality – that ‘knowledges’ about sexuality constitute ideas of what is ‘normal’ in relation to sexuality and bodies (Carabine, 2009). Knowledges that inform social policy making is another knowledge/power nexus technique relating to sexualities and bodies. Carabine (2009) refutes a key critique of Foucault’s work on knowledge/power that it positions individuals as passive victims of discourse – contending that individuals are active agents in resisting and reshaping discourses.

Connected to ideas of normalisation are two other important concepts; disabilism and ableism. Campbell (2009) has offered useful definitions of each concept. Disabilism is defined as – “a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities” (2009: 4). Responses to disabilism typically encompass strategies such as challenging disablist attitudes, promoting mainstreaming and assimilation of disabled people and developing a safety net of benefits and legislation to protect against discriminatory practices (Campbell, 2009). Structural and institutional inequalities within civil society are targeted while values in the cultural arena are also targeted. Ableism is distinguished (Campbell, 2009: 5) as; “a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is then cast as a diminished state of being human”.

3.7.1 Audism, dysconcious audism and phonocentrism

Deaf Studies’ scholars have put forward the concepts of audism, dysconscious audism and phonocentrism. These concepts serve as a way to describe and name discrimination towards deaf people and assist me in developing a critical exploration of deaf women’s access to intimate citizenship.

Deaf scholar, Humphries first coined the term ‘audism’ in 1975. Audism frames the systemic nature of oppression and negative attitudes and experiences encountered at different levels (individual, institutional, metaphysical) to understand how discrimination against deaf people is perpetuated (Bauman, 2008).

> “[Audism] appears in the form of people who continually judge deaf people’s intelligence and success on the basis of their ability in the language of the hearing culture. It appears when the assumption is made that the deaf person’s happiness depends on acquiring fluency in the language of the hearing culture” (Humphries, cited in Bauman, 2008: 240).

It is rooted in the notion of hearing superiority (Bauman, 2008). Davis (1995) refers to this as ‘the foundational ableist myth’ resting on audist assumptions that the norm is to receive language via the ear and communicate via spoken modality. It is an oppressive normalisation practice bound up with ableism (Bauman, 2008) and has implications for policy and practices impacting on deaf women’s intimate citizenship. Audist practices can include expecting a deaf woman to adjust to a hearing service providers’ modality of communicating, as well as a refusal to accommodate communication requirements. This can result in inequitable health outcomes as a result of failing to adequately access information and services (Begley et al., 2009; Steinberg, 2006).

Gertz expands upon work on ‘dysconscious racism’ to develop her articulation of dysconscious audism. She writes that dysconscious audism is a form of audism, related to impaired consciousness, whereby some deaf people “tacitly accept dominant hearing norms and privileges” (2008: 219). She emphasises that this is a distorted way of thinking about deaf consciousness that some deaf people experience. This way of thinking reproduces the ideology that because hearing society forms the dominant majority this makes it more acceptable. She contends that some deaf people do have deaf consciousness but have yet to become fully aware of the wider context of inequality impacting them. They may also internalise aspects of this oppression. In other words, some deaf people may not recognise discrimination they encounter as being in relation to their deafness. This has implications for whether deaf women name particular experiences they have as related directly or not to their deafness.

Finally, Deaf Studies draws on Derrida’s critique of phonocentrism to articulate the process through which deaf people are disabled, described as the phonocentric nature of society (Emery, 2009). This argument contends that “the primacy of speech and phonetic writing in language is not a ‘natural’ human attribute, but the result of a metaphysical and historical prejudice” (Bauman, 2008: 1). It is the belief that spoken communication is most desirable, and society should be organised around spoken language (Corker, 1998).

3.8 Resisting Audism through DEAF-GAIN

As noted earlier, deaf scholars have recently begun to challenge audism by engaging in a discursive shift – moving language and lens towards the value and positive attributes of being deaf. DEAF-GAIN (Bauman and Murray, 2010) is an important aspect of this. The DEAF-GAIN framework proposed by Bauman and Murray (2014) challenges the socially constructed norm of the able-bodied, hearing individual by developing affirmative language and a positive lens on the contributions, value, strength and worth of deaf communities and sign language. This deliberate use of language moves away from a 'loss' or 'deficit' tone (i.e. 'hearing loss' or 'hearing impaired') - instead highlighting the gains and benefits of bio-diversity (Harmon, 2010). It is defined as the "notion that the unique sensory orientation of Deaf people leads to a sophisticated form of visual-spatial language that provides opportunities for exploration into the human character" (Bauman and Murray, 2010: 216). Using this lens allows for a greater understanding of how both deaf people and wider society are 'better off' in some ways because of the existence of deaf people.

There are three dimensions to DEAF-GAIN (BENEFIT, CONTRIBUTE, AHEAD). A number of benefits of DEAF-GAIN are outlined by deaf people in the individual sense. These comprise "enhanced and prolonged eye contact, intersubjective engagement, collectivist social patterns, transnational bonds, less auditory distraction and acute visuospatial aptitudes – all of which contribute to a new perspective on what it means to be deaf" (2014: xxvii). CONTRIBUTE - regards deaf/sign language communities as contributing gains to wider humanity (Bauman and Murray, 2014). An example is that speech is not the only kind of modality by which to produce language. The third dimension is AHEAD. Bauman and Murray articulate that this, "might be understood that deaf people are either poised to transform or have already transformed their benefits and contributions into the public sphere in ways that represent thinking that is ahead of their hearing counterparts" (2014: xxix). They give examples of how deaf people have contributed to architecture through their visual and spatial abilities.

I operationalise this concept in three ways. Firstly, conceptualising deafness as 'gain', not 'loss'. According to Paul (2016: 191) "…the focus on gain might lead to creative solutions to promoting inclusion, employment and a better quality of life for many d/Dhh[44] individuals". Secondly, harnessing anti-stigmatising concepts such as 'flourishing', as through my own research, allows deaf scholars to identify positive, sustainable ways forward towards flourishing of all deaf women, as opposed to focusing upon barriers and obstacles. deClerck, a deaf academic writing in the context of the human rights principle of sustainability and sign language, contends that sustainability requires reflexivity on 'realised and unrealised possibilities of being deaf' (2016). Here, I am exploring the realised and unrealised possibilities of being deaf and sexual and what we can do to achieve transformative, sustainable change and I find much resonance in the concept of 'flourishing'. Linked with resisting audism through DEAF-GAIN is the concept of social capital – how deaf people foster DEAF-GAIN through social capital. Finally, I use DEAF-GAIN to CONTRIBUTE new thinking and bring knowledge of deaf women and sexuality AHEAD.

3.9 Theorising on social capital

Bourdieu (1986), Coleman (1988) and Putnam (1993) have dominated contemporary theorising on social capital. There is no undisputed social capital definition (Martikke, 2017). Franklin (2007) notes that we can loosely understand social capital as a productive resource accumulated from social networks, as benefits from attachment to networks. Concepts, such as trust, connections, social support, reciprocity and civic norms are central to the concept - emerging from the relationships in these networks and in turn enhancing them (Blaxter and Hughes, 2000).

Bourdieu developed a typology of social capital connected to class (economic, social and cultural) and conceptualised this as valuable resources which an individual can gather and tap into through their social networks (Arneil, 2006). This approach highlighted the 'dark side' of social capital where social inequalities and exclusionary ideals can be reinforced. Connected to Bourdieu's concept of 'habitus' (1977), this demonstrates how individuals' opportunities and networks can layer their embodied

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[44] The d/Dhh acronym stands for deaf/Deaf and hard-of-hearing.

social capital and act to embed unequal social positions. Mithen et al., (2015: 27) assert that these inequitable power features are pertinent to disability, “as people with disabilities are often marginalised and economically disadvantaged in society”. This is seen in respect of deaf people having fewer opportunities to access social networks that utilise the dominant language and hegemonic way of communicating. Bourdieu’s conceptualisation has been criticised for its greater focus upon understanding reproduction of domination than opportunities for agency and resistance by dominated groups (Ming-Cheng, 2015). Ming-Cheng has developed the concept of ‘unrecognised cultural currency’ (UCC) to address how “cultural competencies specific to the dominated can facilitate their everyday resistance” (2015: 125). UCC can be used by the dominated to acquire other resources within marginalised spaces. For example, deaf people can use ISL and knowledge of deaf culture to acquire employment in deaf organisations. UCC can also engender everyday resistance to prevent complete exclusion from a field (Ming-Cheng, 2015). This links with the ideas connected to DEAF-GAIN (Bauman and Murray, 2014) as it considers how deaf people can resist dominant, normative ideas and bring thinking AHEAD and BENEFIT from resistance to dominant ideas and lessen their impact.

Coleman (1988) and Putnam (1993) are less critical than Bourdieu of social capital’s negative effects. In addition, they neglect the role of power in social inequalities and ignore the gendered dimensions of social capital and the unequal role women play in building social capital (Martikke, 2017; Mithen et al., 2015; Arneil, 2006). Coleman takes a structural-functionalist approach to defining social capital and considers the structure of relationships between individuals (Portes, 1998). Coleman overlooks inequality and views social capital as a collective asset that universally benefits the whole. Despite limitations, he raises some useful points – that social capital can be a good source of information (Jetti, 2006) and is also useful to marginalised communities (Tonkaboni et al., 2013). This highlights how deaf people may gather information and how their embodied social capital is formed through deaf social networks and spaces ‘in the margins’ (hooks, 1989).

Putnam (1993) focused on the community aspect of social capital. His communitarian approach proposed that social capital components– reciprocity, social networks, trust, norms and civic engagement would act as a public good and remedy to the decline of community life. Putnam tends to favour social capital built up through sustained, face-to-face interaction through memberships of formal networks as opposed to informal. This notion is highly essentialist and can encourage exclusion of those who do not assimilate to the unified whole (Arneil, 2006). It has been criticised for its attempts to develop an objectivist account closely aligned with a neoliberal agenda which reinforces a notion of 'victim-blaming' of individuals for inequality and poverty (Holt, 2008). This has been criticised as being a justification for reducing welfare spending and ignoring material, structural inequalities (Campbell, 2001).

As Campbell further articulates, responses to this have contended that research on social capital looks into the "mediating mechanisms whereby material deprivation impacts on health" (4). Finally, from a feminist perspective, previous social capital theorising has failed to take a gendered analysis. Bruegel (2005) argues that social capital has analytical and political potential but that it must draw in an analysis of power and social interests and take account of the unequal function of women and their disproportionate share of the benefits (Arneil, 2006). It is crucial to attend to micro-relations of power within social relationships, as well as class and gender dimensions (Blaxter and Hughes, 2000).

3.9.1 Bonding and bridging social capital

Putnam developed theorising on two types of social capital, bonding and bridging. Bonding typically refers to strong ties with those in an individual's primary social relationships; family, close friends, neighbours (Babaei et al., 2012). These relationships usually have a high degree of homogeneity. This is where the 'dark side' of social capital is problematised – where insular communities may foster intolerance. As Fraser (2007) has articulated, this 'dark side' can be recognised as a 'politics of recognition' whereby identity politics can be a source of exclusionary politics and systems of domination masking relations of unequal power. As Campbell (2001) notes, research has found higher rates of sexual health diseases in some 'strong communities', with what can be conceptualised as higher social capital, where social capital is linked with unequal and exploitative power relations. Therefore, feminist problematisations of bonding social capital bear important insights. It is important to recognise the complexity of different identities that can be present even within more insular, ‘bonding’ social ties and how bonding ties can operate to positive and negative effect. Positive effects can include emotional support and affirmation (Holt, 2010), while negative can be exclusionary processes such as that seen in far-right movements and Campbell’s (2001) example. Additionally, particular discourses and practices can be present in bonding ties that contour ways of knowing and being in intimate life.

Bridging typically indicates weaker ties with those whom one is not similar to in demographic indicators but similar in financial status and power such as distant friends, colleagues and associates (Jetti, 2006). Bridging supports access across different social groups and can be a source of information and resources outside an immediate group. The deaf community is often spoken about as a ‘home’ and providing a sense of family (Wilkins and Hehir, 2008) that is missing from family of origin for some because of language and communication. While deaf community members often share the demographic indicator of hearing status[45] they may differ across religious, ethnic, age, sex, gender and socio-economic background. However, relationships may still be so strong as to be considered typical to bonding. Bridging and bonding social capital can be present in many groups. They are not strict opposing ideas but ways of comparing forms of social capital.

3.9.2 Embodied social capital

Holt’s (2008: 228) work on embodied social capital, focusing upon “how social capital becomes embodied within individual’s dynamic corporeality” (2008: 228) offers useful ideas. This approach critically engages with and builds on Bourdieu’s social capital theorising, integrating his conceptualisation of social capital and habitus with Butler’s (1993, 1997, 2000) accounts of performativity and subjection.

Holt contends that Bourdieu’s conceptualisation of social capital deals with many pitfalls prevalent in Putnam’s conceptualisation. Bourdieu’s emphasis on how inequalities can be (re)produced and the importance he places on different capitals (social, economic, cultural, symbolic) that can be transformed into different kinds of

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[45] This is not to say all members of the Deaf Community are deaf for example, children of deaf adults may not be deaf but still regard themselves as, and are usually held to be, members of the Deaf Community also.

capital through social networks are useful but should also retain Ming-Cheng's (2015) UCC understanding whereby dominated groups can use UCC to resist. Cultural capital can refer to awareness of and access to information (Byrne, 2014). In this case awareness of deaf cultural information is cultural capital that can sit alongside embodied social capital. Deaf social capital (Wilkins and Hehir, 2008) has been discussed as being nurtured by embodied practices such as being proficient in ISL, having deaf cultural awareness, being involved in deaf events and developing a network of bonding and bridging ties within the Deaf Community. There is a dialectical relationship between embodied practices, embodied social capital and cultural capital (Holt, 2008).

Cultural capital can take the form of institutionalised capital which can be understood as deaf schools, boarding residences, social clubs and spaces. These spaces provide material support to create conditions for developing deaf social networks and cultural capital. Embodied deaf cultural capital can provide one connection by which social relationships can be developed and in turn social capital can feed into attaining cultural capital (Holt, 2008). These interconnections are complex, nuanced and dialectical.

Habitus (Bourdieu, 1977) relates to ways in which the individual develops habitual, unconscious ways of engaging with everyday practices. Norms, understandings and patterns of behaviour become embodied and used unreflexively in the individual and influence particular responses, knowings and patterns of behaviour (Edwards and Imrie, 2003). Key to this research, Holt contends that the norms and values interacted with in everyday practices "re(produce) the hierarchal identity positionings accorded to more or less valued bodies" (2010: 26). Accorded value has implications for individual's subjectification and self-identification – such as whether being 'disabled', or 'deaf' is perceived as a positive or negative state of being.

This does not mean valuations become or are static – they remain contextual and tied up with individuals' social networks (Holt, 2010). Drawing on 'habitus' Holt suggests that through this process such positions become embodied within individuals. However, as Byrne (2014) claims, the 'habitus of disability' can be mitigated through forms of embodied social capital. Thus, this approach allows for a lens towards exploring the ways by which individuals become embodied agents in and through everyday interactions that may be construed as either positive or negative. These relationships can convey capital in different forms which can in turn be used to, as Holt (2008: 2010) and Byrne (2014) argue, (re)produce or transform inequalities. This takes Bourdieu's theory of habitus further. As Holt (2008) points out, he places greater attention on reproduction than transformation. We also gain insight into how participants' identities are valued, and positions are (re)produced.

Holt (2008: 238) describes embodied social capital as relational and contextual and "emphasises how the process of becoming an embodied individual is inherently bound up with the socio-spatial contexts within which people's lives are lived, and with their social networks and relationships". This recognises the contribution of an individual's previous social experiences to their embodiment and how this interacts with everyday practices, their present and future social performances within broader processes of normalisation (2008). Identity locations are seen as intersecting in multiple ways which in turn bestow different forms of advantage and disadvantage. Holt argues that the social norms and expectations that the social agent interacts with also integrate with their subjectivity and relationships. Butler's (1993, 1997, 2000) discussion of performativity and subjectivity aids understanding – highlighting how social capital can be performed and embodied in both conscious and unconscious ways (Holt, 2010).

Joining performativity theory and Bourdieu's theory is useful for considering how material inequalities persist via embodied social identities. This allows for understanding embodied identities such as disability and sexuality as embodied social capital. It also works to challenge norms established in more dominant accounts of social capital by considering the role and power of normalisation. This approach is used in this research to, as Holt (2008) suggests – firstly, establish how individuals become embodied subjects through social relationships; secondly, establish critically in what ways relationships confer capitals and thirdly, how these can (re)produce or transform inequalities towards flourishing.

3.10 Flourishing

> "Positive frameworks for human flourishing provides the language and insights for engaging new questions about how best to develop communities of belonging, connectedness and compassion…"
>
> (Cherkowski and Walker, 2013: 200).

I am interested in how we can transform affective and cultural systems of inequality (Baker et al., 2004) towards the flourishing of deaf women in intimate life. There are a number of places we can look to, to understand flourishing meanings– philosophical ideas of Aristotle *(*eudaimonia), human development ideas (Nussbaum, 2000) that consider how as a society we can live the 'good life', as well as positive psychology literature considering how the individual might achieve well-being, happiness and flourishing (Seligman, 2011; Gaffney, 2016; Keyes, 2002). As a concept it has primarily been developed to measure human feelings and functioning to ascertain if people are feeling good and functioning effectively (Hone et al., 2014). This is important, as valuing individuals' and societies' flourishing is to value the overall well-being and dignity of individuals and groups.

Theorising on human flourishing can be traced to Aristotle's eudaimonia work. Aristotle used a teleological worldview in his conception of flourishing as living well and as the achievement of one's potential as a human being that should be an end in itself (Younkins, 2008). It is a deeper ontological sense of well-being, happiness and pleasure that goes beyond hedonistic ideas of pleasure and feeling good to translate to the overall well-being of the individual. This emphasises a relational dimension to the good life, it should be sought and lived with others (Annett, 2016). Communal good is also the individual good. Within this view is a limited pluralistic notion that holds that human beings can flourish in diverse ways but to the same degree (Gorski, 2017).

Positive psychology borrows from these ideas, attending to traits that support people and communities to thrive. This stance diverges from the traditional pathological approach, tackling symptoms and promoting that well-being is when pathology is absent - to one asserting that flourishing should be examined in its own right. It attempts to understand what factors contribute to and support psychological well-being (Huppert and So, 2013) as a means to measure a positive affective state or overall life satisfaction (VanderWeele, 2017). VanderWeele (2017: 8149) suggests that flourishing is broader than psychological well-being, as a person might indicate they have life satisfaction, yet have no meaningful social relationships or may be living with addiction. "If some notion of flourishing is ultimately of interest, then health itself, along with psychological well-being, and virtue, would all seem to be central components (2017: 8149).

We turn to the social sciences for a broader conceptualisation. Gorski (2017: 29) notes that, critical realists assert that social science has "an axiological concern with human flourishing" and is often interested in the root of oppression and motivated by an underlying, 'tacit concern' with well-being. This turn in social science has been referred to as the 'well-being' turn (Deneulin, 2014 cited in Wilson-Strydom and Walker, 2015). In addition, positive psychology perspectives focus upon how an individual can achieve their own well-being, taking more of a subjective rather than objective view of how well-being can be achieved on a wider scale. This approach to flourishing, while useful in ways, does not capture the depth of the concept appropriate for this research. It fails to consider structural change as also fundamental for flourishing.

In contrast, Nussbaum grounds her work on flourishing in Marxist/Aristotelian notions to explore wider social structures affecting individual well-being. She contends that the Aristotelian understanding of flourishing should be expanded – stating that it means "a complete and flourishing life that lacks no activity that would make it better or more complete" (1997: 119). In other words, it is the degree to which a person can be (beings) and do (doings) what they want to (2000). Nussbaum draws on the work of Amartya Sen who, working in economics, developed a capabilities approach to social justice to question "not how much resources a person can command, but what that person is actually able to do or be – what capabilities she or he is afforded by society" (Kulick and Rydström, 2015: 281). Drawing on Sen's approach she has argued that the achievement of justice involves creating and nourishing conditions that afford individuals opportunities to develop their capabilities and in turn to engage with others to their fullest potential and flourish. This is operationalised by specifying ten basic capabilities that should be available to people so that a flourishing life is possible; (i) life; (ii) bodily health; (iii) bodily integrity; (iv) senses, imagination and thought; (v) emotions; (vi) practical reason; (vii) affiliation; (viii) other species; (ix) play and (x) control over one's environment (2003).

This takes account of subjective and relational well-being, as well as the need to be conscious of and attend to the objective circumstances of a person's life. People experiencing oppression may accept unequal systems as unchangeable (Baker et al., 2004) and "people living in poverty can still report they are happy even though they are clearly not living a flourishing life" (Wilson-Strydom and Walker, 2015: 313). Nussbaum has extended her capabilities conceptualisation to disabled people and criticised other well-established theories of justice, particularly Rawls, for developing exclusionary models of the social contract that fail to encompass disabled people and as such breach social justice (Kulick and Rydström, 2015). She argues that disabled people have not been considered as primary subjects of justice but instead objects of compassion (Kulick and Rydström, 2015). As primary subjects of justice, disabled people are entitled to develop and flourish in their capabilities to live their self-determined understanding of the good life.

Elements of Nussbaum's approach are useful for this research. Firstly, the notion of diverse possibilities of flourishing is helpful. In exploring notions of subjective well-being psycho-emotional well-being, as well as disabilism, is useful to consider. I ask what conditions contribute to psycho-emotional well-being in relation to sexual subjectivity and how can this be nourished to ensure flourishing for all deaf women? A balance between exploring subjectivities and objective conditions and opportunities is necessary. This research seeks this balance by exploring opportunities deaf women have, how they feel about these and how opportunities for flourishing might be enhanced. This is crucial, particularly given the paucity of research that includes deaf people's views (Ubido et al., 2002). Therefore, I draw from elements of the positive psychology approach, as well as from Nussbaum.

It is also important to consider what can be done to promote flourishing and ways of supporting "structures, policies, laws and incentives, financial or otherwise, that contribute to family, work, education, and religious community (which) will likely be important ways in which society itself can better flourish" (VanderWeele, 2017: 8153). Finally, to better understand how flourishing can be achieved a broad focus is necessary, rather than a narrow one of specific disease management – such as looking at intimate citizenship, as opposed to managing STD symptoms for example. Utilising this approach builds up a more accurate picture of not just causes and determinants of flourishing but as WanderWeele (2017) asserts, strategies to nourish flourishing.

The potential for this conceptual lens to contribute to and develop unrealised possibilities for deaf women emerged as the most promising in the context of my literature review which, as discussed, frequently locates deaf women within a negativistic discourse, mired within language of problems, 'vulnerability', 'deficits' or 'lack'. Thus, I draw on the concept of flourishing in a critical manner in this research:

(1) to explore the potential 'flourishing' offers for a discursive shift
(2) to advance new questions on deaf women's lives
(3) to garner deeper understandings of intimate lives and sexuality
(4) to reimagine unrealised possibilities for flourishing

Part C: Theorising Intimate Citizenship

> "Intimate citizenship refers to those areas of life that appear to be personal but that are in effect connected to, structured by, or regulated through the public sphere"
>
> (Plummer, 2003: 70).

3.11 Introduction

Shildrick contends that citizenship in its present form in the globalised world "fails to satisfy the very human desire to flourish (which I understand as the ontological condition of well-Being, rather than well-being)" (2013: 138). This research sets out, not just to explore what flourishing in intimate citizenship looks like, but also *how* it can happen. I seek to illuminate ways past 'deficit' discourses, towards conditions for satisfying human desire to flourish. My approach formulates an understanding of social justice as being a matter of creating conditions and enhancing opportunities for flourishing. At the heart of this research is the desire of deaf women to control their own bodies, sexual health and lives in ways of their choosing. As Lister (2002: 198) writes, "this is the territory where gendered and sexual citizenship meet". I harness the citizenship framework for its underpinning aim, the achievement of equality and social justice;

> "citizenship studies are ultimately not about books and articles, but about addressing injustices suffered by many peoples around the world, making these injustices appear in the public sphere, enabling these groups to articulate these injustices as claims for recognition and enacting them in national as well as transnational laws and practices, and thus bringing about fundamental changes"
>
> (Isin and Turner, 2002: 3).

Intimate citizenship is used as an analytical concept to explore and consider patterns of inclusion and exclusion that support or inhibit deaf women's opportunities to flourish in their intimate lives. As a concept it builds on writing by scholars considering and critiquing sexual and feminist citizenship (see Lister, 2003; Richardson, 2018). It is often used interchangeably with 'sexual citizenship', leading to an indistinct use of the term. I draw on definitions of intimate citizenship that blends Plummer's (2003) and Roseneil's (2013) understandings. Intimate citizenship considers the;

> "laws and policies, social relations and cultures that regulate and shape intimate life (including an individual's sense of self and her close personal relationships), structuring experiences of inclusion/exclusion, recognition/misrecognition, equality/inequality, freedom/oppression, choice/constraint, and autonomy/dependence/interdependence in personal life"
>
> (Roseneil, 2013: 232).

Little previous research explores how deaf women's intimate lives are shaped and given meaning by wider socio-political structural dimensions and their agency in this. Moreover, there is a knowledge gap which ties the intimate lives of deaf women to the promotion of flourishing. To clarify the promise of the 'intimate citizenship' framework and why it is deployed here a general overview of citizenship theory is first set out. Attention then turns to divergent contemporary approaches to citizenship theory that arose out of a resurgence of theoretical attention to citizenship in the 1980's and 1990's. In particular, I examine feminist and sexual citizenship to articulate the concepts intimate citizenship is based upon.

3.12 Theorising and defining citizenship

A general overview of citizenship theories indicates that they can be used either for "normative evaluation and critique or empirical investigation" (LeFeuvre and Roseneil, 2014; 530). Normative theories are concerned with establishing the rights and duties that citizens should have, that is, ideal models of citizenship. Empirical theories are concerned with describing and explaining how people came to possess putative rights and duties. This is not to say they are not concerned with normative elements, they are, but through drawing on empirical facts. Roseneil (2013:1) uses the terms aspirational and analytical as alternatives to 'normative and empirical'. She notes citizenship operates in differing ways; to frame and theorise demands for social change across the totality of interests in a political community. It is also used to develop an analysis of "marginalisation, misrecognition and oppression" and articulate what equitable conditions look like. This research engages with intimate citizenship as a normative theoretical framework in order to explore how conditions for transformative social change might be achieved in relation to deaf women.

Citizenship definitions should be treated with caution as, in themselves, they contain contested concepts such as, identity, membership, community. They raise questions regarding a citizen's rights and obligations and what these ultimately mean. It is also argued that varying definitions of citizenship create inclusionary and exclusionary boundaries, a point elaborated upon where I discuss feminist and sexual citizenship. It is important to acknowledge at this point also that there are limitations and exclusions attached to the concept of citizenship. In this research I am exploring the insights of deaf and hard-of-hearing women. Deaf women are an intersectional group and there are deaf women in Ireland who are currently seeking Irish citizenship or residing in Ireland under asylum seeker or refugee status and therefore excluded from the full range of rights extended to Irish citizens.

As a concept, ‘citizenship’ has been developed across multiple disciplines attracting critical debate (Werbner and Yuval-Davis, 1999). Given the multiple contexts, philosophical starting points and uses, Dywer (2010) and Lister (2003) argue that putting forward a universally accepted definition is not possible. Lister notes that (2003) citizenship is contested at every single level, from the concepts' meaning, to how it may be applied and used politically. She (2003) also comments that it is ‘contextualised’, that its meanings operate in differing ways, reflecting the social, political, historical and cultural context in which it is used. Those who experience exclusionary citizenship practices articulate their resistance to this from the vantage point of citizenship as set out in their national context. This adds to the problematic task of definition. On an optimistic note, Lister (2002: 195) cites Birte Siim to acknowledge that understanding this contextualised notion means that gendered and sexualised effects can be resisted and deconstructed.

Citizenship has traditionally been narrowly viewed “in relation to the rights and responsibilities of citizens within a given nation-state” (Monro and Richardson, 2014: 60). It is not simply legal and political membership of a state but also aspires to detail the protections and obligations of those who wield less power (Janonski and Gran, 2002; Kitchin and Lysaght, 2004). Citizenship was developed to capture the notion of relationships between individuals (liberal theory) or groups of individuals and the state (republican and communal theory) (Yuval-Davis, 2007). Feminist citizenship literature describes this as the social and political role of its citizens and the benefits and responsibilities citizens may access and hold. As Lister (2003) contends, citizenship is a lived experience, has meaning in and affects people's lives through being shaped by socio-cultural factors (van der Heijden, 2014).

3.12.1 Citizenship theorising

Early political thought led to three key traditions developing in citizenship theorising: civic republican, communitarian and social liberal approaches. Stychin (2001) comments that modern understandings of citizenship have evolved from this and are considered to now rest upon the public/private dichotomy. Central to this was the "invention of the sovereign individual in modernist thought" (286). This diverges from the older civic republican approach with its predominant conception of citizenship as obligation to the state and a combined effort by citizens to serve the community and achieve 'the good life' (Beckett, 2006). Communitarianism derived from civic republicanism. Its concerns focused upon community goals, cohesion, shared values and consensual order (Isin and Turner, 2002). It stands in contrast to the idea of the 'self-interested individual' portrayed by liberalism arguing that the self and identity is socially embedded and produced through social relations in the community. In modernist thinking the individual chooses how to live a good life and now citizenship is considered more about rights and entitlements in the public sphere and the private realm has become about the satisfaction of needs (Brown, 1995). This has reinforced a separation between notions of community and responsibility and rights. All approaches have been criticised for their exclusionary nature (Stychin, 2001) as outlined here.

Lister (2003) has argued that civic republican ideas of the citizen as 'male' has continued to have repercussions for how citizenship and the ideal citizen is conceived. Feminists have identified the concept as gendered, associated with the public sphere, reinforcing the public/private divide and affecting normative societal ideas of gender. As Sytchin (2001) notes, to participate as citizens women had to leave the home but simultaneously faced constraints in this because of lack of time and money. In this way the private sphere became devalued and paid employment became valued as a pathway to citizenship. The male subject has had more freedom to move between the public/private spheres than women because of the aforementioned constraints.

‘Modern’ theorising on citizenship is tied to the work of Rawls, Marshall and Berlin – broadly referred to as social liberalism. This approach with its greater focus on ameliorating inequitable outcomes has had the most significant impact on contemporary approaches to conceptualising citizenship. While there are differing strands of thinking within liberal thought (conservative neo-liberalism and neo-republicanism), at the core of each is the primacy of the individual citizen who had the right to live their lives free from any interference. These theories conceptualise citizens as autonomous individuals who act ‘rationally’ to advance their own interests and who make their own choices (Munro and Richardson, 2014). Social liberalism sees a role for the state in extending rights to individuals to offset the effects of inequality and to enable active citizenship (Beckett, 2006).

The work of T.H Marshall, in his influential book on Citizenship and Social Class (1950) in particular, serves as a departure point for considering and critiquing the applicability of the concept of citizenship. Marshall used a tripartite formulation to articulate the rights and obligations emerging from the modern nation-state as typically encompassing: civil rights or legal (free speech, movement, rule of law); political (right to vote and seek office) and social (welfare, unemployment benefits and health care) (Kennedy, 2013). A modern democratic state is expected to provide some combination of citizenship rights and obligations to its citizens but this takes different forms in different states – rights and obligations are not to be held as universal. It is pertinent to consider Esping Anderson who draws on Marshall in his work on citizenship and social rights theorising. Kennedy (2013: 26) writes; “citizenship as a concept is central to the debate on redistribution: some benefits are rights based, others are needs based”. She notes that Esping Anderson’s use of decommodification – a concept that refers to one’s ability to survive outside the labour market, if necessary – is linked to social rights whereby services are received as a social right. This is an important means of measuring the strength of the welfare state and as Lister contends the absence of social citizenship has ramifications for political and civil status (Kennedy, 2013). This is an important point for this research as Lister notes – citizenship can be a force of exclusion and impact individual’s ability to fully participate in society. This is further discussed under section 3.13.

Marshall holds that a liberal-democratic state is required to ensure that civil, political and social rights can be guaranteed. The rights as Marshall set out were rebutted by feminist scholars such as Ruth Lister (1997, 2003) – noting that such rights in Western countries were generally extended to men first and won by women later – for instance the right to vote and to own property. Even now evidence demonstrates that full political citizenship is yet to be achieved in terms of political representation. Marshall’s formulation encompassing civil, political and social rights has been further criticised by feminist scholars (Richardson, 2000) for ignoring the complexities of gender and sexuality (Corboz, 2009).

Examining these gendered implications highlights the lack of universal inclusivity assumed in citizenship (Stychin, 2001). Young also (1989) criticises this assumption of equality. She posits the liberal universal approach is also exclusionary and falsely assumes that laws and policy will apply to everyone equally but typically benefit only those who fit the male norm. She contends differentiated citizenship and group representation is the only way to ensure equality and social justice. Young’s critique bears merit for this research and I draw on these critical ideas to highlight citizenship’s exclusionary nature. In many ways deaf people have also not had access to the inclusive ideal of citizenship as they do not fit the ideal citizen norm or assumptions citizenship rests on (Waldschmidt and Sépulchre, 2019; Emery, 2009).

Fraser (1990) also criticises the limits of civic republicanism and the Habermasian idea of the bourgeois public sphere to articulate that this ‘we’ idealisation contains exclusions. Gender, but also class and ethnicity, (McGarry and Fitzgerald, 2018: xxv) are ignored by working to “mask unequal power relations and systems of domination…by working to silence dissenting voices”. Such ideas have also produced an understanding of the ‘ideal citizen’. Wendy Brown (1995) contends that this understanding is a disciplinary function of citizenship and identity is invariably disciplined through its being recognised.

Thus, it is clear that the contested concept of citizenship needs to be engaged with critically, particularly problematic, gendered aspects as pertaining to deaf citizens. Waldschmidt and Sépulchre (2019) reference Cohen (2009) to contend that citizenship should be understood in terms of a gradient category – full, partial to no citizenship rights. This has meaning for disabled people who often only have partial civil, political and economic citizenship rights. They further note that it is imperative to take a nuanced understanding of citizenship by examining aspects of citizenship that demonstrate the "ableist expectations" and "conditionality of citizenship in connection with disability" (18) – a pertinent point for this research. Deaf people's right to be educated, work and access information and services through ISL or other accessible means has been ignored for a long time. Citizenship offers great inclusionary potential but must be scrutinised for its exclusionary effects – a point which has been raised by those exploring feminist, sexual and intimate citizenship which I now explore. All this raises questions for this research – how does the concern with the normative collective promote particular knowledges that privilege the abled normative sexual body and in doing so overlooks deaf women? And how can we uncover and make sense of exclusionary practices that contour deaf women's intimate citizenship?

3.13 Feminist citizenship

Feminist citizenship problematises traditional citizenship approaches to highlight the gendered assumptions of masculinist approaches underlying and shaping it, contending that 'universalist' citizenship has historically been constructed in and privileged the 'male image' (Young, 1989; Monro and Richardson, 2014). Feminist scholars argue that traditional approaches to framing citizenship, referring to abstract, disembodied and gender-neutral beings is a fallacy and as a category it relied on defining who is excluded as much as who is included. Its universal, inclusionary claims distort the reality of privileges extended to the male, heterosexual, able-bodied citizen and makes invisible and excludes groups who do not conform to this image (Vogel, 1991). The public/private distinction, produces and perpetuates exclusionary citizenship practices and inequalities, impacting negatively upon women, non-traditional families and other groups (Dwyer, 2010; Monro and Richardson, 2014).

This was not to imply the public/private divide should be completely relinquished but rather that private issues must enter the public sphere in order to dismantle the male/public – female/private dichotomy. Confining groups to the private sphere render invisible, serious issues such as domestic violence. Faulks (2000: 125) refers to Weeks' point in relation to the conflicting idea of the public/private divide, noting that "the sexual citizen then makes a claim to transcend the limits of the personal sphere by going public, but the going public is, in a necessary but paradoxical move, about protecting the possibilities of private life and private choice in a more inclusive society". The idea of the gender-neutral citizen is incongruent when citizens have genders, sexualities, disabilities, ethnicities and additional identity markers. On this basis feminist scholarship called for recognition of the exclusionary nature of citizenship and the need to expand its boundaries to include "collective rights and group recognition claims based on difference" (Abraham et al., 2010: 3).

Extending citizenship ideas to address gender inequalities requires more than an acknowledgement of diversity and the disembodied individual (Lister, 2003: 71). It is also necessary to reform the public/private divide and "focus on the informal involvement of women in public life" (Monro and Richardson, 2014: 4). It is argued that the success of men in the privileged, paid work, public sphere is linked to the unprivileged, unpaid caring work carried out by women in the private sphere (Baker et al., 2004). Lister (2003) and Pateman (1989) point out that the lack of status and value ascribed to informal, unpaid work in comparison to waged work is a key feminist issue (Dwyer, 2010) impacting on women's claims to welfare rights. Lynch (2010) contends that women should be included as citizens on the basis of their caring work and as women – gender-neutral citizenship is not adequate. This has been criticised from a disabled feminist perspective in terms of its homogenous assumption of the able-body and overlooking of women who do not fit this gender representation of caring work (Meekosha and Dowse, 1997).

Values of equality and respect for difference are situated within an ethics of care and emphasises the significance of response to the individual. Lister argues that this needs to be balanced with an ethics of justice. Disabled people in particular (Morris, 1993) have contended that the paternalistic language of caring detracts from disabled people's autonomy. Instead a gender inclusive conceptualisation of citizenship is most useful.

This approach recognises the need for a material basis to inclusion – in the case of deaf people, interpreters and making spaces accessible. Lister is essentially arguing that notions of diversity and difference can be incorporated into the conceptualisation of citizenship rights as universal and abstract and there is a place for both. This is useful for deaf women as it encompasses the outcome of rights as well as on what grounds rights are recognised. However, it also raises concerns in its assumption of agency as unproblematic for all. A critical understanding requires realising that agency is shaped in particular ways, can be constrained by wider structural inequalities and that not everyone has the capacity to claim their rights as their rights are often ignored (Baker et al., 2004).

These challenges of difference, diversity, recognition and redistribution under claim-making groups thus expanded the concept of citizenship beyond a status attached to the nation-state (Isin and Turner, 2002). Theorists such as Young (1990) and Fraser (2007) worked to address this and offer a conceptualisation of citizenship inclusive of diversity and difference. Fraser developed a three-dimensional view of social justice to address these concerns and create the conditions for parity of participation; redistribution, recognition and representation, three aspects of social justice which are intertwined and reinforce each other. This formulation is useful in addressing some gaps that remain unaddressed in feminist citizenship theorising. Fraser argues that justice cannot be achieved through redistribution of economic resources alone. Redistribution of resources is key for deaf women who may struggle to access the labour market. However, status equality is also key – whereby identity must be recognised in order that individuals may participate as equal peers in social interaction. For this, Fraser contends that there is a need to change institutions of hierarchal cultural value to ensure “parity-fostering alternatives” (Fraser et al., 2004: 377) and to challenge misrecognition and value deaf people. The third aspect is representation – who counts as a member of community and who is included/excluded. This determines who can make claims for redistribution and recognition (Fraser, 2007). For instance, deaf women are often left un-named in recognition processes – they are not represented, and this in turn affects their claims making on the basis of redistribution and recognition. Those who are not represented are denied political voice and the power to be counted and access justice (McGarry and Fitzgerald, 2018). Citizenship will only be attained for deaf women when each aspect of injustice is reformulated to be inclusive of non-normative bodies.

Feminist scholarship has been valuable in its contributions to creating embodied spaces along with uncovering ways in which false universalism and state policy (Lister, 2003) has overlooked women's rights and their contributions in the 'private, domestic sphere'. However, as Ryan-Flood (2009) points out, this normative citizenship thinking has rarely cast a critical lens on sexuality and must be used cautiously to ensure that a concentration on diversity does not obscure discrimination or risk essentialism (Lister, 2003). Further, feminist citizenship has neglected to include disabled citizens' experiences and to address their use of ableist language in citizenship debates (Meekosha and Dowse, 1997). Some disability-related research has drawn on citizenship to highlight the rights of disabled persons to full and effective participation in society – not to any great extent however. In addition, little work has been done on examining the usefulness of this framework for considering the experiences of deaf or disabled people. From a literature review Sépulchre (2017) has found a very limited number of academic pieces begin from a complex understanding of citizenship (Sépulchre, 2017) and, from my own reading, some use the concept unproblematically. It is necessary to engage in further shifting of conceptual framings to discover the potential of citizenship discourses for deaf women – potential offered through exploring sexual and intimate citizenship discourses.

3.14 Sexual citizenship

Sexual citizenship theory was first developed in Evans (1993) exploration of 'the material constructions of sexuality' where he analysed sexuality as existing in a capitalist, consumerist society and being materially constructed in the relationship between the market and the state. He argued that the sexual is not a natural phenomenon but is highly influenced by and embedded in society, and society is influenced by and embedded in the sexual – there is no fixed public/private boundary. Sexual citizenship was developed to join dimensions of citizenship; legal, social and political. Though sexual citizenship is not distinct from 'citizenship', sexual citizenship was developed as a concept to illuminate heteronormative assumptions underlying the putative public/private divide reproducing sexual inequalities and privileges (Richardson, 2018).

Lister (2002) and other scholars have argued – whilst acknowledging that citizens are embodied beings upon which gender, sexuality, disability and other markers are inscribed - lives cannot be neatly contained. “Thus, many scholars would argue that, ultimately gendered and sexual citizenship need to be theorised as elements of a wider ‘differentiated’, pluralist, citizenship, which embraces diversity and addresses socio-structural division” (Lister, 2002: 191). Richardson (2018: 2) writes that more than two decades on from when Evans and Richardson (2000) first began sexual citizenship theorising, the theory is ‘still a work in progress’. Others point out that it is a slippery term (Kiely, 2014) which is not self-evident (Shildrick, 2013). Weeks (2017: 179) asserts that;

> “sexual/intimate citizenship, like all forms of citizenship, is about belonging, about rights and responsibilities, social exclusion and social inclusion. It is concerned with equity and justice and about the implications of claiming full recognition as social and human beings”.

The idea of sexual citizenship is important as it deconstructs notions of what counts in relation to citizenship and involves recognising one’s right to sexual identity and expression. Lister (2002: 191) contends that until recently the concept of ‘sexual citizenship’ would have been “dismissed as an oxymoron”. Until the arrival of a particular kind of sexual politics two decades ago citizenship discussions almost exclusively pertained to issues circulating in the public sphere (Richardson, 2000). Bodies and sexuality were held to be of the private sphere, thus disconnected from citizenship. Sexual citizenship developed out of a motivation to challenge the ‘universal’ and broaden the concept to encompass sexuality and gender. It first arose from sexual minorities’ demand for recognition of their exclusion from particular citizenship rights – such as the right to marry and raise a family (Stychin, 2001).

As Monroe and Richardson (2014) contend, where the key contribution of feminist citizenship scholars had been to highlight the gendered underpinnings of traditional models, sexual citizenship theory interrogated the heterosexist nature of and heteronormative ideology underlying traditional approaches. Both challenged the confining of sexual and gendered matters to the private sphere and brought their agendas into the public realm. This concept then began to be used to support sexual minority rights claims. This is not to suggest that sexual citizenship is solely about minority or marginalised sexualities.

The sexual citizen must also be recognised as someone who holds a “classed, ethicized, gendered and age-grouped position in society” (Plummer, 2003: 57). Sexual citizens encounter inequalities across the dimensions of identity such as class, age, gender and disability. This can be recognised as Plummer remarks, in how reproductive rights are often inaccessible for people living in poverty. Other instances can be identified such as claims to the right to marry being denied to same sex couples (Stychin, 2001). Kafer (2011: 225) describes ‘the case of the deaf lesbians’ - a white, deaf lesbian couple who had a deaf baby boy conceived with a sperm donor. The mothers used a deaf donor to increase the chance of a deaf child. Their decision is rooted in their view that being deaf is a cultural and linguistic identity. This story was widely picked up upon and they were lambasted on two fronts, ableism and homophobia. Kafer suggests that this story be read as “counter-narratives to mainstream stories about the necessity of a cure for deafness and disability, about the dangers of non-normative queer parents having children” (2011: 236).

The emphasis within sexual citizenship literature lies on sexual identity, (Plummer, 2001) on ascertaining legal and social rights to this identity (Bacchi and Beasley, 2002; Shildrick, 2013) and uncovering and challenging heteronormative processes and practices (Richardson, 2018). Richardson (2018: 30) points out that while sexual citizenship has made significant contributions it also unproblematically carries over “many conventional features of liberal western frameworks of citizenship”. Relevant to this research, as Richardson also elucidates, are how sexual citizenship studies unquestioningly deploy universalising notions of sexual citizenship– how processes of normalisation are reproduced; what is involved in being a member of a community; the production of new ‘others’ and who the sexual citizen is. There has been little critique of the normative underpinnings of sexual citizenship.

In relation to ‘who the sexual citizen is’, Richardson (2018) critiques the problematic decontextualised, individualised articulation of the social citizen she sees emerging out of much sexual citizenship literature. She argues that it is important to retain an understanding of “…the cultural, social and economic conditions that shape the processes through which ‘choices’ are made” (2018: 53). Plummer (2003) also asserts the importance of acknowledging that intimacies and choices are structured and shaped by social divisions and processes. For many people choice-making is restricted (Baker et al., 2004). Financial constraints and the social conditions surrounding social groups are powerful factors shaping choice-making (Richardson, 2018). Much of the sexual citizenship literature has failed to develop an analysis of how these limitations operate.

Furthermore, in promoting an individualised sense of choices and rights, the importance of how sexual subjectivities are constructed is overlooked also. Richardson (2018) refers to the work of Baujke Prins (2006) in this respect, who highlights how Muslim female participants in her research advocate a communitarian conception of their sense of self, ‘as an embedded self’. This echoes across common notions of the deaf community with many deaf people often describing relationality as a central aspect of their sense of self. What this individualistic sense of rights in most sexual citizenship work fails to acknowledge is cultural context where the primary focus is collective rights and social groups. As noted, I am interested in exploring how intimate experiences and choices are contoured in audist/ableist ways and thus the theoretical framework of intimate citizenship gives greater scope and a more appropriate framework for exploring this. As Plummer has argued, intimate citizenship allows for a broader, more diverse range of areas considering ‘rights and belonging’ than sexual citizenship, which tends to solely focus on sexual identity.

3.15 Intimate citizenship

Plummer’s (2001) intimate citizenship concept suggests a more expansive focus than sexual and feminist citizenship ideas and their emphasis on sexual identity/rights and gender. It is a ‘sensitising concept’ that provides signposts for ‘where to look’ (Plummer, 2001). It draws in intimate aspects of the private sphere, beyond the sexual and erotic. Liddiard (2018: 65) suggests considering ‘intimate citizenship’ is one way in which the socio-political processes impacting upon and shaping disabled people’s sexual oppression can be understood.

Plummer intends intimate citizenship to exist in conjunction with other aspects of citizenship, civil, political and social rights. He asserts (2003) that intimate citizenship emerged amidst claims that the public/private divide was becoming more fluid in the wake of radical transformations following LGBT and feminist activism that emerged in the late modern world (Plummer, 2001; Reynolds, 2010). Thus, the concept builds on analyses of heterosexist, gendered principles informing citizenship critiques and Plummer (2003:14) defines it as;

> "the decisions people have to make over the control (or not) over one's body, feelings, relationships; access (or not) to representations, relationships, public spaces, etc.; and socially grounded choices (or not) about identities, gender experiences, erotic experiences. It does not imply one model, one pattern or one way".

LeFeuvre and Roseneil (2014: 537) assert that it is concerned with practices and discourses shaping agency in intimate life. In other words, the intimate citizenship conceptual framework allows us to explore the intimate spaces deaf women engage with and how their access experiences shape their sexual subjectivities. Intimate citizenship gives space to and recognises that 'intimate contexts and issues' such as "family life, sexuality, gender, reproduction and bodily transformations" comprise crucial platforms of struggle for diverse citizens over core issues of 'belonging' and 'entitlement' (Smyth, 2008: 84). The notion of rights and responsibilities is pushed beyond the traditional civil/legal/social rights triumvirate to include rights concerning the body and relationships. This concept echoes the feminist 'the personal is political' contention and asserts there is no fixed public/private boundary (LeFeuvre and Roseneil, 2014).

Liddiard (2018: 56) interprets Plummer's conceptualisation of 'intimate citizenship' as rights of disabled people to "choose how they organise their personal lives and claim sexual and other intimate identities". Unpacking the concept, she draws from Ignagni et al., (2016: 132) who advocate that intimate citizenship is about our rights and responsibilities to make decisions about our intimate relations. The authors write from the context of intellectual disability and intimate rights. Their definition uses the broad concept of 'intimate relations' to refer to multiple spheres of intimate life, sexual identity and expression, friendship and family life, to argue that rights to pursue these relationships, enshrined in the UNCRPD are deeply important. Access to such intimate relationships in turn establishes the affective dimension (Lynch, 2010) and "…the social networks necessary to support employment, educational success, secure housing, family stability, sexual health and well-being, and build resilience against the deleterious effects of structural and interpersonal ableism" (Ignagni et al., 2016: 132). They reiterate that little is known about disabled people's intimate citizenship experiences – the spaces that people can access and the repercussions of this for intimate subjectivities.

As noted, the Irish Deaf Community has only recently won recognition of their citizenship rights as a linguistic minority with the 2017 ISL Bill. Valentine and Skelton (2007) and Emery (2009) demonstrate, that while deaf people might share the same legal entitlements as hearing people, in reality, they can experience an adverse and abstract form of citizenship. This is bound up in the challenge for deaf people of exercising citizenship in a meaningful way when public services and the political system operate in the inaccessible, majority language. Emery (2009) echoes feminist and sexual citizenship points, albeit deaf specific, to posit that 'citizenship' is constructed in the ideal image of a speaking, hearing citizen and privileges phonocentric communication. This has contributed to policies that "have resulted in an entrenched social exclusion of deaf people" (Turner et al., 2017: 1522).

Turner et al., (2017: 1523) consider access to public information intended to be targeted towards deaf communities. They observe that information is broadcast in such a way that limits deaf access to "information, and debates on the state, future and political position of their own community". Findings from a European Union of the Deaf (EUD) survey are cited and express the view that deaf citizens and deaf-led organisations did not feel confident in their understanding of political party standpoints in their country. This consequently restricts deaf people's capacity to access information about civil and political practices 'in a substantive sense' which in turn impacts opportunities to build cultural proficiency in and participate in political processes and wider civil institutions.

"D/deaf people may have rights (to work, to vote, to health care etc.) but they are not always able to exercise them because….they lack the cultural proficiencies to participate in the dominant hearing society" (Valentine and Skelton, 2007: 126). Important for this research, as Valentine and Skelton (2007) recognise, is that language struggles in "one everyday space can shape opportunities in another" (2007: 127) and impact on deaf people being included as equals in the public realm. Without cultural proficiency and language rights, deaf people's ability to exercise broader rights such as accessing information about sexuality-related issues is undermined. I argue that the struggle of the Deaf Community to achieve full 'lived citizenship' in Ireland is inextricably bound up with access to intimate citizenship.

According to Valentine and Skelton (2007) the deaf community, in response to marginalisation and 'civic disenfranchisement' have created their own counter-public (deaf clubs are one example) and their own separatist politics to address issues pertinent to their own lives. This contention parallels the concept of UCC (Ming-Cheng, 2015) and raises a point as to the importance of supporting UCC and deaf social capital through constructing deaf social networks. Emery (2009: 32) finds that despite the exclusionary experiences deaf people encounter, they still "believe very strongly in a sense of duty to their community, whether it is the Deaf community or local geographical communities". Deaf people often 'withdraw' to deaf spaces to tap into the sense of 'belonging' and greater ease of access to information and support that proves more difficult to attain through wider, hearing dominated institutions (Valentine and Skelton, 2007).

3.16 Conclusion

Why is citizenship a useful concept? Roseneil (2013) also asks this question. As feminist critique notes, citizenship still falls short of the mark in terms of offering full inclusion to many. LeFeuvre and Roseneil (2014) discuss the 'complex entanglements' between economic and intimate citizenship and suggest that "it is difficult to flourish as an intimate citizen – to experience a sense of agency and choice, to be able to exercise relational autonomy and self-determination in intimate life – without enjoying a degree of economic autonomy" (550). This is an important point - intimate citizenship is but one dimension within the larger citizenship framework that includes social, economic, political, multicultural and bodily dimensions. FEMCIT (2006 - 2011) contends that these are 'fundamentally interconnected' (LeFeuvre and Roseneil, 2014: 530) and all must be pursued as a totality to ensure belonging and social and political participation for different groups. As Yuval-Davis also asserts (1997: 69);

> "…on its own the notion of citizenship cannot encapsulate adequately all the dimensions of control and negotiations which take place in different arenas of social life, nor can it adequately address the ways the state itself forms its political project".

It should be conceived of as a concept useful for exploring and illuminating some major issues (Yuval-Davis, 1997) regarding relationships between the individual and state.

It is instructive to turn to work attempting to develop citizenship ideas, while insisting on the recognition of citizenship as embodied and the importance of the body. Such work challenges disembodied, universal citizen ideas (Lister, 2007). "Bodies give substance to citizenship and citizenship matters for bodies" (Bacchi and Beasley, 2000: 337). Through this insight citizenship becomes less abstract by being conceived of through embodiment and 'material flesh'. Also significant, particularly in this research, is the intertwinement of inter-subjectivity with the social construction and materiality of the body. This pays attention to the materiality of social interaction and how this constitutes subjects along with power, citizenship and policy. "Bodily materiality, is after all, produced and lived precisely in relation to other bodies (Bacchi and Beasley, 2002: 330). Here is where the strength offered through embodied citizenship (Bacchi and Beasely, 2000, 2002) emerges in understanding deaf women's everyday lives. It allows us to understand that material bodies play a role in subjects' positioning and in turn that the positioning of subjects in social relations has implications for the contouring of the embodied self. Yip (2008) uses a nice turn of phrase; our 'quest for intimate citizenship'. Intimate citizenship can shine a light on how our private decisions and practices are inextricably intertwined with public institutions and policies.

As Clarke et al., (2014: 2) articulate, citizenship as a keyword "is valued and a powerful mobilising image for social and political action". It has been a powerful tool to draw on by minorities claiming unequal treatment. Deaf people have sought to achieve meaningful citizenship, with all the basic rights and obligations that entails, and to address their exclusion by the state. Emery (2009) suggests that while normative frameworks of rights, responsibilities and participation are important, using citizenship could be extremely useful regarding exploring why social policy has yet to engender full inclusion for deaf people.

This critical literature review has enabled me to set out the theoretical and empirical landscape of my inquiry, whilst identifying key knowledge gaps on deaf women's stories of intimate citizenship. Drawing on this learning I move forward with the following guiding questions for my study;

- How do deaf women experience and understand their intimate lives?

- How are deaf women's intimate lives contoured and what are the effects of this?

Chapter 4: Methodology

> "The ideas that we have in research are only in part a logical product growing out of a careful weighing in evidence. We do not generally think problems through in a straight line…I am convinced that the actual evolution of research ideas does not take place in accord with the formal statements we read on research methods. The ideas grow up in part out of our immersion in the data and out of the whole process of living".
>
> (Whyte, 1984: 279-280)

4. Introduction

This chapter presents and reflects upon my research methodology, including the epistemological and ontological perspectives, theoretical influences, research methods, ethical considerations, dilemmas and limitations. I reflect on this journey in line with Whyte's (1984) ideas above, viewing research as borne out of a whole process of living.

My study is exploratory in nature and grounded in an overall qualitative methodology drawing on the interpretivist tradition. I was influenced by and drew on aspects of narrative inquiry (Kim, 2016) and narrative thematic analysis (Reissman, 2008). I carried out twenty-nine in-depth interviews with deaf women, and semi-structured interviews as part of a scoping exercise with nine key informants.

The overall research aim is to explore and understand the intimate experiences and worlds of deaf women in Ireland. To realise this, I set out to achieve the following objectives:

- To explore the experiences and perspectives of deaf women through their narratives of their intimate lives.

- Through this exploratory study, examine and understand how the intimate lives of deaf women are contoured (the lived realities of their intimate citizenship) in different ways and different contexts.

- To establish how to foster, sustain and normalise opportunities for deaf women's flourishing in intimate life.

The chapter begins by providing a comprehensive overview on the research design and philosophical standpoint, including the epistemological and ontological framework. Next a detailed overview of the research methods including data analysis is presented. Following this is a discussion of ethical and reflexive considerations.

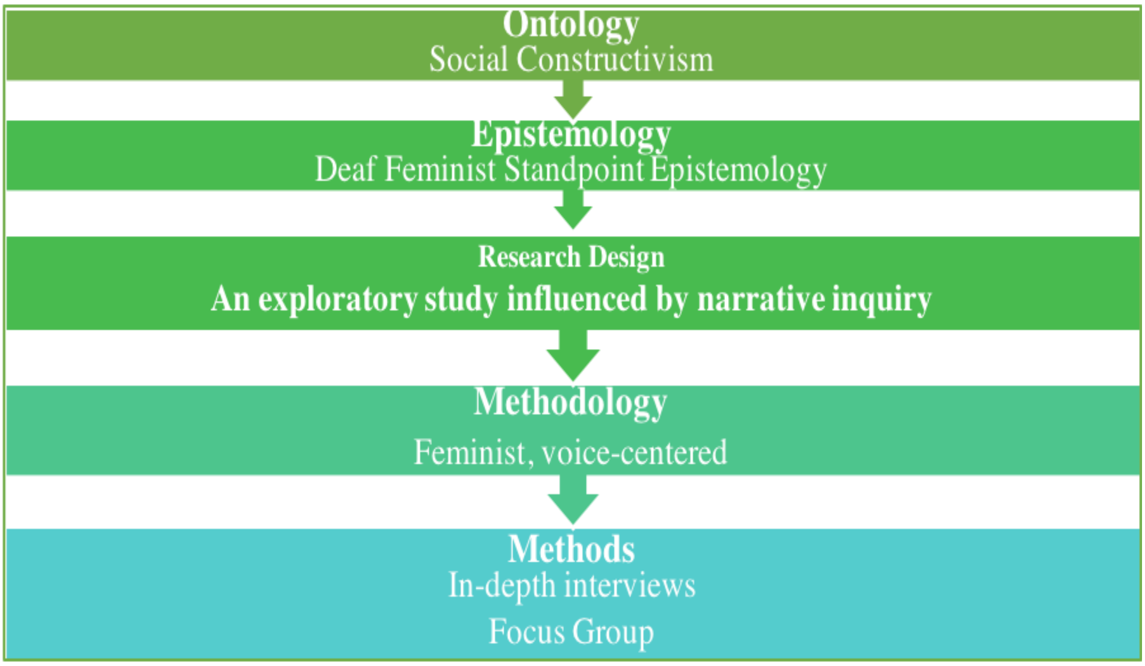

Figure 3: Research design

4.1 Ontological, epistemological and methodological approach

According to Mason (2002: 14), articulating one's philosophical standpoint is to "ask yourself what your research is about in a fundamental way". Multiple debates abound within the social world encompassing various ontological (questions about being and reality) and epistemological (questions about knowledge) assumptions, presenting alternative perspectives of the essence of and knowledge of social things - all of which "tell different stories" (Mason, 2002: 14). Research does not emerge out of thin air – the worldview of the researcher always underpins the starting point of the research and the research journey. This leads the researcher to make assumptions about the nature of the reality being studied, as well as the most appropriate ways of developing knowledge of this reality (Kim, 2016; Walshaw, 2015). Thus, the philosophical assumptions shaping the knowledge making claims of the inquiry should be clarified from the outset.

This research developed under the broader ontological umbrella of social constructivism – a position which contends that social phenomena are in a continual state of being constructed through the shared processes of interaction amongst social actors (Bryman, 2012: 33). To speak of epistemological concerns is to speak of what is considered appropriate in the creation of knowledge, how we know about the world, who are 'knowers' and "the relationship between the researcher and that being researched" (Creswell, 2007: 17). Taking an epistemological position is a paramount step in framing research practice and in knowledge generation. My standpoint derives from the broad platform of interpretivist epistemology which prioritises the "subjective meaning of social action" (Bryman, 2012: 30) and the constructed nature of social reality.

My role as researcher is critical - interpreting research participants' perspectives to construct and present a particular account of these multiple subjective realities. Through this approach I seek to position myself, make my personal values explicit, be clear on how my experiences impact my understanding of the research and to listen carefully to participants to understand their meaning making (Creswell, 2007). This approach is also framed by community development which informs the values applied in this research and discussed further in this chapter.

4.2 Epistemology - Deaf epistemologies

To take a constructivist view is to contend that deaf knowledge of the world, understanding the deaf lens (the deaf way of seeing the world) and deaf ways of thinking and knowing (for example not viewing oneself through a disability lens but a cultural and linguistic one) is formed through seeking deaf accounts of deaf lives (Holcomb, 2010; Wang, 2010). This standpoint emerged from ground-breaking work considering the language and culture of deaf people that challenged hearing ways of seeing deaf people (see Padden 1980; Padden and Humphries, 2005; Wolsey et al., 2017). "Deaf epistemology is focused on visual access, visual learning and visual language" (Wolsey et al., 2017: 574). It inspires academics to challenge audism when producing knowledge (deClerck, 2010).

However, as Hauser et al., (2010) note, deafness is comprised of multiple, intersecting, embodied identities that lead to diverse ways of being deaf and encountering other deaf bodies. Not all deaf people use visual language or visual learning, and this must be recognised in the research process also. Kusters et al., (2017: 9) note that deaf ontologies and epistemologies are embodied – and "indeed, central in deaf ontologies are corporeality and embodied subjectivity which means that our bodies influence our experiences and thoughts". Hauser et al., (2010: 486) comment that similar to how societies impart certain norms and attitudes in relation to gender and bodies they also do so to deaf bodies which has "an impact on what these deaf individuals learn and know, and consequently on their attitudes, interests, and values". This research stresses the use of deaf epistemologies – in line with taking a nonessentialist and non-positivist, deaf inclusive approach that understands that not all participants in this research regard themselves as fully culturally deaf (Young and Temple, 2014).

This stance is useful for its focus on the diverse lives of deaf people, its attention to subjectivity, its reimagining of what it is to be deaf and articulating resistance to hearing and traditional scientific ways of viewing the deaf experience. With this in mind, I incorporated the following deaf framework to centre deaf epistemologies.

4.2.1 Deaf research framework

Previous research has demonstrated negative experiences of research for deaf people (Singleton et al., 2014) for example, researchers failing to make the research methods accessible or disregarding follow up with appropriate dissemination strategies. As Lynch (1999: 54) notes, dissemination should take place outside the academy and in "accessible contexts and language". I am committed to ensuring I do not collude with the long, deeply rooted tradition of doing research 'on' rather than 'with' or 'for' deaf women or reinforce negative research experiences. To this end, following this research a Clear-English and ISL translation summary report will be produced. I will make a longer ISL subtitled VLOG discussing the research findings and make this available to deaf groups. I will hold a presentation in DVI and extend a broad invite to this. Finally, I intend to publish the findings to make an impact at policy and HSE practice level. I aim to set an example for how an ethical and conscious approach can be taken towards research with deaf women. This has been informed through my deaf epistemological stance as well as values and principles grounded in a community work approach (Ledwith, 2011).

Harris et al., (2009: 104) comment that because of the linguistic diversity of deaf people researchers encounter “uniquely difficult challenges for the ethical conduct of research because of issues of power that surround the cultural and linguistic legacy in the Deaf Community”. They set out a terms of reference and principles for what ethical research in sign language communities looks like. This contributes to the framework here with the purpose of ensuring that this research is not “ethically abusive”, a historical problem in sign language communities.

The first stage was to develop cultural competency[46]. A key part of this stage is for the researcher to undertake a serious journey towards understanding themselves in relation to the community. The researcher must gain trust of the research community, examine their own biases and be reflexive. O’ Brien (2017: 67), a deaf academic, has developed four preliminary principles for deaf research[47]. This was a fundamental guide for me, and I sought to adhere to and implement the four principles detailed below;

1. **<u>The primacy of sign languages</u>**

To value and demonstrate respect for sign language as a central part of deaf life. I put this into practice through offering interviews in ISL, discussing informed consent through ISL, offering to employ an interpreter and recording the interview to ensure the full sense of the interview was captured.

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[46] Cultural competency is understood as “a systematic, responsive mode of inquiry that is actively cognizant, understanding, and appreciative of the cultural context in which the research takes place; it frames and articulates the epistemology of the research endeavour, employs culturally and contextually appropriate methodology, and uses community-generated, interpretive means to arrive at the results and further use of the findings” (SenGupta, Hopson and Thompson-Robinson, 2004 cited in Harris, Holmes and Merton, 2009: 112).

[47] This framework emerged from his research on Kaupapa Mãori research principles and a workshop deaf academics.

2. **Self-determination**

Self-determination is understood as deaf research being designed, led and disseminated by deaf people. Research produced needs to be "valued by deaf communities and give back tangible benefits to deaf people, with direct impact on policies or practices that have negative effects on their lives" (2017: 68). As will be discussed later in this chapter, most participants felt this research was of worth and value.

3. **Identity preservation**

It is important as researcher that I hold a positive attitude towards deaf identity and actively promote and develop a deaf academic identity. This principle specifically discusses signing deaf academics. Due to lack of fluency I have not presented through ISL in academic spaces. I am careful to emphasise my deaf identity in presentations as well as to emphasise the inclusion of sign language and deaf research ethics.

4. **Community development**

"All research conducted under a deaf research framework should contribute in some way to the development of deaf communities" (2017: 69). There are many ways in which this can happen. In drawing on and presenting the recommendations of this research I intend to do so through articulating how access to sexual health services and information can be better improved for deaf women.

4.2.2 Feminist Standpoint

This approach to deaf epistemology finds resonance with that of feminist standpoint theory, which, despite various interpretations,[48] is predicated on women's experiences as a starting point in generating knowledge (Haraway, 1998). As Cockburn (2015) notes, standpoint theory is an epistemology, an account of the evolution of knowledge and strategies of action by particular collectivities in specific social relations in given

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[48] See e.g. Harding, 1987, 1991, 1993; Hartsock, 1983, 1985; Jaggar, 1983; Rose,1983; Smith, 1974, 1987, 1999.

periods (331). Further, Harding defines feminist standpoint as “a feminist critical theory about relations between the production of knowledge and practices of power” (2004: 1). Developed as an explanatory theory and methodology for feminist research, this perspective acknowledges that the lens through which the world is seen and experienced by women is distinctive and these socio-political positionalities are valuable sites of epistemic privilege, as opposed to knowledge as understood from the positions of dominant institutions.

Feminist standpoint can be traced to early feminist critiques which identified knowledge frameworks as historically biased, androcentric and monopolised by white, Eurocentric, male perspectives. From this perspective women were not included – their needs were misrepresented, and their experiences often conflated with that of men in the literature. In recognition, academic feminism developed from second wave feminist theorising in the 1970’s, supporting research conducted and written by women. Women became emphasised as the subjects of knowledge in a move aimed at retaliating against the ‘God Trick’ – a neutral subject who spoke with authority and objectivity from no clear position but one whom, under critique, reproduced male hegemonic thinking that traditionally dominated research (Harding, 2004; Haraway, 1988).

This understanding and knowledge generation by feminist scholars led to the creation of alternative knowledge pathways, and reflexive methodologies, whereupon women were positioned at the centre of research (Harding, 2004; Fawcett, 2000; Buzzanell, 2003). Subsequently, Harding coined the term ‘standpoint theory’ and Smith (1989) further developed this by examining the exclusion of women in sociology. She set out a challenge to sociology, arguing that women should be represented but traditionally were absent and excluded through a sociological lens put together exclusively by men. The implications of this were that the production of knowledge was in the hands of these male scholars. This has authority and power, we are governed by these specific ways of knowing (Hill Collins, 2004), this “view from the top” (Smith, 2004: 23). Smith advocated for instead, acknowledging the role and power of knowledge producer in producing knowledge and the strength of the situated nature of knowledge that should begin from the vantage point of marginalised lives. The evolution of feminist thinking witnessed significant critical challenge to ideas which universalise women’s experiences specifically through the discursive position of privileged white, middle-class, heterosexual and able-bodied women (Hill Collins 2000). Here, the intersections of marginalisation become an important part of a critical feminist epistemic lens.

This is a particularly valuable and appropriate methodological frame for exploring how deaf women understand and experience sexuality and access sexuality-related services and supports. Drawing on Elliot (1994: 424), Bowell (2018) provides a clear example to illustrate the value of considering the social location and epistemic knowledge of research participants:

> Person A approaches a building and enters it unproblematically. As she approaches, she sees something perfectly familiar which, if asked, she might call 'The Entrance'. Person X approaches the same building and sees a great stack of stairs and the glaring lack of a ramp for her wheelchair (Bowell, 2018: para 8)

Using standpoint theory in this research means not only valuing the perspectives of marginalised women's voices but also exploring deaf issues from multiple perspectives. To further these insights, I draw on work from FDS which brings together ideas from disability and feminist studies to produce critical insights on gender and disability that "helps to make visible the historical and ongoing interrelationship between all forms of oppression" (Hall, 2011: 4). Importantly this stance recognises that disabled people are also gendered beings, an insight overlooked for a long time by feminist studies (Garland-Thomson, 2011). It is an intersectional way of interrogating oppression and troubling how this has bearing for the lives of people with disabled people's lives. It does so by centralising embodiment, body variety and normalisation in order to rethink, reimagine and recast how embodiment is perceived (Hall, 2011). It foregrounds the critical question of how systems of oppression build in to and reinforce each other to develop "an imaginary norm" (Garland-Thomson, 2011: 16) that bestows privilege on some while excluding others. This is extended for its use in exploring how normalisation is experienced through the lens of audism by deaf women.

As set out in chapter two, Hill Collins and Bilge (2016: 2) define intersectionality as "a way of understanding and analysing the complexity in the world, in people and in human experiences…as generally shaped by many factors in diverse and mutually influencing ways" This is used as a guide in this research for understanding the multiple factors and identities that intersect to shape and contour the intimate experiences of participants in this research.

Feminist standpoint theories, as with much sociological theory, are subject to challenges to conceptual dissonance. As Harding (2004) reflects, feminist standpoint as a theory and a methodology attracts a number of criticisms for reasons as varied as its legacy of drawing on Marxist thought, to its uneasy fit with postmodernism. Postmodernism calls into question the universal category of woman and thus opens up feminist standpoint theory to accusations of espousing essentialism and how it accounts for differences between women. Standpoint theory disrupts the tradition of separating epistemology, methodology, and political strategies. Shildrick, a disabled academic (2012: 9) strongly criticises the use of standpoint theory, contending that it promotes a "hierarchy of truth-telling in which the putatively powerful – effectively the historic oppressors - are not to be trusted" and the argument that disabled people speak the truth of their own experiences is to overextend an authority on truth to the voice of anyone who is disabled. This raises questions about valid knowers and valid ways of knowing approaches which has been subject to considerable critique and contentious debate in how disability research should be carried out (see Barnes and Mercer, 1997; Oliver, 1997). Kitchin (2002: 1) contends that this debate is – "mostly one-sided and dominated by a group of mainly British sociologists". It has not been representative of the experience of disabled people because much of the research has been carried out by non-disabled people, who will never have an embodied understanding of what it is to be a disabled person.

Nonetheless, using the approach of feminist standpoint analysis provides a rich starting point for generating a nuanced knowledge of individual and shared, collective experiences, whilst in parallel, acknowledging differences and challenging essentialist views (Buzzanell, 2003). I draw inspiration from the work of bell hooks (1989) and Hill Collins (1997) on including the standpoints of diverse, marginalised groups and considering the potential of these spaces at the margins. An essential component of standpoint theory relates to the agreement that a standpoint is occupied through collective, political struggle – not simply by virtue of being deaf or being a woman for instance. While individual experience is certainly important, emphasis remains on the social conditions that construct groups (Hill Collins, 1997). Hill Collins' (2000) ideas on black feminist epistemology (ways of knowing and validating knowledge) bears much relevance to this research. In contrast to positivistic modes of inquiry, Hill Collins espouses the credibility of knowledge developed from lived experience and refers to, “connected knowers” – “those who know from personal experience” (Allan, 2013: 3).

In this Hill Collins contends that we should not remove ourselves from research participants’ experiences in a desire to be objective as this positions subjects as objects and ignores an intersectional understanding of experiences of oppression. She further argues for the use of dialogue as opposed to adversarial debate. This posits that knowledge emerges through dialogue between at least two subjects, through lived experience and does not exist objectively. The researcher is also present and tells a narrative that includes the ‘I’ and ‘We’ personal pronouns. The researcher becomes and remains bound up with the narrative unlike the removed, third person language of positivists. She attaches significance to narrative in this way, marking it as a valuable way to develop counter-narratives that confront and challenge dominant myths.

In following these tenets, knowledge emerges through an “ethics of caring” whereby “all knowledge is intrinsically value-laden and should thus be tested by the presence of empathy and compassion” (Allan, 2013: 3). This holds space for and promotes the validity of the thoughts, feelings and emotions of the researcher and contends that emotion evidences the belief of the researcher in knowledge production. There is then a moral expectation of the researcher that they must be accountable to this knowledge. Hill Collins further promotes the need to be cognisant of the tension between group knowledge and diverse experiences as a heterogenous collective – a pertinent point. Deaf women are not a homogenous group - deaf women’s ways of knowing and experiencing are key, but an intersectional understanding of this must be recognised.

4.2.3 Blending deaf and feminist standpoint epistemology

An overarching aim of my research is to foreground and value the voices of deaf women in relation to marginalised and overlooked experiences of deafness and sexuality. Exploring the intersection between sexuality, gender and deafness has been strengthened by rooting this research in deaf epistemologies (Kusters et al., 2017) and feminist standpoint epistemology (Harding, 2004). Use of deaf feminist standpoint theory is important for two critical reasons. Firstly, it allows for exploration of dominant ideologies shaping deaf women's everyday lives and secondly, places value on moving beyond traditional conceptual frameworks to situated knowledge where deaf women from different social locations become "the subjects – the authors – of knowledge" (Harding, 2004: 4). It takes experiences of oppression and structural inequalities of power into the equation in order to produce a "more realistic form of knowledge" (Fawcett, 2000: 4). Using deaf feminist standpoint theory means also considering how gender, sexuality and deafness work together from multiple perspectives. This understanding built from situated narratives can be used as a resource to challenge and transform unjust dominant, hegemonic, normative discourses. Given the limited body of research from deaf feminist perspectives, use of this creative, empowering approach presents new directions for knowledge production and a contribution to the advancement of deaf feminist methodology.

4.3 Exploring intimate lives through qualitative research

The philosophical and methodological roots of feminist research promote that "…a focus on narrative has been argued to better help the social scientist understand individual accounts of more complex daily living, and projects of self" (Miller, 2017: 41). I was attracted towards blending deaf feminist standpoint epistemology with aspects of narrative inquiry in this exploratory study as I felt it offered an appropriate theoretical and conceptual fit for gaining an in-depth, rich description. It assists with hearing and understanding the complex intimate experiences of deaf women. It also serves to reduce power imbalances (Creswell, 2007).

Kim (2016: xv) describes narrative inquiry as methodologically "an interdisciplinary, qualitative research that pursues a narrative way of knowing by exploring the narratives or stories of participants". It is a complicated approach and there are many ways in which it is understood and methods by which it is carried out. I follow Kim's understanding of narrative inquiry as an approach that prizes the stories of laypeople and within section 4.4, 'honouring complexity of lived experience' I set out how following this stance influenced actions I took during the research.

Additionally, I draw being influenced by aspects narrative inquiry together with my worldview, positioning and approach to the research with my background as a community worker. In my research practice I draw on community work values and principles of collectivity, participation, empowerment, equality and anti-discrimination and realisation of social justice and human rights (Ledwith, 2011; CWI, 2016). My research practice is infused and guided by a commitment to the same principles. As Ledwith writes, “community development begins in the everyday lives of local people” (2011: 2) and my research takes this as a necessary starting point. For example, to embed the principle of equality in this research I engaged with spaces that deaf women participate in to disseminate information about the research, such as online spaces on Facebook for deaf women and a conference for deaf women. I further discuss how being influenced by community work values and principles informed the choices and decisions made as well as practical actions carried out during this research in section 4.7 ‘ethically reflexive research practice’, in this chapter.

Conversations with deaf women during the preparation stage of this research led me towards the value and importance of qualitative research designs for collecting stories of intimate lives. Qualitative researchers “study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin and Lincoln, 2005: 3). It is used to understand how individuals make sense of and experience their world and what meaning their experiences hold for them. Mason (2002: 3) maintains that qualitative research strives to develop “contextual understandings on the basis of rich, nuanced and detailed data”. This approach then is useful for gaining insight into the everyday lives and experiences of research participants. A qualitative research design supports the development of an in-depth, rich, and contextualised account of lived experiences. Using qualitative research commits to using participants’ words to tell stories (Hartley and Muhit, 2003). This design aims to put marginalised voices at the centre of the research, avoids essentialising marginalised voices and counters dominant voices. Stone and Priestly (1996) contend that this is important in disability related research as research has traditionally been oppressive and perpetuated marginalisation of disabled people and ‘become part of the problem’. Through this approach voices, that may otherwise be silenced, can be heard and express their own views about their experiences and social worlds.

Qualitative research draws on the interpretive tradition of social research. Interpretivism seeks out the subjective experiences of individuals. This stands in contrast to the positivist tradition which Bryman (2012: 28) describes as "an epistemological position that advocates the application of the methods of the natural sciences to the study of social reality and beyond". This stance is associated with promoting the notion of objectivity whereby the researcher remains impartial from that what is known. It is also described as promoting a realist ontology which subscribes to the notion that reality is external, reliable and stable (Ransome, 2013).

Interpretivism challenges the epistemological and ontological perspectives of positivism. Bryman (2012) maintains that it moves from a focus upon 'explaining human behaviour' to 'understanding human behaviour' - to the subjective meaning of social action and a consideration of the context that individuals lived experiences take place in. This approach emphasises the need to interpret meaning from the point of view of individuals and understands that reality is multiple and relative (Lincoln and Guba, 1985). It avoids imposing constraints on knowledge. In taking this stance the researcher aims to understand new knowledge through an interdependent relationship with the research participants and try to understand and explain, rather than predict, participants' world (Black, 2006).

As part of my preparation I immersed myself in deaf culture and over this time through talking with women and hearing their stories, I realised that a qualitative approach was appropriate and required for the realisation of my research objectives. Through a reflexive process and extended engagement with deaf women I continued to shape the methodology in response to research challenges. However, the 'described account' I present here is not the research as it was 'experienced'. I state this to dispel misleading myths of 'hygienic research' (Stanley and Wise, 1993: 153). Research takes twists and turns and the direction I faced at the end was not the one I started with. As Bell (2002: 209) writes "narrative illuminates the temporal notion of experience, recognising that one's understanding of people and events changes".

4.4 Honouring complexity of lived intimate experiences

Inspired by Leggo (2004: 99) who seeks to "honour the tangled complexity of lived experience", I was drawn to a qualitative methodology to understand how participants make sense of and give meaning to their experiences and to ascertain the insights and assumptions contained within narratives (Bell, 2002). While there are several strategies by which to do this, influenced by aspects of narrative inquiry, I valued foregrounding situated knowledge and voices of deaf women, constructing knowledge with participants and exploring the complexity of bodily encounter (McMahon and McGannon, 2016). Using qualitative research and being influenced by aspects of narrative design allowed me to embrace the "situated, temporal and partial nature" of the research participants' narratives (Langley, 2017: 99). Kim (2016: 6) describes narrative inquiry as "a form of knowledge that catches the two sides of narrative, telling as well as knowing". Drawing on this aspect allows me to delve into and examine the subjectivity, meaning making and multiple perspectives of deaf women in relation to their sexuality-related experiences over time, over their life course, across different places (Clandinin and Huber, 2010). This meant that I explored the perspectives of deaf women from different backgrounds in order to understand their meaning making and what this means collectively. It is an approach that shares experiences and meaning through stories which are then transformed into data – it is a particular type of storytelling that does not prize knowledge of outcomes only, but also prizes knowledge of personal meaning making and experience (Bell, 2002). Clandinin (2006: 44) describes these stories as how we create meaning both individually and relationally. Its strong temporal thread (Bell, 2002) is also particularly useful for understanding how the biographical past contributes to locating bodies in the present (Valentine and Sadgrove, 2013). This meant that I explored what deaf women's understanding of their past subjective experiences of sexuality and deafness meant for their present subjectivity.

All of these elements together are what mark narrative inquiry apart from other methodologies. It is important to note that I did not follow all the imperatives that comprise narrative inquiry as I sought a blended approach that fit with my participants needs, for example regarding time and literacy. Nonetheless, I felt aspects of this approach held value for my research. Whilst influenced by principles underlying narrative inquiry, particularly its relational dimension and the notion of co-construction of knowledge, this research is not a narrative inquiry in its true sense. This research was based on one-off interviews and was not designed around the development of narratives over a number of interviews and data review phases with participants (Wang and Geale, 2015).

The approach I use is positioned within an interpretive framework that recognises people as active subjects, situated within a wider social and historical context and in a world where reality is constructed through everyday practices of meaning making (Smith and Sparks, 2008). As Bell (2002) writes, stories are constantly being reconstructed and do not exist in a vacuum – the temporality of experience (Clandinin and Huber, 2010). Identity and selfhood are constituted through narratives as individuals share storied interpretations of themselves and their experiences through lenses that reflect understandings of themselves as classed, gendered, raced subjects (Valentine and Sadgrove, 2013; Smith and Sparks, 2008).

For example, one participant discussed the importance of her ethnic background and how this was bound up with and shaped her deaf identity and vice versa – how she was seen as a deaf person by her family members and friends of the same ethnic background and how deaf people viewed her through the lens of her ethnic background. These stories might also reject, exclude or reshape stories that do not support an identity they currently claim (Bell, 2002). Story tellers can be limited by the frameworks that they currently have available for telling stories and the selves they construct (Woddiwiss, 2017). For example, some participants stated that they did not know how to put what they were thinking or feeling into words and so halted their point or we tried to approach it a different way through my probing. However, this fluidity, Bell tells us, is not wholly the meaningful part - what individuals share about their ‘internalised world’ (Smith and Sparks, 2008), their beliefs and assumptions is of more compelling interest than the story itself. This is not to say that stories shared are untrue (Engel and Munger, 2007) but stories are formed through casting minds back, through remembering and searching for the words to express oneself. A story might be told in a different way at a different time. Indeed, when I returned transcripts to participants three replied to note they wished to adjust information. Connelly and Clandinin (1990: 4) reflect that this is “a portion of the complexity of narrative”. Importantly for this research, “equally the telling of stories and use of narrative methods by individuals allows for counter-narratives to emerge and be articulated" (Valentine and Sadgrove, 2013: 1982). In this way the process of story-telling is empowering as participants deconstruct dominant narratives. This research seeks to create an empowering space for counter-narratives to emerge in challenge to dominant normative constructions of sexuality, gender and deafness. Plummer (2003) and Liddiard (2018) contend that telling stories has power to create transformative change and are crucial in claiming sexual citizenship.

An additional aspect of narrative inquiry I was influenced by is its demand for relational engagement as it recognises that stories are collaborative (Connelly and Clandinin, 1990; Clandinin and Caine, 2008). Hydén and Antelius (2010: 593) suggest that we might think of this as the interviewee being the primary storyteller and the interviewer being the vicarious storyteller. The focus is upon the primary storyteller and the vicarious storyteller supports the telling. I played this supporting role through offering my stories of intimate life as a deaf woman. In turn participants responded and related or did not relate and, in this way, we constructed meaning and knowledge. However, I used thematic narrative analysis in this research and so this aspect of the research – the production of the narrative - is not focused upon in the analysis writing and methodology. This is typical in thematic narrative analysis (Reissman, 2008). Nonetheless, this relationship of co-production is important to draw attention to particularly because the nature of this research (use of and translation of ISL) meant I had to explicitly probe for meaning to ensure I accurately understood the meaning and was not assuming meaning or losing meaning in translation.

It is relevant how stories are told. This was particularly fundamental for this research where the embodied, performative telling of a story was central. Again, I turned to narrative inquiry for guidance as this approach "draws on and foregrounds the performative act of telling stories as a way to transmit wisdom, experience and memory through the visually orientated, signing body" (West, 2013: 3). Within analysis chapters, I have included reference to gesture, eye movement, emphasis and so on when re-presenting narratives. I have already referred to how I express myself - through body and facial gestures – I did this as a researcher and I paid attention to how participants did the same – the stories in this research are acknowledged as coming from lived, real bodies –it is an embodied inquiry. Both spoken English and signed ISL interviews were approached in this way.

Hydén and Antelius (2010: 589) comment that it is not unusual for "many aspects of the embodied and performed storytelling to be left out of the analysis" in disability research. Of course, there is something lost in the re-presenting of the narratives in this research. Stories have been shared in spoken or signed modality. I have then transcribed and translated and analysed stories in written form and re-presented them in written form. I have lost or failed to capture some of the depth of expression, emotion, feeling and embodiment in doing so. I have tried to mitigate this somewhat through including gesture and paying attention to the embodied aspect of the stories. The 'telling' of the story is also appreciated – the ways in which stories are told, how people are located, identities constructed and what this means – particularly in the context of the story of flourishing that emerged in this research (Smith and Sparks, 2008).

Exploring the narratives of disabled people is regarded as holding value for disability research (Goodley and Tregaskis, 2006; Smith and Sparks, 2008) as a way of gleaning insight into personal narratives and the embodied experiences of disabled people and to locate them in a wider socio-political context. I have noted that the aim of this research is to reveal the radical possibilities, the new worlds and resistance that can be seen from spaces in the margins (bell hooks, 1989). Thus, my inquiry shares overlaps with this agenda, "it bears within it the promise of a kind of scholarship that seeks to practice a deep fidelity to the possibilities of societal and individual transformation, resistance and living life differently" (Smith and Sparks, 2008: 19). Alongside this, West (2013) contends that storytelling is embedded in deaf culture and is the "lifeline" (3) of signing people. I sought to support the re-casting of stories and "deaf-centred counter-narratives" (3) so we might understand radical possibilities and new worlds through foregrounding these counter-narratives.

There is much promise, but also many limitations with the approach I have taken. I am taking the stories of others, re-presenting them and imposing meaning on these lived experiences (Bell, 2002). Leggo (2004: 102) cautions the researcher that we must be careful that we do not misrepresent the complexity of experience. There is a hierarchal power relationship involved in the research in this way (Lynch, 1999). There is also a hierarchal power relationship involved in translation and language which I discuss later in this chapter but, as West (2013: 2) writes, "written English has severe limitations when translating hilarious, moving, mischievous and downright angry stories". Finally, the aim with this research is not to develop fixed, complete outcomes and conclusions but, similar to narrative inquiry, to engage "more toward wondering about and imagining alternative possibilities" (Clandinin and Huber, 2010: 14) and opening up questions and potential for going forward. This dynamic, living and breathing element of the research also speaks to the dimensions of DEAF-GAIN (Bauman and Murray, 2014) which I have discussed– it seeks ways to CONTRIBUTE to thinking and ways to advance and bring thinking AHEAD.

4.5 Embodied research

Drawing on the relational aspect of narrative inquiry, this research is embodied, whereby my body influenced all aspects of this research and not to acknowledge this would be remiss (Ellingson, 2006). This follows Price and Shildrick's (1999: 19) understanding that "knowledge is produced through the body and embodied ways of being in the world". My body holds and is constructed with cultural meaning. It means that it matters that my body is a female, deaf body for this research. This follows on from the point I have made about including reference to and paying attention to bodies in the (re)presentation of stories. This also acknowledges this research as living and breathing – it is not static or inert. The research evolved and was active and as researcher I was part of this, along with the participants. My emotions and subjectivity were also imbricated with knowledge production – as discussed throughout this chapter.

4.6 Ethical considerations

I was granted approval from the MU Social Research Ethics Committee before commencing my study. During the course of fieldwork, the sample demographic unexpectedly expanded, and issues arose around the perceived 'vulnerability' of one participant who expressed they wished to take part in the research. I re-submitted an application to the Ethics Committee for approval and detailed what procedures I would follow specific to this situation. I found this process extremely beneficial on both occasions for preparing for each stage of the fieldwork and ensuring my approach was rigorous, accountable and ethical. Imposing a vulnerable label on any research participant raised a dilemma for me in terms of assumptions around disability and inherent vulnerability – as I have discussed in chapter two. However, as a key ethical requirement, I felt that to follow this process in tandem with a critical reading of vulnerability in my work would strengthen my ethical framework and research approach overall. Along with these applications I followed other procedures for risk reduction, data protection and storage – issues around voluntary participation, informed consent, confidentiality and anonymity were attended to as detailed under 'ethics in practice', all materials from the research (notes, demographic identifying information, video recordings, transcripts) were password protected and stored on desktop PC. The data I collected from filming on a camera and laptop was encrypted and password protected. Following the interviews each recording was transferred over to the desktop PC and deleted from the camera as per data protection legislation.

4.7 Ethically reflexive research practice

As a community worker, researcher and deaf woman I am politically motivated. I believe that society can be a more inclusive place for diverse bodies to flourish in and I believe that research can and should assist this. This research is carried out with a 'goal of social transformation" (Harris et al., 2009: 108) If I did not believe in this I would not have carried out this research. I have already argued that it is important that I do not leave a gap in our knowledge and dominant, normative discourse around vulnerability unquestioned and unchallenged in chapter one, and two. We must think differently and do differently when it comes to audist/ableist ideas that are embedded in discourse and policy and this research aims to contribute to both.

My commitment to this as a community worker and a deaf woman is bound up with the ethical approach that I have taken in this research – the respect I have towards participants. It is also bound up with the approach I have taken in this research, by "follow(ing) research guidelines developed by the community themselves" (Harris et al., 2009: 113). This relates to the deaf framework I embedded in this research and particular steps I took around informed consent and confidentiality and other elements of the research which are addressed in this section.

Clandinin (2006) urges us as researchers to do more than just fill out the required ethics forms for our institutional ethics boards. I sought to act in 'responsible and responsive' ways in this research at all times, towards the dignity and well-being of participants

(Wang and Geale, 2015). It is imperative in ethical research to commit to ‘doing good’, ‘doing no harm’ and maximising benefits - beneficence (Harris et al., 2009) and adhere to the fact that this obligation can “supersede the goal of gaining new knowledge through research” (MU, 2019: 7) . Feminist, disability and deaf scholars have a strong reflexive approach to ethics and I borrowed heavily from their insights in building my ethically reflexive approach to researching intimate lives.

Young and Temple (2014: 57) consider that there are two issues in relation to doing deaf related research. Firstly, “failure to understand population-specific issues means that research practices might well be unethical in their application in specific contexts; and secondly, lack of awareness of the culturally mediated nature of fundamental ethical principles including informed consent, anonymity and confidentiality”. This means that components of ethical research, such as gaining informed consent, are not simple ‘box ticking exercises’ but one that must be culturally mediated.

As the authors note, deaf people are a highly heterogenous group. This was the case in my research – some participants identified themselves as having different levels of literacy. During recruitment I addressed this by delivering information on my research project through an ISL vlog, as well as written. I discussed participating in this research with some participants face-to-face beforehand and secured initial consent this way through ISL. Others were contacted through email or Facebook messenger, but these participants generally identified as having higher literacy. Some contacted me on Facebook messenger after seeing my ISL vlog on Facebook and wishing to participate. This meant that there were a range of capacities within this research. I sought to include such a range of capacities and not to exclude “certain kinds of d/Deaf people” which Young and Temple (2014) note can happen in deaf related research and make invisible the realities of some deaf people. To exclude certain groups of people is unethical and can contribute to dangerous hegemonic discourse that can further marginalise those who have been traditionally unrepresented (Harris et al., 2009). As a community worker, embedding values of participation, empowerment, equality, collectivity and anti-discrimination in this research was crucial and I worked to do so through a number of practical steps as detailed in the following paragraphs.

I strove to make this research participatory and empowering in different ways. Firstly, I sought to build a research advisory group at the beginning of this research. This was not successful. I contacted and spoke with deaf women who have an interest in research, in this topic and contributing to knowledge. It became clear that those who I spoke to were happy to contribute their ideas at the beginning but were not in a position to commit to an ongoing group. As a community worker and ethical researcher, I was conscious that participation must be voluntary, and to be mindful of any perceptions of coercion to participate, however unfounded. This was an additional issue to be cognisant of, for example when participants were recruited through their personal contacts. Here, I ensured that information was provided to the potential participant on the research and I gained their informed consent before proceeding to interviewing as detailed in section 4.8.1

From my initial attempts to build a research advisory group I realised that one-off interviews were going to be most successful. There is an extra dimension to this which also shaped my decision not to commit to a ‘pure’ version of narrative inquiry but rather to be inspired by and draw on aspects of narrative inquiry. Thus, I made this research accessible in terms of carrying out one-off interview that provided a “switch in modalities” (Young and Temple, 2014) from the written to signed or spoken and the formal to informal. In this way I created conditions for participating in this research.

This also had implications in terms of the process of generating knowledge with participants. While the interviews provided an invaluable space to generate knowledge through a conversational partnership with participants, I am aware that co-producing knowledge can be formally recognised as requiring multiple engagements with participants to work through their data. Yet, as Young and Temple (2014: 60) note, universal ethical principles should be culturally mediated. We must understand “the implications of universal ethical principles through a Deaf cultural lens”. Each interview took three-four days to transcribe. To return to 29 participants three or four times with heavy transcripts would have been extremely challenging. Firstly, managing this volume of transcribing would have been extremely time consuming and beyond my capacity as one researcher with an extremely limited budget. Secondly, it would have put some participants in a disempowering position if I asked them to work with me closely on the (re)presentation of their stories in written form considering the literacy issues I have noted.

It would not have been ethical, in my view, to put participants in this position and to do so would conflict with the importance of making this research empowering and anti-discriminatory, a crucial aspect of this research design that was informed by my stance as a community worker. A number of participants may not have been able to participate without this research design. I worked with participants around issues of anonymity and confidentiality in their transcripts and negotiating the data to be used but did not wish to ask them to contribute further than this. This may have been possible if I had worked with a small number of participants who had a good level of English and a greater 'fund of knowledge' regarding academic commitments and I had access to a research assistant who was also an interpreter. However, that would have excluded other deaf women from this research and further marginalised voices that are so rarely heard and as a community worker it was crucial that I moved from the individual and particular to the collective experience through the steps I took. For example, some participants may not have participated if I had included an interpreter. There is a small body of interpreters in Ireland and it is possible that participants would know them personally and would feel uncomfortable sharing private topics in front of an interpreter they use for their education or employment. As Young and Temple (2014: 58) write, "that fundamental issue of heterogeneity has a range of implications for ethical research practice".

Additionally, I sought to do an exploratory piece of research, to carry out the first piece of research on this topic in Ireland and desired to speak to a range of women from different social locations to develop a broader understanding of the issues contouring the intimate lives of deaf women in Ireland. This approach also embedded the community development principle of collectivity in the research design. Thus, I sought to interview a larger number of participants than is usually typical in narrative inquiry. These objectives thus shaped the methodological decisions I made and methods I chose. I view this research as the start of something bigger and began with collecting a wide array of stories which is the primary obligation of a community worker (Ledwith, 2011). From this there is the potential, in conjunction with deaf women I have built relationships with through this research, to build solidarity with other deaf women outside of this research around the issues arising from the study and to look at the potential for collective action. This has led to a positive story which is important.

Young and Temple (2014) point out there is the considerable issue of “credibility” which Harris et al., (2009: 112) contend is connected to the integral issue of ‘cultural competency’. They define this as “related to the researcher’s ability to accurately represent reality in culturally complex communities”. Cultural competency is built through reflexive practice and working alongside and learning from members of the community one is engaging with. The researcher must have “trusted or verifiable cultural competence to engage in research alongside, with and for deaf people” (Young and Temple, 2014: 64) and this enhances the validity of the research. This is also related to building rapport, which is an essential skill of any competent researcher. Before this research commenced, I spent two years building my relationships in the Deaf Community. I furthered this at a formal level through sitting on the board of two deaf organisations and at informal level through building friendships with deaf people, volunteering as a youth worker in a weekly deaf youth club and attending cultural events such as plays and talks and mingling with deaf people from different backgrounds.

I have built up my credibility over this time evidenced through being approached by deaf people to join three other deaf committees/boards, positions which I had to decline due to time commitments. Singleton et al., (2015) state that building rapport with participants shows respect for them personally. As researchers we must be mindful of how we build rapport in small communities and strike a balance. My approach was to build rapport through being involved in community activism such as being a member of Deaf Community Together for Yes, a deaf campaign group[49] that communicated accessible information to deaf people on the Repeal the 8th campaign. I also have a presence through responding to posts on deaf social media sites and attend deaf social events. Through all this I built rapport and even if I did not know one deaf person personally, they trusted the recommendation of another deaf person and met me on this basis. Some also knew my face from meeting and casually chatting with me at deaf events. All this was an important commitment to building cultural competence and

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[49] See Facebook Group – ‘Deaf Community Together for Yes’ for further information.

rapport. Importantly however, this was not always to further my own research, but I wanted to make friends and I liked the people I was engaging with. I value these friendships and seek to maintain them. This is my own DEAF-GAIN; BENEFIT. I am not ‘leaving the field’ after this research but will maintain my friendships and connections.

This also means that the boundaries are blurred but I maintained them and will maintain them through ensuring I never divulge anything to do with my research beyond overall findings. I never indicated that someone participated in my research, even though some participants did divulge that they took part. For example, at a dinner one participant discussed our interview and what she got out of it and how interesting it was. This put me in an awkward position where I did not want to respond to anything personal, she stated so I chose to sit and listen and nod along. It also brought up another issue. Participants divulged information about other deaf people to me in interviews, people whom I will and do encounter again. It was important that I manage this – which Young and Temple (2014: 71) describe as “keeping information confidential from myself” and ensuing it does not impact my relationship with other deaf people. This required a process of “forgetting” this information.

Shakespeare (1997) has pointed out a concern associated with researching and presenting disabled people’s sexual lives. He highlights that such research can potentially be used in voyeuristic ways by researcher and readers. Liddiard (2013: 3) found tension in her research between accessing the data and “by enabling disabled people to speak about their sexual lives and subjecting their lived experiences to a lack of privacy experienced throughout public and private life; thus, serving to objectify their sexual selves and desires”. With this in mind there were considerable ethical concerns attached to my research and the ethics of researching intimate lives.

I have discussed the philosophical and pragmatic aspects of challenging vulnerability in the previous chapters. Here, I critically challenge the idea of inherent participant ‘vulnerability’ regarding ‘sensitive’ research. As discussed, ‘vulnerability’ is a contested concept (Brown, 2015) and I found it problematic to apply this concept to participants and have addressed my reasons for this in chapter two. This is not to say that I should not be accountable and follow the principal tenets of ‘do no harm’ and minimising risk to participants. However, all participants in research are vulnerable, my participants were not vulnerable because they were deaf. At all stages this research was committed to minimising any risks to participants by virtue of their participation in the study. I did not do this through a lens of protecting ‘vulnerable’ participants but because this is good, ethical research.

I built a supportive environment through careful, sensitive questioning that minimised the risk of being unnecessarily intrusive. I took participants’ lead on how far I could or could not probe into their experiences and regularly checked in to ask if it was okay if I asked certain questions. I reminded them they did not have to answer anything they did not wish to, and I remained alert to the need to move on from any topics of distress. An additional risk to be cognisant of is maintaining confidentiality. There are risks that participants can be identified from the research. In two cases I felt that I could not maintain confidentiality if I included details about incidents that happened to two participants. In both cases I felt it was best to exclude these particular narratives. This was important in order to adhere to the principle that ‘doing good’ must come before gaining new knowledge. Thus, there are harms and risks associated with this kind of ‘sensitive’ research. However, these can be and should be managed to ensure deaf women are at the forefront of knowledge production and to acknowledge the “preciousness and power” of participants’ narratives (Liddiard, 2018).

Related to the ethical issues of this research and its ‘sensitive’ nature, I must be accountable to participants. Firstly, I was available through email and social media. I made it known that participants could contact me at any time. I asked participants how they felt about me doing this research and included that in this methodology. I took a cautious approach towards (re) presenting stories and ensuring I was purposeful with this. I sought to honour participants’ stories as faithfully as I could, to ensure stories were represented and thus understood with as much accuracy as possible.

Finally, as Aluwihare-Samaranayake (2012) details, it is important to be cognisant that participants abilities to change their circumstances may be constrained due to cultural, economic or political domination. In this context, as a researcher, I have a responsibility to contribute towards achieving social justice. On this basis participants deserve more than “respect, courtesy and honesty. They have a right to the social power, empowerment and emancipation that comes from the rising knowledge" (Aluwihare-Samaranayake, 2012: 66). This relates to the process of dissemination that I discussed under section 4.3.1. I will go beyond disseminating the research back to participants and work to disseminate this information at policy and academic level.

4.8 Ethics in practice

Next, I discuss what additional ethical considerations were key in this research – in other words, ethics in practice;

4.8.1 Informed consent

Prior to interviews, participants were sent information sheets about the research questions and their rights during the research process. This was followed by a face-to-face discussion (through ISL or English) immediately before the interview. During this time the camera was not switched on. Once the participant indicated their consent, I asked if I could turn on the camera to record.

Three options were provided to document informed consent. Firstly, signing a consent form. All participants took this option. Secondly, participants could give informed consent through ISL and a short video would have been made or finally, verbally on the tape or video recorder. Developing and ascertaining participant understanding of informed consent and the ongoing nature of informed consent was given careful consideration.

As Young and Temple (2014) write, there are extra considerations around the concept of informed consent with deaf people. Referring to Pollard (1998) they state that the concept of informed consent may not be familiar to some participants due to reasons such as, "having a smaller fund of knowledge and information in comparison with hearing people" (2014: 61). While the researchers warn not to place participants in a 'victim or vulnerable role' by automatically assuming a lack of knowledge it is wise to give time towards drawing out the concept of informed consent at the beginning of each interview.

Drawing on evidence based best practice I adopted the following practices to ensure ongoing informed consent;

- I continuously checked for ongoing consent of participants by checking before, during and after interview
- I provided accessible written and signed information i.e. using suitable terminology and interpreting any written English information into ISL
- I ensured participants fully understood the purpose of the research, what would will happen with the data, how it would be stored and what would happen with the research
- I reminded participants that they could withdraw from the research at any time, including post participating
- I ensured participants had access to their transcripts and could alter them as they saw fit

No participants objected to the use of video recording when I checked for consent to recording. Before beginning an interview, I reiterated that if I asked a question that the person was not comfortable answering they could simply respond they did not want to answer. I also reminded the interviewee that if they mentioned something in the interview that they did not want me to document that was also their right.

4.8.2 Confidentiality

Protecting confidentiality through anonymising identifying details was a big concern. The Irish deaf community is small, and confidentiality and anonymity were stressed by every participant. I had to find a way to address the objectives of the research, theorise across a number of cases and critically represent the complexity of participants' experiences and positionalities (Clandinin and Huber, 2010) whilst also blurring identifying details. Therefore, bounded segments about particular intimate experiences are included in the analysis chapters. Where necessary I change details such as places, names and so on. A common concern across the literature dealing with ethics in social research with minority groups generally and in Deaf studies specifically is that of confidentiality. Meador and Zazove (2005) write that Deaf Community members, conscious of their privacy, may refuse to take part in research out of suspicion that their anonymity will not be preserved. It is recommended that clear phrases such as ‘no names’ are used to counteract any worries and reassure participants. This was noted with all participants as well as guaranteeing that other identifiers such as where they lived or worked would not be included. This is also key to my decision to use thematic narrative analysis in this research which allows for further anonymity.

4.8.3 Transcribing and anonymity

I am competent in, but I am not fluent in ISL. There is great complexity involved in the act of translation and a number of points in relation to this to explain. Firstly, I ran into some confusion in understanding three of my participants fully and I was acutely aware of the great risk of mistranslation of meaning in these cases. All interviews were transcribed from ISL or English into English text – thus I shifted from one modality into another (Young and Temple, 2014). While all participants were offered an interpreter, no participant requested one for interviews. Later I sought and secured permission from five ISL interviewees for an interpreter to transcribe our interviews. I also asked five English interviewees for permission for an English-speaking transcriber to transcribe our interviews. I returned to each participant and reiterated that I would like to employ a transcriber for assistance with their interview. This was noted at the beginning of our interview, but I wanted to ensure ongoing consent. All participants confirmed their consent. In effect there were four different transcribers (including myself) involved in the transcribing process. All transcribers signed confidentiality forms. This aspect of the research was approved through the MU Ethics Research Committee application. One ISL qualified interpreter and two English transcribers were employed by the MU Access Office. The ISL interpreter was employed from Bridge Interpreting – a sign language interpreting agency.

I transcribed the remaining interviews myself. Each took me three – four days to transcribe and was a complex process. Nevertheless, I found the transcribing process invaluable. It allowed me to further delve into and sit with the interviews, immerse myself in the data and draw out the common themes across the data. I ran into the issue of misunderstanding or being confused by some phrases and sought to clarify these by recreating a short video of the sentence (that omitted any identifying information) and clarifying meaning with a deaf person who agreed to support me in this process during the translation period. On reflection these interviews should have been carried out with an interpreter present and, if I repeated the process again, I would change how I approached these interviews. However, it is worth noting that including an interpreter in the room could also have impacted on the interview dynamic and the data collected. In relation to other interviews I took great care during the interview to work hard to ensure I understood meaning and in turn make myself understood (Young and Temple, 2004).

I sought to represent the meaning conveyed in each interview as accurately as possible. This process required careful thought. I was aware of the limitations of my ISL to written English translation ability and sought to navigate this in a way that afforded participants privacy by ensuring I did not have to ask a professional interpreter to translate all the interviews but also ensure that I accurately represented meaning. I approached this complex issue by including reference to humour, gestures, laughter, pauses, silences and facial expressions and the meaning or tone that this conveyed within brackets. For example I referred to a participant rolling their eyes to convey exasperation or shrugging their shoulder to convey being dismissed.

It is important to clarify that this means that the structure of narratives differs across the analysis chapters. To convey that that some participants were using signed English or spoken English with me I followed an English grammatical structure. To convey that the interview was ISL and to assist with managing the impact of my limited ISL to written English translation skills I approached the translation by following an ISL grammatical structure as best as I could and including reference to gesture and tone to highlight the depth of feeling and nuance that the participant had conveyed.

This approach was followed less closely by the two English transcribers who only had an audio recording and thus included verbal cues such as pauses or laughs. I followed up on these interviews by re-watching the taped interview and documenting additional important visual contextual clues. In relation to the ISL interviews – it was necessary for the interpreter/transcriber to have access to the video given the visual modality of ISL. They followed English grammar and did not include the extra aspects of the conversation. My approach was to try and follow ISL grammar as best I could and to include deaf words (e.g. “Foo”)[50], gestures and facial expressions to hold as much life and meaning in the data transcription as possible. This followed interpretive and constructive epistemologies where attention is paid to how something is said in recognition that it is important how a point is constructed (Young and Temple, 2014). Young and Temple (2014: 143/145) highlight that there are issues when “attempting to represent signed utterances in two-dimensional space (on paper) when in reality they occur in four dimensions” and “historically transcription has been a problem in studies where data have been collected in sign language”. Deaf academic, Ladd (2003) has cautioned researchers to be aware of these issues in translation. I returned transcriptions (and video recordings where requested) to all interviewees for their feedback, assurances of accuracy and the possibility for them to remove or edit information.

My re-presentation is imperfect. It raises dilemmas of how to navigate complex issues such as producing expression in written English. West (2013: 5) notes;

> “the recording and re-presentation (by a hearing person) of stories told by, for and about, deaf people – whose history is arguably largely one of discrimination and marginalisation – is a methodological, epistemological and political minefield. It places issues of power, representation, cultural translation and conceptual equivalence firmly in the spotlight”.

I am a deaf person, but these issues of power and representation remain pertinent. I emailed transcripts to participants – some of which followed an ISL grammatical structure written in Deaf English, similar to “the English written and understood by Deaf BSL (British Sign Language) users that displays non-standard grammar and lexical choice but incorporates a Deaf cultural perspective with the English” (Stone and West, 2012; 659). One participant asked me to re-write the interview following English grammatical structure. The narrative presentation was negotiated in this way. Stone and West (2012) note that one must be mindful of presentation of sign language narratives, and think of the readership, losing something in the translation, as well as readers thinking this is simply poor English. The researcher must think carefully about what

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[50] This is noted in chapter 6 under 6.9: ‘Negotiating deaf embodiment in intimate moments – the labour and the pleasure’.

their aim is when re-presenting interviews. My aim is to strengthen the representation of the diversity of language use, along with the depth of expression and embodied communication within interviews.

The importance of identifying the act of translation/interpretation is a key issue in literature exploring research with Deaf Communities. The final product of this research is published in English. This raises what Young and Temple (2004) call ‘hierarchies of language power’ – translation in this context is not a simple one of translation from one language to another but, in a way, “collusion with the historically oppressive significance of English in Deaf people’s lives” (Ackerman and Young, 2001: 186). English has long been promoted as a ‘better way’ for Deaf people to communicate and sign language has been ignored as a legitimate language in which to learn and communicate. This has deep resonance for Deaf people. Unfortunately, it is not possible to publish this PhD in ISL given the practical requirements of the traditional academic PhD. However, I will disseminate the research findings using ISL and clear, accessible English - therefore going someway to challenging this disempowering language hierarchy and committing to the principles of the Deaf research framework.

4.9 Recruitment, accessibility and cultural awareness

Recruitment took place in 2017 and I conducted a number of interviews as follows:

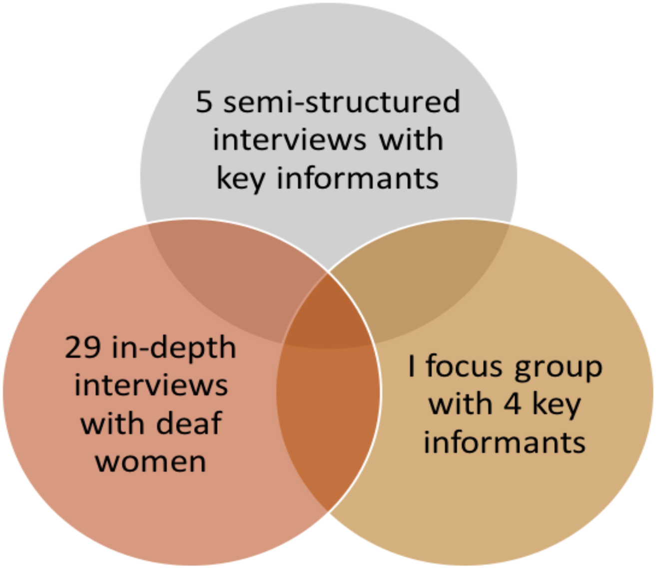

Figure 4: Interviews carried out.

4.9.1 Scoping exercise

I carried out one focus group with four key informants and the other five were one-to-one semi-structured interviews. These were carried out as a scoping exercise and for the purpose of collecting context setting data and to gather information about the wider field that service providers are working within. The scoping interviews were conducted with two social workers, six community resource workers and a social care worker. Five of the practitioners are deaf. Many of the practitioners had expertise to contribute towards formulating recommendations in this research. Practitioners were based in rural and urban environments – eight were attached to a deaf service and one was attached to a disability service. They supported the research by providing contextual information in relation to sexual health services and information and what they perceived as key priorities from the perspective of their role/service. I identified each key informant either purposively through my own knowledge of them or they were recommended to me in a chain referral/snowball by other key informants because of their knowledge in this area.

4.9.2 Sampling, inclusion/exclusion criteria and recruitment

Participants were for the most part recruited using purposive sampling, online advertisement and snowballing strategies. Purposive sampling is carried out to recruit participants in a strategic way “so that those sampled are relevant to the research questions that are being posed” (Bryman, 2012: 418). The criteria for inclusion in the research was established according to demographic, geographic, linguistic, communication and educational characteristics of participants I wished to include in this research. I sought to interview participants from a range of locations (urban and rural) in Ireland within particular age brackets: 18-25, 26-35, 36-45, 46-55, 56-65, 66-75. I developed the following criteria for purposeful selection and participation in my research;

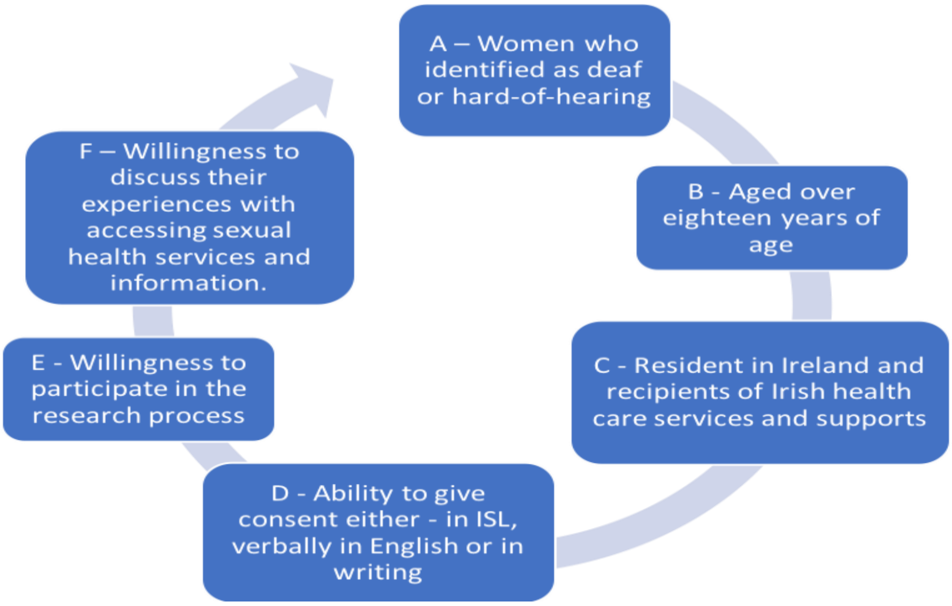

Figure 5: Criteria for participation

I excluded women from this research who did not identify as either deaf or hard-of-hearing. At particular stages in the research I reached saturation point with some criteria and then excluded participants who matched the criteria. For example, I interviewed a sufficient number of participants aged under 30 and moved the focus of the recruitment to over age 30.

The following table introduces the participants. I sought to generate maximum variation in my sample. I selected different participants due to family background (deaf/hearing), school (deaf/mainstream), sexuality, where they are currently living (urban/rural), their educational or employment experiences, children (parents/not parents) and age. While I was happy with the degree of diversity, it was intended to have a larger cohort of people who identified as other than white and heterosexual, but this did not happen – four women identified as other than heterosexual and one woman identified as from a non-white ethnic background[51]. I made efforts to diversify sampling through snowballing but found it difficult to get responses. This is a limitation of this research, an aspect that future research could address.

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[51] I do not give specific details about this participant's ethnic background here to maintain confidentiality and anonymity.

	Name	Age	School	Identity	ISL user / oral / both	Sexual Orientation
1	Ann	Early 70's	Hearing/Deaf	deaf	Both but doesn't use voice	Straight
2	Addison	Mid 20's	Deaf school	HoH	Both	Straight
3	Aileen	Late 20's	Mainstream and deaf	Deaf	Both	Straight
4	Elena	Early 30's	Mainstream and deaf	deaf	Both	Bisexual
5	Finnoula	Early 70's	Deaf school	Deaf	ISL only	Straight
6	Hannah	Mid 20's	Deaf school	Deaf	ISL only	Straight
7	Holly	Early 20's	Deaf school	Fluid deaf	Both but prefers ISL	Straight
8	Jessica	Early 20's	Deaf	Deaf	ISL only	Straight
9	Kerry	Mid 40's	Mainstream	Deaf	Both	Bisexual
10	Ruby	Early 20's	Deaf school	Deaf	Both but prefers ISL	Straight
11	Sadie	Mid 20's	Deaf school	Deaf	ISL	Straight
12	Beatrix	Early 50's	Deaf school	Deaf	ISL	Straight
13	Rachel	Late 20's	Deaf school	Deaf	ISL	Straight
14	Christina	Late 50's	Deaf school	Deaf	ISL but oral with family	Straight
15	Irene	Late 20's	Deaf school	Deaf	Oral and ISL	Straight
16	Stephanie	Mid 20's	Deaf school	deaf	Oral and ISL	Straight
17	Sybil	Early 40's	Deaf school	Deaf	ISL	Straight
18	Eve	Mid 40's	Mainstream school with deaf unit	Deaf	ISL	Straight
19	Barbara	Mid 50's	Deaf school	Deaf	ISL	Straight
20	Veronica	Late 30's	Mainstream and deaf	Deaf	ISL	Straight
21	June	Early 50's	Mainstream	HoH	Oral but knows ISL	Straight
22	April	Mid 30's	Deaf school	Deaf	ISL	Straight
23	Sophie	Mid 40's	Deaf	Deaf	Oral and ISL	Straight
24	Vanessa	Late 20's	Mainstream – Deaf	Deaf	ISL	Straight
25	Betty	Late 60's	Mainstream	Deaf	Both	Straight
26	Catherine	Early 70's	Deaf school	Deaf	Both	Bisexual
27	Harriet	Early 30's	Mainstream	Deaf	Both	Straight
28	Liv	Mid 40's	Deaf	Deaf	ISL	Lesbian
29	Colette	Mid 30's	Deaf	Deaf	Both	Straight

Table 1: Participant Profile

Snowball sampling strategies were used to assist this aim - this is a process of building a sample through referrals whereby one research participant introduces the researcher to another. This is a frequently used approach in qualitative research with marginalised groups (O' Leary, 2010). For example, I asked a participant in her early 20's if she could put me in touch with someone within her age bracket who she felt would be interested in the research and willing to contribute.

I wished to interview people outside Dublin and asked participants to draw on their social networks to facilitate this by contacting someone they knew who would fit the sample to ascertain their interest. The majority agreed to do so. After an indication of interest, I followed up directly by sending the potential interviewee an information sheet. I was in a good position to use this approach as I was familiar with ten of the first cohort of participants. Thus, I first directly contacted ten women with whom I had engaged with prior to beginning data collection. Some of this cohort had indicated they would be interested in and available for an interview when I formally began my research. Following purposive sampling, I used snowball sampling which generated a further 19 participants. Snowball sampling is useful when trying to access hard-to-reach populations. I used this as I wanted to meet people that I did not know personally in order to enhance knowledge production. There are limitations with this approach – participants are likely to suggest people they know well, those they are connected to. This means that people who are outside of these existing networks were at risk of being marginalised and the research is at risk of limiting diversity of participants (Woodley and Lockard, 2016). I built up a couple of chains of unconnected knowers and this along with use of online spaces via an ISL vlog (video blog), assisted me with building a wider network and to mitigate the weakness associated with snowballing.

In relation to ISL vlog advertisements I developed and subtitled a number of vlogs detailing the research objectives as well as introducing myself and giving my contact details. With the permission of each Facebook group administrator I uploaded these videos into various Facebook groups that are specifically set up for deaf women living in different areas around Ireland. Through this recruitment method I recruited and interviewed five deaf women.

Example of one research recruitment video;

Hello Deaf Women for Deaf Women!

In addition, I delivered a presentation on the research at a National Deaf Women's Conference, 'Let it Go', in late 2017. At this conference I noted I was enthusiastic to meet with anyone who was interested in contributing to the research. While a few people expressed interest in participating in the research unfortunately no one followed up with me after the event. If I were to undertake this again, I would seek to travel to deaf women's clubs throughout Ireland and present on my research to encourage potential interest in participating.

4.9.3 Research location and making research materials and spaces accessible

Thirteen of the interviews were held in DVI – a deaf friendly space. Thirteen were held in the person's home, workplace or where they were studying. Three were held in the hotel I stayed in when I travelled outside Dublin to meet participants. Locations were chosen by participants according to what was most convenient for them. The majority of the interviews took place in Dublin. Some participants did not live in Dublin but were visiting DVI and we took advantage of their visit to meet there. I also travelled outside Dublin to locations in the midlands, south-west and south-east to meet participants and in these places met participants in their home, workplace or the hotel I was based in.

Specific locations are not named to ensure anonymity and confidentiality. Given my ethical assurances to participants I strove to anonymise the data as far as practicable by using pseudonyms, changing locations and place names. I also modified details such as how many children a participant had and used general age categories rather than specific ages in order to reduce the risk participants might be identified.

Some spaces required management such as adjusting curtains or blinds and moving tables and chairs in order to see each other clearly and to feel physically comfortable. Interviews, on average, lasted up to two hours. This included the time to discuss the research aim and objectives as well as to translate and fill in the consent form.

To ensure the research was accessible and culturally appropriate, a number of steps were taken with recruitment materials. It is important to understand the particular learning and visual needs of deaf people and to include this in written research material, for example the information and consent form. There is limited information in relation to literacy levels of deaf people in Ireland (Mathews and O' Donnell, 2018). Internationally there is greater availability. Irish researchers, Mathews and O'Donnell recently carried out a study exploring literacy among deaf mainstream students in Ireland (2018). They cite findings from "Holt's (1993) landmark study…which found the median reading age of 17-year-old school leavers was 9.5 years. Similar results were found in a 1990 study carried out in Ireland which reported average reading ages for 16-year-old DHH pupils at 9.2 years of age (James, O'Neill and Smyth, 1991) and again in the US nearly a decade later (Traxler, 2000). Mindful of this and following good practice recommended by previous deaf researchers, I distributed research information using two formats – a subtitled vlog and accessible written material[52].

Linked to the issue of low literacy and considering cultural norms, the written information distributed was developed to adhere to ethical and deaf/disability friendly guidelines. This was not an approach that every participant required but I followed this approach as a general rule in order to ensure my information was clear. I used disability friendly font and formatting - Verdana font, size 12 and double-spaced lines - (NDA, 2002). Written information was kept as straightforward as possible. Detail about the

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[52] See Appendix 3,8 and 9.

research was given through the vlog and written material. A substantial amount of time was given to reiterating information at the beginning of each interview. In respect of cultural norms, the information form included a photo of me, clear signposting and labelling. This action, while small, is an important acknowledgement of Deaf Culture. As Young and Hunt (2011) explain, there are a number of aspects to this; firstly, it allows the deaf person to locate the researcher within their visual memory. Secondly, amongst the Deaf community people are often referred to and known by their sign name. A deaf person may know who a person is by referring to their face / description or their sign name but be unfamiliar with their spoken/English name (Young and Hunt, 2011). As Young and Hunt further stress "small examples like this underline the primary relevance of cultural competence to ethical research practice with and within Deaf Communities and cultures" (2011: 17).

Using social media as a site for recruitment has been identified by deaf researchers as a useful and ethical approach. As McKee et al., point out, "Many research studies have failed to fully engage the Deaf community, leading to confusion, mistrust, and refusal to participate in the research process and a cross-cultural conflict between the Deaf and research communities" (2013: 321). Their research used vlogs and social media tools (Twitter and Facebook), to inform and recruit deaf people. This approach is also encouraged by Lunnay et al., (2015) who suggests that such research should be underpinned by the "traditional ethical principles of respect, integrity and beneficence" (2015: 100). This tool, when used correctly, can be highly useful for facilitating recruitment, interactions and sharing research data. Lunnay et al., (2015) also suggest the researcher should disclose their own personal identity through their practice and make one's personal Facebook page available, which I did. There was tension here with the potential challenge of sharing one's personal Facebook page but on balance, I felt it was an important step in challenging traditional power differentials in research.

Finally, I did not offer an incentive to participants – their participation was voluntary. I did write each person a card thanking them for their time and contribution. I also put together a small package such as a scarf, plant, or ornament to show my appreciation. I gave key informants a small plant or chocolates as a thank you token.

4.10 Research Methods

The methods used to collect and analyse data are presented and explained below.

4.10.1 Data collection

> "Qualitative interviewing is a great adventure; every step of an interview brings new information and opens windows into the experiences of the people you meet"
> (Rubin and Rubin, 1995; 1).

Prior to formally conducting interviews, I carried out a pilot interview with one deaf woman who did not take part in the research, as she did not fit most of the sampling criteria. However, she agreed to participate in a pilot interview in order to provide support and constructive feedback. This provided key learning for me. My first formal interviewee also gave me strong feedback on ways to develop and improve my inquiry. Both interviews were extremely constructive and fed back ways to develop a clearer and accessible (more 'deaf friendly') style of asking questions and generate a more straightforward interview guide.

Each interview brought its own challenge – I was always nervous beforehand. I felt honoured upon completion that each person was willing to sit with me and share their story. Each participant was asked to complete a short demographic questionnaire prior to the interview as well as signing a consent sheet. Interviews elicited information by beginning with a causal probing of the interviewee's background – education, family, employment. This approach served to ease us both into the interview, taking a life stages approach to data collection from which I could then use transitory questioning to move towards the key themes as set out in the interview guide. The interview guide drew on the guide developed by Liddiard (2011) in her research. From this, I developed a tentative interview guide suitable for my research objectives encapsulating key themes I wished to explore with the interviewee[53].

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[53] See Appendix 6.

Following the initial settling in period of the interview described above, I opened up thematic inquiry by asking participants about their childhood and menarche. From this we developed a rough chronological sequence and moved into adolescent years where we discussed topics of dating and relationships as well as first sexual experiences. Depending on the life circumstances and age of the participant we also discussed pregnancy, miscarriage, labour, menopause, cervical check-up and so on. This brought us through themes of learning and doing, how to enhance opportunities for this, flourishing and so on. Conversations were rarely linear - we moved forward and backwards. There were times that participants gave broad statements during their responses, for example - "*I feel it is better to be in a relationship with a deaf man*". Probing further into this kind of opinion statement I would try to make effective use of follow up questioning to gain a better understanding of their perspective, asking for further explanation of their meaning and if they had an example to illuminate their meaning. Usually this provoked deeper conversation.

4.10.2 Approach to interviewing

Developing the necessary skills as an interviewer was a steep learning curve for me. With hindsight, I missed some opportunities to follow interesting avenues of enquiry. I tried to encourage participants to speak for as long and as freely as they wished on each topic. This also draws on another aspect of narrative inquiry which is "to generate detailed accounts rather than brief answers or general statements" (Reissman, 2008: 23). Some participants elaborated in detail indicating that they were comfortable to share freely. Others were more reserved and succinct and in some cases I probed more, or if I sensed resistance, moved on. As outlined, the aim of this research was to explore the intimate experiences and worlds of deaf women across temporal, social and geographic spaces. Accordingly, the story built over the course of the interview and stories took different forms (brief, long, in-depth) (Reissman, 2008).

I became more comfortable with the interviewing and aware of how best to pose questions to elicit deeper, richer data, (for example avoiding the use of closed yes/no questions) and to reciprocate in the interviews in order to allow the data to develop with ease. According to Rubin and Rubin (1995) the interview is invented anew each time, and this was certainly the case for me. Interviews did not follow "the model of a “facilitating” interviewer who asks questions, and a vessel-like “respondent” who gives answers, (this) is replaced by two active participants who jointly construct narrative and meaning” (Reissman, 2008: 23). Harnessing this approach is also deliberate in terms of displacing power dynamics. Reissman (2008) reflects that the interviewer gives up control. I do want to overstate this however, I did not entirely ‘give up control’ and power dynamics did not evaporate completely, I still steered the conversation and topics. However, I began by asking where participants would like to start and often participants asked that I start the conversation and so I put forward a suggestion at the beginning that their family, school, friends and then their learning in their early years would be a nice starting point. The majority felt that was fine and interviews followed on to be convivial, moving with ease between topics. As Reissman (2008: 24) sets out, the rules of everyday conversation applied – “turn-taking, relevance, and entrance and exit talk” – in the journey from one story to another. In this way I followed Hill Collins’ (1990, 2000) ideas around dialogue, used to generate and co-construct knowledge and listen to knowledge claims.

Rubin and Rubin (1995) have elaborated on their concept of ‘conversational partners’ to describe their approach to qualitative interviews. They state that “interviewees in qualitative interviews share in the work of the interview, sometimes guiding it in channels of their own choosing” (1995: 10). This approach assumes that the interviewee is an active partner in the conversation/interview – not an object of research. Rather, both interviewer and interviewee co-operate together to produce a shared understanding. This was the approach used in this research, fitting well with my deaf epistemologies’ framework and how deaf people often work together well to achieve meaning with others. This approach is also mindful of the diverse needs of interviewees – some are “self-revelatory, others more restrained and formalistic” (1995: 11). I encountered diverse interviewee needs in my research and sought to respond to the needs of each person appropriately. Maxwell (2013) also describes some interviewees as engaging in an interview on an intellectual level without revealing any personal information while others might disclose personal information but be reluctant to reflect critically on this. This reflects my experience– while some interviewees appeared comfortable recalling experiences, in contrast, when I probed further for a reflection of their feelings on an experience, they became reluctant to disclose further.

Regarding key informants, I used a semi-structured interview[54] and developed an interview guide to this end. A semi-structured interview retains flexibility to an extent. It begins with a guide for questioning (O'Leary, 2010) and then shifts according to the flow of conversation. I developed my guide to cover particular topics relating to collective sexual health and key concerns and issues that informants were aware of in their role, as well as recommendations they would make on this basis in order to address gaps in current knowledge. Using this method allows for comparison of data across key informants.

4.11 Thematic analysis of interview data and data presentation

> "Qualitative analysis transforms data into findings. No formula exists for that transformation. Guidance, yes. But no recipe. Direction can and will be offered, but the final destination remains unique for each inquirer, known only when—and if—arrived at"
>
> (Patton, 2002: 432).

Maxwell (2014) contends that in any qualitative study the analysis must be carefully designed. Creswell (2007) agrees, describing this as a 'custom built' process. The researcher must make clear decisions about this and ensure that it fits in with and is informed by the rest of the research design. As a feminist researcher I sought to give primacy to the data generated by the participants, to ensure their lives and experiences were at the centre. I needed to ensure that the analytic tools were appropriate to this task. I again was influenced by narrative inquiry. Thematic analysis is a commonly chosen method in narrative analysis in the search for meaningful insights as "it can be applied to stories that develop in interview conversations" (Reissman, 2008: 54). I felt it was the most appropriate approach towards analysing interviews about intimate life that encompass a wide range of narratives of this aspect of life. It also assists with exploring the meaning making revealed through this process. Use of this method requires a focus upon 'what' is said, not 'how' (Reissman, 2008). This was not a straightforward task – as an analyst I had to pay close attention to the story in its own terms and ensure I did

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[54] See appendix 8

not simply reduce the narrative into categories that address the research objectives (Woodiwiss et al., 2017).

Maxwell (2014) advocates for analysis to begin after the very first interview and to be consistent with this along the way. My first batch of interviews took place very quickly, one after the other. I could not follow this approach to the letter because of this. I wrote field notes following interviews and soon after transcribing a batch of interviews began to develop a detailed analysis of this batch of interviews.

The data in this research was dense and managing this density was challenging. In preparing for thematic analysis the first step was to carefully read each transcript several times and watch back each interview simultaneously as part of the process of drafting a number of observation notes using a systematic format. Interviews were first organised by age cohort (e.g. 18-25, 26-35) when beginning analysis and then biographies were "interpreted and compared as constituted in the research process" (Reissman, 2008: 57) to understand the story emerging. Exploratory data from key informant interviews was subjected to thematic data analysis. A number of memos were written in the margins of transcripts capturing my interpretations and reflections on concepts and ideas that emerged from reading the data as a whole.

Following this I began to generate conceptual diagrams (mind maps) outlining meaningful segments and patterns across each participant's interview data – the comparisons and contrasts and the 'counter-narratives' (Creswell, 2007; Miller, 2017) that I 'heard' and 'saw' across the data. I began to organise the data to understand the key assumptions and code these (Reissman, 2008). Codes from these sequences were then used as a stepping stone to "develop tentative ideas about categories and relationships" across all participants and the emerging story before moving towards deeper thematic analysis to find theoretical links (Maxwell, 2014: 105). Thus, the data was analysed in an inductive way. Creswell (2007: 151) describes this as a loop – whereby the researcher moves from "the reading and memoing loop into the spiral to the describing, classifying and interpreting loop". A set of questions posed by Miller (2017: 46) was helpful with this. These questions encourage the researcher to think about the chronological order that the storylines might follow. For example, some questions encompass:

- what is dominant and what is absent in accounts?
- What language and words are repeated?
- What strands of discourse are apparent? How do accounts shift over the course of the interview?
- What appears to remain unspoken?

These questions assisted me with “think(ing) backwards and forwards, up and down and across (the) data” (Miller, 2017: 47). I then separated these categories under themes and sub-themes that began to form coherent analysis chapters. This was facilitated through manual colour – coding and copying and pasting in Microsoft Word.

4.11.1 Storying and restorying

Although participant biographies in relation to their intimate experiences were explored – only segments of data are reproduced in the analysis chapters under themes along with my interpretation and reference to theoretical and conceptual frameworks. Restorying from the stories in the data is a complex process – the aim is to present the complicated breadth and depth and multi-layered narratives within the research (Clandinin and Huber, 2010). I have already touched upon the process of restorying above – reading and analysing in order to understand the lived experiences within the data and then organising this story within chronological sequences in order to retell this story (Ollerenshaw and Creswell, 2002). I approached this element by organising chapters along a spectrum of experiences that take place at particular points across the life course.

Within the analysis chapters these segments take varying sizes and shapes with the aim of allowing them to breathe as they are. However, how things are said is not the key focus of my analysis – “in thematic narrative analysis, emphasis is on “the told” – the events and cognitions to which language refers (the content of speech)” (Reissman, 2008: 58). The analysis focuses upon the story being told and the thematic meanings across accounts. This is not a neutral activity “stories reflect and constitute the dialectics of power relations and competing truths within the wider society…they can serve as sites of resistance, as a means to challenge dominant regimes of truth" (Reid and West, 2015: 2). I also include detail about where and when these stories took place – at home, in school, in boarding residence and who the other characters in the story were in order to build up a rich context. All of these elements were drawn together to give an account of participants' experiences and tell a new story that disrupts and displaces hegemonic ideas in relation to deaf women and sexuality – a story of flourishing and how we can enhance opportunities for flourishing.

4.12 Policy data analysis using Bacchi's (2009) WPR approach

Along with narrative thematic analysis of participant interviews I also carried out policy analysis using Bacchi's WPR approach as set out in chapter two. It was used to interrogate the policies set out in chapter two in order to understand how they position and construct deaf women and sexuality. The questions used to assist with this analysis are further set out in appendix 2. I applied the six questions that Bacchi set out to understand that deaf women were constructed as 'vulnerable' and often omitted from policy representations.

4.13 Reflection on me as embodied researcher

This section reflects upon the ways in which my deaf, gendered positionality and embodiment influenced the research and my relationships with participants, as well as how the research in turn has impacted upon me. In doing so I locate my biography within the research as well as within the principles and values to which I adhere. Stanley and Wise are emphatic about the need for feminist research to ensure "experience and feeling" (1993: 60) is embedded in the core of the research as part of the practice of integrating feminist principles within the research.

I have discussed my positionality in chapter one and here I reflect more on what my positionality means for this. My perspective is not a culturally Deaf perspective. I do not claim to have or fully understand any other perspectives than my own. I use my lens as a deaf, female, heterosexual, middle class, white researcher to position myself in relation to the experiences of the research participants and to gain insight into these experiences. As a young person I attended mainstream school at primary and secondary level. I attended intensive speech and language classes to improve my access to speech and first language, English. I regularly attended audiology clinics to maximise my hearing potential. I did not learn ISL until my mid 20's and rarely met or mixed with other young deaf people, nor did I attend Deaf Community events until this time either. Upon reflection I grew up with a biased view of the Deaf Community and people who used ISL. I had no understanding of the beauty of ISL or how much it could potentially have enhanced my life and access. "Hearingness was the (my) goal" (Harmon, 2013: 168) and for years I made many efforts to 'pass as a hearing person' by disguising my deaf embodiment through actions such as 'improving' my voice, wearing my hair down to cover my hearing aids, and refusing to learn ISL (Goffman, 1959; Bruggeman, 1997).

My positionality opened up opportunities, relational connections and challenges for me. Research participants have made themselves vulnerable. I strongly side with the argument of Stanley and Wise (1993: 177) that if participants are prepared to do so, so must I. I found it difficult to be vulnerable during interviews and I found it even harder to be and feel vulnerable on paper. Behar (1996: 14) contends that such exposure "has to be essential to the argument, not a decorative flourish, not exposure for its own sake". This tension provoked anxiety in me and required constant reflexivity to track whether I was contributing to the research by doing so, was it "self-serving, and superficial, full of unnecessary guilt or excessive bravado…or lead(ing) the reader not into miniature bubbles of navel-gazing, but into the enormous sea of serious social issues".

This research raised considerations and dilemmas in relation to the concept of 'insider/outsider' research. I have discussed the fluidity of deaf identity and how my own deaf identity has developed. This highlights the reality that there is no monolithic insider view – "there are multiple insider views, multiple outsider views. Every view is a way of seeing, not the way" (Wolcott, 1999: 137). DeMeulder (2017) discusses this idea in relation to deaf researchers and contends that, to some extent, deaf researchers who carry out research into the groups to which we belong are 'insider' researchers "based on deaf ontologies and employing deaf capital". In contrast, embodied aspects such as linguistic capital in English, and being a member of the academy extends privilege. This means we are not quite insider which is also shaped by our other markers such as sexuality, class and ethnicity. DeMeulder contends (2017: 123) that it "is vitally important that deaf scholars display awareness of this privileged status and remain self-reflective practitioners; otherwise they risk simply reinforcing hegemonic structures and perceptions of oppression".

Regarding this I found Hill Collins' work (1986) on the 'outsider within' and the "connected knower" (2000) instructive. While I related to some experiences of deaf women, I have not grown up within the Deaf Community and do not use ISL as my first language. In these ways I felt an outsider while feeling an insider in other ways. It was important I paid attention to my own constantly evolving language and social ideologies and their potential influence on me and the research. Additionally, as Lynch (1999) reminds us, as academics we are still part of the cultural elite through freedom to write and discuss.

There is emotion work/emotional labour (Hochschild, 1983) involved in interviewing and transcribing. I use emotional labour to mean management of my own emotions - "to be there for subjects…and for the research" (emerald and Carpenter, 2015). Participants shared stark insights as well as joyous ones. Both sides of the spectrum comprised "emotion-generating situations' (Dickson-Swift et al., 2009). I felt connected to participants during and after interviews and I have continued valued friendships from this process as an outcome. In terms of the emotional management of the research Dickson-Swift et al., (2009) note that many researchers manage this emotion work through informal network support of trusted friends and family as well as de-briefing sessions with a supervisor - both of which I also engaged with.

Reflexivity is integral to and valuable in the research process. This is described as a more abstract way of understanding and articulating the impact of the researcher (their values, experiences, interests, beliefs, ethics) on the research (Ransome, 2013), as well as the impact of the research on the researcher. I have described how engaging in this research process has given me a deeper understanding of deaf culture and this has shaped the research as it proceeded. Simultaneously, it has shaped me – I have engaged in reflexive thinking about my values, principles, ethical research, and this has challenged me to disrupt my own thinking in order to rethink and reimagine. Young and Temple (2014: 44) rightfully point out that there are "different consequences in the choices made about who should do research with d/Deaf people, not just what the author might or might not reveal of herself". Consequences occur on various levels –

epistemological and ethical, and this demands consistent engagement in reflexivity. I have drawn out my reflections upon these points in earlier sections of this chapter – this meant I had to clearly draw together my epistemological stance and this had consequences for power dynamics and the relationship building process. It had consequences for how knowledge was co-constructed and negotiated and how I designed research materials.

4.14 Building relationships, power relations and foregrounding the voice of research participants

"There is an inescapable power dynamic involved in conducting research with a community of which you are not a member, in particular when there is a history of oppression against that community" (Mathews, 2017: 12). Issues and tensions in research with the Deaf Community by hearing researchers have been documented for a long time - particularly the resulting feeling of disempowerment during the research process and exclusion from research outcomes that many deaf people have experienced (Baker-Shenk and Kyle, 1990).

Establishing relationships has taken place mainly through my volunteer or professional links. These links were separate to links built for this research and were not carried out purely for the purpose of the research. However, they ended up forming a core part of my 'cultural competence' building. Maxwell (2013) refers to this as the first main component of utilising qualitative methods. Through my voluntary work I have established diverse relationships that contributed to this research. Over this time, I have engaged in a number of different deaf groups. My commitment to learning ISL began three years before this research was even a consideration. During the PhD journey I committed to increasing my language proficiency through consistent practice in deaf spaces such as IDYA events and meetings and seeking feedback for improvement. This development in my linguistic skills meant that it was possible for the many of the ISL research interviews to be carried out in ISL and translated by me into English. I have good lipreading skills and so I followed mouthing as well.

Early in the research I experienced tensions with the question of my fit for this research. Young and Temple (2014: 42) point out that the issue of who should be doing research within different communities is “a contested issue” that arises in both deaf and feminist academic writing. My concern was grounded in my biography. As noted, I have not grown up as a ‘native’ ISL user nor was I involved in the Deaf Community until I was in my mid 20’s. Throughout the research I probed a number of participants for their views on the topics of the research agenda and who should do deaf research. In relation to the first point the overall consensus was positive - participants felt the research agenda was of value and worth their time investment. Most expressed that they are extremely interested in the research findings. Those who participated in other research felt the research topic was different as other research had largely looked at education or employment so in participating in my research, they had an opportunity to explore another aspect of their embodied deaf identity;

> **Elena**: “…I look forward to reading your research findings…I just think the majority of it is mostly on education and you know. So that's why when reading it I was like ooh! (expresses interest) 'maybe a little bit exposed of myself but fuckit!….”

> **Addison**: “I think it’s a really good em topic to bring into the Deaf Community, you're taking a bit of a risk, not risk, but a lot of deaf people I think wouldn't be able to talk about this. It's like, it’s like it’s a big taboo…so I think it’s important that you're bringing this topic into the Deaf Community”.

As referenced in the preceding paragraph, an important point of contention is who should do deaf related research. Some participants were keen to share their own personal story and challenges they have encountered in order to contribute to change and better policy making. Five characterised themselves as valuing the production of deaf research and being keen to participate in deaf related research. Some participants felt they wanted to offer their support to me as we had a pre-existing relationship.

> **Barbara:** “First I always support deaf women doing research, wow, like you involved, studying and you're a deaf woman. I know you're mainstreamed but you still part of us so still 'ah wow' (expresses support deaf women doing research) …That's my view. Research about deaf women and sexual health in Ireland wow

> important. Information spread. When you publish paper in future, I want that so I'm willing to be involved for that.)…”

Other key topics in this vein consider power relations. Lynch (1999: 48) discusses how research can act in a colonial manner and create images of inequality and groups into which participants have no input and which are often recorded by “professional middle-class experts who are frequently removed from their culture and lifestyle”. She also notes that this is particularly prevalent with groups whose cultural traditions are strongly oral. Bearing this in mind along with my other actions, at the beginning of this research I was motivated to use an emancipatory, participatory approach (Oliver, 1997). I broached the idea of establishing an advisory group but, as noted, was not successful.

I came to accept the pure emancipatory/participatory approach presents a number of challenges. I reluctantly concurred that I too would face similar challenges to researchers that have gone before me. In relation to this I found Shakespeare (2010) helpful and came to agree with his assessment where he reflects that it is difficult to completely equalise the research relationship and there will always inevitably be an unequal outcome that is weighted more positively in favour of benefits to the researcher. I also developed concerns that requesting people to volunteer their time to a research project that I ultimately benefit from in terms of an academic qualification was to perpetuate an unfair dichotomy. As Lynch (1999) comments, as researcher I produce the final text and ultimately retain power of definition, a power relation that is hard to completely escape even with good intent and practice. Thus, I felt moving away from this approach was appropriate.

As noted, I implemented guidance from the insights of Mathews (2017) and other experienced researchers in the area of disability[55] and deaf research (Kusters et al., 2017; Young and Temple) when developing a conscious research design. I sought to develop a reflexive, effective and meaningful strategy that stressed avoiding the perpetuation of oppressive hierarchal research experiences while also promoting positive and equal power relations. In this regard, Deaf Studies and Feminist Studies,

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[55] Shakespeare (2010) and Hill Collins (1990, 2000) have set out clear guidelines on how to be accountable to research participants and remain committed to ensuring fair representation that serves to highlight the voices of the participants.

both of which are inherently political activities that foreground particular principles and values, were influential in leading my research practice.

4.15 Methodological limitations

I have referred to the understanding that participants may tell one story now but may tell another at a different time. This does not mean that stories are to be regarded with suspicion or are ‘untruths’ but there is a challenge that we must not succumb to “the all-encompassing nature of these stories” (Woodiwiss, 2017: 15). To do so excludes other stories that do not gel with this and sets out an agenda that others must follow, or risk not being included or seen. There are additional limitations and weaknesses with this methodology, which I have touched upon throughout writing in this chapter such as time factor, resources and design constraints. I sought to reflexively address these throughout the research process and implement steps through culturally appropriate and ethically robust research practice to address any perceived methodological weaknesses.

4.16 Conclusion

This chapter has provided an overview of the epistemological, ontological and methodological framework of this research. I have outlined the data collection methods, analysis and ethical and reflexivity considerations in order to contextualise how I navigated this research. The following chapters consist of the re-storying of the intimate stories told by the research participants and the key themes that emerged from this.

Chapter 5: Intimate lives of young deaf people

5. Introduction:

This chapter looks specifically at the factors and discourses contouring the early (adolescence and young adulthood) years of participants' intimate lives. I explore participants' accounts of their early sexuality-related experiences to understand how their experiences were constructed and the contours of these lived experiences. My analysis reveals that particular social spaces and processes are key in terms of young people's resistance to competing discourses at the intersection of sexuality, gender and deafness. This understanding of resistance draws on Ming-Cheng's (2015) unrecognised cultural currency (UCC) concept. She defines UCC as cultural skills (knowledge or informal know-hows) used to acquire resources within marginalised spaces to resist or lessen the impact of exclusion. Using UCC can assist with generating material resources or greater autonomy (Ming-Cheng, 2015). Deaf inter-subjective relationships and social networks were highlighted as strongly contributing to offsetting knowledge access inequalities. From this starting point 'flourishing' emerged as a strong overarching theme and acted to displace and allow for reimagining at the intersection of deafness and sexuality.

The socio-sexual developmental period of adolescence and young adulthood is a crucial time for many and a natural starting point to begin exploring participants' broader intimate experiences. Sexuality journeys, the importance of which can often be overlooked, are significant during this period (East and Orchard, 2014). Shah (2017: 3) writes that "disabled children are excluded from important social processes and childhood socialisation by differential mechanisms of surveillance and segregation, and consequently are prevented from developing their sexuality and exploring their sexual identity and body at the same level as non-disabled children". Other literature (Bahner, 2018; Liddiard, 2018; Davies, 2000) also writes about the time of youth for young disabled adults as exclusionary and frequently containing limited or inaccessible sex education. Existing deaf-related studies indicate that deaf people face difficulties when accessing health information for a number of reasons such as peer misinformation, inadequate school instruction, parental reluctance to provide health education and insufficient opportunities to acquire reliable information (Job, 2004). These findings can be extended to sexual health and sexuality-related information.

Bronfenbrenner's (1977, 1979) social ecological conceptual framework is applied as a scaffold to organise this chapter and understand the contextual nature of participants lived intimate experiences. This framework conceptualises the micro level influence (peers, family, classroom, boarding residences), meso level influence (school, community and media) and finally the macro level influence (cultural beliefs and values, policies and laws). The scaffold is helpful for organising the analysis of the complex interactions and inter-relationships between the social and environmental contexts that influence and shape participants' intimate lives. It assists with uncovering dynamics of power and the reproduction of knowledge within and between these contexts. The dialectical nature of the relationships between these three levels are thus illuminated through this scaffold.

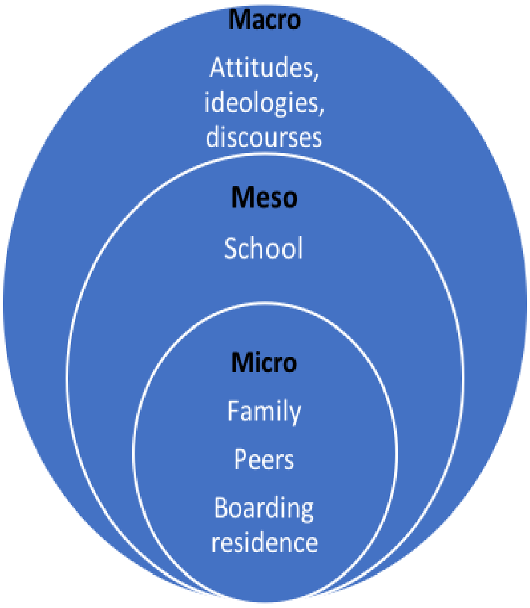

Figure 6: Social ecological model of factors contouring young deaf people's intimate lives

5.1 Exploring the intimate experiences of young deaf people

Participants' accounts explicated sexuality socialisation experiences in the home, with peers, the boarding residence, and school. On the whole, participants indicated they had some kind of sexual education. However, most did not receive formal, school-based sexual education. Rather the majority described building their sexual knowledge informally through deaf friends and media. Participants who attended mainstream school also referenced their hearing friends as important. Learning often occurred in opportunistic patterns, for example a parent answered a one-off question, or two friends happened to have a conversation. This meant that for the majority, their sexual knowledge was informally patched together when growing up.

Around half of the participants, mostly the younger age group (under 30), felt comfortable with their depth of sexual knowledge but acknowledged reasons such as an informative parent or that they had good literacy skills as playing a key role in this. They had not experienced much greater sexual education in school than other participants their age. Literature exploring the intersection of disability and sexuality tends to reflect on these sexual knowledge gaps for disabled people as being tied to the 'mythconceptions' (Job, 2004) of disabled people as 'vulnerable' and 'in need of protection' (Bahner, 2018). This view rarely arose amongst my participants who pointed to particular social practices such as, attending a school with a Catholic ethos; staying in a boarding residence away from parents during the school week; having parents with traditional views, being a young person, or language communication issues being prevailing factors contouring their sexual knowledge building. They did not discuss feeling perceived as 'asexual' and being denied access to information on this basis. However, there are some particularities to the deaf experience in relation to communication issues and being a deaf boarder, which are explored throughout this chapter.

I contend that it is important not to practise a form of what I see as 'diagnostic overshadowing'[56] that may happen in literature which points to stigma tied to non-

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[56] Diagnostic overshadowing is a term used to refer to the process whereby health professionals presume that symptoms present are connected to a person's intellectual disability or mental health and thus provide an inadequate or wrong diagnosis (Jones et al., 2008; Blair, 2019).

normative bodies as the core issue contouring disabled or deaf people's sexuality-related information access. It is imperative to acknowledge that participants expressed that they encountered social and cultural responses related to stigma, as well as structural challenges and limitations in their sexual education. However, it is equally important to stress that the majority expressed that they had overall positive feelings of satisfaction and 'flourishing' towards their intimate lives, sexual subjectivities[57] and how they feel they are perceived as sexual beings.

This draws on Thomas's (2007) notion of psycho-emotional disabilism or rather psycho-emotional wellbeing. east and Orchard (2014: 337) assert that lack of appropriate sexuality-related communication with young disabled people can contribute to negative implications such as "lower self-esteem, sexual identity confusion and doubt regarding their status as a sexual being". However, societal stigma was presented by only a few of my participants as being an aspect of their sexual subjectivities. In addition, very few referred to ideas of internalised disabilism in terms of their sexual subjectivities as a young person, even while noting encountering material and structural limitations. Indeed, upon broaching the 'myth of asexuality' some expressed surprise at the suggestion that some may not consider deaf women desirable sexual beings.

In contrast, participants felt that their sexual education was couched in discourses of protectionism and danger, but this was influenced primarily by perceptions of them as 'young women in need of protection'. It was not because they were deaf. This must be noted from the outset because, as already mentioned, much research that explores the sexuality-disability intersection reflects upon 'asexual identities' that disabled people often feel are ascribed to them and the negative impact of prevalent societal misconceptions about disabled people's sexuality (Bahner, 2108; Liddiard, 2018). My participants' narratives contrast with this prevalent view and is discussed in greater depth in the next chapter.

Taking an intersectional perspective, a stronger emphasis was placed by some participants on the challenges of growing up in heteronormative contexts or feeling

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[57] In discussing participants' 'sexual subjectivities' Tolman's definition of sexual subjectivity (2005: 5/6) is utilised; "a person's experience of herself as a sexual being, who feels entitled to sexual pleasure and safety, who makes active sexual choices and who has an identity as a sexual being".

stigma regarding being a single parent than on audism/ableism stigma in their sexual subjectivities. This is not to completely disregard the impact of ‘the system of normative standards’ (Bahner, 2018) which certainly ties into audist attitudes and barriers winding through participants’ narratives. This will be touched upon here and elaborated on in subsequent chapters.

5.2 Micro: early sexuality influences and experiences

This section explores the immediate environment (the micro) contouring participants’ intimate experiences. It explores spaces (home, school, boarding residence) and relationships (parents, peers, boarding staff) that participants discussed.

5.2.1 Building images of engaging with the sexual self – recollecting menarche

Menarche[58] was often the first topic touched upon with participants, a topic most were able to remember with remarkably clear detail – one interviewee recalled the date, the time and what she was wearing! Participants had differing experiences. More than two-thirds recollected that they had no explicit knowledge about ‘what a period was’ before menarche. This echoes research that discusses menarche as often occurring in contexts “cloaked in secrecy, taboo, and negativity” (Costos et al., 2002: 49). Many participants described menarche as being a shock and thinking something was wrong. However, participants then described attaining more information from a family member, peers or residential staff[59] which ameliorated confusion, whilst simultaneously teaching them management and concealment of the ‘unruly body’ through being taught how to use sanitary towels. While the initial experience may have been one of consternation, no participants spoke about holding trauma, as has been referred to within other literature exploring girls’ menarche experiences (Burrows and Johnson, 2005).

Participants indicated receiving mixed messages when learning about menstruation. Some recalled messages suggesting menstruation was a taboo topic. Some noted their primary school provided a lesson in 5th or 6th class but they had experienced menarche

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[58] Menarche refers to the first menstrual period.

[59] Twenty of the research participants resided in the ‘boarders’ (deaf school boarding residence) when attending primary and secondary school. ‘Residential staff’ refers to the care workers in the boarders.

prior to this. Thus, they learned about menarche when it happened. Finally, the last cohort expressed learning prior to menarche. This meant menarche was almost a 'non-event' as they were prepared.

Barbara explains she learned about menstruation through her deaf friends. Her hearing, ISL using, mother provided her with sanitary towels but no additional information.

> **[Barbara – mid 50's]** "...yes I remember my family no (expresses tight lipped about this topic). My friends 'ah periods every month'. Me (expresses totally surprised at this information). 'Really?? Why??'. 'Red, red period'. Me (expresses taken aback, not fully understanding). Then one day me (expresses looking at underwear). 'OhmyGod' (expresses tapping Mam). 'Mam look at me' (expresses pointing at underwear). Mam (expresses reacting in a tizzy) – give me pads. That's it. That's it. Me (expresses totally confused) back to school. Back to school (expresses telling friends in excitement). 'I got period!'. Friends (expresses reacting excitedly). 'Same, same, same!' (expresses all the other girls saying they had periods too). That's all. What – why – nothing".

Elena and Kerry described how they had no knowledge of menstruation before menarche. Both are deaf of hearing families, attended mainstream school at the time of menarche and used English as a first language with their families.

> **[Elena – early 30's] -** "…It was summer I think, had very bad pain and I went to the toilet and then told Mam and Mam went 'that's okay, that's okay', then she explain it. I just, I just *couldn't* get over it. How that, we can go through it. I said, 'it's very bad pain'. She said, 'some months you won't get bad pain, others you will, you might get lack of sleep, you might be in bad form' and so as time went, I wouldn't say it took me a long time, I'd say soon enough I was able to understand how to keep clean and that kind of thing with periods. But 'emm I just wish I had known before you know? I think, whether from my Mam or the school I think it's important to know beforehand".

> **[Kerry – mid 40's]** "I found out by trial and error! I didn't realise I was gonna have a period at all. Nothing, it was a big shock to me!".

Costos et al., (2002) note that mothers are typically the primary information source about menstruation, as part of being more likely to provide sexuality and healthcare information in the home (Kelleher et al., 2013). In relation to deaf children research has shown that mothers tend to be the key source (Jackson and Turnbull, 2004 cited in Smith et al., 2012). Costos et al., (2002) refer to the work of other researchers who have argued that mothers should be well informed and supportive about menstruation. This is not always the case as mothers can be uncomfortable with the topic and many parents tend to deflect responsibility to the school. Anxiety over extending sexual knowledge at the 'wrong stage' seems to be a factor in parents' willingness to charge educators with deciding when and what is the appropriate information to impart (Jackson and Scott, 2010). Participants exclusively positioned mothers, female peers or female staff as the person to whom they turned to during menarche.

> **[Sophie – mid 40's]** "My Mam never told me about periods. No. Not because she was an awful mother, no, she was brilliant, we just didn't talk about them things. The same with my sister I think maybe she thought that was for the school to do….but they didn't I didn't learn from them either. There was no, nothing. You know. The nuns it was like all 'sshhhh, sssshhh, ssshhh' (expresses turning head away and holding hand up and shutting eyes tightly to ignore the conversation) (laughs) you know. I learned from my friends in the boarders. We were all talking. That's how I learned".

> **[Sybil – early 40's]** "I really, I was in the boarders[60], learn, talk about periods. I remember I got period very late. Waiting, waiting, waiting. When I got it, I straight to one person. I know girl have it. She older than me. So I ask 'I got period' and then she give me pad. She tell me, you do this thing (expresses stick it to underwear). 'Ah okay'…went home, told my Mam, my Mam 'oh okay' and then she give me pads…But mother never talk about it, never. She just 'period okay' (expresses handing over the pad) and that it".

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[60] In this research I use the term boarders to refer to the boarding residence that participants lived in during the school term. Boarders is the term used by all participants and so I follow their lead on this.

Other participants discussed having positive menarche experiences. They were prepared through discussions with their mother, friends and using informal sources such as magazines. Harriet speaks of her experience as being ‘almost a non-event’. She is from a hearing family, attended mainstream school and used English as her first language. She had ease of communication with her mother and hearing friends. Jessica is from a deaf family, attended deaf school and was surrounded by ISL users. Harriet’s and Jessica’s experiences suggest their positive menarche experiences may be related to their access to people who have language proficiency in their first language and who were willing to provide support. Both also described possessing good literacy and gathering information on menarche independently. These narratives highlight how the conditions for flourishing in intimate life can be created.

> **[Harriet – early 30’s]** “em yeah my experience wasn’t very memorable when I was expecting my period. I learned a lot from my friends and magazines. I read a lot of magazines when I was younger. I got one every week and I read them and I educated myself on sexual health and periods and contraception and all of that. And then so when my period eventually came, I was about fourteen or fifteen, then it was like ‘oh okay’. It was kind of underwhelming”.

> **[Jessica – early 20’s]** “Before when we were in primary school, we had a class about puberty, and my mother talked to me when I was younger. But that’s all and then I went into first year and I asked my friends and well, lucky all my friends bit older than me so they knew things and they could tell me what to do”…..“We had a teacher in primary school who explained about a man, a woman, their body is different. Bit young, it was interesting but I didn’t learn too much there – it was through my friends. They showed me how to use pads and what a tampon means, how to use it, they told me it would happen every month. My Mam, mother, told me how to use it too, so I learned through my mother and my friends”.

Their experiences stand in contrast to Vivian’s and Shauna’s experiences. Both are from hearing families but had different communication experiences to Harriet and Jessica. Communication was characterised as challenging.

> **[Vivian – late 30's]** "I remember I was in fifth class – in pain – went to the toilet and find a lot of blood. But I never told my family, I was afraid. So I didn't know what that mean for a long time – I'm afraid to tell. But my mother – I would say I was maybe in sixth class – mother was trying to explain to me with a book, different things, but I didn't understand. Just lost".

Shauna **[early 70's]** explains she got her period when she was 14 and another girl in the boarders explained what to do. She went home during the summer break and her mother ushered her into the room and gave her a towel without explanation.

> **[Grainne]** "Why do you think they didn't explain more to you?
> **[Shauna]** I think it was probably communication. Even if my mother couldn't explain it because it was not how things were done back then I had two older sisters who could have told me and they didn't so I think it was about communication. The same I didn't understand written language that well at the time and they couldn't sign".

Below, Christina **[late 50's]** concludes her comment with the observation that her sisters 'have hearing'. This indicates that she feels they have additional information sources. Research demonstrates that young people glean over 80% of their information through incidental learning (Hauser et al., 2010). This is not an avenue of information open to every deaf child.

> "My access to information – very weak. I learned from friends in school – learned from my friends, not home. Mammy never told me – and my sisters said that Mammy never told them but they have hearing…".

Vivian, Shauna and Christina refer to communication barriers that studies show can exist between hearing parents and deaf children. 5 – 10% of deaf children are born to deaf parents, meaning that for the majority of deaf children, "the acquisition of sign language does not follow a normative path" (Leeson et al., 2009: 2). They further report that many families rely on a highly idiosyncratic and systemised use of gesture developed at home, if they attempt to use sign language. Thus, acquisition of sign language as a fully grammatical language only occurs when children come into contact with other deaf children and adults. For children born into a hearing family who often have no experience with how deaf people live and learn this can create considerable barriers from a young age (Hauser et al., 2010). If the parent lacks ISL fluency or does not possess a sexuality-related sign vocabulary then related conversations can become problematic and young deaf people may miss out on support and incidental learning about relationships and sexuality (Hauser et al., 2010). This can be seen in Vivian's case where her mother could not communicate effectively with her and she was 'lost', she did not understand menarche.

However, it is important not to be reductive and filter all experiences solely through a deaf lens. In Vivian and Shauna's cases the language barrier with their families seems to have exacerbated their self-described information deficit. However, Shauna also experienced menarche in a time where there was no official sex education policy implemented in schools[61]. Vivian experienced menarche before her first sex education class which was provided in her third year of secondary school. Her experience echoes others who commented that their sex education classes came after their first sexual experiences. Looking at the experiences of these research participants, aged 23 – 73, reflects that deaf women's experiences are also constructed in developing socio-cultural practices across time. This reflects themes of secrecy and silence found in other feminist research uncovering social representations of menstruation (Burrows and Johnson, 2005). This is consistent with Leane's (2014) findings which explored Irish women's sexuality and reproductive experiences (none of whom identified as deaf) during the period 1920 – 1970. She found that women predominantly spoke of difficulties experienced around sexuality and reproduction.

However, in Hannah's **[mid 20's]** case she is a young person who attended deaf school at primary and secondary level. She should have had access to information through ISL and the RSE programme which was not the case. Her narrative raises a question about RSE pedagogy in deaf schools;

> "Yeah the school was teaching about periods, but not like, full information. Like detailed information – like what you would do if you got it for the first time, or

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[61] The RSE programme was introduced in 1997.

> how to use pads, nothing. Just explained that women get periods because they can have babies. Nothing like, about how it happens every month or….And at that time I never really paid attention in school because they never really signed much – that teacher I had was always talk, talk, talk. I missed the information. So I missed that about periods and I was young – I was only ten so I think if I got it maybe twelve it would have been fine because I would have known before but I was ten".

These narratives indicate that even if a young deaf person shares the same first language as their mother or the school, they are still not assured of unhindered access to accurate sexuality-related information. This explicates the complex nature of conditions for flourishing. We can recognise that deaf women's experiences are constructed in normative, audist contexts and we can see how this gives us insight into particular ways that deaf women may employ strategies such as UCC (Ming-Cheng, 2015) in deaf social spaces to negotiate and resist exclusion. Here Ming-Cheng's (2015) UCC idea becomes useful for understanding how 'dominated groups' use UCC or cultural skills of their marginalised group to facilitate practices of resistance. We see how peer networks were crucial for resisting knowledge exclusion and allowing for flourishing. For example, Vivian's and Shauna's parents did not know ISL. Vivian's mother tried to teach her through a book and spoken English. Vivian characterised her literacy as weak and communication with her mother as difficult – her learning needs were not met in an appropriate way. Where many participants encountered this challenge, they resisted exclusion (Ming-Cheng, 2015) by seeking information clarity from deaf friends or other informal sources. Thus, access to informal information sharing and learning from peers emerged as a strong theme with many participants indicating these channels were empowering by equipping them with some sexual knowledge access.

5.2.2 Building sexual knowledge; informal learning through parents and peers

Sexual knowledge building is a concept developed by White (2006) and used by Naezer et al., (2017: 713) in their research. It allows for thinking broadly about 'learning sexuality' as, "not just as 'facts'; but as the entire 'bank of information' that an individual builds up about sexuality". They propose this broad definition takes cognisance of learning formed in non-formal settings. Many participants repeatedly emphasised the importance of non-formal settings.

Regarding informal learning, participants typically observed their knowledge gaps as being met through sources such as family members, friends or media. These narratives provide insight into the agency deaf women demonstrated in resisting audist/ableist barriers. They also highlight the broader need to address gaps in formal school-based sex education programmes.

5.2.3 The role of parents

As outlined, research demonstrates that parents' influence is key to a young person's sexual development, yet many do not discuss sex or relationships with their parents (Hyde et al., 2009; Kelleher et al., 2013; Swartz, 1993). Learning is a complex issue and communication barriers can compound this for some. However, research participants, as well as the wider literature (Edwards, 2015), comment that parents of children (who are not deaf) typically practise avoidance or protectionist strategies. Therefore, while communication issues may play a role, it is not always the core factor. For instance, parents may practise protectionist strategies out of a concern that they might inadvertently encourage their (hearing or deaf) child to take an interest in sexual activity.

Holly **[early 20's]** explained that coming from a deaf family she had access to good communication with her deaf mother who also used ISL as a first language. Her mother was a strong advocate of sex education as she had become pregnant at a young age. She shared detailed information with Holly to ensure different outcomes for her, which Holly described as positive because information delivered through school was patchy.

> "Oh yeah my Mam taught me about sex and that stuff when I was a young age – her belief was that you best tell them young so that they are well prepared later in life. At the start when I was really young I was like 'oh my god, what's that, mam get away!'. But then later I look back and I was glad – because of her I'm well aware and I have a better knowledge. I was the one who told my friends about sex

> and those things. They were like shocked and I was happy because I was the one who told them".

Holly's experience was unusual, most participants stated that they did not access in-depth sexual education from their parents. Kerry's **[mid 40's]** experience was more typical;

> "I think about eh, my mother never said anything to me, she just left a book – I was a bookworm, loved books. I couldn't follow the tv because there were no subtitles so books were my outlet. Em my mother just left a book explaining about boys bodies and girls bodies – what they look like…but that was it. There was no other discussion about that. I was 13 then, about 12.
> **[Gráinne]** Was there conversation about it if there were follow up questions?
> oh nonono (shakes head, laughs). No, my mother did say – 'you got the book did you?'. 'Yes'. 'It's a good book isn't it?'. 'Yes' (expresses awkward atmosphere and avoiding each other's eyes). 'Well if you have any questions you can ask me' and I was like 'really?!' (expresses snapping head around in complete surprise) and she kind of went (expresses blushing), she became too embarrassed and I think she wasn't that kind of person you know, she'd never had that conversation with me".

Sadie **[mid 20's]** from a deaf, ISL using family described that her parents reacted awkwardly when she asked sexuality-related questions. She felt some of this was because of her age as when she was 18 her relationship with her mother changed. She felt they could then discuss topics such as losing virginity and relationships more openly. Previously she felt that responses conveyed an "alternative truth", suggesting avoidance and protective strategies on her mother's part. This is a typical experience of young people generally (Hyde and Howlett, 2004). For example, she asked her parents to clarify what HIV was when she was eight. Their response captures their ambivalence to open conversation. She also stated that as deaf parents they too encountered information access challenges.

> "…and they said 'ohhh' (expresses reaction of slow surprise) but they never really had kind of em conversation about it. It was kind of really short, brief and finished

> (expresses door shut on the conversation). You know what I mean? But at the same time I don't think my parents really fully understand what HIV mean – at that time as well, you know my parents are deaf as well. You know?"

A similar point about being from a deaf family, that it does not necessarily always mean having more access to information because of less communication barriers, was spoken about by Addison **[mid 20's]** whose parents are deaf;

> "…but whereas my mother, no I don't think my mother had an understanding herself like…she did understand a period right but I don't think she understands how it works like the whole, how the whole female system works….she couldn't explain it to me, do you know what I mean?"

For participants, being from a deaf family did not ensure increased access to sexuality-related information in comparison to being deaf of a hearing family. Young people across different linguistic backgrounds commonly encountered silences and sparse protectionist discourses that seem to be predominantly linked to gender and youth, rather than being deaf. What this meant in relation to sexual subjectivities is discussed in chapter six.

It is interesting to consider sexual socialisation opportunities between deaf and hearing families. Frank (2017: 218) cites research demonstrating that deaf children of deaf parents do better academically, linguistically and socially "when compared to deaf children with hearing parents (due to different levels of communication access)". However, this does not seem to extend to sexual knowledge and can be mediated by other factors for deaf people – for example communication barriers or being a boarder can impact the creation of the necessary bond for such open relationships.

Shauna **[early 70's]** felt that boarding[62] had an impact on her relationship with her hearing family;

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[62] There are important contextual factors to bear in mind in relation to the participants who were boarders. Older deaf women described returning home from boarding school just a few times a year as we see by Shauna's (mid 70's years old) story. Returning home changed to a frequent visit once a month or every two weeks for participants aged mid 50's onwards (depending on the distance to travel). Now it is every weekend for the boarders, regardless of distance.

> "We went home for two weeks at Christmas, two weeks at Easter and then in the summer we would be home for two months. I never went home any other times to see my family. That is one thing I lost while in the school and that was the close family that I had".

Ruby **[mid 20's],** who went home every weekend echoed this, feeling she could not speak to her hearing mother about sexuality related issues and remarked that this might be because of lacking a strong mother-daughter bond. Communication was not expressed as an issue for her.

> "No, no even now I don't talk to her about sex 'cos I don't feel comfortable – maybe 'cos I live in the boarders and we don't have that bond. And maybe now, because even now I wouldn't say to her, 'okay I have sex now'. I think she know but if something happened with sex or anything I wouldn't tell her".

It is possible the opportunity to develop the bond to allow for personal conversations was disrupted for boarders. Parents may also have assumed the school was providing information. However, the lack of a strong family bond was also echoed by a few older deaf women who were day pupils and lived at home, so this was not necessarily a generational or residential factor. It also seemed to be communication linked. Also important is that where participants discussed the lack of information access within their hearing or deaf family, they navigated this, particularly through developing a shared knowledge base with friends, again explicating their use of UCC (Ming-Cheng, 2015).

Some participants did have good access to sex information from their parents or felt comfortable raising the topic, but the majority described encountering silences and resistance from their parents. This was common with deaf and hearing parents and thus family background is not always the primary factor contouring young deaf people's sexual knowledge access. Young people also quickly understood taboos around these topics which contoured their knowledge and practices while simultaneously being exposed to normative views that encouraged heterosexual relationships and marriage (at appropriate ages).

As Jessica **[early 20’s]** of a deaf, ISL using family describes;

> “Me, I wouldn’t mind but I don’t think anyone tells their parents first, it’d be after (laughs) that my parents know. But if something was going on I’d tell them, I would but I’d probably tell my friends first. Friends first and my parents afterwards. But I think it’s normal for people my age not to tell parents first”.

5.2.4 The importance of peers

Several older participants (over 30) who attended deaf school discussed sexual knowledge building as predominately taking place through casual chat with peers in the boarders or classroom. Participants stressed that school was not useful in terms of sexual knowledge building and they used their social networks and UCC (Ming-Cheng, 2015) to facilitate resistance to knowledge exclusion. Younger participants also did not find formal learning through school extremely useful but referenced it as a source of some information. They, in turn, stressed the importance of their deaf social networks. This had two effects, furthering their sexual knowledge and thus their field resources, and enhancing their autonomy. With greater knowledge comes greater capacity for choice-making, lessening the impact of exclusion from other knowledge sources.

> **[Sophie – mid 40’s**] “oh Janey, I got it all from my friends….yes not in a classroom, school no. There was Biology but it was more biology about the reproductive system. But that wasn’t (shakes head)…you know. I learned it all from my friends (expresses chatting all around, all the time). Always chatting, that’s how we learned. I remember being very shocked (laughs). ‘Oh that’s how babies are born!’ “.

> **[April – mid 30’s]** “I also remember at the time the boarders would talk very openly about masturbation….back then as we were all becoming sexually active we would talk about things like that with each other. We would never talk to our families or anything, it would always be with each other…. I know we were lucky too because it was the 90’s and even though we were run by the Catholic church and it was old fashioned we were still able to talk among ourselves”.

Peers and inter-subjective relationships emerged as the strongest factor ameliorating knowledge gaps and shaping access to information. This was consistently referenced across all age groups and emerges as a strong theme in this research.

5.3 Meso: School

Many participants described formal teaching as exploring sexuality in a limited manner and often reproducing normative gendered social and cultural representations of the body. Such messages were also shaped by notions of 'compulsory heterosexuality' (Rich, 1980) and often positioned young people as 'at risk', 'potential victims' or 'vulnerable to'. Participants' points echo the work of Fine who identified the 'missing discourse of desire' and called for its insertion in American sex education.

> "The naming of desire, pleasure, or sexual entitlement, particularly for females, barely exists in the formal agenda of public schooling on sexuality. When spoken, it is tagged with reminders of 'consequences' – emotional, physical, moral, reproductive and/or financial (Freudenberg, 1987). A genuine discourse of desire would invite adolescents to explore what feels good and bad, desirable and undesirable, grounded in experiences, needs and limits. Such a discourse would release females from a position of receptivity, enable an analysis of the dialectics of victimization and pleasure, and would pose female adolescents as subjects of sexuality, initiators as well as negotiators"
>
> (Fine, 1988: 33).

Participants also focused upon practical (generally heteronormative) knowledge gaps, such as not learning about STD's or different contraceptives. In other words, they discussed the purpose and relevance of their sex education to their lives. Allen (2007) notes that this is a repeated critique of sex education in other places which considers how limiting sex education overlooks students' agency, the role of desire-pleasure and the fact that these issues are part of everyday life in school.

Both Ruby and Jessica pointed to formal sex education gaps they felt should have been addressed;

> **[Ruby – early 20’s]** “Yeah I worry about it a lot and my school didn’t really have proper sex education. They did explain a bit but I felt not enough.
> **[Gráinne]** What did they explain?
> **[Ruby]** They explain ‘oh what is a boy body’, ‘what is a girl body’ that you can get pregnant without a condom and show a video. They maybe talk about that two time and so it wasn’t really good like ‘what does HIV mean?’ I don’t really know those things…”.

Jessica **[early 20’s]** echoed this point;

> “Yeah, SPHE class, really that was crap because say from first year to sixth year we had a different teacher every year. So not the same teacher. So from first to sixth, it was just repeat, repeat, repeat. Just about friendship, that’s it, nothing about, like just a short bit about relationships, but that’s it, really very short and the teachers were different all the time, it was just focused on friendship only. Nothing about sex or, really nothing until sixth year”.

Mayock et al., (2007:16) write that sex education is an essential aspect of supporting young people to “move comfortably…into the realm of sexual activity” and schools play a key role in this. The HSE report (2018a) notes that there are greater risks and adverse sexual health outcomes associated with young people becoming sexually active early (before 16), namely, exposure to unplanned pregnancy and STI’s. Thus, young people should be taught this information.

Addison **[mid 20’s]** shared her experience of her first-time having sex. It was spontaneous, and no contraception was used. She attributes this to lack of knowledge;

> “No we didn’t like, that’s the thing, I was like young, I was like so clueless, no contraception, nothing. I was 15 at that time and I think like my SPHE teacher she would have been teaching us when I was a bit older than 15, teaching us when I was like 16 and that’s when I think they probably expected us to be, you know, going out there with guys”.

This research supports Hyde and Howlett's (2004) findings that sex education in Irish (mainstream) school settings varies. The lack of formal channels of comprehensive, critical sexual education is not particular to deaf students but a feature of experiences of both mainstream and deaf settings. From Addison's narrative we can see how this can have additional implications. Students are then compelled to draw on UCC (Ming-Cheng, 2015) to access information, which may not always be reliable. While participants shared stories of disempowerment through limited sex education, they also shared stories that highlighted their agency and resistance through seeking alternatives. This comprised building Deaf Community links; fostering these links to access information and support and creating and attending intersectional spaces within the Deaf Community such as Greenbow[63]. This is discussed in greater depth in chapters six and eight.

Interestingly, although many participants attended a deaf school or unit no one discussed having conversations that touched upon the embodied experiences of being a deaf young person exploring their sexuality. Other disability-related research discusses the need for disability specific topics within the sexuality curriculum (Bahner, 2018) and the importance of creating space for discussing topics such as 'disclosing your disability online' when trying online dating for example. Baker et al., (2004: 155) note that non-recognition in education commonly happens through a group "not being named or known". The presumption of heterosexuality often leaves LGBT people unnamed and thus not accepted on equal terms as heterosexual people (Fraser, 2004). This can be extended to non-normative sexuality where not being named in RSE inputs, manifests normative sexuality assumptions. This can have implications whereby, "young people are denied a social space and language for reflecting upon a defining part of their personal and social identity" (Baker et al., 2004: 155) and thus have less space to explore their self-understanding. The authors suggest that syllabi should be abilities-proofed, as well as gender and class-proofed to assist with challenging recognition inequalities in the wider cultural system.

Participants in my research referred to the need for greater access to sexual education, but this generally implied 'mainstream sex education' and did not mention a deaf

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[63] Greenbow is a Deaf LGBT information and support group.

perspective. Much research referring to the importance of including a disability perspective works with young people with an intellectual disability who have educational requirements (Kelly et al., 2009), or a physical disability who are seeking advice on their particular impairment needs during intimacy. My research demonstrates that deaf women who socialise with or share the same educational spaces as other deaf people can somewhat address sexuality-related questions through their informal social network. Therefore, this point may not have had much relevance to participants.

5.3.1 Deaf social spaces

Sexual knowledge building was shaped in particular ways across age groups. Deaf social spaces, such as the 'deaf ladies' club', especially acted as essential channels of information for older women who did not have access to informal channels such as subtitled television programmes. The importance of deaf social networks, spaces and UCC (Ming-Cheng, 2015) again emerges in Beatrix's and Finnoula's narrative.

> **[Beatrix – early 50's**] "…never learn the facts of life from an adult or marriage course – never – I always learn from deaf. I went to the marriage course and I already know facts of life – I know, know, know….it was like when I left school I don't understand how get pregnant – just sex but didn't understand it could make a baby – I thought nothing happened – but at that time just carried on. Later (realised) you can get pregnant from sex (expresses surprise / revelation) did not know that when I left school – don't know. That was early 1970's".

Finnoula **[early 70's]** was a boarder for ten years and a day pupil for one year before leaving school and living at home with her mother until her mother passed away. Nonetheless, her mother never shared sexuality-related information with her – she relied on the deaf club for information;

> **[Gráinne]** "…you mentioned that you never really talked with your mother about relationships, or sex or periods…
> **[Finnoula]** That's right – never, nothing
> **[Gráinne]** How come?
> **[Finnoula]** I hear everything in the deaf club – at home, nothing.

> **[Gráinne]** Did you talk with men and women there?
>
> **[Finnoula]** No, no women only. My friends only. Men, no way. Sex and children through friends. I had some married friends…”.

Literacy difficulties also affected consumption of print media in young adulthood for some. Reflecting changing social and educational practices younger deaf women referred to print media as a key source more frequently, as well as to using the internet for research.

5.4 Macro: The developing sexual self; surveillance and ‘the authoritive gaze’

Participants also recollected experiences of exploring and developing a sense of their ‘sexual selves’. Social contexts primarily referred to were: the boarders, school and informal spaces such as a Scout club or train/bus journeys. Some participants elucidated processes of surveillance and regulation in formal and informal social spaces. The data illuminates’ participants’ gendered sexuality experiences as entailing processes of governance and surveillance, specifically institutional processes. This contrasts with disability-sexuality research finding young disabled people being positioned as asexual but fits with research finding disabled people are treated as hypersexual (Liddiard, 2018). This emerged as a dominant theme – particularly from participants who attended a deaf school and resided in the boarders. The research sample is largely heterosexual. However, some such as Hannah, illuminate the intersectional experience of regulation. She explicates that whether with a boyfriend or girlfriend she was monitored and subject to disciplinary actions whereby boarding staff reported such ‘incidents’ to her parents.

> **[Hannah – mid 20’s]** “Yeah definitely, I was watched. Every time I did something with my boyfriend or girlfriend the boarders always ring my Mam for everything. For example, one time the boarders once saw me and the girl I was with, just once, having a simple small kiss. They were outraged and giving out and rang my Mam and saying ‘you can’t kiss a girl!’. They went mad at me. But like it was the same situation with the Scouts when being picked up after. The house mother would be like ‘come on, on the bus we have to go’. I’d reply ‘oh just one second, one second, I want to say bye to my boyfriend’. And it would just

> be a quick hug, peck and off on the bus. But afterwards there would be comments with them saying ‘Hannah took such a long time to get on the bus, busy kissing boys!’. So that kind of thing and telling my parents everything. So I feel we were watched all the time”.

Jackson and Scott (2010: 101) contend that issues around sexuality and youth raise tensions. While sexuality has increasingly been acknowledged as an affirming aspect of life for adults, it is still conceptualised as problematic in relation to young people. Participants descriptions’ of how their sexual selves were regulated reflect Jackson and Scott’s (2010) ideas that young people are expected to mature and develop along a linear set of stages that occur at the appropriate age and any diversions are perceived as problematic. This perspective centres on the young person as ‘becoming adult’, rather than on their present being as an active social agent. Carmody and Ovenden (2013) suggest this overlooks young people’s (intimate) citizenship through constructing them as the not yet ‘adult norm’ and restricting their sexual knowledge and exploration.

My research participants’ situated narratives demonstrate how their bodies and desires were and are regulated. Their narratives reinforce research that has found that conventional, protective discursive strategies are often invoked by parents, other adults and institutions of the state as young people start to explore their sexuality (Hyde et al., 2009; Carmody and Ovenden, 2013).

> **[Sophie – mid 40’s]** “Now I loved my school. But uhm I don’t know. I don’t think they gave us a very positive view…. I mean the discos in school (rolls eyes) ‘don’t get close’, (expresses being pushed away if they got too close). I mean it was all very innocent. We would have been dancing. I would have been very shy growing up, very, very shy. And erm there would be, if some boy even gave me a hug well they would run over and pull them apart. ‘You’ll probably get pregnant that way!’. You know?”

A number of young participants discussed their feelings about monitoring and surveillance they felt subjected to. Some also described encountering disciplinary actions (such as incidents being reported to their parents) in relation to observed displays of sexual behaviour by authoritive figures such as a parent, house mother[64] or teacher. These encounters happened in panoptic spaces such as the school, boarders, discos or Scouts club where the 'regulatory, authoritive gaze' was present. Participants shared the view that they felt they were perceived as requiring control and protection through institutional observation and disciplinary techniques. Such stories also indicate that their sexuality expressions as young women were treated as problematic.

> **[Sadie – mid 20's]** "…erm I was very independent when I was young - my Mam allowed me to go to town when I was twelve, thirteen and meet friends and come back home at six or seven. But in the boarders I wasn't allowed to go outside to the garden – must have a supervisor with me, following me around – or go to the shops – it was just down the road. No (must have) supervisor with me".

> **[Eve – mid 40's]** "Mother. Warning me. Because boarding school told my mother, said 'I heard you were kissing boys'. Mother shocked. Warning. 'Be careful!' (expresses looking up at mother giving warning and feeling confused but nodding along). I was only small so (expresses went over my head). 'Alright' and then ignore and back to hugging and holding hands with the boyfriends. I remember".

These narratives brought Foucauldian ideas to mind in relation to the panopticon (meaning 'all-seeing'). Foucault's (1991) proposed metaphor of the panopticon was a 19th century prison design where prisoners' cells were built in a circular design around a watchtower placed in the centre. Prisoner's cells were flooded with light and they could not tell if someone was observing them from the watchtower. They could be observed at any point and with this knowledge were forced to self-regulate their behaviour. The panopticon offers a model for thinking about how power operates through surveillance. For Foucault (1991), this typified how disciplinary power operates and is deployed in modern western societies. It has been argued that such surveillance has become inculcated in everyday institutions such as schools, hospitals and prisons. These practices in turn encourage self-surveillance and self-regulation of one's own behaviour.

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[64] House mother is the term used for female boarding residence care staff.

The visual nature of deaf people and spaces means that watching and being watched is relied on more than the auditory-related sense of 'eavesdropping' or listening. Young hearing people with hearing parents may be 'kept an eye on' through parents over-hearing their interactions. In relation to deaf people's behaviour and relationships, being, at times, visually observed and monitored was emphasised. This model serves to shed light on how the sexual agency of young deaf women was regulated and shaped through techniques of institutional power – ringing parents and informing them about their children's behaviour. Young people were then aware that their behaviour was being observed and subject to sanction if deigned inappropriate. O' Connell and Deegan (2014: 234) comment on the relevance of Foucault's model (1991) in terms of how "the systems of power or operations of power within practices and disciplinary institutions…resonates with the experiences of 'institutionalised children' in deaf schools in Ireland". While not all of my research participants attended deaf schools or boarders, twenty did and thus this insight bears relevance for their experiences.

5.4.1 Attitudes and discourses contouring young deaf women's intimate lives

Some participants felt that conservative, moral or protectionist discourses framed the sex education they did have. Discourses alluded to sex as 'risk' and 'danger' and positioned young women as "in need of a protective discourse rather than an educative, comprehensive one" (Edwards, 2015: 267). This parallels Jackson and Scott's (Jackson, 1982 cited in 2010) points on how sexual knowledge is a key boundary marker between children and adults.

While younger deaf women were exposed to discourses of protectionism and danger within their families and formal sex education, they also spoke more strongly than older participants (over 30) about problematising these discourses.

> **[Sadie – mid 20's]** "erm the school covered more like, protection, erm STI, relationship how does it work? But at the same time they keep emphasising that it should be at least a two year relationship before you have sex with that person. But I feel like that's their opinion…and the worst thing is that they say it to girls who already lost their virginity. Obviously the teachers didn't know that but just

> says (expresses patronising attitude) ‘girls you better wait at least two years or after until you have sex’ but I, I lost mine already so…”

Bahner (2018) refers to work by Ringrose (2013) and Allen (2005, 2011) to discuss how sex education often employs tension between discourses of protectionism and regulation which most participants felt was the case with their education. A few participants did not attend an Irish primary or secondary school but dissatisfaction with formal sexual education classes emerged in both Irish and non-Irish narratives. Participants, whose narratives are included below, discussed their formal sex education and reflected upon the conservative, protectionist ethos and lack of in-depth information. We did not have an in-depth discussion about topics but rather their reflections on their experience and what stood out as useful or unhelpful. This is not to say that all participants described their experiences as negative. Rather, in the context of reflective narratives constructed through their current knowledges, they identified absences and particular discourses encountered and what this meant in the context of their sexual knowledge building, as well as perceived repercussions for their sexual expression.

Some acknowledged that their SPHE teachers took risks in sharing information. This was framed by participants as being ‘lucky’ for them. Others commented that, while they had some sex education, the content had been de-eroticised and delivered in a passive way, through video recordings and thus they did not pay full attention.

> **[Aileen – late 20’s]** “…we did have maybe third or fourth year we did have education about different contraceptive methods and STI’s a little bit, it wasn’t a lot. Like you have to remember the Catholic ethos of the school, so you can’t really tell them about condoms and so on”.

> **[Harriet – early 30’s] “**…there is like one section in the book that was talking about sex and it was like two people having sex but it was like a cross section diagram with all the parts labelled and it was not erotic at all but it was covered with a black piece of paper to block it out. That’s how conservative this school was like you don’t, ‘don’t wanna be showing the children that!’. You know ‘avert your eyes away’. Erm yeah, so I learned nothing in school”.

As noted earlier, participants' accounts reveal their experiences were constructed in developing socio-cultural practices across time. Younger participants had greater access to information sources such as magazines that provided insight into sexual and intimate concerns. The internet, the growing availability of subtitled videos and youth websites such as SpunOut.ie, subtitled television chat shows such as 'Embarrassing Bodies' and films were mentioned as resources some young participants used for sexual knowledge building. Younger participants more commonly shared narratives that spoke of flourishing in this context.

In contrast, older participants reflected that they had minimal information access in general. They also reflected on particular sexuality meanings transmitted, either through their 'patchy' information gathering in formal contexts or through information derived from a book, with greater negative emphasis. They reflected on how this had repercussions for their embodied sexuality experiences rendering them 'nervous' or 'afraid' of boys, kissing or sex.

> **[Barbara – mid 50's]** "Eighteen. Eighteen. School. Nuns – if you were kissing – open your mouth – called French kissing, mean led you to get pregnant. I always believed that. Me (expressing reacting in astonishment). Nun explained, wrote up on board 'French kissing can make you pregnant'. 'Really?? Really?? Really??'. I was fourteen. Me (expresses fearful and shrinking into self) afraid. But that's all. Never learn sex education. Nothing. Nothing".

> **[Shauna – early 70's]** "In my time we had no tv, no books, no information, nothing really about sex at all in Ireland. I had no interest myself either…I remember when I was about 16 or 17 a girl from the north came down to talk about sex with us. But it was literally just open your legs, mammy and daddy in the bedroom, lock the door and that was it. …They took us all in one by one then and showed us this small book that had a drawing of a man and a woman and they pointed to parts of both and said, 'don't ever let that, touch that'. I was laughing I had no clue what she was talking about. Then she reminded me that marriage comes first. That all stuck in my head even though I didn't think I had actually learned anything. Later when I met my boyfriend straightaway, I was saying 'no,

> no, I am not allowed'. The lesson about no sex before marriage had obviously stuck in my head…".

Foucault (1991) writes about how we become self-disciplining. Barbara and Shauna's sexual behaviour and embodiment was subject to self-regulation and governance, a point also arising in other participants' narratives. The particular discourses older participants encountered became a formative aspect of what contoured their sexual subjectivities and self-disciplinary practices. This is evident in Shauna's narrative where she says, "no I am not allowed". This contrasts with younger participants who engaged with wider discourses from sources such as media and friends. They expressed critically questioning and resisting protectionist and moral discourses and governing practices as indicated by Sadie's narrative, "but I feel like that's their opinion".

5.4.2 Exploring the sexual self; stories of problematising, negotiation and resistance

Alongside descriptions of surveillance, 'the missing discourse of pleasure' and sexual knowledge building gaps many participants also recollected their desire to and engaging in typical developmental sexual exploration stages such as dating, sexual activity or relationships. This was conceptualised as a normative, positive part of adolescence, albeit contoured by factors set out above. What is also revealed through, particularly younger participants narratives, is the emergence of problematising social practices, agency, and resistance. Some young participants spoke of reimagining and creating their own understandings of what their intimate citizenship and sexual lives should look like in the face of constraints and a gendered double standard. For example, Ruby challenged boarding staff by asserting that she had a right to meet her boyfriend and there was a need for systemic change.

> **[Ruby – early 20's]** "Sometimes after school we'd go to the shop and I'd see him there and sometimes we'd text and say 'oh we'll meet up after school on Thursday' but really we'd rarely meet because really the boarders aren't really allowed to see the boys, it was always 'oh, no, no, no you'll be kissing, no, no, no" so it took a long time until I was maybe 17 and I joined the boarders committee and said 'I've had enough, you have to allow us to meet the boys

> because maybe some people will be sneaking off and kissing somewhere else. I think it's stupid because it's an important thing to learn about!'. So they said 'okay and once a week you can meet at the boarders at around six o' clock, seven o' clock in the sitting room while the staff watch'".

Aileen and April problematised their experiences. Aileen does so in contrast to deaf boys who were also boarders. She asserts girls were more restricted and had less freedom;

> **[Aileen – late 20's]** "But the girls, the boarders, they would meet the boys when, after school, some of the boys would've come up, the boys had more freedom, the boys were allowed go by themselves, they didn't have to be supervised, whereas the girls had to be supervised. They weren't allowed to go to the shop on their own, they had to go with the house mother".

April **[mid 30's]** also speaks of the surveillance and restriction she encountered as a young person in the boarders;

> "…do you know the tv programme 'Brookside'? It was a long time ago but it was a big deal at the time because they were the first tv programme in England to show two women kissing. I remember at the time we were all sitting down watching it in the boarding house and we were laughing and joking in a good way. One of the nuns happened to come into the room at the same time and when she saw what was on the tv she gave out to us all and switched off the tv! After that we all still went and talked about it".

Participants also discussed resisting surveillance through different strategies. For example, participants often met boys[65] at the train station or bus stop on a Friday and Sunday evening when travelling between home and the boarders. They would exchange letters or phone numbers, so they could text. These narratives explicated differing ways some participants resisted institutional practices that positioned them as needing

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[65] The majority discussed dating experiences with males at a young age even if they identified themselves as lesbian or bisexual in adulthood. Four participants identified as lesbian/bisexual but all stated that they did not explore this in their youth. One participant did but said she later identified herself as heterosexual.

protection and monitoring. In this way they asserted some autonomy over their own intimate lives.

> **[Liv – mid 40's]** "Reet[66] – in boarders had no freedom. No freedom. I only meet boys on Friday, meet them at the station, have a chat, did kiss, talk, start from there – write letter back and forth every week. Sometime meet shopping. Arrange to go shopping and meet shopping".

A small number of participants also explicitly problematised how their sexuality was desexualised, describing how emphasis was put on aspiring to love and relationships by teachers as opposed to understanding their own sexual subjectivities. Such discourses fit with research that finds that these are common constructions of young women's sexuality which excludes considering their sexual subjectivity (Tolman, 2005). Tolman argues that to ignore sexual subjectivity is unsafe and unhealthy, it is important for safe, responsible sexual decision making.

> **[Sadie – mid 20's]** "I think I was lucky to have this teacher – she wasn't too bad, she was open and one time we were kind of laughing ergh embarrassed about these things and she said '*stop* laughing, this is a natural thing' like you don't have to be kind of (expresses awkward and tentative) 'look at me, I'm talking about it' and then she kind of hmm 'ask me any questions at all' and one girl asked her about her sex life and she said em 'of course I enjoy having sex, I enjoy having sex with my (expresses pious attitude) with my *husband, my lovely husband'* and 'we really erm, we followed the right way' and we all kind of like (expresses looked suspiciously at her) it's a bit 'hmm' (expresses loaded message)".

Other participants similarly shared stories of striving to maintain their agency, negotiate sexual norms and make sexuality-related decisions. This is described in greater depth in the next chapter. Overall, resistance to gendered cultural norms emerged more strongly than resistance to audist/ableist cultural norms. As noted, this stands in contrast to other research with young disabled people (Bahner, 2018). One reason that the majority of

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[66] Reet is Deaf English – meaning 'right'. It can mean 'right', 'that's right' and to express agreement with someone's opinion or comment.

participants put forward this framework of flourishing in the face of gendered discourses (not audist/ableist discourses) is perhaps because the majority (twenty) had attended school with and often socialised with other deaf people, so it was because of being deaf they flourished, not in spite of. This also highlights the importance of UCC (Ming-Cheng, 2015) again whereby normative ideas were resisted through drawing upon cultural currency. This possibly meant their perceptions of their body were through a normative lens, through being with others who had similar embodiment to them. Through socialising with other deaf people and rarely experiencing isolation in this respect they may rarely have encountered stigma. O' Connell (2016: 656) who attended the Cabra deaf school for boys writes "it is important to point out that I did not experience stigma when communicating with other deaf children but only in interactions with my (hearing) teacher". This suggested a sense of feeling or knowing the potential effects of occupying a 'stigmatised identity' (Goffman, 1963).

5.5 Conclusion

A key aspect of this research is to understand how deaf women reflecting on adolescence and early adulthood make sense of their sexuality-related experiences; the factors contouring their intimate experiences and how the conditions for flourishing in intimate citizenship can be fostered for all young deaf women.

The dominant story that emerged was of the intersectional, embodied nature of gendered deaf intimate lives. The period of young adolescence presented a critical time for many. Not every participant expressed desire for increased sexual knowledge building, access or sexual experiences. The majority expressed satisfaction with their intimate lives overall and a sense of flourishing while noting aspects that could have been improved.

One of the strongest themes was the significance of inter-subjective encounters with peers and drawing on UCC (Ming-Cheng, 2015) to ameliorate sexual knowledge gaps reinforced by school and parents. Younger participants (under 30) consistently referred to peers and other informal sources such as media as a key information source. Older participants also consistently reinforced the importance of deaf peers and social networks.

While institutional and parental influences contoured intimate lives in particular ways, many participants also expressed agency and satisfaction with their young sexual subjectivities and intimate lives. This serves to dispel the ‘vulnerability’ narrative so commonly attached to disability and sexuality. Differing factors play a role in contouring sexual subjectivities; communication, language, literacy, parents’ guidance and gaps being addressed or not addressed by peers and schools. This demonstrates that this is a complex issue mediated by varying factors. Those who expressed stronger narratives of flourishing had better access to information at formal level, good communication with parents, higher literacy levels, strong peer networks and use of UCC (Ming-Cheng, 2015).

What also emerged is a story of sexual subjectivities constructed amongst competing discourses. On the whole, participants expressed that these discourses were predominantly rooted in ideas of protectionism as they were viewed as young women. This stands in contrast to literature exploring the sexuality of young disabled people (Bahner, 2018; Liddiard, 2018). While young deaf women occupy what are often perceived as non-normative bodies, it was generally felt that from an intersectional point of view their embodied experience of occupying a *young*, *female* body played a greater role in constructing their gendered sexual subjectivities and experiences.

Two participants indicated explicitly encountering discourses rooted in audism/ableism with another four expressing an awareness of stigma towards their non-normative sexuality. No definitive conclusion can be drawn from this research as to significant differences between the sexual subjectivity experiences of young deaf women who attended deaf school and those who attended mainstream school. However, the data tentatively suggests that deaf people in mainstream schools may be more likely to encounter audist/ableist stereotypes in relation to their sexual being and this has the potential to contour their sexual subjectivities and capacities for flourishing as intimate citizens. This is explored in more depth in the next chapter.

Chapter six: Negotiating intimacies

6. Introduction

I explored with participants their experiences of dating, relationships and the intersection between deaf embodiment and identity. Romantic relationships and intimate experiences are often an integral component of an individual's life, a source of love and joy and a space where identity, connection and individuality can be shared and expressed. We know little about this for deaf women and lack an understanding of deaf womens' embodied positive sexuality experiences that draw in subjectivity and agency and challenge a 'victim-centric' view. As evidenced, much of what is available is grounded in a 'problem' or 'deficit' approach. This chapter seeks to present participants' stories of flourishing in negotiating intimacies and thus resists and reimagines this broader approach in which research exploring deaf women's lives is so often situated (Joharchi and Clark, 2014).

I first explore nuances linked to participants' accounts of their deaf identity before setting out the ways this intertwines with and contours their sexual subjectivities. I then explore participants' views of deaf/deaf and deaf/hearing relationships and the labour and pleasure that can be involved with both and the ways in which deaf women seek to flourish in relationships. Two participants are in same-sex relationships. However, I do not explicitly outline this in the analysis as to do so provides too much identifying information. As such the knowledge produced here is largely based on heterosexual experiences.

Some participants discussed the physical and psycho-emotional labour and pleasure that dating as a deaf woman can involve (for example the effort that is involved in lip-reading a new person on a first date in a loud, dark bar and thinking about when and how to disclose their deaf identity). Additional narratives spoke of navigating a sense of felt stigma through use of strategies such as concealment and selective disclosure strategies (Goffman, 1963) in online dating. All this is explored to understand what contours deaf women's intimate experiences and how deaf women navigate and resist this.

Data is presented in terms of deaf identity being on a spectrum, intersectional and socially constructed, as reflected in the narratives. Concepts of and experiences of stigma, discrimination and audism/ableism were clearly articulated by most participants in relation to contexts of education, employment and information and service access. However, in relation to intimate life and sexual subjectivities, narratives presented more complex accounts. This could be connected to the fact that some participants have contributed to research that discussed deaf experiences of employment and education. As such these topics have been previously discussed in-depth and there has generally been more academic attention to these topics. Conversations about work and education may also be regarded as less personally intrusive or emotive than conversations on intimacies. As the oft quoted Anne Finger asserted (1992: 3);

> “Sexuality is often the source of our deepest oppression, it is also often the source of our deepest pain. It’s easier for us to talk about – and formulate strategies for changing – discrimination in employment, education and housing than to talk about our exclusion from sexuality and reproduction”.

6.1 Deaf identity and sexual subjectivities

O’ Connell (2016) uses Goffman’s theories to explore what is meant by ‘passing for normal’ when occupying a stigmatised identity as a deaf person. I harness this perspective to draw out what stigma can look and feel like for some deaf women in relation to intimate life. Goffman describes stigma as “the state of being disqualified from social acceptance” (1963: 1). This can mean the rejection of an individual as a consequence of an attribute being “deeply discredited” (3). As deaf individuals can ‘pass’ for non-disabled on first encounter, they may be less impacted by such perceptions that affect people with more ‘visible’ disabilities. This can be tied to Goffman’s ideas that differentiate ‘discredited’ from ‘discreditable’ identities. In ‘discredited’ the individual assumes their differential embodiment is visible and they must manage social encounters, whereas in ‘discreditable’ identities their differential embodiment is not immediately visible, and they can manage information on this basis.

The hierarchy of disability phenomenon suggests some disabilities are socially constructed as being more acceptable than others. For example, Deal (2003) outlines that mental illness and intellectual disability are ranked as ‘least preferred’ with arthritis and asthma as ‘most accepted’. He cites Tringo (1970) to explain that those who “rank as least preferred will have the most difficulty in being accepted by society” (2003: 898). He does not outline where deafness resides in the hierarchy and I cannot find another clarification. However, the recent National Survey of Public Attitudes to Disability in Ireland (NDA, 2017) revealed that members of the public agree that disabled people have the same right to fulfilment through sexual relationships as non-disabled. Agreement increased for people with ‘hearing disabilities’ (77% to 90%) when compared to 2011. In addition, support for disabled people having children if they so desire was highest for adults with vision or ‘hearing disabilities’ (85%). Thus, we could speculate that if the hierarchy of disabilities were to be applied in Ireland today that deaf people may not be extremely low on the hierarchy. In other words, they are ‘more accepted’.

Drummond and Brotman (2014) assert that the positioning of able-bodiedness and heterosexuality as normative, through social and cultural representations, contributes to devaluing the bodies of differently embodied individuals. “Further, this positioning reinforces expectations and ideals related to women’s bodies, sexuality, sexual function and sense of self, which significantly impact their lived realities” (535). In other words, they suggest that the ways in which differential embodiment is perceived will contribute to negatively contouring disabled women’s sexual subjectivity.

As is outlined, some participants discussed encountering stigma and discriminatory attitudes, as well as barriers in sexuality-related and reproductive services. However, when the discussion diverged to sexual subjectivity and intimate life, few felt they encountered explicit stigma or discrimination. This is discussed at length in the following sections.

6.2 The sexual subjectivities of mainstreamed participants

Ten of the participants had links with a mainstream school and five of these were in mainstream for the entirety of their schooling. The majority of these ten indicated that there had been challenges for them in accepting their deaf identity in a fulfilling, positive sense. Two expressed encountering explicit psycho-emotional disabilism (Thomas, 2007) from peers and their mother and discussed how this impacted their perception of themselves as a sexual being or mother. The remaining did not refer to explicit disabilism but did refer to holding internalised ideas that they should conceal their deafness. This suggests they dealt with internalised pyscho-emotional disabilism.

Harriet **[early 30's]** drew out her experience as a mainstreamed deaf woman. She was afraid of being perceived as 'the deaf girl' as a young person but is now confident and open in her deaf identity;

> "I think my deaf identity is much stronger now because I spent years denying that I was even deaf. I was always 'I'm hearing, I'm hearing, I don't need extra help, I don't need – I'm not special', you know. I just wanted to blend in as much as possible. And I did that successfully in lots of ways. But it was hard work and my mother was very like 'you should go meet people like you' and I was (expresses offended reaction). I took offence to that, I was like 'what do you mean people like me?'. I actually was a little bit patronising when I saw people signing, I thought (expresses dismissing the idea) 'ew ergh, I don't need that, I don't need to sign, I can talk, I can lip-read you know, I'm not like them'. Which was very patronising now I think about it but I didn't know enough, …erm I definitely was, I definitely didn't like wearing hearing aids and for most of my life I didn't wear them in school, even though they were like – 'you need to wear hearing aids' but I was so determined to lip-read and I was like 'no I don't need hearing aids', I was fine. So I got away with that but then a large part of it was being paranoid about what people thought of me. Like 'aw the deaf girl' (expresses patronising attitude). Like that was both, I cared about what both sexes thought to be honest".

June **[early 50's]** identifies as hard-of-hearing (HoH). She also attended mainstream school and described how she struggled to accept being HoH growing up. Later in life she started to mix with the Deaf Community and is now learning and using ISL. She did not know where her struggle with being HoH came from. She had supportive family and friends who did not portray her being HoH as negative. She did not perceive being HoH as an issue when she was dating or in her long-term relationship from her mid-twenties onwards. She felt it did impact on her confidence in her early adulthood as she started to go out more to socialise in pubs and discos. She had to navigate being HoH when socialising through making tactical use of light. She never disclosed that she was HoH with men she dated which worked to mask that she was HoH.

> **[Gráinne]** "So, and then you started to meet boys when you went to the pub, and what was that experience like?
> **[June]** Oh, it was not good. It was not great. I didn't know what it was like around them. I found it hard…To have a conversation yeah it was very hard. I used to go out and I never used to wear my hearing aids. I didn't…But then again, I was very good at lip reading and, I noticed when I was in the pub people talked louder their voices go up, so my pitch was high and I was able to hear what they were saying. Yeah so, I was fine with the background music and all that people have to talk louder so I was fine. If I was outside of that atmosphere I would be lost in conversation completely. So, I kind of wasn't helping myself either".

I have not found research exploring the experiences of deaf people who attended mainstream or deaf school in terms of sexual subjectivities. However, in terms of deaf identity, research exists arguing that mainstreaming can isolate deaf children and affect their identity and self-esteem (Jarvis, 2002). Angelides and Aravi (2007: 477) note that mainstreamed deaf children describe experiences of "loneliness, rejection and social isolation". They find that children in deaf schools seem to experience better interpersonal relations. Jarvis (2002) writes that mainstreamed deaf children are rarely exposed to positive images of deafness and may view being deaf as an impairment rather than a cultural difference. Leigh's (1999) research finds that one third of participating deaf students felt low self-esteem in mainstream school. Finally, Olsson et al., (2017) also finds that generally social inclusion was better in a deaf school.

Mainstreamed participants rarely went into detail about their school experience. However, as they spoke differently to participants who attended deaf school about their struggle to accept their deaf identity, it could be surmised that this struggle was linked to being mainstreamed and often the only deaf person in their immediate environment. Three spoke of feeling socially included, yet still struggling with their deaf identity. Regarding how this was bound up with sexual subjectivity Kerry reflected on her experience.

Kerry **[mid 40's]** attended mainstream at primary and secondary level and discussed how she felt negatively perceived as a sexual being. She encountered explicit audist/ableist desexualising attitudes that contoured her early sexual experiences and expectations. She used English as her first language with family and friends. Kerry discussed how her peers had a strong influence on her feeling perceived as a non-sexual being because of being a deaf person. In this she talks about the explicit pyscho-emotional disabilism (Thomas, 2007) she was subjected to by school peers;

> "When I was in school I think I was the joke of the class. No-one wanted to be seen with the deaf person. Em I wasn't seen as anything to be attracted to. I remember one boy asked me to dance at the disco, it was a mixed school, and there used to be loads of relationships. I used to be jealous of they had relationships and I (expresses didn't) just…but I remember a boy asked me to dance and I danced with him feeling (expresses really proud and happy) 'oh I'm starting to get accepted' and then I seen other boys pay him (expresses laughter from the boys) while paying him they paid him to do it for the laugh. And I felt very hurt, em I'd say it only bothered me in the last two years of school. When I went to college it was a different story. There wasn't the same judgemental attitudes. But there, I was 'the deaf girl', a person with a disability. I was put in the same class (attitude wise) as someone who had Down Syndrome. In the same, like I was looked at the same way. 'Aww poor Kerry' (expresses patronising attitude)".

This was reinforced by her mother's attitude to her as a deaf sexual person, expressing that she would be unlikely to find a relationship. Becoming involved with the deaf community provided an opportunity to displace these internalised audist/ableist ideas and challenge the psycho-emotional disabilism shaped by peers and mother. She began to reimagine what she knew about deaf people and sexuality. Later she began to flourish in her dating life and went on to have children and marry.

> **[Kerry]** "I remember my mother saying 'oh well, you'll probably never meet anyone who wants you, you'll have to accept that'. She wasn't very positive about me ever thinking of that. So I grew up with no expectations. But I remember being shocked when I came into the Deaf Community and saw (expresses

> incredulous) 'people can get married, deaf people can get married and have relationships!'. It was a little bit, I don't know why, I was just very naïve thinking 'oh I wouldn't be the same as them'. Yeah I was very taken aback that 'oh yeah should be natural that deaf can meet another deaf person and go out and get married (expresses shaking head fazed by this information) it just, it never occurred to me".

Shah (2017: 2) notes that "disabled young people have historically been excluded from dominant processes of socialisation and learning that prepare people for love, sex and reproduction". We see from the previous chapter that deaf people can experience challenges to acquiring sexuality-related knowledge. This can have repercussions for sexual expression, such as unsafe sex as in Addison's case[67]. Here, we see an additional facet - that constructions of non-normative sexuality can also have psycho-emotional repercussions for sexual expression. Liddiard (2018) writes that a shift in normative expectations as a result of exclusion from social and sexual spaces occurred for young disabled people in her research and this confirmed their status as 'Other'. Here we also see Kerry's exclusion from normal heteronormative sexual acts is not empowering for sexual expression and constructed her as 'Other', which she experienced as 'devastating'. She grew up with no expectations of having a relationship because of this. Similarly, participants in Liddiard's (2013: 121) research felt that "a relationship, love and sex were 'out of reach' as a disabled person - a form of sexual oppression internalised though ableist constructions of disabled people as lacking sexual agency and opportunity".

Vivian **[late 30's]** attended mainstream school and later a deaf unit. She used English as her first language with her family but now uses ISL. She talked about what it was like growing up with her mother who did not hold positive views of her as a deaf person. She reflected on what it meant for her as a young mother and this raised a similar theme to Kerry. She was not supported to make any informed choices in relation to having or raising her child. It was difficult for her to navigate this because of a lack of accessible information and resources. Following engagement with a social worker, attaining a qualification, developing links with the Deaf Community and being able to support her

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[67] This is under section; 5.3 Meso: school.

own family financially, she built up the confidence to move out of her family home and take over raising her child independently. In this she refers to resisting her internalised pyscho-emotional disabilism and challenging her mother's oppressive attitude towards her as a deaf mother. In this she overcame 'barriers to being' and 'barriers to doing' (Thomas, 2007).

> **[Vivian]** "When I was small I always think I was the only deaf in the world. So I didn't realise there was lots of deaf there – so wish I met them before when I was young but (expresses acceptance of the situation) but meet later, later, later…Before I didn't know you can have children. Funny because when had child mother said 'you're not able to look after child because you're deaf'. I was like (expresses totally baffled but accepted) 'okay'. So my mother look after my daughter for two/three years. Until I meet deaf – saw a lot of deaf mothers. (Expresses thinking to myself) 'you and you and you and you and you – but my mother said deaf can't look after children. But no, but no, but, but, but. I was like (expresses thinking in confusion) so after saw loads said 'Mam you're wrong'…"

Kerry and Vivian generate insights highlighting the importance of deaf role models for young deaf people and their families. Role modelling has received some limited attention in the literature in terms of language, identity, employment and young deaf people (Rogers and Young, 2011). It is not only 'enriching' for the young person themselves, but also for their family. In Rogers and Young's (2011) research, deaf role models highlighted that hearing parents' expectations of deaf children and people can be low. Interacting with other deaf people in a professional capacity can help hearing parents to realise what it is possible for their child to achieve and to have positive, high expectations of them. Expectations can be related to 'everyday ability' such as learning to drive, going on holiday and 'educational ability' such as attending university. Wilkens and Hehir (2008) recommend that deaf students should have access to deaf role models as it can increase their social network knowledge and reduce mitigate isolation. It seems role modelling could also be important for young deaf people and their hearing families who have no prior experience of deaf people as mothers or sexual beings entitled to a relationship. This experience could be exacerbated through attending mainstream school and having few to no deaf links.

6.3 The sexual subjectivities of participants who attended deaf school

In comparison, participants who attended deaf school from a young age spoke less or not at all about struggles with their deaf identity. This parallels Mousley and Chaudoir's (2018) research where participants reported low rates of internalised stigma. Barbara attended deaf school throughout her education. She had a supportive hearing, ISL using, family. She has a strong deaf identity and links with the Deaf Community. She has dated both deaf and hearing men and is now in a long-term relationship with a deaf man. She felt the suggestion that deaf people might be viewed as non-sexual beings because of the link to differential embodiment was not an issue that arose for people in the Deaf community. Rather the 'hard work' of communication between a deaf and hearing person on a date via writing back and forth was the issue. Where the deaf person does not use their voice and the hearing person does not know ISL was more likely to be the key element disrupting the potential for a romantic relationship. She felt social ideals of cultural aesthetic expectations of gendered appearances – of attractiveness and beauty - were of more importance than being deaf. Research from Theunissen et al., (2014) has found that deaf teenagers in their study did not feel more insecure about their looks than hearing teenagers.

Barbara **[early 50's]** recalled once telling a hearing man who approached her to flirt in a pub that she was deaf, and the man subsequently disengaged. She was not sure if this was related to her deafness being perceived negatively or the evident communication complexities. This point around 'hard work' or 'labour' was echoed by the majority of the participants who attended deaf school and is discussed further in the chapter.

> **[Grainne]** "…So I was wondering how you felt as a deaf woman – did you ever feel less attractive because deaf – well really that people didn't see you as a sexual person because you were deaf or no?
> **[Barbara]** That is a good question…. (thinking) Deaf Community, I think we don't have that – 'deaf no'. Of course pretty, attractive, always 'oh like, like, like' and then relationship. But I never thought hearing view. I don't know. I never thought. But yes, I remember hearing, hearing different – different – writing…I don't know. I don't know. Maybe me identity. Communication, writing back and forth, nothing think 'oh pretty or deaf'. Nothing think barrier – just hard work (writing back and forth) hard work. Everything forget about them just lipreading,

> communicating, writing. I think that's my focus. Lipreading, voice, speech. My focus. Maybe that's why, I'm not sure. But if in pub I sometimes, a long time ago, long time ago, when young, in pub. Boy trying to flirt, flirt – me (expresses explain) 'sorry I'm deaf'. 'Ahh' – gone (expresses leaves immediately)".

Liv **[mid 40's]** who attended a deaf school discussed how she found it challenging to accept her lesbian identity, but never struggled to accept her deaf identity. This raises interesting points regarding the intersectional experience of how gender and sexual orientation shape the experience of being deaf (Kusters et al., 2017) and how these intersect to shape everyday experiences. While she felt being deaf was 'normal', she did not feel the same about being lesbian when she was younger. Later she accepted her lesbian identity and dated hearing people but found that communication was difficult to manage as women she dated did not know ISL. It was hard to develop a meaningful relationship because of this. Now she feels a deaf/deaf relationship would be easier, but as the lesbian Irish deaf community is small, she would prefer to date someone from outside Ireland, perhaps the UK. Thus, here we build an intersectional understanding of how Liv's deaf identity shaped her dating experiences and her dating experiences with hearing people shaped her desire to have a deaf/deaf relationship.

> **[Liv]** "Oh I already accept deaf when young growing up (expresses that was never an issue). I always accept, always accept that.
> **[Gráinne]** Reet that was never a problem – your deaf identity was never a problem, you were always comfortable with that growing up.
> **[Liv]** Reet, reet, it was fine.
> **[Grainne]** Yes, but lesbian, that was more difficult?
> **[Liv]** Yes difficult. Very, very difficult. I found it very difficult because I'm worried about how society view me…I found it very difficult…".

"Deaf identities are always in the making, and if settled, only temporarily so" (Breivik, 2005: 2). Within this section I have aimed to capture and present a sense of the fluidity of intersectional deaf identities, positionalities and language practices that are referred to by participants. I have done so to demonstrate the complex ways identities intertwine with participants' intimate lives and sexual subjectivities. This presents the backdrop to participants' stories of negotiating intimacies.

6.4 Negotiating parents' perceptions of deaf/deaf relationships

The majority of younger participants discussed holding expectations of a long-term relationship or marriage and children. Where they did not respond affirmatively reasons such as 'not liking children or the thought of childbirth', 'fear of commitment', 'fear of divorce', 'ideological disagreement with the institution of marriage' were noted. Only a few participants discussed how their parents portrayed their future potential to get married or have children as a deaf woman in protectionist or negative terms. Otherwise marriage and relationships were generally not expressed as unattainable. Research has revealed the myth that disabled women should be grateful for any kind of romantic relationship (Esmail et al., 2010; Rembis, 2009; Lloyd, 2001). Many disabled people have internalised ableist notions of sexuality and disability and express feelings of low self-esteem in relation to their own sexuality (Rembis, 2009). As a consequence of oppressive attitudes disabled people may find fewer opportunities for love and relationships (Cheng, 2009: 114) and may have no expectations of love and relationships (Liddiard, 2013). This was not the case in my research. The majority of participants did express expectations and self-esteem about being regarded as a sexual being.

Two participants described their parents' initial encouragement to partner with a hearing person over a deaf person. In Liddiard's (2018) research on disabled people's intimate lives she names this kind of attitude as prejudicial behaviour. However, my participants described this as a misunderstanding of the 'deaf world' by their parents, whose attitudes to deaf/deaf relationships shifted positively upon developing an awareness of the fulfilment their daughter gained from the deaf community and their deaf/deaf relationship. Shauna **[early 70's]** described a marriage proposal from a young hearing man she briefly dated. Her parents initially tried to encourage her towards a deaf/hearing marriage by approving his proposal. She felt her parents had done this because of misunderstanding her need to be with other deaf people and did not understand the sense of connection she accessed in the Deaf Community.

> **[Shauna]** "David was hearing. I didn't want to marry him…
> **[Grainne]** You only wanted to marry a deaf man?

> **[Shauna]** Yeah at that time I was only happy in the Deaf community and didn't want to live in the hearing community.
>
> …………
>
> **[Grainne]** Did your parents want you to marry a hearing man?
>
> **[Shauna]** I don't think it was that exactly. I think it was more because they didn't understand the deaf world at the time. They had no awareness around it…Shortly before I left school one of the girls' parents were away or something so my parents agreed she could come home with me for the holidays. My father noticed at the time that I was much happier in myself when she was there. We were laughing and joking together in sign and my father could see that. It was the first time they had seen that and it made them realise I needed to be with other deaf".

Christina **[late 50's]** also married a deaf man. She described her parents as initially harbouring reluctance about this, due to mislaid concerns that he may not be able to financially support their future family because of being deaf. Her parents never learned ISL and only communicated with her husband through gesture or writing. This meant it was challenging for them to get to know her husband in a meaningful sense. Her parents came around to supporting her marriage after a small intervention from the deaf parish priest. Christina described how her mother did not seem to understand how fundamental the deaf world and communication was to her;

> "Mammy said to me, I was always frustrated and cranky teenager – very cranky until I married and I'm not frustrated or cranky anymore. She think because I was in love, but no, no, it's because access to language. I think because access, my husband is deaf, I have full sign language (expresses full, constant communication). Mammy think because I'm in love – no (shaking head at this conclusion). No, no, no – love and access".

Shauna and Christina's narratives demonstrate that they were viewed through a normative gendered lens by their parents and expected to marry as young women. However, their parents also held an audist/ableist lens and expected them to marry a hearing man who could 'provide' for them. Both resisted this and married deaf men.

6.5 Negotiating deaf/deaf relationships and the impact of the small nature of the deaf community

A minority of participants reflected on the challenges of navigating dating a deaf man also connected to the deaf community. Privacy was cited as a core concern for some participants who relayed that dating in the deaf community, because it is small, runs the risk of attracting gossip. This is not an unusual view. Valentine and Skelton (2009: 49) note that their deaf research informants expressed concern about seeking information in deaf spaces "because gossip spreads quickly in any insular community". Therefore, a desire for privacy can contour some individuals' concerns about dating other deaf people.

Addison **[mid 20's]** felt that if the relationship broke up, managing the overlap between her private, romantic life and public, community life could bring an added layer of stress that she would not have to deal with if dating a hearing person;

> "Hmm…hearing person…umm…a lot of deaf people, I know, I…I feel that it'd be more like a hard-of-hearing person I'd date, not completely deaf because…with a deaf person, a lot of people would know us, a lot of people, so say for example if we dated and we broke up, everyone would know what happened to us, whereas if you date a hearing person like they're gonna go off into their own world and I'll go off into my own world and we'll just properly go our own ways".

> **[Elena – early 30's]** "But I was glad that didn't work out with him because I just felt the Deaf Community are so small. I rather it be someone not from the Deaf Community because at the time when I was a teenager, in my late teens, my friends, deaf friends I'm talking about, like whoever they got on with would know who had gone with who. So that's one thing that did put me off because those boys, they had been keeping scores on what – who's the best fuck".

Therefore, dating in a small community requires navigating the challenges of 'everyone knowing everyone' and the desire to maintain one's own privacy. At the same time a deaf/deaf relationship has a number of benefits, such as communication, as Shauna and Christina referred to and participants below elaborate on.

6.6 The role of communication in negotiating deaf/hearing relationships

A number of other participants, such as Ruby **[early 20's],** discussed the importance of communication. Ruby has only been in relationships with deaf men. We spoke about what her particular relationship preferences were. She reflected that while she is now more open to a deaf/hearing relationship than as a younger person, she is currently in a relationship with a deaf man. She feels that she can communicate more easily and express her deaf sense of self more authentically within a deaf/deaf, ISL using relationship. This speaks to the complexity of sign language which is not just a language 'of the hands', but a visual, spatial and facial language (Mohr, 2014).

> **[Gráinne]** "Yeah and one other thing about staying with him, he was deaf right, was that important to you?
> **[Ruby]** Back then it was important to me because I felt like I needed to be really communicating, so my language, and I felt if hearing people I might sometimes struggle, or sometimes I might be like 'umm what?'. And they might get pissed off at me, and be like, get fed up that I didn't understand but umm now I wouldn't mind a hearing person but mostly I prefer a deaf person.
> **[Gráinne]** Is that because they sign or just better communication?"
> **[Ruby]** It's sign and communication, like I feel comfortable, like if I'm making facial expressions, they are the same – hearing people might think though 'oh I'm angry' but no, no, no".

Ruby feels there is potential for hearing people to misinterpret her negatively. Thus, she moderates and presents her deaf self differently in hearing company, to have her message received how she wants it to be received. Hall (1980) writes about the encoding/decoding model of communication – whereby a message receiver decodes the produced message for meaning. Produced messages may be decoded to mean something else according to the receiver's own perception and ideals. In order to encode a message a sender can use verbal (words, signs) and non-verbal (body language, facial expressions) to send a message. It is possible for the receiver to wrongly decode the meaning based on their perception. As English speakers often do not understand how meaning is conveyed through signing, misinterpreting is possible which could affect how intimacies are negotiated. This point also arose with other participants and is explored further in section 6.9. This speaks to how language and communication play a role in producing and shaping intimacies. A hearing person might get ‘fed up’ by misinterpreting the message and shape their response on this basis. There is less potential for this to happen in a deaf/deaf relationship. Thus, communication concerns are one aspect contouring the negotiating of relationships as April explains.

April **[mid 30’s]** described that when she was younger, she preferred to date hearing people and had short term (circa six month) relationships with a few hearing men. She also had short and longer term (circa two year) relationships with deaf men. In general, her preference is for relationships with hearing men who know ISL because she feels that she always had more fun and emotionally intelligent conversations with hearing men that she dated than with deaf men. She felt communication challenges had contributed to her deaf/hearing relationships ending;

> “The older I get the more I am leaning towards deaf – I would have always preferred hearing but as I am getting older I am leaning more towards deaf, primarily because of communication. I am tired of communication issues. I’m not using that as an excuse for being lazy either, I think in general I still prefer hearing but just for communication I would say deaf…I think I have just always preferred hearing and if they learned sign language that would be my ideal situation…Communication is a huge part of a hearing relationship. I think most hearing, and people in general prefer the easy way. I think a lot of them are not seeing the longer term when you get together. They are only thinking short term. Obviously they know I am deaf but I don’t think they really consider what that means. It’s a shame really, it makes difficult for deaf like me to be in relationships with hearing people. Some deaf have been very lucky to meet hearing who can sign or who have learned to sign. I would love something like that for myself”.

6.7 Perceptions of deaf/deaf versus deaf/hearing relationships

Holly **[early 20's]** and Aileen **[late 20's]** discussed their views on deaf/hearing relationships and the role of communication.

Holly expressed that it would be fine if they were hearing but they should learn ISL, thereby emphasising the importance of communication;

> "It doesn't really matter, what I think is most important is that he's able to understand me and I'm able to understand him and I think it's important that person should learn ISL too cos' its' not fair for me to talk, talk, talk all the time you know what I mean, so meet halfway but I've found a deaf person and so (expresses – that's my situation)".

Aileen spoke to her preference of hearing men as she loves music, but they also should learn to sign ISL and understand her 'deaf world' too;

> "I would like both (laughs) I would like a hearing boyfriend, that would be able to sign really well and so I wouldn't have to worry about night time and I could just come home, take off my hearing aids and relax and sign y'know, just be nice if the boyfriend could fully sign and so I wouldn't mind a hearing boyfriend. I'd prefer it in a way because I like music and a lot of deaf boys don't like music the way I like music…so it's hard…because you're trying to fit into both worlds and trying to find the boy or the man who will have both or understand both".

Some participants expressed ambivalence about their preference for a deaf/deaf relationship, as opposed to deaf/hearing. These participants reflected that a deaf/deaf relationship can offer certain advantages which can be very meaningful such as communication and equality. They did not have a preference for a deaf/hearing relationship, but they do have a preference that a hypothetical hearing partner is respectful of their deaf embodiment. It is crucial that their partner should be open to learning ISL and what their deaf identity entails as this gives deep insight into part of what constitutes them.

Aileen **[late 20's]** describes this as one of the reasons she had split with a previous hearing boyfriend. He made no effort to learn ISL or show interest in the Deaf Community and this meant he didn't really get to know the 'real her';

> "yeah well, one of the reasons why we split up is, he just didn't know me, the real me, my culture, my identity…"

When reflecting on relationship experiences, issues related to language, communication, community and deaf identity featured strongly for some participants who had dated or been in a relationship with a hearing person. Some conceptualised their experiences as feeling a tension between a 'deaf world' and a 'hearing world'. While my analysis is mindful of not reproducing exclusionary binaries, it is important to remain true to participants' words and expressions. This is the articulation of their deaf epistemology; deaf ways of knowing the world.

> **[Addison – mid 20's]** "It's hard to explain 'cos I think only strongly deaf people will be like, 'this is my world' and then the hard-of-hearing people, it's hard because you can actually interact with hearing people and then you make friends with them and you try to introduce them to the deaf world and they're like 'what?'. So you know what I mean…it's hard….I was actually talking to someone recently, a hearing person, and I was like 'oh hearing people' and he was like 'you call us hearing people?' and I was like 'yeah you call us deaf people' but I don't think hearing people realise how different both worlds are".

The relationship between deaf identity and relationships is not immutable. Many participants expressed their views on having a deaf/deaf or deaf/hearing relationship as being open. Research has positioned intimate relationships for disabled women as representing a site of difficulty and conceived of as impossible for some (Liddiard, 2013, 2018). In my research however, for the most part, participants narrated their choices to have or not have a relationship with agency and with confidence in their own sexual subjectivity. My research thus offers a challenge to the myth that disabled women have difficulty finding partners or fulfilling relationships. Here, deaf women are cast as strong, autonomous, sexual beings who are sexual, not 'in spite of being deaf', but alongside being deaf.

6.8 Negotiating deaf embodiment in intimate moments – the labour and the pleasure

Participants spoke about how they experienced their deaf embodiment in intimate moments. ‘Intimate moments’ does not always refer to sexual moments. It also means relational interaction with another person in an intimate context. There is little research exploring the embodied experience of being deaf in intimate moments or deaf/hearing relationships. In this research varying meanings were produced from participants’ reflections on their subjective intimate experiences. Meanings suggested themes of ‘deaf labour’ and pleasure. By ‘deaf labour’ I mean labour that is particular to deaf people, lipreading, concentrating on talking and hearing and attempting to pass as hearing. These meanings reveal the layers of complexity at the intersection of deaf embodiment and subjectivities.

Liddiard (2013) contends that the requirement for disabled people to carry out forms of emotional labour in intimate lives constitutes a form of psycho-emotional disabilism. She draws on Hochschild’s (1983: 7) idea of “the labour [which] one is required to induce or suppress feeling, in order to sustain the outward countenance that produces the proper state of mind to others”. She writes that emotional labour takes many forms and can often be performed in the home. There is often a gendered aspect to this, whereby women are required to manage their own feelings, as well as others in the home. Within my research participants spoke about ‘effort’ in deaf/hearing relationships; navigating the physical setting, keeping their hearing aids on until they felt comfortable not to, and working to focus on hearing and lipreading. Contrasting Liddiard’s (2013) findings where her participants engaged in this labour to stay in a relationship, in my research this labour often engendered resistance in the form of participants preferring deaf/deaf relationships that required less ‘deaf labour’. At the same time some participants resisted audism/ableism in their deaf/hearing relationships by carrying out gendered, deaf labour to support their partners to communicate more appropriately with them.

The majority of participants who had experiences of intimate moments with hearing people presented accounts that referred to gradually feeling ‘fed up’ of the labour involved and desiring greater ease of communication. No participants expressed deeply negative feelings about this, but presented examples capturing the kind of emotional labour that can arise in intimate moments with a hearing person. Some presented these accounts to explain why they had chosen or deeply valued their relationship with a deaf partner. At the heart of all of these accounts is the desire for meaningful connection and communication.

For example, Betty and Harriet had experience of dating hearing and deaf men. Both described the labour of lip-reading and feeling tired of this. They found greater ease of communication with a deaf partner.

> **[Betty – late 60's]** "Yes, yes I had boyfriends, two, three, four boyfriends but they were all short-lived. It just broke down and I think it was a communication breakdown. They didn't understand I need to lipread and they would whisper into my ear and I'm going (expresses shaking head in bemusement at the misunderstanding) 'g'way stand in front of me' (expresses looking at lips) 'ohyeahyeahyeah' and they found that frustrating and I found it frustrating. Or else they would stand close to me (clasps side of face and ear) or holding my head (clasps both ears) and the hearing aids'd be whistling and (expresses startled reaction) 'oh what…What's that? What's that?'".

> **[Harriet – early 30's]** "Yeah so when I got with my partner he was my first, and only, deaf boyfriend so when I first got with him I was actually seeing another hearing guy. So it was interesting to see the parallel. Like I was dating this guy for a few months and it was going okay but he was actually really hard to lipread so I don't know how we managed to stay together but he was really nice. But then I started – I met my partner and it was just interesting to see the difference. I would go on a date with the hearing guy and then I would feel really tired after. Because I would spend all night trying to lipread...Trying to lipread him and to lipread his friends and all that and then go on a date with my partner now and it was so easy to communicate…..whereas I found myself kind of getting ready for a night out with the other (hearing) guy kind of like (expresses bolstering myself) 'okay, here we go' ".

Harriet’s narrative describes the emotional labour she undertook to bolster herself to get ready for a date. It is also important to acknowledge the intersectional nature of labour. While this research cannot contrast participants’ narratives, as my research is only with women, it is important to consider the gendered, deaf nature of labour where women often carry out emotional management in their dating lives and relationships.

Some other participants discussed labour but had decided to work with their hearing partner to encourage them to communicate clearly and adjust to them as a deaf woman. For example, Addison **[mid 20’s]** described experiencing frustration when her hearing boyfriend tried to whisper in her ear and difficulty lip-reading him in a dark cinema. Both felt frustrated and lost patience. This led to a frustrated conversation where Addison expressed the view that he needed to be patient and communicate better, or their relationship would not work out. She resisted audism/ableism in this way. Her boyfriend responded and promised to learn ISL and have patience communicating. Addison described this as important, firstly, because she can feel her own hearing deteriorating, and secondly, because she wants her partner to be able to socialise with her deaf family and friends. Beyond this, it is important for Addison that her boyfriend gets to know her authentic self, which includes Deaf English expressions as discussed below. This illustrates how Addison had to carry out emotional management around being frustrated and upset and communicate with her boyfriend to assist him to understand her viewpoint;

> “…Foo[68], but the other day I found myself talking to him and I was like ‘foo’, and he was like ‘what?’, I was like ‘emmm, its Deaf English you know what I mean’, and I explained to him, ‘it just means oh whatever, it just depends on the context’ and he’s like ‘okaaay’ (expresses confused face) and I was just like ‘foo’ just don’t worry. It was nice though to have, to actually share my deaf language with him, you know and it’s important to me because I naturally say ‘foo’ all the time and it’s good to know what it means…”

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[68] Foo is another deaf word like ‘reet’. It means different things in different contexts and can mean ‘can’t be bothered’, ‘don’t care, I’ll ignore that’ or is used to express reaction to a remark regarded as silly or stupid.

Sadie **[mid 20's]** described how she has only been in relationships with deaf men and is currently in a relationship with a deaf man. This was partly connected to social circumstances. She attended deaf school and clubs and felt she only had the opportunity to meet deaf men. Another influence guiding her preference for a deaf/deaf relationship was her deaf father. He suggested that she should try and seek a relationship with another deaf person as it was likely she would never feel as excluded in life with a deaf partner. They could share the psycho-emotional effects of being left out. He felt she might have a greater chance of feeling excluded with a hearing partner;

> "with a hearing person you may be really good relationship, everything's perfect, but you always feel left out – you know with a deaf person you will never feel left out".

Sadie also noted that even in her non-intimate interactions with hearing people she feels labour. For example, she has to think twice when using English. This takes away from the natural flow of conversation for her and means she is not authentically sharing her deaf identity but shaping it to be suitable. While she did not base her relationship decision on her father's suggestion, she felt it resonated with her as she has felt this frustration and laborious work.

> **[Sadie]** "…you know like text, sometime I want to text, say em – like I use ISL grammar in text like sometime with a deaf person (expresses easy, quick, back and forth conversation) it's fine but a hearing person I have to think. You know em what to write – its' not natural for me to write English (expresses casually sending offhand text without paying attention) – I have to look, make sure my English is right so kind of like, there's a little bit of pressure there. Even though I'm sure they don't care but for me, I care (expresses awkward situation). You know?…with a deaf person yeah you think about 'oh is it funny' or flirty or something…but with a hearing person you think of grammar (emphasises the difference). Like that's not fun, if you have to think…'how do I word it?'….how to make it sound like I'm not (searches for word) offending anybody…I know that it mean nothing but for me it's kind of like (expresses hesitating carefully over text) how does that sound like for a hearing person?....like deaf jokes you know what I mean like (expresses humorous bantering over text) for deaf its' funny but

> hearing person might be like (expresses unclear to them) ‘I don’t get it’ and I’m like ‘fuck’, back off, little bit (expresses reserves, feel went too far)…yeah”.

Aileen **[late 20’s]** expressed similar thoughts in terms of the gendered/deaf labour involved in negotiating deaf/hearing communication in intimate moments. She described how she gradually negotiated her deaf embodiment in intimate moments as the relationship progressed. Based on some of her experiences she felt it could be better to have a deaf/deaf relationship, as she would be able to embrace her deaf embodiment during intimate moments without having to labour and adjust. She did not want to feel pressured to always have to put effort into hearing and talking, which is more work for a deaf person than hearing. It requires actively paying attention. With a deaf boyfriend she does not have to worry about keeping her hearing aid in and paying attention to talking. She can relax and enjoy the intimacy. This is the pleasure as opposed to the labour;

> “Like sometimes it’s nice to have a deaf boyfriend because, like, when at night time when I take the hearing aid off and I’m in bed and whatever and they’re talking to me and I want to take my hearing aids, I don’t want to be hearing, talking all the time. But with the hearing boyfriend at the start of the relationship, I always leave one hearing aid on and then sleep on this side (right side) so when they’re talking to me at night so I can hear what they’re saying. But as the relationship goes on, I become more confident and I tell the hearing boy, ‘I’m gonna take my hearing aid off now, so don’t talk to me, don’t talk to me!’ (laughs) and I just do that (takes hearing out and puts it away) and I’m just (gestures - waves arms) ‘can’t hear you, can’t hear you!’ (gestures – cuddles) and that’s it you know, so and that time when the deaf boy stayed with me and we were in bed together it was really, really weird that we were signing and I was lying in bed with him and it was just…it was really weird because I never had the opportunity to sign with a boy when lying in bed and then I don’t know, it was just strange but it was nice at the same time because I didn’t have to worry about the hearing aid or even waking up in the morning (gestures – quickly snapping to attention and quickly putting hearing aid in)…”

Sophie has been in relationships with deaf and hearing men. She felt when she was younger, she only wanted to be in a deaf/hearing relationship. Now she is more open to both, but still has a small preference to be in a deaf/hearing relationship. She linked this to the small size of the Deaf Community. In relation to her embodied sense of intimate moments there was a small difference for her between deaf and hearing relationships but nothing she considered remarkable. Within her narrative the theme of labour in intimate moments also arose; needing to push someone back to lipread them in the dark, switch on the lights or to teach the person some small signs to aid communication in intimate moments.

> **[Sophie-mid 40's]** "It was a little bit more difficult, not very, very, very difficult…No it wasn't plain sailing. Oh you know, maybe writing things down. Or and then if you're up in the bedroom you know, and its' all dark, ah! Maybe if the light is off. I tried to teach him some little signs you know – so when its' dark and in the bedroom you know what they are saying because I wouldn't have (expresses lipread what they said). I kind of – I missed all that. I would have liked to have been able to hear. You know? So (laughs) just little things might have…I'm laughing at it now. Er little things like that erm you know? Maybe talking to you and you were 'ugh' (expresses pushing person up to be able to see their face properly). Pushing them back you know. And then the lights go on or whatever".

Finally, Ruby **[early 20's]** discussed psycho-emotional disabilism, referring to 'barriers to being' as well as 'doing', in deaf/hearing relationships. She has stopped herself flirting with hearing men in clubs because of assuming they would not like her because she is deaf. She has also disclosed being deaf which has resulted in a potential date disengaging with her. She attributes this to her disclosure of deafness;

> "yeah when I go to a nightclub and I go 'oh I like that boy, I want to talk to him' and I think 'he won't like me cos I'm deaf or if I met on Facebook or text the next day and 'oh I'm deaf' and they're like 'oh okay' and don't talk anymore (nods ruefully) 'right okay'…."

Deaf embodiment is thus (re)produced differently and through different types of intimate relationships, whether deaf/deaf or deaf/hearing. This emerged as similar for participants in same-sex and those in male/female relationships. For some, their relationships required physical labour; (concentrating on hearing, talking and lipreading) as well as emotional (feeling fed up and frustrated). For some this became too much. Others felt happy to continue this labour for what they feel they get out of the deaf/hearing relationship. In this, all participants alluded to their resistance where they saw better possibilities for themselves and worked to transform their personal circumstances to achieve these possibilities and flourish in their relationships.

6.9 Negotiating online dating

Online dating as a means to meet a potential partner has "added a new dimension to the way people find and cultivate romantic relationships" (Saltes, 2013: 96). The internet has been found to be useful for disabled people by allowing a way to access the outside world without access concerns (Cheatham, 2012). Valentine and Skelton (2009: 45) refer to research suggesting that technology may play a potential role in "undoing disabilities", a view stemming from the social model contention that disability is constructed through social barriers.

The experience of online dating was discussed by seven participants, the majority of whom were under 30. It was evident that participants who engaged with online dating have a complicated relationship with it. It appears that 'successful' online dating in some cases is linked to English proficiency and good literacy. These factors can present an issue when trying to communicate through writing whereby the other person may not understand the writing. This is important to note as not all deaf people have high literacy. Writing back and forth could be more complicated for some deaf people who may have difficulty expressing themselves clearly through written English, as well as difficulty understanding written messages they receive.

A few participants discussed how they chose to navigate online dating and manage potential perceptions of their deaf embodiment. Irene's **[mid 20's]** and Aileen's **[late 20's]** narratives below illuminate the labour involved in managing a date's potential expectations and ideas. Both participants are deaf, use ISL, speak English and have good literacy. They both felt it was best not to share via online chatting that they were deaf. Rather it was best to wait until a physical date to disclose in person as they were aware it could ‘put a date off’. Additionally, the person might assume they cannot speak or hear as Aileen points out;

> “…when I’m online, I think especially with the dating apps, I don’t tell people I’m deaf…(coughs) because first off, I don’t tell them because they’ll probably think I can’t speak or can’t hear…I never tell boys before I meet them that I’m deaf so….then I probably tell them ‘oh I’m deaf’, y’know (gestures person is taken aback) bit of a shock on their face and I say, ‘I didn’t want to tell you before because you’ll probably assume I can’t speak, can’t hear, probably don’t wanna meet me lalalala’…so there is a bit of (gestures hesitation) I don’t tell them before….I always like to look at their reaction, because if they’re like (gestures frozen) if they freeze, then I know they’re not comfortable but if they’re like (gestures nods, nods) then I know, y’know then I can see they are accepting and I like when they ask questions, ‘how did you become deaf?’ or if they’re interested and ask questions and I like that, I prefer if they ask me questions about being deaf rather than not saying anything and just (gestures – freezes) ‘oh my god, oh my god’ and just freak out or whatever”.

> **[Irene]** “Yeah, yeah – I wouldn’t tell them the first thing when I was chatting to them but 'em on the website or text message no, I would tell them when I meet them face to face. Because I think that would make them, put them off me through the (pointing at phone) but through the face-to-face they were just like (expresses slightly awkward, taken aback) ‘oh right’ and then you just get through the date, you just ‘em meet for a drink and then after that you know its’ kind of like ‘oh I’m gonna meet my friends’ and then just left and you know that’s the end of it you know. Yeah, yeah – so. It sometimes shock them but sometime they’re just like (expresses nonchalant) ‘oh whatever’ and just you know they just. I didn’t take it seriously – I knew that it was um difficult for them to understand and you know you just kind of move on and you know then”.

Other participants also discussed utilising the disembodied nature of online dating to conceal, ‘pass’ as hearing and await an opportune moment to disclose being deaf. The visual nature (photos) of online dating does not necessarily pose an issue because deaf visual signifiers such as cochlear implants (CI's) or hearing aids can be concealed. Previous negative dating experiences, stigma awareness and concern with managing deaf stereotypes were motivating factors behind decisions to conceal and manage disclosure.

Participants who are bi-modal (speak and sign) indicated that they are most comfortable with online dating. This may not necessarily transfer to off-line interaction, as in the case of Ruby **[early 20's]** who is bi-modal and felt anxiety about being able to understand her date and manage communication norms. Ruby's narrative speaks to the specificity of concerns that a deaf person may have to manage and navigate in intimate encounters;

> "…I was thinking if I meet him, will I be able to understand him, will he be able to understand me, what if not and then its' very, very awkward? I told my cousin, she said 'that's a normal thing'. I said, 'no it's not - you feel nervous but I'm worried about how to communicate and that's different'".

Ruby also referred to encountering inappropriate comments after disclosing her deaf identity online. She felt it was a dilemma over when to disclose, that perhaps she should wait so the person can get to know her, but on the other hand if she does wait, she will feel 'bad'. She felt that comments she received detracted from deafness as a positive identity. It is an important part of her identity and she found this reductive response frustrating.

> **[Ruby]** "…after a while 'oh just to let you know I'm deaf. He said 'oh okay', he didn't talk to me after that…sometime I think I should have told it later so he can get to really know me but I felt bad if I hold it till later so that's why.
> **[Grainne]** And he didn't ask you any questions, no?
> **[Ruby]** Well he did, they did, they asked really stupid questions, like they'd say 'if you have sex do you have to wear hearing aids?' and I'm like 'is that all you have to ask?' You're not asking what does Deaf mean? Why do you wear hearing aids? Why does it have to be about sex? (closes eyes and shakes head in frustration). And so I just stopped talking".

As such today's ICT offers potential for deaf people to meet a partner but in Irene's and Aileen's cases, they contended that they had to use it in a particular way to move to the next stage of meeting someone face-to-face. Thus, there is labour involved in its use. Research exploring the intimate experiences of women with an amputation raised interesting themes paralleling my research. Mathias and Harcourt (2014: 396) refer to work by Murray (2005) finding that when embarking upon a relationship, concealment can be useful as it allows the woman with an amputation to be seen for who they are, rather than the amputation taking priority. At the same time the woman must then decide when to disclose and thus the situation may provoke anxiety and they may feel as though they are acting deceptively. Saltes (2013: 98/99) writes, in relation to disabled people, internet dating and disclosure; "in the context of online dating, the question of anonymity is less about projecting a false representation of self and is more about having the control to decide which aspects of self will be revealed and when". This does not seem to be possible for all deaf people as some may not have the English proficiency, as in Liv's case below, or the personal comfort to do so. As Ruby did, they may feel compelled to disclose out of concern that the other person may feel deceived.

Liv **[mid 40's]** speaks to the challenge of 'passing' when writing in online dating. She has tried online dating but expressed that it "never work for me" and felt that her grammar has presented difficulties. While reading English is not an issue, she explained that her writing has a tendency to follow ISL grammar and some people online perceived her English as "very bad". Thus, for her, meeting a woman face-to-face presents a better way to connect and she does not perceive online dating as conducive to this. Her narrative illuminates that dating online could be a way for deaf LGBT people to meet more potential dates as the deaf LGBT community is small and some people prefer to date outside this group. However, difficulties can present with using online dating due to the predominantly writing based nature of online dating.

> **[Liv]** "No, no, writing back and forth online – give up quick. Gave up before meet. Because of how English look I think. But I accept that and just move on.
> **[Gráinne]** Did you say before – so say when you were writing back and forth did you tell them you deaf? 'I'm deaf'.
> **[Liv]** Not straightaway no – depend person – sometime person not very nice – 'you very bad English' so (expresses done with that person)

> **[Gráinne]** Bad what?
> **[Liv]** English – they say 'have bad English'. Me (expresses done with them then). I never mention deaf in first place – say later 'I'm deaf'. 'Oh sorry' – and not the same (expresses disconnect after that point). I lost trust. Just stop and move on. Difficult – internet online – difficult".

Online dating sites primarily use written English as a communication medium, at least initially. Therefore, online dating does not seem to present as a promising site of possibility for those with literacy issues – particularly if comprehending written English is also difficult. Deaf people have traditionally had a complicated relationship with ICT – being excluded from the potential advantages perpetrated through radio, television and phones because of its auditory nature. Valentine and Skelton (2009: 49/50) refer to this as "information poverty" that has been "deeply implicated in how d/Deaf people have been disabled in everyday life". Their research indicates that deaf people now have higher information literacy, partly through being enabled to gather information through the internet without the need for mediation by hearing people[69] and many deaf people are benefitting from internet access.

They also point out that while the internet has facilitated access for deaf people, this is by;

> "allowing D/deaf people to 'pass' as hearing online and therefore to avoid having face-to-face contact with hearing people in offline space. In other words, the internet enables the incorporation of deaf people into hearing society – by allowing them to take up the subject position of hearing" (2009: 55)

Stigma (Goffman, 1963) can also be managed in this way. They argue that because deaf people are 'passing as hearing', this is effectively contributing to deaf separatism in the real world, having different and contradictory impacts for deaf people. Benefits of the internet are not accessible to all deaf people as not all deaf people have the literacy skill at hand to successfully participate. Thus, their differential embodiment and 'discredited

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[69] Interpreters, family members or friends may need to interpret information as can be the case with phone, radio or television (if it does not have subtitles).

stigma' can still be more immediately visible (Goffman, 1963). The legacy of the complicated relationship with ICT is extended to and reinforced in these contexts also.

In online dating some deaf people may face similar challenges, inevitably reaching a point whereby 'passing' is no longer sustainable if a decision is taken to move the online interaction, offline. These points raise interesting points for the experiences of deaf women accessing intimate citizenship through online dating. Deaf women can flourish through managing disclosure and information online to dismantle 'discreditable' identities and celebrate diverse intimate embodiment. Others feel they navigate and resist stigma better through offline personal interaction and thus celebrate their differential embodiment and flourishing better in this way.

6.10 Conclusion

In this chapter, I explored the nuances of labour and pleasure in deaf/hearing and deaf/deaf dating and relationships. Different strategies are employed to navigate these challenges – such as resistance and managing disclosure. While some participants did speak about an awareness of stigma and how it contoured some of their dating experiences, as well as how they approach dating, it was also not a hugely prominent or remarkable part of their present sexual subjectivities. For example, no participants spoke about internalising negative notions as a consequence of negative dating experiences, as Esmail et al., (2010) found in their research with people with 'visible disabilities'. Esmail et al., (2010: 1153) point out that "traditionally, people with invisible disabilities are not stigmatised as readily as those with visible disabilities". I contend that this point is pertinent to the majority of participants' experiences also. Additionally, many grew up with links to the Deaf Community and therefore had a sense that there were other 'non-normative bodies', similar to theirs. As a deaf participant in Zitzelsberger's (2005: 398) research reiterated, her "physical difference (was an) important embodied signifier of identity and culture". A similar view in this research is evidenced through the majority of the participants not expressing any concerns about meeting normative social expectations and expressing pride in their identity, which a hearing partner must accept.

According to Esmail et al., (2010: 1151) disabled women “struggle to reclaim their sexuality, as they face societal stigma regarding aspects of gender and physical impairment”. It is argued that this experience is rooted in images portraying disabled people as lacking sexual capacity (Parker and Yau, 2012) or as asexual (Vaughn et al., 2015). Thus, we know that disabled women often encounter social experiences bound up with bodily representations that “impose cultural meanings and values that delimit and distance their embodiments from normative standards of ‘acceptable’ bodies” (Zitzelsberger, 2005: 399).

No participant expressed the view that they perceived themselves as encountering significant barriers or low self-esteem in intimate relationships or when exploring their sexuality. In turn, none of the participants felt that they were perceived as asexual because they were a deaf woman or had reduced opportunities to date. This is not to say that ‘deaf bodies’ are not represented differently in “western cultural discourses and practices” (Zitzelsberger, 2005). The literature shows they are and that deaf women do engage in labour to manage this. But for the majority of the participants this is not what constitutes their lived experience of their embodied selves. This perhaps speaks to what Mitchell (2001) has described as ‘hypervisibility’. Mitchell notes that deafness is not ‘visible’ until a person is moved to communicate, whence deafness can become visible through hands or speech, if one does not ‘pass as hearing’ through articulate speech. Therefore, until this departure point the ‘deaf body’ may not be ‘hypervisible’ through possessing normative appearances and thus can meet perceptions of what is regarded as ‘attractive’ in western gendered contexts. Within this chapter, it is evident that embodiment is produced and experienced in multiple ways and demonstrates that it is crucial not to universalise the embodied experiences of disability, gender and sexuality. It also demonstrates that deaf women flourish in many different ways in their intimate lives, highlighting the intersectionality of intimate lives.

Chapter 7: Intimate troubles, public issues; access to sexual and reproductive healthcare and information

7. Introduction

This chapter seeks to uncover "universalising norms that marginalise those who don't conform to hegemonic normalcy" in relation to access to sexual and reproductive healthcare (SRH) services and information (Sherry, 2004: 769). Here common instances of exclusion when accessing SRH services and information and processes of normalisation are observed. Such processes may often be overlooked in terms of how they contour access to intimate citizenship. Topics discussed include access to general practitioners (G.P.) and sexual health services (including cervical screening) and sexual health information; use of interpreters and access to reproductive healthcare information and services. Themes that arise center on the hegemonic dominance of ableism and normalisation within the medical field and how deaf women navigate and resist this.

An overarching aim of this research is to contribute, through the analysis, to disrupting 'deficit' and 'problem' approaches to deaf women's sexuality. This is done by illustrating the many ways deaf women's unequal experiences are contoured and exploring how deaf women resist and navigate audist/ableist processes and practices. From this we can reimagine the possibilities at the margins (hooks, 1989). As Shakespeare comments (2000: 162) "any account of disability has to show the ways in which people resist disabling barriers. It has to show that people can and do overcome discrimination and prejudice". However, it is crucial that this reframing also acknowledges the lived realities of the inequalities that persist for deaf women in the public sphere as a means to expose and dismantle them. It is important that this research uncovers structural inequalities as a means to build towards social change, as well as demonstrate how deaf women resist and navigate structural inequalities.

7.1 Knowledge on SRH for deaf women

We lack a breadth of research exploring the SRH experiences of deaf women[70]. Literature available indicates that deaf women in Ireland and outside experience

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[70] See available research: Young deaf people's sexual and reproductive health needs (Deafax, 2014); Access to cervical cancer information for deaf women (Wollin and Elder, 2003; Wang et al., 2010);

unequal SRH access (Begley et al., 2009; Steinberg, 2006, Ubido et al., 2002). Leeson et al., (2014: 196) outline that there is little research on deaf people's healthcare experiences in Europe and "reference to Irish deaf people's experiences in healthcare contexts generally tends to be documented along with other experiences in more broad-based studies". Thus, this research study lacks extensive literature to draw on, particularly regarding SRH and from an Irish context. Hommes et al., (2018:1) note

> "health disparities in disease outcomes and preventative services among the deaf and HOH population compared to the general population are well documented; deaf and HOH individuals tend to have fewer doctors' visits; participate in fewer preventative services such as mammograms or colonoscopies; and often experience misunderstandings with their clinician regarding medication and follow up procedures".

This is consistent with Steinberg et al., (2002, 2006) who found that deaf female participants in their study evidenced a lack of health knowledge around cervical screening or prescribed medications such as HRT.

Good SRH are essential elements of good well-being and health for every woman but is often delivered in a universal manner without cognisance of diversity (Drummond and Brotman, 2014). Deaf women have SRH health needs similar to hearing women. Yet, generally, how deaf people use and access healthcare services and information is different (Steinberg et al., 2005). Research indicates that disabled women lack equitable access to SRH healthcare and information (Tilley, 1996). Drummond and Brotman (2014) and others (Campbell, 2017; Kitchin and Anderson, 2000) have suggested that the failure to acknowledge disabled women's sexuality lies in the traditional ableist, heteronormative construction of disabled sexuality by health and associated medical disciplines. This results in a limited approach whereby focus is on viewing disabled people as in need of 'cure', thereby shoring up unequal SRH health outcomes by overlooking disabled people's SRH needs (Joharchi and Clark, 2014). Kitchin and Anderson (2000: 1163) comment that "these understandings are reproduced through the

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Pregnancy and maternity care access for deaf mothers (O' Hearn, 2006; Steinberg, 2006; Begley et al., 2009; Gichane et al., 2017); Deaf mothers and breastfeeding (Chin et al., 2013); Sexual health behaviours of Deaf American Sign Language users (Heiman, et al., 2015); HIV/AIDS prevention efforts – implications for deaf or hard-of-hearing people (Winnigham et al., 2008; Bat-Chava et al., 2005).

use of cultural representations and myths and are evidenced in the planning and design of family planning clinics and the information and services they provide". As this existing evidence base suggests inequalities in SRH information and service access, a key objective of my research is to explore deaf women's SRH information and service access experiences in Ireland.

7.2 Access to and within G.P. services

Emond et al., (2015) find that deaf people in their research use primary care more frequently than the general population, but also found that 44% of their respondents had challenging experiences in their last G.P. visit. These findings echo my participants' experiences. Most felt that they would be most likely to go to their G.P. for SRH healthcare. Paralleling Emond et al., (2015) many commented that communication challenges and poor attitudes were predominant issues at the G.P.

Participants frequently relied on communication alternatives such as lip-reading and writing notes at the G.P. These alternatives can be disadvantageous. Steinberg (2006: 263) explains that lip-reading relies on visual cues to decipher a non-visual language (English) and "the majority of speech sounds are produced in the mouth or throat and are not visible on the lips". As such lip-reading strategies can be risky to rely on considering it is estimated to only accurately interpret 20% to 30% of spoken English (Hommes et al., 2018). Additionally, evidence suggests the average reading age for deaf people in the EU is 8.5 to 9 years (Leeson et al., 2014). Thus, literacy issues can present difficulties when relying on notes. To rely on these alternatives can affect the quality of care received (Harmer, 1999).

Emond et al., (2015) notes that UK equality legislation puts the onus on the service provider to make reasonable adjustments, which also applies in Ireland under the Equal Status Acts (2000 – 2015). However, Edmond et al., found that this is not happening, even with cost-neutral adjustments such as "collecting Deaf people in person from the waiting room, booking appointments online, or communicating using text messaging as an alternative to the telephone" (2015: 96). Similar incidents were frequently mentioned by participants such as Aileen **[late 20's]**;

> "I'm in the waiting room waiting to watch for them walking in the door cos my doctor's is very awkward…It's a house so they could be shouting at you from the

> stairs and the waiting is room is down the stairs there (signs the location) and they shout 'Aileen, Aileen!' and I can't, I probably couldn't hear them because there's talking going on so then sometimes they come in like (expresses annoyance) 'Aileen! Come on!' and I'm like 'oh that's me' you know, and I'm a bit embarrassed with that you know because there's no need for that. Just come in, say 'Aileen', you don't have to shout from the stairs, but you're too lazy to walk down".

The most common experience from participants who used ISL as their first language was brevity and lack of detailed communication in writing by medical service providers – something Steinberg's (2006) research also finds. This theme did not emerge as consistently from the narratives of bi-modal participants – signalling the privileging of spoken, majority language in medical contexts. Despite the language privilege experienced by some, it is evident that deaf women in Ireland, across the spectrum of deafness, are still frequently experiencing medical sites as spaces of exclusion and inadequate treatment as elucidated by Ann **[early 70's]**;

> "…I went to a consultant and I wrote a question to him. The consultant write back in broken, broken communication...Brief, brief. No, just…'x-ray'…just one word, 'x-ray'. He just wrote one word, x-ray. 'When?' 'When?' 'When x-ray?' 'When?' 'Now?' 'Next week?'...'Operation, operation' (shrugs – expresses questioning the doctor). 'When?' 'Where?' You know?...".

While Ann's narrative highlights information inequality it also reflects her frustration with treatment by medical professionals – an additional aspect of healthcare access discussed by other participants below.

7.3 Participants' perceptions of attitudes and treatment by medical professionals

Participants commonly articulated frustration regarding medical providers' attitudes. This theme emerged most often from participants over 30. It is likely that this is connected to more interaction in medical contexts due to age. Equality legislation has resulted in some positive material gains for deaf women in Ireland, for example in education. However, such incremental gains have not necessarily contested "the underlying attitudes, values and subconscious prejudices and misconceptions that figure an enduring, albeit often unspoken, intolerance" (Shildrick, 2012: 5). Campbell (2017: 9) refers to literature exploring how inaccessible infrastructure generates exclusion and acts as a barrier to sexual health.

Eve **[mid 40's]** and Irene **[mid 20's]** spoke of their resistance to discriminatory behaviour in their G.P.'s – narratives which displace and reimagine the passive, victim-centric framing common within literature (Joharchi and Clark, 2014). Both illuminated the unwillingness by their G.P. to facilitate deaf access requirements, consequently causing frustration.

In Eve's case, she requested an interpreter and the G.P. receptionist refused to facilitate this. Eventually, through Eve self-advocating, this situation was resolved. This chimes with Emond's et al., (2015) contention that developing cost-neutral accessibility is possible but frequently does not happen;

> "…so me ask (for interpreter). 'That's private'. Refuse. Because reception phone book for interpreter. 'Yourself' (expresses to do it herself). 'I want interpreter'. Reception refuse. 'If phone then reception will know about your health problem. That is private'. Me little bit confused but try to explain to reception 'you just need to book interpreter that's all'. Reception person refuse 'no, no, no, private, no'…Now campaign again and again and again to get access for everything. It improve, improve".

Irene also experienced discriminatory attitudes from her G.P. Following similar self-advocating improvement has been realised;

> "…So um I did have a few bad times with my G.P. she couldn't understand my deafness and she couldn't understand why I don't understand her….I'm like 'no I really need to hear you and I need you to speak slowly so that I can understand'…my G.P. kind of lacks that deaf awareness and she didn't care and she didn't give a shit about you know. And I said 'if you want to have' – we didn't have a very good relationship and I would sometimes be so angry at her that I just walked out and I left…she wasn't treating me like a normal patient, she

> was just, you know. And the next time I came in I said ‘if you want to have a working relationship with me you need to understand this’”.

These narratives indicate the ways in which deaf women act as strong agents in self-advocating and navigating inequalities and poor attitudes contouring their healthcare access.

Elena **[early 30’s]** and April **[mid 30’s]** are comfortable attending one-to-one medical appointments independently. However, each described the tension and stress of remaining constantly alert in the waiting room, poor access to booking appointments or challenges when following up on test results which highlights the audist/ableist attitude of their G.P. They also describe how they navigate these; in Elena’s case waiting to discern whether she has been called and in April’s case travelling into the G.P. office. These narratives similarly capture Thomas’ (2007) notion of psycho-emotional disabilism – the management of outward structural inequalities can cause internal stress and tension.

> **Elena:** “…sometimes I hate when, if I’m in the waiting room and it’s just myself and one person then that’s fine but if five or six I’m like (expresses on alert) every time a person come out for the announcement, the name I’m like (expresses anxious on edge of seat to catch the name). You know, ‘that my name? That my name?’…I just wait for a few seconds and if nobody get up I’m like (expresses over casually asking) ‘Elena? Aw grand’”.

> **April:** “For example most G.P.’s won’t use email...The system needs to be improved. Sometimes a G.P. will say they don’t want to email and then I have to go all the way into the office where other people do not have to do that. Often I don’t need to see the G.P. I just have a quick question to ask and I would prefer to be able to do that by text. You see hearing people phoning in those questions all the time and I would like the same equal access”.

April **[mid 30’s]** and June **[early 50’s]** discussed how they felt perceived as a sexual being. They felt this aspect of their embodiment had been responded to in a patronising way or overlooked. Both connected this to their being deaf. April expressed the view that G.P.'s must change their perception of deaf people as 'vulnerable'. Her G.P. asked if her mother was present, thus positioning her in a patronising way as lacking the agency to make her own decisions. As detailed, Job (2004) has found particular 'mythconceptions' regarding sexuality pertain to deaf people. This can limit access to sexual health services and information and moreover these ideas can be internalised. Here, April and June are cognisant that they were viewed in a pathological way in terms of their sexuality by their G.P. Both however, did not refer to these ideas having an impact on their sexual subjectivities, rather emphasising material and emotional impacts. It affected their experience of accessing information and caused frustration through resisting medical providers' poor attitude.

For example, April has to push back and say "no, they can tell me the information". She challenges this attitude by letting them know she does understand the topic at hand;

> "I have noticed… a lot of G.P.'s will look at all Deaf and consider them vulnerable and they need to change that attitude. They will shorten the language they are using to the point that it is patronising. I want more information and to be treated like any other person. It's like they look at me and make an automatic assumption that I am deaf so I don't know or understand what they are saying. They assume I don't understand about sexual health and I only know the basics about periods and pregnancy and so on. I am quick to let them know that I do know what they are talking about. Sometimes they will ask if my mother is here with me and again I will tell them that no, they can tell me the information...It's with normal G.P.'s about sexual health I find it varies from G.P. to G.P. The people in the sexual health clinics are great…I think the sexual health clinics are great, they are very supportive".
>
> **June:** "…I actually think, when I think back, I think I was hard of hearing, he told me was I was deaf as well. He didn't know what to do, he didn't know how to communicate and then I think he never thought of me as a person who had sexual needs. He would never discuss those things with me…So, it was like, he never educated me on anything. He didn't see me as a person".

Along with attending G.P. services, participants also attended sexual health clinics, experiences of which were largely described as positive. Specific sexual health centres such as Well Woman and the IFPA were noted as generally accessible. One negative experience was noted by Ruby **[early 20's]** which echoes April and June's experience of differential treatment, which was again connected to her deaf embodiment. At this time Ruby was 17;

> "umm…that time I went, the first time I went I got the (birth control) implant, she was saying (uses facial expression to indicate 'ridiculous') 'oh because you're deaf', she was treating me deaf, like bit stupid? And the staff[71] she was saying, 'just talk to her like a normal person, and I'm here to translate yeah'…and she said 'yeah'...she like, she don't really talk to me normal, like she kind of ask stupid questions about deaf".

Such narratives indicate the need to develop deaf inclusive patterns of behaviour in G.P.s. Equally, providers' pathological views of deafness must be challenged. They point to the need for doctors to not, inappropriately, focus on deafness and to recognise deaf women as sexual beings. I have referred to this in the previous chapter as a form of 'diagnostic overshadowing'. Harmer (1999: 92) refers to research by Shapiro (1993) to note that a health provider "may…have difficulty assessing a patient's health problems or illnesses unrelated to the individual's particular disability".

As Nasa Begum writes (1996: 3), "although the glory of the medical world does not shine in a local doctor's surgery, a G.P. can often act as the passport to a whole range of services and supports". Communication barriers in the primary healthcare setting can contribute to unequal health outcomes and diminish the effectiveness of health information (Hommes et al., 2018). Poor attitudes can serve to position deaf women as asexual or not capable of sexuality – a position that contrasts with their lived experiences.

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[71] A staff member of the school boarding residence accompanied Ruby as she was 17 at this time

7.4 Perceptions of using interpreters during intimate healthcare settings

The perception of using interpreters during intimate healthcare settings arose frequently. Participants commonly felt that this was more ‘awkward’ than using an interpreter in a less personal appointment (such as a broken leg) feeling that SRH was very private.

As Addison **[mid 20’s]** noted;

> “I wouldn’t want them knowing ‘oh she has Chlamydia’. I wouldn’t want them knowing my history. I feel that’s quite personal”.

One factor noted as increasing the sense of ‘awkwardness’ of using an interpreter in intimate healthcare settings was knowing the interpreter personally or that they would see them again in employment, education or social settings. Harmer (1999: 98) writes of a similar experience with deaf people in the US and states that it means it is difficult to “provide the deaf individual with the same sense of privacy as that routinely given to hearing individuals”. She further states that gossip and embarrassment are key concerns, which may result in some deaf people failing to address their health issue. Failure to access care did not arise in this research. Participants accessed healthcare but chose to navigate communication themselves.

Of the three participants below, Ruby **[early 20’s]**, Aileen **[late 20’s]**, and April **[mid 30’s],** all use ISL, have access to lip-reading and some sound and two are bi-modal. All expressed the view that they prefer to protect their privacy in SRH situations. April similarly felt that she preferred managing SRH appointments without an interpreter.

> **Ruby** “…I would just go myself, I’d be embarrassed about bringing an interpreter ‘cos a lot of interpreters you know, even though they won’t say *anything* but when you look at their face – you’re like, yeah you know I got the test for an STI, you see (interpreter saw it), and it feels awkward”.

> **Aileen** “if you’re going into St James, there’s a lot of waiting around…Imagine if you were to bring an interpreter – you’d be sat in the waiting room all day going (expresses nodding awkwardly at each other, uncomfortable silence) you know?”.

> **April** “I don’t want to have an interpreter there when I am talking about my sex life. I don’t mind interpreters for general things, but I am not comfortable having them there for that kind of discussion… Some of the interpreters would be similar age to me or they would be friends of friends etc…so I would be wary of using them. I don’t always trust interpreters either, some of them I definitely don’t trust. Even though I know they are bound by confidentiality rules I still know that information can leak out so I prefer not to use them”.

7.4.1 Challenges of rural versus urban settings

The narratives of the two participants below elucidate additional challenges in relation to interpreter[72] usage. Vivian is based in a rural community, with two interpreters serving the area. She wants to protect her privacy as she knows the interpreters well and so she sometimes brings her daughter to interpret for her in medical situations. Vivian’s narrative highlights the rural/urban divide and privilege in relation to interpreter access and in turn how this contours access to intimate citizenship. The interpreter shortage, “is particularly acute outside urban areas and further marginalises rural-based deaf people (CIB, 2017: 5). While participants stated they trusted interpreter confidentiality, they also stated a desire to keep their intimate life private. To use the same interpreter for work and sexuality related issues was discomforting. Nonetheless, given the shortage, to use different interpreters is not an option for some rurally based participants. This parallels findings by Leeson et al., (2014) whereby patients may choose to use family members over interpreters to protect privacy.

> **[Gráinne]** “Oh your daughter – you will bring her?
> **[Vivian]** Yeah, yeah. I think that I am not comfortable with the interpreter here at home. We know each other. Like because we know each other.
> **[Gráinne]** You socialize together?
> **[Vivian]** (nodding) yeah”.

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[72] Leeson and Venturi (2016; 28) indicate that there are 111 trained interpreters in Ireland and an estimate of 70 to 75 of qualified interpreters are currently practising as interpreters. As such, the number of interpreters’ available for full-time work is not large and presents challenges for speedy access to interpreting for deaf ISL users.

Yet, concerns arise regarding use of non-professional interpreters. This raises problematic issues in terms of appropriateness, for example, a young child relaying serious, medical information to their deaf parent(s) (Leeson et al., 2014: 188). This can also risk miscommunication (CIB, 2017) as a non-professional interpreter has a greater chance of translation inaccuracy (Harmer, 1999).

Hannah **[mid 20's]** recalls using the GUIDE clinic in St James' Hospital, Dublin and, albeit with a wait of three hours, was able to access an interpreter the same day – a situation that is probably unlikely in a rural service. Hannah also feels a sense of embarrassment with regard to using interpreters for SRH concerns but has become used to this over time;

> "Definitely embarrassing yeah!...if I'm talking about sex I'd be really embarrassed like, how do you sense how the interpreter can react to that, because sometimes you have some who are just mortified, they go so red, or laugh, or maybe awkward, so it's tricky…I remember now I went to the STI clinic in James Hospital, so I just went because I saw information before that says you can walk in and ask for an interpreter…So I went to James' Hospital, told them I was deaf and needed an interpreter and I waited for three hours for an interpreter to come, I had to stay and wait. So they were fine, it was a bit awkward, the interpreter was there and like you need to lay down with your legs open and be nice if it was just the nurse but I remember it was fine…I felt that they treated me with respect but at the same time it was bad for the interpreter because they had to comfort and hug me because I was really upset but the interpreter is supposed to be removed and professional in the situation but I was crying and everything so she had to hug me…".

7.4.2 Using an interpreter to support deaf partners

Some participants felt it was crucial to have an interpreter for their deaf partner who needed information access as well – such as during pregnancy, labour or an operation. Elena **[early 30's]** felt this would be essential for her deaf partner;

> “Yeah, yeah I would because my partner is deaf as well so…so if my partner was the next of kin they need the access for information. Now my partner (expresses strong deaf) deaf, doesn't talk like me, completely deaf. They would need an interpreter”.

Thus, it is important to ensure a deaf partner also has full inclusion. Narratives thus highlight how deaf women often navigate a desire to maintain their private life through using alternative communication strategies, but as noted, this raises other considerations in terms of risk. It points to the need for a larger pool of interpreters to be available nationwide. Regarding G.P. appointments most participants rarely used interpreters, citing reasons such as cost, and the waiting time involved[73] as Holly **[early 20’s]** notes;

> **“…**its’ just annoying because for the interpreter you need to book three weeks before and so that’s long and so I always just go myself”.

Jessica **[early 20’s]** felt comfortable with interpreter confidentiality and so she is always comfortable bringing an interpreter to appointments. She speculated that other deaf people may not always understand the seriousness of the ethics that interpreters are bound by;

> “Yeah I would if it was a critical appointment, something important, I'd bring an interpreter. But if I knew the interpreter I'd feel awkward. But having gone through the system I'm aware that the interpreter must be confidential. Young people don't think interpreters are confidential but I know interpreters are confidential”[74].

The broad consensus in the literature is that quality of information and care improves with use of professional interpreters in medical situations (Leeson et al., 2014;

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[73] Interpreters should usually be given two – three weeks’ notice as there is a small pool of availability.

[74] Sign language interpreters are expected to maintain high standards of conduct and abide by their professional code of ethics. In order to be accepted as a member of the Council of Sign Language Interpreters in Ireland (CISLI) for instance, interpreters must abide by requirements to follow the CISLI Code of Ethics and Guidelines for Professional Conduct. Point 1.1. in the document sets out the confidentiality requirements of interpreters - **“**1.1.1 Members will respect the privacy of consumers and hold in confidence all information obtained in the course of professional service. Members may be released from this obligation only with their consumers’ authorisation or when ordered by law” (CISLI, 2011; 3).

Steinberg et al., 2002). Participants agreed with this. However, narratives reflect a different reality because of pragmatic reasons such as time restrictions, limited interpreter numbers, and concerns (which may be mislaid) around confidentiality.

7.5 Negotiating inequalities in SRH information and services

Borrowing a phrase from Shildrick (2012: 5), it can be argued that lack of inclusive SRH structures is rooted in "a psycho-social imaginary that disavows morphological imperfection". This psycho-social imaginary and ableist attitude is reflected in social policies and public spaces that "privileges corporeal wholeness and predictability" (Shildrick, 2007: 54) and fails to adequately recognise or fully respond to deaf women's corporeality and SRH information needs.

"Access to health information is one of the essential components that contribute to a deaf person's generic and deaf-specific health and quality of life outcomes" (Kushalnagar and Kushalnagar, 2018: 71). There are a range of health information seeking behaviours according to language use. The authors (2018) note that deaf people who are bi-lingual in ASL (American Sign Language) and English and are younger are more comfortable and likely to seek information on the internet and social media as language level presents less of a barrier. Those who use ASL only are less comfortable.

Holly **[early 20's]**, speaks to difficulties associated with the lack of medical information available in ISL and how she navigates this. This demonstrates how written material is often grounded in audist/ableist assumptions of dominant language use and good literacy which fails to fully respond to deaf women's requirements.

> **[Holly]** "Yeah you know, Well Women Clinic you know? For example, I went in and they gave me a leaflet with heavy English….but like I have to go home and google it myself – the information – or ask my Mam, she's deaf".

Literacy issues can pose challenges to information gathering for some deaf women, particularly in relation to new vocabulary. Individuals may have a low fund of health knowledge to draw on, due to lacking incidental opportunities in both formal and informal contexts to build this (Harmer, 1999). Further, there is a general lack of health material available in ISL, meaning individuals often do not have access to health promotion messages, impairing their knowledge access and preventative health care (Kuenburg et al., 2016). Doctors can often fail to be aware of this and accordingly present health related information in inaccessible ways (Harmer, 1999). Additionally, as other participants noted, services can be inaccessible, thus affecting SRH management.

Both Elena **[early 30's]** and Aileen **[late 20's]** recollected accessing the emergency (morning after) pill. This has been available in Ireland without prescription since 2015. Elena discussed having to ask a hearing friend to make a doctor's appointment via phone call for her (prior to the 2015 legislative change) to get a prescription. This added stress to a self-described 'panicked' situation. To access the pill, she first had to disclose her situation to a hearing friend. Given that other participants referred to relying on someone to make phone calls for a doctor's appointment it is likely that other deaf women have experienced a similar situation. It could also have had ramifications in terms of unwillingness to disclose and thus an issue not being dealt with in time, or at all.

Aileen noted that accessing the morning after pill is easier now as she can go straight to the pharmacy. The difference in access and the greater privacy afforded indicates how legislative changes can be essential for supporting control over SRH for all women, and with particularly positive impacts on intimate citizenship for deaf women. Thus, we see that deaf women's experiences are situated within the broader story of women's sexual health in Ireland and inequalities that all women face can have particular impacts for deaf women. The particular contours of inequalities in SHR healthcare access was a key topic during Repeal the 8th campaigning. Seeking an abortion outside Ireland can be complex for deaf women[75]. The U.K uses BSL (British Sign Language) so a deaf woman using ISL may not understand a BSL interpreter. Additionally, booking appointments via phone is not manageable for all women. Women with literacy issues can face an additional challenge in deciphering written health care material following an abortion (Byrne, 2018).

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[75] On 25th May 2018 a referendum was passed in Ireland to remove the constitutional ban on abortion (Field, 2018). Prior to this, abortion was illegal in Ireland and women in Ireland seeking an abortion often sought one outside Ireland in places such as the U.K.

Aileen further commented that in the pharmacy she still encounters communication issues, albeit of a different, and not insurmountable nature. In response to these she prefers to wait until the environment is suitable for her needs and so employs navigation strategies to protect her privacy.

> **[Aileen]** “And then when I go into the pharmacy, one thing I can't do is whisper, you know,…you can't whisper so it’s *'eh I need to see a pharmacist'*...'oh what's it about?'...and there's like a queue of people behind you so and then you're like 'the morning after pill' (expresses cringing and covers eyes) and it's *just,* it's *so* awkward …So I always find that really embarrassing because there's people in the queue and they know what I said, the morning after pill, and they know I had unprotected sex…So that's hard but then you're brought into the private room and its fine and its one-to-one and sometimes it’s difficult if the person is foreign…But I always try and, when I go into the chemist (expresses looking around and waiting) and wait until the queue dies down and then I'm like (expresses scurrying over) and then I run over you know and hoping there's no one behind me but it doesn't always work”.

Inaccessible infrastructure can be disempowering and, in the case of many participants, requires creative and inter-relational labour in search of maintaining sexual health. Moreover, these inequalities, as Shildrick (2007: 55) also argues, carry meaning and results in “management by nonrecognition”. April commented that she regularly gets sexual health check-up’s and has used different services. While she has always experienced positive treatment from staff, she notes that some physical infrastructure could become more deaf friendly. April notes small, but essential, changes for developing an inclusive space that recognises diverse needs. These echo suggestions by Emond et al., (2015) and Ubido et al., (2002).

> **[April]** “A lot of organisations like the Irish Family Planning Association are not accessible. When I arrived there they had an intercom on the door, so even trying to get into the building is hard. It is the same in St James’ Hospital, the gynaecology clinic they have no visual sign there as to how to get in. There is no visual guide as to where to go…I eventually found it but even in there I was not sure I was in the right place. There was not enough visual guides there to let me

> know. The Irish Family Planning Clinic is fine once you get in the door but still an issue actually getting in. They are the two I know of anyway…They all need Deaf awareness training on how to be more Deaf friendly. They all need to improve. Actually the Well Woman clinic on Berkeley road – do you know it? … the one on Berkley road was very bad and not Deaf friendly at all. They have metal bars on the window, it is very hard to access".

Participants specified that they had learned about different contraceptives informally from their friends or partners, a theme that also emerged in chapter five. The majority of sexually active participants used or had used either condoms, the contraceptive pill, the 'withdrawal' or 'family planning method'. Participants frequently commented that they had gone to their G.P. and requested further information on options. Few felt they had received satisfactory, in-depth information on their options. One participant, Sadie **[mid 20's]** experienced 'mood swings' having commenced birth control medication and discovered the connection to birth control pill she was taking, herself. Others experienced unexpected weight gain. In each case it was evident that participants had failed to receive adequate information about potential side effects. Harmer (1999:102) states that to give informed consent requires the patient to "understand all of the pertinent information about their health condition, available treatments and the probable risks and benefits of each treatment option", which in Sadie's case had not happened.

Hannah's **[mid 20's]** and Vivian's **[late 30's]** narratives point to the need to generate ISL resources that provides SRH information and to make these available to deaf people in order to support informed choices. They also point to the need for greater deaf awareness at primary care level.

> **[Hannah]** "Really, my Mam was there and she was talking to the doctor and then the doctor explained it to me, but not, I didn't understand the language, but Mam would interpret a bit and be like 'the doctor said you can get that bar or pill or whatever but I think it's better for you go get the bar because you could easily forget to take the pill so better get the bar. And I said okay. Because I didn't really get the full information, the details. – I was put on the spot. Because she was there I feel pressure".

Harmer (1999) notes this issue commonly arises with young deaf people where they visit the health provider with their parents. The parents and health provider will communicate, and the young deaf person will be excluded from the conversation and have little knowledge of what was discussed. “Parents and providers are often unable to communicate complex information to the child during these visits or they do not make the time or effort to do so” (84). In Hannah’s case this affected her autonomy and giving of full informed consent.

Vivian had a similar experience to Hannah where she did not access full information about the coil from the doctor but gradually built up a fund of information through learning from her friend. This is similar to participants’ narratives in chapter five. Harmer (1999: 76) writes that “deaf children living in residential schools learn to rely on their school-age deaf peers for information and support. As adults, they continue this pattern”.

> **[Vivian]** “So my friend used coil - she felt it was great - so I asked her "how do you do it?" she said "doctor" blahblahblah and so I went to the doctor. I'm on the coil now for eight years…Because my friend explain to me what she have herself so I (expresses interested and understand) said that is good to use. So okay - so I look it up, google - to see what it is, see it suit me, so first I was on tablets - feel sick. Got different tablets - two different ones. But feel sick. So third was the coil. Suits me better. So I'm on it since then. Doctor explain clear? Not really. I have to research it myself”.

The experiences of Hannah and Vivian are not unusual in this research. Other participants spoke about needing to use family members or friends for assistance when navigating the medical system because of a lack of accessible alternatives. This system creates a disempowering situation where the deaf, sexual woman is forced to disclose private information to a friend or family member, or make decisions without full information, to ensure their sexual well-being, as Harmer (1999) and Leeson et al., (2014) also discuss. In Hannah’s case her mother insisted she use birth control and thus infringed on her right to control her own reproductive health. This was further compounded through lack of full information. Thereby, doubt arises as to whether full informed consent is really given. Throughout these narratives the need for infrastructural change such as: accessible booking systems, deaf awareness by medical professionals and Clear English and ISL translations of SRH information is evident.

7.6 Engagement with cervical screening programme

Developments in cervical cancer care have meant that "cervical cancer is an increasingly controllable disease through prevention (sexual abstinence and human papillomavirus (HPV) vaccination), early detection (adherence to recommended screening guidelines for Pap tests), and prompt, appropriate treatment" (Wang et al., 2010: 354). It is essential that women access information and services about cervical cancer in order to ensure their survival (Wang, 2010). Yao et al., (2012) found that deaf women participating in their study had less cervical cancer baseline knowledge than hearing women. The study developed a captioned ASL cervical cancer education video and found using this as an intervention successfully increased cervical cancer knowledge amongst deaf women.

There are other ways that deaf women can learn about cervical checks. Holly **[early 20's]** recollected that her grandmother and mother had explained to her she needed to attend cervical screening. In addition, she had seen posters in public toilets;

> "…yeah right…But they have posters in toilets? Have you seen them? Or the TV advertisement? Old to young, young to old. And face changes, eurgh scary".

She pointed out that these posters may not be accessible for all deaf women however;

> "because maybe they see the poster but it is full of English and they maybe see but (don't take it in) 'what's that?'. But if it was maybe in ISL or simple diagram or something they maybe 'oh yeah'. You know what I mean? It's really heavy English. And with articles its' really heavy English".

Other participants had learned from friends or they received an appointment letter from the hospital. Some participants were aged under 25 and over 60 and have not yet or have stopped engaging with the programme. I asked these participants if they were aware of the purpose of the screening, the majority were - a few expressed doubts.

Some participants are not attending screening as recommended which is every 3 to 5 years where their results remain normal (HSEb, 2018). In addition, while all sexually active participants over 25 years of age were aware of cervical checks some had yet to attend a screening. All except one participant indicated that they knew they should go soon but had been delaying it.

Liv **[mid 40’s]** discussed her recent cervical check-up where afterwards she received a letter notifying her that she had abnormal results and should attend a colposcopy examination. Liv described feeling stressed because she did not fully understand the letter and she had to ask friends to help her decipher it. In addition, Liv had an interpreter present at the appointment. While she felt this was good as it ensured she had clear information access, she also felt uncomfortable as she knew the interpreter personally and felt reluctant to share details of her sex life through this interpreter. She was also uncomfortable with the interpreter seeing the screening. In Liv’s case it would have been helpful to receive information about her results through ISL and choose the interpreter herself. Luckily, she had access to other support, feels comfortable seeking information online through English and was able to manage her confusion through using these strategies.

> **[Liv**] “I was upset, because I have no information, just get letter. That letter - no ISL - nervous - I did research online - read, read - learn by myself, I did talk friends too - …because hearing - they hear more quick - me ask a few friends for advice - they explain me - they said some did have that check to be on the safe side - said 'okay' then went to hospital for c-h-i-l-o-a-p-y - right - have interpreter provided - first time have interpreter provided - before that have smear test but never brought interpreter to anything else - but in that hospital have to provide interpreter - but in Holles Street hospital - but interpreter, I know her very well, but same time me not comfortable**…**Because I know her very well, for example, meet doctor there, sit down and talk, doctor ask me questions about my sexual life - for example 'when last time did sex with person?' I feel not comfortable because interpreter was there. Me have no choice - the hospital booked interpreter themselves”.

Rachel **[late 20's]**, Irene **[mid 20's]** and Hannah **[mid 20's]** are all eligible for the cervical check but all have yet to attend. All have been sexually active, and one has a child. When I asked Rachel initially if she was aware of cervical check, she confirmed she was but had not attended and did not feel she needed to attend.

> **[Rachel**] "Yeah I know it's 25 but I was never asked…No the hospital never sent me a letter or anything. I don't know why. When I turned 25 the hospital never sent me a letter to come in for a check-up. They never contacted me.
> **[Gráinne]** Do you want to get it done (cervical check)?
> **[Rachel]** No thanks. I don't feel like there is any need for it. I am very healthy and my body is healthy".

Irene's narrative spoke to privacy concerns that can arise for deaf patients who bring a family member for communication assistance. She was reluctant to disclose that she was sexually active in front of her mother and thus did not make an appointment for a cervical check when questioned by her G.P;

> **"**No I haven't gone yet, I remember I went to the doctor last year about it when I was 25. And 'em, well this is another thing, I was a bit afraid of 'em, I didn't really tell them that I lost my virgin because I was with my Mum and I didn't want to tell my Mum that I lost my virgin at 19 or maybe 20, I don't know…because my Mum was my interpreter for the doctor…and she said 'well if you're not having sex then you don't need it'. So I was kind of like 'okay' so 'em I came back home and realised I, I shouldn't have done that".

Hannah shared that she had delayed her appointment because she was nervous due to lack of clarity about the process and whether she would have access to an interpreter;

> "No nothing, like I got a letter about a smear test but I did not go because, I kept delaying it and putting it off because I don't really know about – like I know I can look on the internet about it but like do they know about interpreter or should I just go in or I feel like there's no information, nothing. So I have an appointment for June, this month, next week so I'm going then but it took me a long time because I was feeling embarrassed because no information".

These narratives thus indicate that there is scope for improvement in information provision to ensure that all deaf women attend cervical check-ups. They also demonstrate how deeply embedded audist/ableist normative understandings of bodies are within SHR services and information provision.

7.7 Accessing maternity care services and information

There has been some attention to deaf mothers' experiences when accessing the Irish maternity care system. Steinberg carried out research with eleven deaf Irish mothers in 2006. Steinberg (2006) and Begley et al., (2009) found communication issues emerged as the principal difficulty faced by deaf mothers in maternity care at both interpersonal and institutional level. Kennedy and Murphy-Lawless (2003) note that pregnancy can be a lonely and alienating time, particularly for new mothers and they take on many new challenges. It is important to be cognisant of how these challenges are experienced and navigated by deaf mothers. In my research eleven participants are mothers and have twenty-nine children between them.

7.7.1 Prenatal care

Begley et al., (2009) and Ubido et al., (2002) cite experiences such as waiting for appointments as a source of frustration for many deaf women. On the whole there is rarely a visual call system meaning that deaf women may miss their call and thus their appointment. Both Harriet **[early 30's]** and Kerry **[mid 40's]** described waiting for appointments as being difficult. While Harriet was able to navigate the system because she had an interpreter, Kerry did not and had frustrating experiences as a consequence.

> **[Harriet]** "I suppose the interpreter for the hospital stuff more because erm things like the waiting room and the system for calling your name, it's em a speaker so I wouldn't hear that. Or like if they're telling people erm, 'so people who are here for the third time sit here', 'people who are here for this appointment sit there' and then they are at the end of the room shouting. I wouldn't get that…I wouldn't overhear conversations but my interpreter did. That's how we figured out the

> system. And then the speaker said, ‘Harriet go to room five’. So my interpreter would get that...”
>
> **[Kerry]** “I remember then I went to, I went to semi private, but still there were so many of us. They were calling names outside and I’d miss my slot. And I’d be told ‘oh no you have to wait an hour because you’re back at the bottom of the list again’ – but no one came in and called me, things like that (expresses frustration). It was a lack of awareness at the time…”.

7.7.2 Antenatal and postnatal support and information access

Antenatal information and support refer to accessing information sources and support such as pregnancy literature, maternity care appointments and antenatal classes that assist in preparing the expectant mother for experiences such as labour and breastfeeding and ensure the pregnancy is progressing well.

Steinberg (2006) notes that gathering information is a complicated matter for deaf mothers. In her study participants gathered information from different sources; G.P’s, doctors, antenatal classes, other deaf mothers, the internet and books. However, several did not regard their G.P. as a resource for information, thus “relying solely on resources of information situated outside the healthcare system” (260). In my research mothers most often consulted books, the internet or friends and family members for information in relation to their pregnancy. Antenatal class attendance was rare. Only three attended antenatal classes.

O’ Hearn (2006) carried out research with 23 deaf and 32 hearing women on satisfaction with prenatal care. Deaf women overall were found to be less satisfied with their prenatal care and quality of communication, had less prenatal appointments and less information from their G.P. than hearing women – issues similarly found by Gichane et al., (2017). Steinberg (2006) asserts that communication difficulties experienced during this period can be traced back to attitudinal barriers and misconceptions on the part of medical professionals. Reflecting these studies’ findings, the two most common issues arising in this research were in relation to antenatal and postnatal information and support - antenatal classes in preparation for labour and support for breastfeeding.

Sophie **[mid 40’s]** noted that while she had an interpreter for her hospital appointments, she did not have an interpreter in antenatal classes. She struggled in the classes and gave up and felt this had an impact on her labour. Of the two others – both attended private one-to-one antenatal classes with a midwife. Rachel **[late 20’s]** paid for the private class while Harriet’s was covered by the HSE. Harriet **[early 30’s]** expressed that on paper her labour had been difficult, and she experienced complications. However, because she was prepared through attending antenatal classes and had an interpreter present at the birth, she felt informed and remained calm.

> **[Sophie]** “For the appointments in the hospital, the checkups. Yes I had someone to sign for me. But to be honest I would have preferred the antenatal than that. I could have coped with the checkups. I never went to ante-natal classes. I stopped. There was so much going on it just - (expresses couldn't catch anything). So we stopped. So that caused me difficulties in my labor. My labor was a nightmare. Nightmare. Right. I think antenatal classes are very, very important…So em…I didn't know how to push because I never went to the antenatal classes. Then the surgeon went 'she's not pushing right'. The girl was signing for me. And I was like ‘uhh’, I didn't, I didn't know. They said I was breathing all wrong. I think it was because I didn't go to my antenatal classes, I think that was why that happened. I just didn't know”.

> **[Harriet]** “Yeah I did ante-natal too which was - so because we were deaf, and we had the interpreter, they were like 'oh we'll just do three hours all together'. Just the two of you and the interpreter so we were like 'great', so that was ideal”…And after that it was fine because it was just, the birth was…long and so em, I knew what the doctors were talking about, I knew what the nurses were suggesting and I knew what that meant, or that meant or whatever. They didn’t have to – they did explain it to me but I knew so that helped me to stay calm through everything. Even though on paper the birth looked like it was horrendous, so many interventions...But actually my experience of it wasn’t bad…so I wasn’t traumatised or anything but I could have been! (laughs) if I didn’t educate myself”.

In relation to maternity services deaf women “report lower satisfaction with overall quality of antenatal care…but when provided with access to the interpretation services they need, they report higher satisfaction” (Gichane, et al., 2017: 2). My research findings parallel wider literature in this respect.

7.7.3 Use of interpreters during labour

Eight of the eleven participants used interpreters during their labour. It was agreed by the majority that it is essential to have an interpreter during labour. Seven participants had given birth in the last fifteen years with a total of nine births in Ireland[76] between them and interpreters were present at five births.

Vivian **[late 30’s]** and Sybil **[early 40’s]**, gave birth without an interpreter present and acknowledged they would not do it again. Both were not aware at the time that they could have requested an interpreter and the HSE would be required to bear the cost.

> **[Gráinne]** “And now if a young deaf mother was going to hospital what would you say to her?
> **Vivian:** I would say to book an interpreter. Make sure she get full information. Ask plenty of questions. Do not go through the same as I went through”.
>
> **[Sybil]** “Ohhh yes, *definitely yes* - 100% I would get an interpreter full stop. But *now* there is more and more awareness about deaf have rights to get interpreter in the last…(expresses roughly) four years. More awareness. Before (expresses nothing really). Barriers, block, block, block. But now (expresses it doesn't compare, it is much better)”.

Steinberg’s (2006: 264) research echoes the same point about the need for interpreters. Vivian’s and Sybil’s experiences are problematic, highlighting the disempowerment many deaf women have faced. Instead of viewing the medical system as an important and essential resource, it becomes something that must “be negotiated and engaged with as little as possible” (2006: 268).

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[76] Two participants gave birth in countries outside Ireland.

Kerry **[mid 40's],** did not have an interpreter present for her first labour but self-advocated for one for her second and described the difference in access. She is bi-modal and described herself as a good lip-reader but stressed that to be a good lip-reader is not enough during labour. As the respondents in Steinberg's (2006) study and two participants here commented, lip-reading takes energy and concentration which a deaf woman in labour does not have.

> **[Kerry]** "Labour is so important – when you are in labour, you *need* an interpreter – it doesn't matter how good you lipread, how good you communicate. Having an interpreter at the birth was *so, so* important for me. 'Em, because when you're in pain, you're not able to clearly focus on what's being said. So when there's a person signing you'll take it in better, visually, than focusing on what's being said – processing lipreading **no.**...The first time I had no interpreter, the second time I did. Big difference - more positive the second. Yeah because there was a lot of communication breakdown (expresses stressed) ugh, I mean they made decisions without even discussing it with me, they said they did, they mentioned (expresses file) patient said yeah but I never said yes to anything...'wh', wh' wh' what?' You know (expresses lost in communication)…".

Christina **[late 50's]** is an ISL user and is not bi-modal. Her second last labour, described below, required emergency surgery. Christina was distressed because she was uninformed about what was happening before this and in the immediate aftermath of surgery failed to receive answers to her questions. Her deaf husband also had no access to clear information during the emergency surgery. Neither Christina nor her husband gave consent to the procedure. Additionally, Christina describes being dismissed during her attempts to find out what had happened and where her child was, when coming around from surgery. This was a frightening experience that put Christina in the position of being the last to know what had happened to her body, as well as what happened to her new-born. Christina felt that if an interpreter had been present, she and her husband would have had full information access which would have prevented stressful guesswork. The contrast between Kerry's and Christina's cases serves to reiterate that interpreters should be an essential component of maternity care services for deaf women. Additionally, we see that her autonomy was overlooked during and after labour.

> **[Christina]** “So (expresses unconscious peacefully) - (expresses awake with a start) first thing I saw is my husband writing with the doctor - my husband (expresses writing intently) - me (expresses waving for his attention) my husband (expresses breaks concentration for a second to say 'baby girl' and then back to writing with doctor) - (expresses ignores me and back to doctor) - me (expresses waving in agitation at him) - (expresses husband holding up finger to wait, wait, wait - with one eye on me but focused on doctor) 'one second, one second! - very serious' (expresses looking at husband for attention and answers urgently) but back to sleep again (expresses passed out again)….And just (expresses passed out) and woke up see my husband (expresses writing intently with doctor) and me (expresses flapping hands asking 'what happened, what happened?') and stomach sore! (expresses husband quickly look at her but paying attention to doctor 'serious, serious, serious!' - writing intently). ‘You lost a lot of blood’ – ‘but baby??!!’ – ‘oh fine, fine, fine’! (expresses back to writing) and me (expresses in agony of not knowing but passes out to sleep again). Wake up – ‘**baby** - where baby??! Where baby??!’ – ‘soon, soon, soon’ - (expresses passes out to sleep again)…So I think, think, think - if have an interpreter there - easy - interpreter there all the time (expresses interpreter signing) 'calm down'”.

While the small sample size of deaf mothers’ limits comparability to Steinberg’s (2006) study, the findings here suggest a growing awareness amongst deaf women in terms of their rights to accessible obstetric care. While eight of the eleven mothers used an interpreter during labour, only two had access to an interpreter during antenatal classes which indicates there is still scope for improvement in maternity services for deaf pregnant women.

7.7.4 Breastfeeding and deaf awareness in the maternity ward

Respondents in Steinberg’s (2006) research reported that they had little support with breastfeeding, struggled to breastfeed and in many cases gave up. Chin et al., (2013) report that features of Deaf culture and ASL can support overcoming breastfeeding challenges. This is relevant to this research as mothers were predominantly taught how to breastfeed through English. Seven commented that they had attempted to breastfeed. Of these, five remained breastfeeding. Two expressed that they had not received support to breastfeed and so gave up which they found disappointing. Kennedy (2003) writes that breastfeeding relies on a materially and socially inclusive context. Material and social circumstances in this research can mean supporting the use of a deaf alarm that will vibrate or flash to alert the deaf mother to their baby crying. It can also mean supporting a mother through appropriate language and accessible information. She also writes (Kennedy, 2015) that the 2012 HSE Infant Feeding Policy for Maternity and Neonatal Services states that all parents have the right to receive information to make evidence-based decisions on how to feed their child and staff should support women in this. Data from my research indicates that this is not happening for deaf women.

Sybil **[early 40’s]** refers to the idea of a ‘low fund of information’ (Barnett et al., 2011). She did not understand the new breastfeeding vocabulary presented. For example, the nurse wrote down the word ‘latch’ when explaining to Sylvia how to breastfeed. She did not understand ‘latch’ as she had not learned it before. Ubido et al., (2002) note that women in their research often did not understand new vocabulary and jargon. They were unfamiliar to a person whose first language is sign language.

In Sybil’s case not understanding what the nurse was explaining had resulted in her feeling discouraged to continue breastfeeding;

> “…Really, very bad. When I was trying to breastfeed, there was struggle, struggle. Nurse write down, explain, me (expresses can't understand) not clear (expresses distressing experience). Struggle, struggle, struggle. Breastfeeding very bad, first child, six weeks, painful. I decide to give up. It didn't work out. Second one, try again same. Nurse explain, me, not clear. Third one, same. Now I hear all my friends, go through breastfeeding, perfect. How?? Realise more better information now. Wish I could go back that time. Better information but (expresses that's how it was). At that time there was no media - where to get information. The websites (expresses not accessible) no information. Me really struggle. Disappointed. Fail with breastfeeding. Just (expresses disappointing experience)...Like the writing, like the baby should latch - like latch. Me

> (expresses confused) I don't know what that mean. That word - I don't know what it. Lots of new words”.

Beatrix **[mid 50’s]** in contrast, discussed how her nurse visually demonstrated and wrote down how to breastfeed. She repeated this until Beatrix felt comfortable and thus enabled Beatrix to continue breastfeeding;

> “…I decide breastfeed and then after born the interpreter left, then the nurse helped just action, not talk, just action (demonstrated) (expresses breastfeeding baby and trying to get milk out) - bring the baby face (expresses onto the breast) me okay, fine. And then next day (expresses struggle with breastfeeding) but gone, myself. Struggle. Sore...I don't know what to do. Sore (expresses messy and painful). Frustrated. And then…other nurse - the nurse stay with me for one hour. Stay. Write names. Write. She showed me how to (expresses latch baby) patience. Kept trying and trying again and again. Again (expresses messy and stressful). Repeat, repeat, repeat. Through my eyes (mean seeing it in action) ah clear. Nurse kept checking, checking, checking. Busy, busy, busy... Stay and after a while I know what to do. After that better because breastfeeding for a long time. Stay with me. Repeat, repeat, repeat. Help”.

Sybil’s and Beatrix’s narratives demonstrate the importance of ISL breastfeeding resources and the potential benefits of an interpreter when a deaf mother is learning how to breastfeed. My research findings parallel Steinberg’s (2006) research. Findings indicate that there is still room for improvement regarding breastfeeding and post-natal support for deaf mothers in Ireland to ensure the mother is supported and empowered to parent in the way she chooses.

Finally, mothers noted that they encountered difficulties in the hospital after the birth which were frequently linked to nurses’ lacking deaf awareness. A few mothers noted that they had prepared to take care of their new-born by bringing in a deaf baby alarm[77] to the ward. However, this would be set off anytime any baby in the ward cried so was

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[77] A deaf baby alarm responds to a baby’s cry and alerts a deaf mother by flashing a light or vibrating. This is useful when a deaf mother cannot hear the baby’s cry and is particularly used at night. However, in the labour ward it will react and notify the deaf mother anytime any baby cries which can disturb the mother’s rest.

not helpful in this context and disrupted their sleep. Therefore, they ended up having to turn the alarm off. Nurses and other mothers failed to understand that they could not hear their own child and often did not offer support with this.

> **Vivian [late 30's]:** "…I was not happy with one or two nurses because I was in room with six women and babies as well. So I bring the baby alarm. So any time any of the babies cry I wake up. Its' not mine - it's all the other babies. If someone else's baby cry I wake up from them. So bother".

Vivian's narrative further illustrates the unequal contours of deaf mother's experiences in the labour ward. Her autonomy to care for her new-born and to nurture the mother-child bond through baby cue/parental response was neglected by ward staff. Thus, there are additional ramifications to the lack of deaf awareness within the maternity care systems that need consideration. There are a number of ways in which the autonomy of new mothers can be and should be facilitated. Kennedy (cited in Kennedy and Murphy-Lawless 2003: 51) writes that the maternity period encompasses pregnancy to when the child is one year old and "official maternity policies should be designed on this basis for all women". It is important that the needs of deaf women are embedded in policy and thought about, not just in pre-care but also follow up care after the baby is born to support access to mother and baby classes for example. Maternity care should be 'woman-centered' (Kennedy and Murphy-Lawless, 2003).

7.8 Conclusion

Begley et al., (2009: 21) write that health inequalities are "unnecessary, avoidable, unfair and unjust". It is clear that there are numerous ways SRH services and information access can be optimised for deaf women but have yet to be addressed. My research findings are not a departure from previous research (Steinberg et al., 2002; Ubido et al., 2002) and serve to highlight that deaf women are still marginalised and frequently encounter multiple disempowering SHR structural inequalities and institutional barriers. A number of recommendations arise from this and are addressed in the final chapter. While many women in this research self-advocate and insist that the service provider work with them, other research demonstrates that many deaf adults may not be in a position to do this as a result of being continuously disempowered in the medical system (Harmer, 1999).

Shining a light on these instances is important for revealing the knowledge/power nexus and processes by which deaf women and differently embodied women are frequently marginalised and ignored in terms of their particular SRH information and service requirements. The knowledge/power nexus can be understood as how certain knowledges about bodies and sexuality have become normalised and shape policies and practices that have material effects by impacting upon and shaping deaf women's intimate lives. Foucault's (1980, 1990) understanding of power and knowledge is useful here. Foucault understands power as constructing bodies of knowledge which produce norms and truths that organise everyday structures and processes that further exert power. This shapes knowledge about what constitutes normative sexuality and bodies from which practices are shaped that contour deaf women's experiences. These experiences occur in schools, G.P.'s, sexual health centres and services as well as hospitals. Such spaces regularly engage in audist/ableist practices that serve to perpetuate inequalities for deaf women. Moreover, through privileging the majority language, good literacy and the normative subject, the deaf sexual citizen is often forced to subject to the public in the private when seeking to foster their sexual well-being. For example, through using an interpreter.

The issues raised in this research are not specific to deaf women, they are relevant to the lives of all women living in Ireland. However, for the differently embodied deaf women, this configuration of practices and inequalities is disproportionate, producing the 'unequal deaf sexual citizen', demonstrating that deaf women may be sexual citizens but we "are not equal sexual citizens" (Bell and Binnie, 2000: 142). What we also see alongside this are stories of how deaf women create their own spaces of resistance and employ particular strategies grounded in UCC (Ming-Cheng, 2015) and deaf social capital to generate their meaningful access to intimate citizenship. This fits with Harmer's (1999: 74) contention that deaf women "…by necessity…tend to turn to each other for information and support", an aspect of this research which is further elaborated on in chapter eight.

Chapter 8: The flourishing deaf intimate citizen: DEAF-GAIN and social capital

8. Introduction

The previous three chapters explored how many participants spoke of flourishing in their intimate lives alongside wider structural challenges. This chapter turns to consider what may explain the positive embodiment of deaf women, their intimate flourishing and how participants navigate and mitigate institutional inequalities. Within this chapter, I suggest that DEAF-GAIN (Bauman and Murray, 2014) and embodied deaf social capital are two critical factors mediating processes of exclusion. I argue that at the heart of this research is a story of how deaf women foster their embodied social capital through embodied social practices and transform this to strengthen their intimate citizenship. This is not to say that embodied deaf social capital is a determining factor for unproblematic access to intimate citizenship. Rather, I suggest that embodied social capital is one way that participants mitigate potential negative effects of infrastructural and psycho-emotional obstacles contouring access to intimate citizenship. This chapter explores the different deaf social relationships and processes participants engaged with; peers, family, school, boarding residence and community networks and how these can confer particular knowledges, shared values and power that, for some, extend their autonomy to mitigate wider structural inequalities. Here, I also discuss the possibilities I have observed for flourishing and what can be done with this going forward. I discuss that flourishing is not just an individual experience. It requires connection and drawing on the experiences in collective spaces and solidarity in marginal spaces.

Deaf intercorporeal encounters emerged from narratives as a factor countering potential material and psycho-emotional effects of audism/ableism. The concept of 'deaf intercorporeal encounters' builds on Shildrick's (2012) work on 'intercorporeal encounters' which draws on Merleau-Ponty's phenomenological understanding that, "…biological, social and discursive bodies are equally unfixed and mutually constitutive" (2012: 25). This relates to how the individual is in a constant state of becoming and being and knowing itself and others through encounters with the "flesh and blood" of others. From this perspective the individual body is not distinct from the experiences of the social world in which it is submerged, as it is in a constant state of affecting and being affected by other bodies in the world.

The objective of this chapter is to examine ways deaf women flourish in their intimate lives and to explore how UCC (Ming-Cheng, 2015) and DEAF-GAIN are drawn on in relation to intimate citizenship.

8.1 DEAF-GAIN

> "Why had all the doctors told me that I was losing my hearing, and not a single one told me that I was gaining my deafness?"
>
> (Bauman and Murray, 2014: xv)

The above quote, attributed to Aaron Williamson (Bauman and Murray, 2014), refers to Williamson's thought process where he wonders why no-one had told him he was gaining his deafness after he lost his hearing at seven. The concept of DEAF-GAIN is still quite new – I have yet to come across research using it in the context of deaf intimate lives. I draw on 'DEAF-GAIN' here as it is a valuable lens, giving insight into how deaf women view being deaf as a GAIN, providing them with positive, useful channels of support such as unrecognised cultural currency (UCC) (Ming-Cheng, 2015) in relation to their intimate lives. UCC, embodied deaf social capital and DEAF-GAIN are referenced within participants' narratives of how they use deaf networks as resources and opportunities to share and seek information and support. As such I am adhering to the concept's principle that "the biological, social and cultural implications of being deaf are not automatically defined by loss but could also be defined by difference, and, in some significant instances as gain" (Bauman and Murray, 2014: xv).

Blankmeyer Burke (2014: 11) counters the implication behind the quote, 'blindness separates you from things, but deafness separates you from people', arguing that in fact membership of the signing deaf community "may actually confer an advantage regarding intimacy" and that there is a relationship between DEAF-GAIN and intimacy. She is speaking of intimacy in the sense of a close relationship between two people with all the characteristics of social capital, 'trust, bonding, mutual caring and openness'. She is also speaking in the sense of how communication through the modality of sign language operates, i.e. how sustained use of eye contact (deaf gaze) in sign language interaction may lend itself to generating a closer sense of intimacy. These components of DEAF-GAIN can also be understood as UCC (Ming-Cheng, 2015). Blankmeyer Burke posits that there is a probable distinction in how DEAF-GAIN is experienced by deaf people who are not strongly linked to the Deaf Community and those who are.

Many of my research participants discussed the BENEFIT of their deaf relationships – conceptualising these links as conferring advantages that assisted them in navigating audist/ableist contours of intimate citizenship. While Blankmeyer Burke concentrates on intimacy in communication, I am expanding this to consider DEAF-GAIN: BENEFIT in relation to intimate citizenship. Two additional dimensions of DEAF-GAIN; CONTRIBUTE and AHEAD are also centred here. I apply CONTRIBUTE to suggest that deaf people/ISL communities confer a contribution by demonstrating flourishing in intimate life despite normative ideas of what constitutes sexuality and indeed flourishing not in spite of being deaf, but because of being deaf. This contributes significant GAINS to understandings of what it is to be and to flourish as an embodied sexual being. I posit the third dimension of DEAF-GAIN: AHEAD is drawn out to understand that deaf people contribute thinking in terms of how we challenge ideas and structures designed around normative sexuality and ways of being sexual. This thesis makes a contribution in this way and brings ideas AHEAD by challenging normative ways of knowing, being and flourishing in embodied sexuality. In this way wider society experiences DEAF-GAIN as well as deaf people.

8.2 (Re)producing deaf embodied social capital and DEAF-GAIN

As outlined in chapter three, I also explore embodied social capital. Holt describes her research on embodied social capital (2003, 2004) through examining how disability is (re)produced as embodied identifiers by children and adults through everyday practices within schools. In doing so she elucidates that being cast as disabled can shift within different contexts. This has parallels to my research also, relating to how young deaf people in mainstream school in chapter six discussed how they were cast as occupying non-normative sexual bodies by other school peers. In contrast, participants in deaf spaces and relationships expressed different experiences.

This casting particularly emerges in narratives of participants who did not have Deaf Community links growing up. This explicates how norms given to positioned identities are dynamic across different contexts (Holt, 2008). Participants expressed feeling 'fed up' of the challenges of meeting hegemonic, exclusionary, audist norms and feeling less excluded in deaf spaces where communication norms supported deaf embodiment. In chapter six, Kerry **[mid 40's]** and Harriet **[early 30's]** discussed feeling a sense of non-normative embodiment in their mainstream school linked to norms and expectations (re)produced in their social networks. Harriet discussed how she sought to 'pass as hearing'. This conveys a sense of her feeling her embodied social capital was accorded different 'value' in the dominant hearing context.

Here, we also see effects of past experiences on their current social relationships and the sense of DEAF-GAIN. Both discuss coming to a realisation that they could BENEFIT from engaging with other deaf people and learning ISL and thus transformed their 'habitus of disability'. Past experiences influenced the GAIN they felt in their present deaf interactions and an awareness of the embodied social capital they could draw upon. In doing so, they could develop more resources for navigating unequal contours shaped by dominant hearing society. For instance, Kerry states she knew by learning ISL she could harness UCC (Ming-Cheng, 2015) and use interpreters to follow college lectures. Here, she negotiates audist constraints through engaging in embodied deaf social practices. Both realised they could (re)produce deaf embodied social capital by engaging in deaf spaces and in doing so also transformed their habitus of being deaf into one that was positive and valued.

> **[Kerry]** "I remember going in to, we all had to attend a lecture….And then they provided an interpreter. It was the first time I'd ever even seen a formal interpreter. Ever. And that went over my head. So I didn't know sign language, and I didn't know what she was saying. I remember there was a deaf person here and a deaf friend either side and me going (expresses elbowing both persons either side) 'whew' (expresses lecture going over my head) and them going both ssshhh! We're listening! And I went (expresses surprised and confused) 'how do you follow it?!'. 'We're watching the interpreter!' (expresses two persons responding impatiently). Gasps (expresses dawned on me). And that's when it really hit me, they had sign, even though they didn't show it much. They were able to follow the sign language...That's when it hit me, I had to learn".

> **[Harriet]** “Motivation?...I think, I think because.... it was nice to...I felt like it was kind of, like the social side of things wasn't as much work and I started to enjoy that rather. Up to that time I was, at that time my hearing was starting to go down a little bit and then I was starting to have less and less patience for sitting and pretending to laugh... All that erm, it was much less hard work and I was just really enjoying the easy communication”.

In Harriet’s case she engaged in the Deaf Community because she enjoyed the social relationships and ease of communication – another form of UCC (Ming-Cheng, 2015). She previously felt no desire to be involved with the Deaf Community or learn ISL because of some ingrained negative ideas. She transformed this through realisation of BENEFIT and further transformed her ‘habitus of disability’ which (re)produced her deaf embodied identity.

8.3 Deaf social networks: Experiences and BENEFIT

Wilkens and Hehir (2008) argue that it is crucial to understand the value of deaf social capital gleaned by deaf children. In general, little is known about the social capital of young deaf people (Wong et al., 2018) except to say they may face challenges in building bridging social networks because of language, communication and social skill difficulty. Within my research no participants referred to problems with building bonding ties in school years but rather referred to concepts such as, ‘good friends’, ‘trusting them’, ‘depending on them’. Therefore, they indicated how their embodied deaf social capital was constituted through particular deaf spaces and embodied practices.

Deaf friendships and bonding ties were predominantly established in school or the boarders. These ties and networks shifted and were often sustained into adult years, continuing to act as a BENEFIT in terms of information and support sources. Beatrix **[early 50’s]** and Aileen **[late 20’s]** spoke of the meaningful friendships they fostered in the boarders – a theme echoed by other participants. In these spaces they engaged in embodied practices that could be understood as constituting UCC (Ming-Cheng, 2015) such as learning ISL and deaf humour. Establishing these bonding ties was important for drawing on sexuality-related support and information. Bruegel (2005) points out that social capital is really only effective when there is an already existing ‘rooted history’ that can be harnessed. Beatrix and Aileen described how information access was difficult when they were younger, particularly before widespread internet, and so they relied on using UCC (Ming-Cheng, 2015) through deaf social networks for exchanging sexuality related knowledge. In this way these relationships conferred social capital in the form of knowledge and support. This however, is not a determinant of accurate sexual health knowledge, but was engaged in to mitigate the contours of knowledge inequalities.

> **[Gráinne]** “Yes, yes and um now there is a lot of chat about cervical check - how do you feel about that - do you feel comfortable, aware or?”.
> **[Beatrix]** “Great, great - yes aware, more information. Make sure you know before you decide - great internet brilliant - best thing that ever happened. I wish 30 / 40 years ago but (expresses what can you do?). Different - we survive through information from friends. Risky…”.
>
> **[Aileen]** “Yeah we were all kind of open and talked about losing virginity and blah blah blah. I think - we're very close, we're able to talk to each other, I think, I hope anyway. If I'd have had questions I'd ask my friends, I wouldn't ask my parents, I wouldn't ask a teacher. Like at that time the internet wasn't great, there wasn't the same access to information there we can get now. It was limited, very limited, 2005 / 2006, limited. So you kind of just relied on what you saw at the doctors, in the waiting room or if you got an information pack you'd (signs reading) I'd read it, but you wouldn't get that much information from other areas, just your friends…”

Both Aileen and Beatrix discussed embodied deaf social capital as playing a strong role in shaping their knowledge. Here we see BENEFIT and CONTRIBUTE in terms of their knowledge building and how embodied deaf social capital is (re)produced and drawn upon to navigate wider structural inequalities. Jessica’s **[early 20’s]** narrative echoes similar themes;

> “…When I was young, I learned from the older ages in the boarders, because mixed, the younger girls were with the older age in the boarders, so when I was in the boarders I learned about condoms from an 18 year old. She was like (gestures

> 'look at this') playing you know….she showed me the condom, you know thinking it was cool, just like 'agh, look at this' because you know it was mixed so 13, 14, 15, 16, 17, 18 were together. And they were telling us about sex so I learned from them…I learned a lot from my friends yeah".

This is not to say that accurate knowledge is always passed on, but that using UCC (Ming-Cheng, 2015) and social networks shaped knowledge and resistance to exclusion in particular ways. These relationships, many expressed, became core information sources which they regarded as ameliorating potentially difficult situations. Jessica and Sadie **[mid 20's**] referred to how they benefitted from friendships across different age groups and gave examples of this. Wilkens and Hehir (2008: 278) contend that conceptualising social capital as a valuable resource could be useful for "the promotion of positive school and life outcomes" for young deaf people.

> **[Sadie]** "…um my school friends yeah (expresses emphasis) *really, really depended on my friends* for kind of information yeah - like tampons - how they worked, how to put them on...erm I did try to have sex erm the first time. But very painful and I asked a girl like 'is that normal, the feeling?' and the girl says that 'oh, normally first time you kind of bleed when you first have sex'...and I was (expresses taken aback) oh the school never told me about that part. Like I didn't know you could bleed the first time. And I thought there was something wrong (expresses friend reassuring me) no, no, no, that's normal, normal, normal (expresses expelling breath in relief) oh thank goodness, I'm normal. You know what I mean?".

Thus, Sadie acknowledged feeling reassured by this information from her friend which she had not learned about through the school and this was her **DEAF-GAIN: BENEFIT.** These narratives illuminated that deaf schools and boarding residences formed key contexts in which to draw upon embodied deaf social capital. Christina **[late 50's]** similarly discussed the importance of her school social networks and how she had learned about periods from friends but also learned "wrong things". A pregnancy myth was shared amongst her social network until someone used their extended social network to dispel this myth. Her narrative highlights that while participants may regard their embodied social capital as playing a significant role, knowledge was not always accurate.

> **[Gráinne]** “What kind of things did you learn from them?
> **[Christina]** Oh wrong things - I remember when about I was in first year, I was in first year and we had a class in first year - (expresses sitting back nonchantly) one girl, one girl of about twelve or thirteen - she came in and was very excited 'Igotmyperiod!' - 'you?, you?, you?, you?' (expresses question being asked around the room) - one girl, nothing, we all (expresses staring at her baffled) 'Nothing? Nothing? Nothing?' ...'ohmygodohmygod' - then we went to the disco - went disco - meet, meet, meet boys - we never had french kiss, never had that - never - that girl had french kissed. So we think - she never have a period - she's pregnant - she's pregnant! Poor girl. From french kissing! (laughs) We all (expresses deeply worried and concerned) reet, reet, maybe, maybe, maybe. Long time worried - 'ohmygodohmygod' (expresses holding mouth while staring at girl in worry for her). Poor girl - she should not have french kissed! She should not have french kissed! (expresses worry continues and continues) Reet! No period! So she worry and worry and worry for a long time - we all (expresses biting lips and clasping hands tightly in anxious worry with her). Wrong information and then one girl asked hearing sister and sister said 'that's wrong!' - so relief! No access - wrong information. That's how we all think – ‘ohmygodohmygod’”.

Absence of formal sexual knowledge building sources, leading to reliance on informal sources, could potentially have repercussions for holding false knowledge and thus being a negative effect of relying upon bounded social capital. As noted in chapter five, reliance on informal, inaccurate knowledge could heighten risk taking behaviours resulting in negative outcomes (Mayock and Byrne, 2004). Receiving sex education is correlated with “a postponement of sexual activity and increased contraceptive use” (Hyde and Howlett, 2004: 14). It is important that young people are equipped with the knowledge and skills to make informed decisions about sexual behaviour. The HSE report (2018a) notes there are greater risks and adverse sexual health outcomes associated with young people becoming sexually active early (before 16) namely, exposure to unplanned pregnancy and STI’s.

8.4 (Re)production of exclusionary patterns and outcomes of bonding social capital

Embodied social capital is differentially constituted which can be linked to the range of bonding and bridging ties available to an individual. Stephanie **[mid 20's]** describes herself as bi-modal, has grown up in the Deaf Community, attended deaf school and boarding residence, and therefore has engaged in processes of building deaf cultural capital. She comes from a hearing family and often presents herself as HoH. She compared her experiences of participating in the same deaf social networks to another deaf female friend. She felt her embodied deaf social capital played less of a role for her in comparison to her friend, and this was linked to "how deaf she wasn't". This ties into her habitus and the 'value' she felt was accorded to her deaf embodiment by other deaf people. Her friend was described as having more bonding and bridging ties within the Deaf Community because of having deaf parents and siblings which shaped the deaf social networks and UCC (Ming-Cheng, 2015) available to her. In contrast, Stephanie's deaf embodiment shaped her participation in deaf social networks differently and thus contoured her experience of embodied deaf social capital, whereby deaf people were more likely to support her friend's events over hers. This speaks to the diversity and complexity of embodied locations within deaf social networks and how differently valued embodied identities are (re)produced and how insular practices can be reinforced in deaf spaces (Holt, 2010).

> **[Stephanie]** "You know? And you're trying things in the deaf community where the deafer you are, and if you have deaf family, things are easier for you within the deaf community, opportunities are given to you, you are accepted better you're not questioned with decisions that you make….let's say if I were to get a friend of mine….she's very involved with the deaf community, …if she were to do everything that I'm trying to do in the deaf community…(it) would be big, people would come through, people would support things like that based on the fact she's deaf, deaf, deaf. She's deaf parents, deaf family, everybody in the deaf community knows her, they would show up and they would actually be interested in what she had to say. Even if I were to write everything she has to say and how to say (it), but because of who she is, it's more popularity, than it is the truth".

This symbolic capital was spoken about as being ‘privilege’ that was available to her friend in a different way. This had different outcomes for Stephanie and meant “things were not as easy for her” within the Deaf Community. Symbolic capital intersects with embodied social capital to confer greater advantages. Stephanie spoke about how this was a conscious understanding for her, but unconscious for her friend. This relates to the unconscious process underlying habitus, as well as the ‘dark side’ of the exclusionary nature of social capital, that is present in the Deaf Community, as in any small bounded community.

On the other hand, Stephanie also has access to linguistic capital as she is bi-modal and bi-lingual in ISL and English. Byrne (2014: 122) includes linguistic forms of capital in her research exploring the experiences of deaf and visually impaired young people in third level education. She describes linguistic capital as “those presupposed and naturalised forms of written and spoken competences demanded by the cultural arbitrary, and which make it difficult for some young people with disabilities to fully participate in the field of learning on an equal basis with their non-disabled peers”. As she further articulates, sign language users often experience difficulty acquiring and converting capital because of this linguistic difference. In this case, this linguistic capital intersects with and supports Stephanie’s ‘bridging social capital’ outside the Deaf Community – thus embodied social capital can take a different form for her.

Stephanie also spoke about encountering patterns of behaviour (such as gossip or lack of solidarity) in the Deaf Community that at times she experienced negatively. This has led to difficult experiences. She suggested that norms and behaviours have been established by older members of the Deaf Community which are (re)produced among younger members, as drawn out in the discussion of ‘habitus’ in the previous section. She strongly feels that this needs to be transformed to create more inclusive, positive behaviour patterns. However, while she acknowledged negative effects of bonding social capital in this way, for her, DEAF-GAIN: BENEFIT outweighs negative effects. Therefore, she feels compelled to nurture her deaf social networks because of DEAF-GAIN.

> **[Gráinne]** “…Do you get something, is it worth it to you to be in the deaf community now?...

> **[Stephanie]** …You know? There’s so many cons, but there’s so many amazing people, there’s so many great experiences and opportunities and I love the deaf community so much. I love being a part of it...That makes it so much worth it...”

Participation in deaf spaces did not always convert into transformative, positive effects for all participants. Different spaces and processes (re)produce embodied social capital in differential ways and can also regulate sexual embodiment and knowledges around sexuality.

Christina’s **[late 50’s]** and Barbara’s **[early 50’s]** narratives elucidated that their embodiment, UCC (Ming-Cheng, 2015), knowledge and ways of being were shaped in particular ways through their social networks and as such embodied social capital was regarded as playing less of a role for them. This gives insight into the importance of UCC (Ming-Cheng, 2015) and deaf social networks for resistance to wider societal marginalisation. Both participants previously used UCC (Ming-Cheng, 2015) and their deaf social network during menarche (which may have been regarded as a more socially acceptable topic to discuss). This changed later. For instance, Christina and Barbara discussed incidences where they did not access other sexuality-related information from their deaf female friendships due to refusal by their friends to discuss these topics, which both attributed to taboos surrounding sexuality-related topics, as opposed to the cohesion of their social network. Silencing and taboos formed the dominant construction of sexual embodiment in the social network they engaged in. This in turn taught them that these topics were taboo, and they should also be silent. Thus, their practices and ways of knowing were regulated by the embodied practices of other deaf women in this way and this (re)produced wider constructions of female sexuality and discourses around sexuality. Both tried to resist this by asking questions but repeatedly encountered the same practices. This shaped their experiences of their sexual embodiment and limited the options available to them, which made resisting and navigating wider inequalities a more complex process. This is not to portray both as passively adhering to or feeling fearful of transgressing these practices, but rather choosing to (re)produce these practices and self-regulate to maintain their social networks.

Christina shared that the consequences of this were feeling lonely and emotionally unsupported. This related to her experiences of pregnancy, labour and menopause. She found it harder without knowledge and support from friends, given wider structural issues contouring her information access. Her knowledge deficit was heightened due to wider information obstacles; her literacy was lower when she was younger, there was no interpreter at antenatal classes and her family were all hearing and had never learned ISL. When support in her social network was limited her emotional capital (Reay, 2004) also diminished. Reay (2004: 60) defines emotional capital as "generally confined within the bounds of affective relationships of family and friends and encompasses the emotional resources you hand on to those you care about". In Christina's case it seems that available emotional capital is limited as a consequence of a habitus contoured by discourses of silence and the imposition of a value system which discouraged particular kinds of intimacies.

> **[Christina]** "Yes, yes nervous - especially about labour. Nervous - because no information and me before go to Deaf Lady Club - every month, once every month. They won't talk about birth. (expresses prudish - ignoring the topic) 'see for yourself' and so (expresses stomach churning anxiety)…I think it was taboo at the time - no-one talk about it. When child was born I was in shock - some of my friends visit me and I (expresses tried to talk about the labour) and 'yes, yes' (expresses shut me down - would not engage) 'yes, yes good, beautiful baby'. They don't (expresses enthusiastic clambering and questioning) 'what happened?' Whatwhat?'. They don't. So I was like (expresses retreats and shuts up - holds index finger over mouth to silence myself and hold back my words)…"

Christina also discussed her experience of isolation during physical and emotional symptoms of pre-menopause. At this time, she had no access to information or support amongst her friends who refused to speak about this topic. She says this reserved attitude has now changed and she often sees friends openly discussing menopause in a private Facebook group, as well as in her friends' text messaging group.

Barbara echoed similar experiences of limited information access among friends in relation to her sex life. As a young woman she tried to share her experience of losing her virginity, and later on other sexuality-related concerns with her friendship group but had been silenced in a similar way to Christina. She learned that she should (re)produce these practices. She discussed how the characters in ‘Sex and the City’ spoke openly about their intimate lives. She expressed feeling jealous that these characters could have these open conversations that she desired. While Barbara did not express encountering any practical, health impacts as a consequence, she did express a sense of longing for emotional female support and a desire to engage in more open practices of sexual embodiment;

> “Yes, yes still, think if I have a problem I would look on the internet, not ask my friends. I would love ask my friends. But no. But I would love, I would love to able. Years and years and years and years said about boyfriend (expresses closed off by friends and this carried on in the same way) 'oh my god new broke virgin' (expresses knows this is a silenced topic and feeling frustrated about this). Little baby born, lost interest for a while, little while, lost interest. But friends don't talk about it.
>
> **[Gráinne]** Oh you mean you lost interest in sex after your baby was born?
>
> **[Barbara]** Yes after baby born yes. Talk to no-one. Me ask my friends 'you same?' (expresses brief, short answer) 'yes' (expresses then stop, no more conversation on the topic entertained). So always (expresses continued like this). So still today don't share with my friends”.

Thus, in this section we see the importance of deaf relationships for mitigating and navigating wider structural inequalities. Where it is harder to access knowledge through these relationships this can reinforce wider inequalities and thus impact upon flourishing as an intimate citizen. We can also see how knowledge and embodied social practices were shaped in particular ways through silencing and how this impacted on participants’ ways of knowing and being. The preceding sections contextualise participants’ social networks and relationships, as well as illuminate the practices by which embodied social capital was available in particular ways. It demonstrates that this was differentially experienced across age groups. This also provides insight into the intersection between UCC, cultural capital, emotional and embodied social capital.

8.5 Inclusive practices for transformative embodied social capital

Within this section the focus is upon considering embodied practices and how this can constitute and transform participants' access to intimate citizenship. Within participants' accounts it was evident that BENEFITS that emerged were both tangible and intangible. Different kinds of relationships and practices and the role they played in their embodied social capital were referred to by participants.

8.5.1 Peers

Interestingly, when some participants discussed the importance of their peers in gathering sexuality-related knowledge, phrases 'thanks to them' or 'luckily' were used. This indicates that participants were conscious that their social networks were valuable and that they may have experienced a significant gap without them. These ties were presented as useful across the intimate life span from menarche, sex, being pregnant, raising children and experiencing menopause. There is evidence to suggest that deaf networks are critical for quality of life. Gerich and Fellinger (2011: 112) found in their research with older Deaf people that "social capital in the sense of d/Deaf relationships is the source of personal resources that contribute to life quality".

Peers engaged in different practices for passing on information and support. Ruby **[early 20's]** emphasised the value of her social networks when gathering information and support during contraceptive decision making and addressing gaps in her sexuality-related knowledge which she presented as patchy;

> "…my class was split and my friend she heard a lot of stuff. She was LCA and I was LC. She had more classes, she had a SEA class, she had more like extra classes, where they talk about that. My class didn't so there was not enough sex information, I didn't know about condoms so she would come back and tell me. Yeah so um there was not enough sex information. And I didn't know about contraception until my friend, she was in a relationship before…so they wanted her to wear an implant (rod implant for arm). So I walk in and my friend was like 'do you wanna get the implant cos you're in a relationship?', 'Yeah, yeah, yeah, I want one' so I got the implant…".

Both Sadie **[mid 20's]** and Liv **[mid 40's]** also noted that their peer relationships were valuable, especially since they did not have particularly open relationships in relation to their intimate lives with their parents when younger. Their parents were described as practising avoidance techniques with regard to sexuality-related topics, meaning the value of their peers became heightened in this context. Bruegel (2005: 13) advocates for an approach that differentiates social capital "by the degree of transformative power embodied in it". These narratives suggest that peers hold the most powerful degree of transformative power and play an important role in terms of embodied social capital. Where these social ties are missing a sense of emotional loss is also conveyed, as suggested in Barbara's and Christina's narratives in the previous section.

Sadie discussed consulting her friends for information about a variety of topics and learning from their experiences. For example, she was interested in using the contraceptive rod[78] but became wary of this option based on a friend's negative experiences. Her social networks have supported her through different experiences such as first-time sex and exploring contraceptive options. Her narrative also touched on the role of bridging capital as she benefited from what her friends learned from their parents;

> "…**Luckily** I have good friends as well so I wasn't feeling 'aw my Mam didn't have a conversation with me' just went 'oh didn't have the conversation' pff (expresses ambivalent attitude) - just talk to my friends who talk to their mother and say what their mother say. And I was like (expresses soaking up the information) and get the information that way - so (shrugs). Social capital! (laughing - referring to concept discussed recently).
> **[Gráinne]** Yeah exactly! And so 'em then when you were younger would you have relied more on your friends than on your own research on the internet if you had questions?
> **[Sadie]** Internet - not really...no - I can't really remember if I looked on the internet, but I don't think so no. It was through people I think really yeah".

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[78] A form of long-acting contraception put under the skin inside the arm.

> **[Liv]** "… I think that day teacher never came to class - we were all bored - just talking about sex - facts of life - a girl brought up about condoms and AIDS - herself have family deaf - she very....I'm happy I met her - same class, this girl - she tell us all about sex - I learn from that and she very open minded. Because her family deaf, her family teach her and she teach us. Like role model. Explain us about that - and she teach us about gay/lesbian as well and safe sex and HIV (expresses broad, lots of topics were explained). It varied - I learned from 15 to 17 - same class both of us. I learn, learn, learn - big **benefit** to learn from her - herself, straight and married - but open minded and looking back, **thanks to her"**.

Again, both narratives reiterate use of UCC and BENEFIT and CONTRIBUE dimensions of DEAF-GAIN and the value accorded them by participants, particularly in light of wider structural inequalities.

Betty **[late 60's]** is of a similar age group to Barbara and Christina. In comparison to their experiences, she felt she could openly access information within her group of friends. When she was going through the menopause, she felt she had an "easy time of it", in terms of her symptoms and her available emotional support;

> "…I had a small group you see, small group of women. We would talk about it, discuss, 'what, what, what? Right, right, oh that's right, oh that's a - oh yes, I see'. We would talk about it, about four or five in a small group. We were a small, small group. They were older than me and had been through it you see so would (expresses pass the information on down). 'oh right, okay'. 'Try this, try that, eat this, try that'. Different things that worked for them...with the group of deaf friends. They were great, great. About two, three, four of us very close together. We would (expresses discuss everything) together. We would not be deliberately starting it, chats and tea and coffee in each other's houses. Then it would pop up. Naturally, intuitive. 'Oh I cannot sleep' 'Why?' 'Oh I had to get up and change my nightdress two or three times' 'Ahh' (expresses conversation continues from there) that kind of thing, we would share that kind of information".

The preceding narratives together illuminate the intersectional nature of participants' intimate lives. Narratives change across generational, gendered experiences, demonstrating participants lives are contoured by particular cultural and sexual discourses prevalent at that time. Narratives also reiterate BENEFIT from peer support. To understand how embodied social capital is drawn upon for BENEFIT, it is important to consider wider practices and processes, such as UCC (Ming-Cheng, 2015), which enable or constrain possibilities for flourishing.

8.5.2 Role models

Cawthon et al., (2016: 115) comment that barriers experienced by deaf individuals typically contribute to limiting their learning opportunities, and "particularly opportunities to build social capital". They argue that deaf role models critically facilitate building social capital within the young person's immediate social context. As noted by some participants, in the boarders they shared a dorm room with other girls younger and older than them. This meant they were exposed to a variety of topics, particularly in relation to intimate lives, which some characterised as useful for information gathering. These social ties were not presented as friendships as such, but they were presented as guides and important information sources, so they could be conceptualised as role-models. Participants did not refer to anyone as acting in a conscious capacity as 'role models' but they are conceptualised in this way, because of the informal, yet crucial role they played for some of the participants as young people.

Cawthon et al., (2016: 115) refer to barriers deaf people frequently encounter across personal, academic and professional life to note it is, "frequently proposed that role models meet an important need for successful navigation in such contexts". Ruby **[early 20's]** and Hannah **[mid 20's]**, both described differing scenarios of incidental learning. They casually observed older girls' conversation in relation to sexuality topics, piecing together information from what they observed and built on this. Cawthon et al., (2016) propose that navigational benefit is important for young deaf people – whereby they learn strategies for navigating a range of life situations from deaf people who have already been through similar situations. Ruby and Hannah echo similar themes – discussing observing other young deaf women engaging with young men, or discussing sexual health matters, for information on what they should do.

Ruby discussed observing the behaviour of older girls in Scouts' club and how they engaged with boys in this space. She felt that this informed her understanding of how to act and behave, what norms and behaviours she should (re)produce;

> **[Gráinne]** And you know you mentioned the older deaf girls, did you learn a lot from them?
> **[Ruby]** Yeah, when I go to Scouts, I watch what they do and how they hang around with boys and how they…their behaviour…It was kind of hard for us to learn, 'ok how does the relationships work' because they don't really see it until after when we are older and it's like oh okay, I can see how relationships work".

Hannah felt that she learned about sexuality-related topics from observing older girls in her dorm chatting;

> "The first time I knew about real sex was I think about 15/16 so late. The older deaf girls were talking in the boarders. Because we were mixed groups – my group (I interject to clarify if Hannah means friendship groups) – No, there were different groups in the boarders, like different houses, but my house, my group the girls were aged 4 years in the difference. So if I was 16 mean the oldest was 20. So when I was 14 the girls would be 17/18. So sometime I get information from them. So for example 'oh I finished pulling a boy last weekend at the nightclub'. I was observing all these conversations. So sometimes I would get information from that".

Thus, here we see that participants articulated some learning from older role models and the BENEFIT of this knowledge, albeit it may not be accurate.

8.5.3 Family networks and community ties

Some women discussed their family ties. However, family ties were generally conceptualised as less useful than friendship or community ties in terms of information access. This correlates with literature (Hyde and Howlett, 2004) and findings in chapter five which found that parents were not key sources of sexuality-related knowledge. Additionally, this could be linked with, as some participants expressed, losing the family bond through being a boarder or because of communication barriers with their parents, as Ruby and Shauna discussed in chapter five.

Sybil **[early 40's]** was one such participant who did not have a strong bond or frequent communication with her mother or siblings, partly because of communication but also because of personality differences. For example, she portrayed one of her sisters as being a private person who would not discuss topics such as menopause. However, she emphasised that her deaf sister-in-law passed on a lot of information to her, such as the correct food to eat or not eat during pregnancy. This was particularly useful for her as she characterised her links to the Deaf Community as weaker during her pregnancies;

> "I remember, I got a small book about pregnancy and facts 'you should not eat', 'should take folic acid', I remember, I got - lucky I got book from magazine…Got small book, very, very basic, very basic English. So I read, interesting, pictures, lots of pictures, I remember that...So that book helped me a lot….
>
> **[Grainne]** If more questions would you talk to friends?
>
> **[Sybil]** Not really, really it's like basic, like must get folic acid, you know they say must take it because protection for bone, something, protection stomach. Keeping baby stronger. You know. That's it. More. You must avoid to eat like coleslaw. Really mayo. Because of egg. Keep away from that. Some friends warning, do not eat that. Lucky I have a sister-in-law…got more information from her, she have children before me. She learn a lot from her family... So she (expresses feedback) me information about do not eat. I learn, learn more from her and I learn from book, read…"

Finnoula **[early 70's]** also discussed how she had no access to information at home through her mother. Information she gathered about sexuality-related topics was through attending the Deaf club;

> "I hear everything in the deaf club - at home, nothing.
>
> **[Gráinne]** Did you talk with men and women there?
>
> **[Finnoula]** No, no, women only. My friends only. Men, no way. Sex and children through friends. I had some married friends...Learned through gossip you know -

> talking about their children over tea, like ‘boyfriend and girlfriend live together now’…”.

Therefore, we see how UCC (Ming-Cheng, 2015) and deaf social networks are again used to mitigate wider structural inequalities of knowledge building and flourish in intimate life.

8.5.4 Deaf community organisational and virtual ties

Finally, the last theme in valuable social connections that emerged from participants’ narratives related to deaf organisational and virtual ties. While these ties were described as beneficial and good information sources for some, it did not emerge as the strongest information source. In terms of dimensions of transformative power of social capital (Bruegel, 2005) and contours of social capital it can be viewed as a weaker dimension.

Organisational ties refer to linking in with workshops and events led by organisations such as National Deaf Women of Ireland (NDWI), Chime or IDYA. Virtual ties relate to online deaf community led groups on Facebook noted by some participants. In this section, organisational and virtual ties are blended together, as they were both noted within participants’ narratives to a similar degree.

These ties were never referred to as a source of emotional capital (Reay, 2004) or support, but in terms of providing accessible information (expanding funds of knowledge) and creating the conditions for conversations through discussions in the online groups. These ties are important to foster. Research by Gerich and Fellinger (2011: 111) found that “larger deaf networks provide social resources that help to support personal resources, which in turn promote quality of life”. Their research was carried out with older deaf people. They note that the context for young deaf people may be different with the presence of technology such as the internet, CI’s and better educational opportunities. Within my research, older participants discussed using technology, friends and organisational ties as information sources – all of which expand their deaf network and information sources.

Shauna **[early 70’s]** recollected that when she was growing up, she encountered discourses of silence and protectionism in relation to sex. Reflecting on the current situation she felt that deaf organisations have made an impact on challenging discourses and material outcomes for deaf people through providing accessible workshops and presentations. Because of these additional resources deaf people have access to more sexuality-related information. There is also less taboo surrounding these topics;

> “…In terms of sexual health I think there is a lot of awareness now surrounding it. There are a lot of active groups like the women's coffee morning where the discussions are much more open. They are not afraid to speak out anymore. In the past they would have been but they are no longer afraid to speak out about sex and sexual health. Things are much more open now compared to the past…There are more lectures about it, more Deaf organisations organising presenters, courses, and talks about it. That has helped a lot. And of course they are talking about it among themselves a lot more openly now too. If someone doesn't understand something they have seen or read then someone else in the group will explain it to them or they will all end up having a chat about it in general”.

It has been suggested that the internet is a useful information source for deaf people because the use of text and images (visual communication) is prevalent, as opposed to verbal communication (Wong et al., 2018). For example, Facebook supports sharing videos in ISL. Participants noted they had learned from ISL videos posted within a private Facebook group for deaf women, as well as the ensuing comments on such videos. Wong et al., (2016) carried out a pilot study with 29 young deaf and HoH Australian people to explore their online social habits, social capital and literacy. Their findings indicated a positive link between young people’s hours of internet use and ‘bridging social capital’. This suggests that “the internet assists teenagers in connecting with others outside their immediate networks and expanding their worldviews” (2018: 465; 2016: 103). They note that a positive relationship to ‘bonding social capital’ is not present and conclude that the internet has not replaced the importance of intercorporeal interactions as “a source of socioemotional support” (2018: 465).

Sybil **[early 40’s]** discussed how she gleaned more sexuality-related knowledge through a talk organised by NDWI as well as virtual deaf spaces. The talk created the space for her to discuss and learn from other deaf people. At the same time, she also found Facebook groups helpful and watched health-related ISL videos on YouTube.

> **[Sybil]** “Yes, yes. Erm I remember the doctor, I remember the doctor recommend me to use the cervical test (expresses long time ago) when I was 24 or 25 (expresses around that age). I never heard of that. (expresses new information) 'Okay'. Then they said 'come every three years'. At that time I remember I never talk about that but now oh a lot of people talk about it. I went to...presentation in the women group. They organise presentation about cervical test. I went to it, interesting. Learn from that. 'Ah!' realise must have test every three years. That, more awareness about that…Being involved in women - NDWI. I more learn from them and I think maybe Facebook. And I think more, I meet, meet people in Deaf Community now...when Facebook start more meet deaf friends, normally women conversation. Talk about man violence - different thing so (expresses in that way). I learn from that (expresses 'ah really')”.

Liv **[early 40’s]** discussed her experience of coming out as lesbian. She felt reluctant to discuss her feelings with family and friends when she was younger out of fear of judgement, as she had been exposed to discourses that positioned her sexuality as ‘wrong’. Additionally, because she was deaf, she felt concerned about going to hearing support groups because of communication. Thus, her available options were shaped by her deaf embodiment and wider sexual discourses. She became friends with another lesbian deaf woman, and both decided to attend a support group together. They drew on each other for support to go into this hearing space. Thus, UCC, embodied deaf social capital and DEAF-GAIN: BENEFIT was available in this form and assisted with navigating wider structural inequalities.

Liv expressed that this support group was helpful, but later felt that she needed a Deaf space for ease of communication. Around this time Greenbow[79] was in its genesis and she joined. Liv expressed that she found the resources and relationships generated through Greenbow extremely helpful. This later presented deaf LGBT relationships and DEAF-GAIN: BENEFIT to draw upon, that was helpful for knowledge and sense

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[79] Greenbow is an organisation for LGBT deaf people.

making for her sexual embodiment. Here, we also see how Liv's embodied locations intersected in different ways and (re)produced different forms of advantage and disadvantage.

> **[Liv]** "…(nodding) to a group we would write back and forth to communicate. Lesbian group….So went in, meet woman group, sit, ask for a support group and information, events - and involved - start from there.
>
> **[Gráinne]** And that group was good help or?
>
> **[Liv]** Very good - very helpful.
>
> **[Gráinne]** Yeah and so you stay with that group for long time or?
>
> **[Liv]** Involved in it for a while - they have meetings, me want to go to meetings - they, organised to book an interpreter for us and linked with DeafHear (then NAD) DeafHear 'okay' - book an interpreter for us. Then we went with an interpreter. Sign in meeting….but involved, felt need deaf gay and lesbian group. 'Right' - 'where is deaf?' - meet together - coffee, very quiet place - all nervous, don't want others to know because not 100% come out. Need support group first…."

From this section we see another layer of embodied social practices that contributes towards embodied social capital whereby deaf women BENEFIT from engaging in wider deaf spaces – in online and in physical deaf spaces led by community groups. This is another important dimension contouring deaf womens' embodied social capital and flourishing in intimate life.

8.6 Conclusion

As Wong et al., (2018: 465) write "very little is known about the social capital of adolescents who are DHH". This research has made a key contribution to advancing knowledge on UCC and social capital of deaf adolescents and adults and how this is transformative for flourishing in intimate lives. Additionally, it is contended that advancing analysis through UCC and embodied social capital can be used to highlight the ways in which structures of power are (re)produced and how they may be addressed (Bruegel, 2005). This research has contributed to understanding embodied practices and processes that contour deaf women’s intimate lives, and in what ways embodied social capital is drawn upon by participants to navigate inequalities.

Different dimensions and intersecting relationships constitute embodied social capital. Deaf women engage with these dimensions, UCC and relationships in different ways in order to draw upon their embodied social capital to further their own autonomy. It is clear that embodied social capital is not a simply benign force but one that can be used for transformative change in supporting access to intimate citizenship.

Returning to the capabilities approach as set out by Sen and Nussbaum is important here. As Hartley Dean (2009) notes, the capabilities approach is not the same as abilities. This approach refers to people’s freedom to live and devise lives of their choosing and that they value. He outlines that “equal inputs do not necessarily give rise to equal outputs because human capabilities – the real freedoms that people have to fashion their own way of living – may be objectively constrained” (2009: 2). This approach advocates that justice means providing measures that support individuals to engage with each other to their full capacity and to flourish (Kulick and Rydström, 2015).

Within this research, we see that deaf women are exerting their own capability to fashion lives of their choosing, and that they value, through drawing on embodied social capital, despite a lack of equal inputs in relation to needed supports at structural level. This research highlights that lack of accessible resources and services is a crucial issue to be addressed. I also contend that the capabilities approach is limited in its applicability in the context of living an intimate life that a person values. This is demonstrated through participants’ narratives of resistance and navigating structural inequalities contouring their intimate lives.

The capabilities approach promotes having opportunities to develop one’s sexuality and be satisfied in one’s intimate life (Kulick and Rydström, 2015). However, we see in this research that participants are forming their own opportunities to flourish by navigating the inequalities that contour their intimate lives and by engaging in and linking with deaf spaces. In doing so, participants demonstrate their own capabilities to be sexual and pursue fulfilment in their intimate lives that are of their own choosing, despite the fact that in many ways the conditions to do so are inhibited at structural level. Finally, Dean's (2009: 267) critique that the "capability approach to equality is framed in terms of freedom, but not solidarity" is significant. Solidarity through drawing on embodied deaf social capital is highlighted frequently across this research and to overlook the importance of this would be remiss.

Different social practices and processes are used to mitigate the wider structural inequalities layering participants' intimate lives. Narratives elucidated the importance of both bonding and bridging ties supporting deaf women to flourish in their intimate lives. Differential forms of embodied social capital contour deaf women 's lives, which should be critically regarded as and treated as a valued resource with the caveat that social capital is not suggested as a panacea for inequalities. Recommendations on this basis are outlined in the next chapter.

In this examination of how embodied social capital is constituted it is also evident that this intersects with other aspects of capital such as cultural and linguistic social capital which contour embodied social capital. Participants' identities as deaf or HoH intersects with their sexual orientation to confer them with more advantages or fewer as the case may be. For example, Liv had unequal access to hearing lesbian groups. She navigated this by writing notes and going with a deaf friend for support, before eventually finding Greenbow. Embodied social capital is drawn upon to navigate inequalities which can also be conceptualised as DEAF-GAIN. Factors such as language privilege, family support, education level are important to take into account in understanding how embodied social capital plays a role in deaf women's lives. As pointed out by Stephanie, the deaf community is also subject to issues of micro-power, and bounded capital can also contribute to negative effects.

Moreover, a key contribution of this research is to demonstrate that deaf women may not be flourishing as sexual citizens but are flourishing despite normative ideas on what constitutes an intimate citizen. This returns to the CONTRIBUTE and AHEAD dimensions of DEAF-GAIN by contributing and advancing our knowledge on the intimate lives and experiences of deaf women in Ireland and how these narratives challenge wider discourses positioning deaf women's sexuality as 'loss' or 'deficit'. This has adhered to the DEAF-GAIN principle of turning this language and these ideas upside down to reveal the value, strength and worth of deaf communities and ISL for deaf women's intimate lives.

9: Bringing it all together; the story of flourishing

> "Flourishing…is an ecological metaphor for imagining growth, interconnection and well-being…shifting our attention toward the capacities that promote vitality, generativity, well-being…prompting us to see the system from the perspective of what is working well, …"
>
> (Cherkowski and Hanson, 2018; 124)

9. Introduction

This research is a story of how deaf women seek to thrive and flourish in their intimate lives through nurturing their relational connections. It has demonstrated that there are many ways by which deaf women resist and navigate sexual and intimate normalcy to claim their intimate agency and construct positive sexual subjectivities. It is also a story of the many audist/ableist contours of their intimate citizenship and the implications of this. My research has illuminated an interrogation and a challenging of normalisation at the intersection of sexuality and disability is required.

I feel privileged to have carried out this research. I did not expect to take this particular research journey, nor to arrive at these conclusions. I began with a different standpoint, one grounded in my exposure to the limited, largely negative focus on the intimate lives of deaf women. Themes of lack of control, disempowerment and discrimination, prominent in research, rang loudly. I anticipated that these themes would rise to the surface in participant accounts. I came to realise these assumptions positioned deaf women in an oppressive, victim-centred narrative that did not reflect the lived lives shared with me. In contrast, strong themes of 'intimate agency' and 'relational autonomy' (leFeuvre and Roseneil, 2014) emerged from this research and challenged my assumed dominant themes of oppression, marginalisation, exclusion. My standpoint evolved as my assumptions were challenged through becoming immersed in feminist and critical disability studies as well as utilising an inductive approach. This is of course part of the uncomfortable, thrilling journey of inquiry.

Along the way, as the research fell apart and came back together, I sought out an appropriate way to frame this research, which led me towards the ‘flourishing framework’. This follows Humphries (2008) contention that deaf research can stand to benefit from a focus upon deaf ontologies and epistemologies which Kusters et al., (2017: 9) suggest is “a focus on the whole picture – both oppression/inequalities and positive experiences” for deaf people. The story that has emerged, and that I discuss here, is quite a hopeful one I feel, one that illuminates pathways towards greater flourishing for deaf women. I have not found a completely positive picture but through complex, nuanced narratives of resistance, intimate agency, relational autonomy and UCC (Ming-Cheng, 2015) I have uncovered that there is room for innovative and responsive ways forward to flourishing through processes of disruption and reimagination (Bacchi, 2009).

This chapter brings together key themes, as well as the wider contributions and applications of this research, as set out in figure 6. I do this by relating my findings, through my conceptual framework, to the research aims and key objectives.

Beginning this research, I set out with the overarching aim of exploring how deaf women in Ireland experience their intimate lives**.** The central guiding questions were;

- How do deaf women experience and understand their intimate lives?

- How are deaf women’s intimate lives contoured and what are the effects of this?

With this in mind I operationalised my research through the following objectives:

- To explore the experiences and perspectives of deaf women through their narratives of their intimate lives.

- Through this exploratory study, examine and understand how the intimate lives of deaf women are contoured (the lived realities of their intimate citizenship) in different ways and different contexts.

- To establish how to foster, sustain and normalise opportunities for deaf women's flourishing in intimate life.

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The following conceptual map addresses the key contributions and findings of this research;

Figure 7: The story of flourishing

9.1 Research summary; reimagining ways of knowing deaf women's lives

This research has provided a story of the lived intimate lives of deaf women and demonstrated that there are complex relationships between language, community, gender, sexuality and deafness, as well as the other intersectional social divisions and systems of inequality I have referred to across the analysis chapters (Baker et al., 2004).

My analysis revealed that deaf women's lived experiences of sexuality and intimacy are diverse and contoured and mediated by a number of factors.

As noted, there is little foundational research considering the positive sexuality experiences of deaf women, a gap this research has sought to address. As discussed in chapter one and two I also sought to do so in line with seeking to make a contribution to the need to generate an evidence base of sexual health information, which the National Sexual Health Strategy sets out for 'vulnerable' groups that they describe as 'at risk'. My data responds to the three goals they set out as;

- To ensure that everyone has access to appropriate sexual health education and information;
- To ensure that high quality sexual health services are available and affordable;
- And ensure that good quality data is available to guide the service.

I evidence where there is a need to improve access to education and information, as well as services, across the analysis chapters through the developed data.

My contribution also links with the CONTRIBUTE and AHEAD dimensions of DEAF-GAIN (Bauman and Murray, 2014). There is limited research considering deaf women's intersectional lives (Coogan and O'Leary, 2018; Brueggemann and Burch, 2006). My research contributes valuable knowledge by making visible deaf women's experiences. By taking this intersectional approach it CONTRIBUTES to gender and sexuality scholarship in Ireland by exploring the ways in which intersectional ways of being contour deaf women's experiences of intimate life in Ireland. Including participants aged from early 20's up to mid-70's has also given insight into what has changed for women and for deaf women over this time period in Ireland. I have drawn on feminist literature exploring connections between the body and citizenship – two disciplines that have rarely engaged with each other, despite a considerable overlap between the two (Beasley and Bacchi, 2000). I have expanded their use into deaf women's lived experiences. My research expands the contribution to knowledge, beyond the traditional ways of knowing deaf lives, in the public sphere in terms of education and employment and I demonstrate that private or intimate lives are also worthy of attention as sites of contention and resistance. In this way, I contribute to bringing thinking on deaf women's lives AHEAD. Finally, this research also offers useful foundational information for policy developments concerning women and intimate life going forwards from maternity care, sexual health services and abortion services, to name a few. It also makes recommendations for how service providers can be more inclusive of deaf women. I address this under the section, 'an agenda for flourishing'.

9.1.1 The contours of audism/ableism

A major finding from my research is that the intimate lives of deaf women are contoured by audist/ableist processes and practices in the form of discriminatory attitudes and of structural inequalities. Their experiences of intimate citizenship are located in the cultural and affective systems which need to be reformed and reimagined (Baker et al., 2004; hooks, 1989). These experiences are embedded within a larger ideological and sociocultural and policy context of normativity and discourses of silencing. Participants rarely expressed their gendered sexuality as being unrecognised. On the contrary a majority expressed feeling subject to gendered, protective discourses, particularly as young people. This is drawn out across chapter five and six.

Throughout chapter six and seven we see that issues of access to sexual health information and services emerged as connected to the cultural imaginary and ableist, normative understandings of the body and sexuality. This is reinforced by lack of recognition and misrepresentation in relation to sexuality and deaf women's intimate lives, thus rendering deaf women's gendered sexuality overlooked or unrecognised. This is connected to feelings of stigmatisation and marginalisation by participants. For example, June[80] spoke about how she felt there was a link between being a deaf woman and the lack of engagement by her doctor in relation to her sexual health. Participants spoke about the labour of navigating these contours and negative processes of interaction, exclusion and lack of recognition. In addition, audism/ableism has played out differently and has been experienced in different ways by participants – particularly between those who attended a mainstream school, those who attended a deaf school and those who are bi-modal and those who are not. For example, those who are bi-modal

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[80] June refers to this in chapter seven under the heading 7.3 'Participants' perceptions of attitudes and treatment by medical professionals'.

were less likely to discuss difficulties with deciphering written material but did discuss challenges of poor attitudes in medical contexts as June discussed.

9.1.2 Troubling 'mythconceptions' of deafness and sexuality

The concept of psycho-emotional disabilism, or rather psycho-emotional wellbeing (Thomas, 2007), emerged as a key aspect of many of the participants' feelings towards intimate life and their own sexual subjectivity. This contrasted with other disability-sexuality research (Liddiard, 2018). As such, this was an interesting research finding and one I view as illuminating and an important contribution. As a finding, it troubles 'mythconceptions' surrounding sexuality and deafness (Job, 2004) and brings an extra dimension of understanding to intersectional gendered deaf research. Significantly, when discussing their gendered, sexual experiences many participants did refer to gender and sexual norms and being aware of the contours of these norms on their sexual subjectivities. However, this was not the case for many in relation to their differential embodiment. Few participants connected notions of 'unsexiness' or 'not being attractive to others' to their deafness or differential embodiment.

These findings stand in contrast to the majority of the experiences of participants who had links with mainstream school and to other research I have come across exploring the sexual subjectivities of disabled women (Bahner, 2018; Rembis, 2009; Davies, 2000). This chimes with research by Bat-Chava (2000) who found that those who had a deaf or bi-cultural identity had higher levels of self-esteem in comparison to those who identify with a hearing or marginal identity.

9.1.3 The convergence of audism and ableism

An additional important element of my research is demonstrating the converging of audism/ableism which contours deaf embodiment and intimate citizenship, as well as illustrating the diverse forms that this converging can take. In considering this aspect of how the intimate lives of deaf women are contoured I also outline how findings in this respect contribute to a significant research gap. To draw out the nuances of how audism/ableism converge means beginning from the distinction between the two, according to their respective academic fields. The research gap I refer to is centred upon the points of contact between Deaf Studies and Disability Studies (Corker, 2002; Robinson and Adam, 2003) as outlined in chapter three.

Participants spoke about more than language rights. Language rights are critical, but there is also an important point to consider about being perceived through a lens of normativity and being seen as ‘other’. The subjective deaf embodiment of the deaf English user with few or no connections to the Deaf Community, is as important as that of the deaf ISL user who does have connections. However, their respective subjective deaf embodiment may be differently experienced - an additional research gap (Kusters, et al., 2017: 4) this research has sought to address.

The aforementioned authors write that there is a need to “look beyond traditional concepts” in Deaf Studies. Founding concepts such as Deaf culture and Deaf community “have become *top down concepts*, leading to “frozen” ways of thinking and structuring descriptions and analyses of deaf lives”. Later scholarship identifies “the need to make bottom-up accounts of deaf ontologies and epistemologies more explicit and regards them as *embodied* ones” (2017: 9). The authors identify that an additional problem with Deaf Studies has been an exclusion of marginalised deaf people and promotion of a rigid view of deaf people, to the exclusion of deaf people with different backgrounds and “preferences with regard to use of amplification and signed/spoken language” (2017: 11). Language rights are a significant argument to advance. However, we must go beyond understanding deaf people as only sign language users. Deaf people have different communication preferences and understand their deaf embodiment in different ways. Thus, if we expand the lens on deaf embodiment, opportunities to gain an increasingly nuanced understanding of deaf embodiment and also, importantly, to write the body into the picture will in turn increase.

This research makes a contribution to this signposting for a ‘sensory turn’ in Deaf Studies through including deaf women of different ages, ethnic backgrounds, relationship status and sexual orientation who use “fluid and hybrid language practices” (2017:17). By using concepts of deaf embodiment, flourishing and intimate citizenship to explore the intersections of gender, sexuality and deafness I contribute to the small body of research available considering deaf women’s lives. Deaf Studies has often put forward a disembodied, degendered idea of the deaf person in its assertion of concepts such as culture and community and language rights. This research provides a new and innovative perspective by going beyond these concepts to explore and understand the gendered, embodied experiences of deafness within broader experiences of audism/ableism, thus contributing to the emerging literature in this field.

This is aptly illustrated through Irene's[81] story where she discusses the challenge she encountered in advocating her doctor to treat her with respect. She advocated for the right to express her authentic deaf embodiment and to cease being forced to adjust to the doctor, but for the doctor to adjust to her. Irene was using English as her first language in this scenario and did not express that language was the contested site for her. Rather, a poor attitude towards her deaf embodiment was the site of conflict and demonstrates how deaf embodiment is the site of contesting ideologies;

> **[Irene]** "you know she was, she would just mumble and she wasn't looking at me and that kind of thing…erm you know if I was very sick and you would not be hearing well and she might '**em 'why can't you understand me'!**' and all that you know".

The concepts of audism/ableism differ as discussed in chapter three. There is room for interrogating the tension between both concepts and their overlaps in producing experiences of discrimination for deaf people and this provides insight into points of contact between Deaf and Disability Studies.

What Irene is speaking of echoes the experience of audism in one sense; "**why can't you understand me!"**. There is a particular expectation of Irene conveyed here, with the doctor certain her way of communicating is superior and Irene must fall into line with this. Irene resists and pushes back against this ideology and asserts that the doctor must adjust her own behaviour – she must reimagine how to communicate. From this, I argue that it is possible for us to also experience discrimination based on how we use our bodies to hear and how we need others to use their bodies back – to look directly at us, to make eye contact and speak clearly. We are not meeting a particular kind of self and body through this requirement. It is necessary too for (hearing) others to adjust their particular way of using their body, thus the normal view of how the body is used is

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[81] This is also discussed in chapter seven under 7.4 Participants perceptions of attitudes and treatment by medical professionals

being challenged in this way. Irene was requesting the doctor to use her body differently to communicate, to look up and at her. This brings in an ableist understanding of how we use our bodies to communicate and converges it with audism – our normative understandings of hearing.

Linking ableism to able-bodied deaf bodies is a complicated process, because it is possible for the deaf person who is walking down the street to pass as a hearing person, until they sign or speak (Harmon, 2010). Thus, we can tap into and benefit from able-bodied privilege. This was shown through the majority of participants experiencing their bodies as normative in intimate relationships, but shaped by deaf embodiment. For example, Barbara[82] discussed her view that deaf people do not feel that their deaf embodiment is something viewed as unattractive because they present a normative appearance. However, deaf embodiment can present as an issue for potential partners in terms of the labour required in communication. Few participants discussed feelings of being othered in this sense aside from mainstreamed deaf participants, as Harriet and Kerry describe in chapter six. This experience could be compared to the same privilege that someone with an invisible disability can also experience. This is a really crucial point because, if the goal is to consider how can we foster and normalise opportunities for deaf women's flourishing in intimate life we must bring *all* deaf women along with this – not just ISL users who are connected to the Deaf Community, but mainstreamed deaf people also, who have the potential to be isolated. As evidenced in this research, there are multiple dimensions to how women experience their bodies and deaf embodiment. This must be made visible and recognised in order to understand how this is bound up with their experiences of intimate citizenship. Being deaf is about more than linguistic (ISL) and cultural (Deaf Community) markers, but also how we use our bodies and engage with other bodies and the dialectical relationship of how our bodies and embodiment are contoured by how our deaf embodiment is perceived.

I argue that true transformation will not take place on the basis of language rights alone. There will still be deaf women who use spoken language as their primary modality and who will still encounter discrimination on the basis of their differential deaf embodiment. Language rights are not necessarily what this group of deaf women will

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[82] This was discussed in chapter six under heading 6.4; 'Sexual subjectivities of participants who attended deaf school'.

advocate for or want – rather desiring a broader imaginary of the diverse body and better response to this. Thus, we must go further than attending to deafness through linguistic frameworks, by which I mean advocating for change for deaf people through language rights only. We must embrace a cultural intersectional framework to challenge and reimagine the audist/ableist cultural imaginary to produce an understanding of a diverse citizen that hears, communicates, talks and expresses in diverse ways – is sensory in diverse ways. Otherwise oppressive effects of stigmatisation and audism/ableism, like in June's and Irene's narratives will never be fully dismantled and we will not truly foster and normalise opportunities for flourishing for all deaf women.

This research contributes to ongoing discussions (Burch and Kafer, 2010) around how Disability Studies and Deaf Studies can bear potential for each other through useful insights and ways forward. The particularities and access needs of disabled people and deaf people are different. Nonetheless, the underlying ideologies constructing access issues bear much in common with each other and reinforce each other, particularly considering contemporary deaf worlds (Kusters et al., 2017) and the increased mainstreaming of deaf children (Mathews, 2017) which continues to be the norm, as well as technology that is assisting this. All of this means that what it means to be deaf is changing. The context of the deaf community, and the question of who is deaf and who claims to belong to the deaf community, is in a state of flux because of these contested issues (Scully, 2012). I am not arguing that Disability Studies can give an adequate account of the experience of deafness or vice versa. However, there are overlaps that can be fruitful to embrace in order to understand in what ways the intimate lives of deaf women are contoured, and how we can address wider inequalities outside of a linguistic or communication lens.

9.2 New ways of researching deaf women's intimate lives: contributing to research with, and alongside, deaf women

This research makes significant empirical and theoretical contributions. In this research I used a creative, inclusive and inductive approach, influenced by aspects of narrative inquiry, to understand and analyse participants' narratives. To address the overarching inquiry aim I explored the narratives of twenty-nine deaf women, as well as building context through service provider contributions. From these accounts the concept of flourishing was explored through the intimate citizenship framework as set out in chapter three.

This was achieved by developing an innovative, positive methodological and theoretical scaffold that centres deaf women's voices and subjectivities and allows for an exploration of social structures. This comprised the WPR (Bacchi, 2009) framework, drawing on aspects of narrative inquiry, flourishing and intimate citizenship. In this I engaged in 'a politics of doing' (Bacchi, 2010) from the language and conceptual devices and framework I used, to the way in which I carried out this research. There is no other research in Ireland, to my knowledge, which utilises this particular approach towards this topic. I sought to contribute to methodological development, as well as to contribute towards positively impacting inequalities encountered by deaf women (and as always throughout this research, I include myself in this) on a practical and policy level.

The WPR framework (Bacchi, 2009) was employed in this research as it offered a great deal of possibility, for re-thinking and re-imagining at the intersection of deafness, sexuality and gender. It allowed the narratives of deaf women to be located within their socio-cultural-historical context. It was useful for uncovering silences and gaps and the ways that discourse becomes embedded and contours women's lives and how knowledge is produced on this basis. As a tool it is useful and important for thinking through critical analysis of policies and their effects. Blending this approach into my research enhanced the contribution my research has made and the contribution it can make going forward. It is important to note that this was an initial exploration yet it has revealed much in terms of the positioning of deaf women. Though a tentative exercise it demonstrates the potential for a more extensive application of the WPR approach to policy analysis in order to critically advance 'ways of knowing' deaf women's lives and indeed all lives in Ireland.

Thus, at a theoretical level, this research contributes to work using intimate citizenship and the WPR framework by expanding and adapting them for use in the area of deafness, sexuality and gender. In particular, it was useful for uncovering how conceptualisations of and presumptions of 'vulnerability' and the normative body are constructed and embedded in sexuality and disability policy and discourses. This is a misrepresentation that deviates from the lived experiences and views of deaf women in this research and, I would argue, of other deaf women too. I discuss my critique of this misframing further in the next section and where we can go from here.

In relation to the methodological contribution, using a blended approach influenced by aspects of narrative inquiry, was the most appropriate approach. I brought together a qualitative approach influenced by aspects of narrative inquiry and that centred a deaf feminist standpoint epistemology. This supported my primary intent of developing a contextualised, deep, rich insight into participants' lived experiences of gender, deafness and sexuality. As Plummer (1995) asserts, intimate citizenship is primarily a subjective experience and narrative meaning making facilitates the most authentic way of exploring this. The relational aspect of narrative design provides much potential in deaf studies and the development of deaf methodologies. This is a way of constructing knowledge *with* and alongside others and not *for* others (Lynch, 1999) and produces deep, rich data for theorising. It would not have been possible to answer the research questions any other way and positioning deaf women's voice in this way highlights deaf women as the experts in their own embodied experiences. This approach also allows in-depth, deaf gendered epistemological reflection from the bottom up on how we can equivalise opportunities for flourishing in intimate life and think otherwise about the intimate lives of deaf women.

Additionally, analysis informed by narrative inquiry was useful. I considered the personal and social dimensions of stories which can lead to juxtaposing positions in narratives (Clandinin and Huber, 2010). Participants' narratives allude to multiple, complex experiences of hurt, and marginalisation alongside stories of empowerment, agency and strength where deaf women actively assert themselves as gendered and sexual beings. Stories are lived and told, and they are told in the process of ongoing experiences. This is connected to the temporal nature of experience "in which participants are simultaneously participants in and tellers of their life stories" (Clandinin and Huber, 2010: 11). The story that is told in the present, may not be the story that is told in the future. Narrative "involves working with people's consciously told stories, recognising that these rest on deeper stories of which people are often unaware" (Bell, 2002: 209). Through drawing on the notion of temporality we can make sense of narratives as lived and living stories and participants as tellers of stories. This research concludes while participants still continue the process of living and telling stories (Clandinin and Huber, 2010).

Thus, there are stories within stories which are situated within wider social dimensions. I had to be true to these entangled narratives of stories within stories whilst recognising that it is impossible to tell the 'whole story' (Leggo, 2004). The story will change and be retold. Participants reveal subjective truths according to the diverse social contexts and relationships that they live through their bodies and minds – they are not 'objective truths' (Wang and Greale, 2015: 195; Leggo, 2014) that are true for all deaf women – they are the unique, valuable truths of the women in this research. Smith-Chandler and Swart (2014) note that exploring a range of perspectives can contribute to challenging normative ideas of disability by bringing forward an alternative sense of what disability means from disabled people's perspective. In this research a range of narratives gives insight into the multiple dimensions of lived experience of deafness and sexuality. It is important not to misrepresent this and thus be complicit in the re-silencing of deaf women. Leggo (2014: 104) describes this as honouring the ragged edges and pieces that do not fit. Room was given to nuances and jagged edges in the re-presentation of stories in recognition that stories are constructions of an interpretation that people have of themselves at that time, one that leaves out certain tellings in order to construct this interpretation.

Furthermore, research methodologies drawing on narrative inquiry provide much potential for critical and anti-oppressive research in Deaf Studies - to contribute in terms of DEAF-GAIN, through CONTRIBUTING knowledge that is AHEAD. Through this inquiry, recommendations at practice and policy level, emerged from participants' insights – a group whose opinion has rarely been sought and whose existence is rarely noted in policy. This is not to imply that there are no weaknesses in this methodology, there are limits to it and the ideal of course is to strive towards a pure model of emancipatory research that builds in participation at every single stage (Lynch, 1999). This, however, takes great skill, time, financial resources and commitment from research members.

Kusters et al., (2017: 22) point out that there is an elephant in the room in relation to hearing scholars doing deaf research, and hearing scholars in deaf research must reflexively position themselves within "broader sociocultural patterns and power relations". This includes deaf researchers also. We do not get a free pass on the basis of our corporeal similarity to participants. Power differentials are imbricated through deaf/deaf relationships also and we must think about and write about our positionalities and the hierarchal imbalances with as much of a critical eye as hearing scholars are urged to do. I have set out my background in the research and made reference to English as my first language. My background carries a particular power imbalance in this research as I am not a fluent signer. Additionally, this research has been carried out at a high academic level. While I am making every effort to address power imbalances through a number of measures, I have educational and literacy privilege and I am a deaf scholar that has been mainstreamed for all of my education, uses spoken language, a CI and hearing aid. I have a different background to some of the research participants. All this brings power imbalances and an intersectionality to my positionality that is critical to acknowledge. I cannot connect to and deeply understand all the experiences other deaf women in the research shared because of our differential positionality. This is a point that Kusters et al., (2017: 27) make, that as a mainstreamed deaf scholar I may not be able – and I know I have not been able to -"understand fully or appreciate the ontologies following from a deaf school background, often the background of people who are considered to be more traditional or core members of deaf communities".

All of this matters, and what I do with all this matters, from bringing a deeply reflexive, feminist, deaf and community work approach to this research, to what I do when this research reaches its culmination. I have gone into detail about how I implemented an ethical, deaf friendly, reflexive approach in chapter four. I do not intend to cease this research when I receive my PhD. I am committed to and view this research as a platform for other work to begin from and to start addressing the 'agenda for flourishing' set out below. I have started disseminating part of my research back to the deaf community by participating in two deaf Irish conferences. The first conference was led by NDWI and the second by Irish Deaf Research Network (IDRN). At both events deaf women attending expressed their keen interest to hear more about this research. Deaf women approached me during the break at the IDRN conference and asked me to travel to their specific deaf women's group to present when research is completed. This welcoming response in person, as well as the online discussion linked to the conference, indicates that there is an appetite for this particular research, as well as this kind of research.

This is also evident in participants' responses to this study. Many felt it was a unique, important topic. This is why they felt it was worthy of their participation, that it has value to them and to other deaf women. Two expressed that had they experienced research fatigue but that this research offered something new, so they decided to come out of 'participant retirement'.

It is important that I respond to this support and interest as so many scholars fail to return research knowledge to the Deaf community. This is an important aspect of research alongside deaf women. There are a number of steps to take in this regard, which I have detailed in chapter four. For example, I will develop an online summary and seek for it be hosted and find a permanent home on the IDRN website for those interested in finding out more about the research. These spaces hold a great deal of transformative potential, not just for those who seek to ask questions, but additionally, workshops can be held in these spaces to facilitate a discussion of the findings and to seek community responses on how findings can be put into action.

9.3 Reimagining ways of framing deaf women's intimate lives; the flourishing framework

> "Positive frameworks for human flourishing provides the language and insights for engaging new questions about how best to develop communities of belonging, connectedness and compassion…"
>
> (Cherkowski and Walker, 2013: 200).

I sought to make a new contribution to knowledge through the concept of flourishing. Using a positive lens as Cherkowski and Walker (2013) argue is useful because what we pay attention to, we reap more of. If we examine what is working, going well - we gain clearer insight into how to promote this and create sustainable conditions within which to facilitate positive social change. In taking this positive framework I committed to creating a new platform and language from which to create alternative ideas that could displace traditional, hegemonic notions that serve to reinforce exclusion and marginalisation and have stigmatised and marginalised women for so long, restricting their access to intimate citizenship. This research is a ‘politics of doing’ in this way (Bacchi, 2010).

In creating and operationalising the conceptual framework of flourishing I have blended diverse insights. Drawing on the data, experiential learning from my community work background and insights from Ferrall (2011) and Nussbaum (2011) I have suggested what flourishing might look like and how we might understand it in relation to intimate citizenship. It is within the context of ‘loss’ and ‘deficit’ and from a critical deaf feminist perspective that it became crucial to explore a new direction at ontological and ideological level. I sought to use a positive, intersectional lens that would support a shift in language and thinking so we can reimagine ways forward for thinking about and living intimate lives**.**

I conceive of flourishing as the end goal - the task of achieving a high-level of intimate well-being, thriving and fulfilment at all levels of intimate life and the ‘politics of flourishing’ is the process, whereby the conditions for this can be nourished in line with principles of equality, inclusion, participation and empowerment. This works in tandem with the ‘politics of doing’ (Bacchi, 2010). Flourishing is a simple term with complex underpinnings and an overall state of well-being that is no easy task to achieve given its multi-dimensions and complex links to relationships and societal structures. Within this research I have drawn on the concept of flourishing to;

(1) explore the potential ‘flourishing’ offers for a discursive shift
(2) advance new questions on deaf women’s lives
(3) garner deeper understandings of intimate lives and sexualities
(4) reimagine unrealised possibilities for flourishing

There are many dimensions involved in the achievement of flourishing at the level of intimate citizenship. It is a multi-dimensional construct and, as Ferrall (2011) reflects, requires a ‘paradigm shift’. It requires quite fundamental changes in the affective and cultural systems that perpetuate inequality (Baker et al., 2004) as I allude to in my discussion of intimate citizenship. This research cannot exhaustively capture all of the factors that contribute towards the end goal of flourishing in intimate life. Within the boundaries of this research I have however, contributed to developing an understanding of flourishing as a political concept that can be used as part of the process of achieving a flourishing intimate life. I have also highlighted that flourishing is an inter-relational experience and that there is a collective and solidaristic aspect to flourishing. We see this in the ways that UCC and embodied social capital are drawn upon and used by deaf women to advance in their intimate lives and to resist processes of exclusion.

Operationalising the intimate citizenship framework contributed to developing an understanding of possibilities for advancing and normalising the belonging and recognition of deaf women across a number of facets of intimate life. It provides what Weeks refers to as a “discursive form” (2007: 162) for identifying what is possible and what is desirable and thereby how we can move towards inclusion to achieve full intimate citizenship rights for deaf women (Weeks, 2007: 12). Facilitating conditions for flourishing in intimate lives for deaf women is thus a prerequisite to parity of opportunity for real intimate citizenship.

I now draw together the main findings and locate them within the existing theoretical and empirical research in order to outline what the research findings mean. This also identifies, ‘where to from here’ - how injustice can be rectified and, as Fraser (2007) writes, how parity of participation for deaf women can be improved. At this point in the writing, the question arises as to ‘what does all this mean’ overall and ‘what now?’. In other words, I consider the conditions necessary for flourishing in relation to intimate citizenship and the ways we could seek to further bring this about. This moves to the third objective of my research; how can we foster and normalise conditions for deaf women’s flourishing in intimate life. I draw this out over the following sections.

9.4 An agenda for flourishing: implications of this research for policy and practice

What are the implications of this research going forward? The aim of this research has been not just to make a new intellectual contribution but also to reflect on tangible future directions for policy and practice at micro, meso and macro level (Bronfenbrenner, 1977, 1979). Such suggestions have been set out earlier in this chapter and in more detail in the recommendations in the final chapter. They are also detailed further here as a way to outline how we can create the conditions for flourishing and parity of participation in intimate life for deaf women.

9.4.1 UCC, embodied deaf social capital and DEAF-GAIN

I have referred to how participants spoke about how resistance was facilitated in differing ways, but primarily through drawing upon UCC (Ming-Cheng, 2015) and embodied social capital across all the analysis chapters. UCC is discussed as resources and support shared through inter-relational encounters in deaf spaces to resist processes of exclusion. It emerged as a critical tool for flourishing. This draws out the BENEFIT dimension of DEAF-GAIN. Deaf women broadly BENEFIT through drawing on UCC. Deaf women harnessed a positive sense of their deaf identity and relational autonomy in the form of embodied social capital to resist and navigate contours of inequality and to generate meaningful access to intimate citizenship.

I argue that flourishing in intimate life is an additional form of DEAF-GAIN, a form that I have yet to come across in wider literature. This BENEFIT can be seen most strongly in the contrast between the narratives of participants who described experiencing a struggle in terms of their sexual subjectivities and deaf embodiment and those who did not. Those who experienced more of a struggle had fewer connections to other deaf people and deaf resources and considered themselves to be more part of the 'hearing world'. bell hooks describes the space at the margin as "a site one stays in, clings to even, because it nourishes one's capacity to resist" (1989: 20). Some participants described why they nurture their links to other deaf people - I contend that it is a strategy that nourishes capacity to resist and to flourish within this larger context of audism/ableism that many narratives elucidated. These spaces can take different forms for deaf people (deaf ladies' club, IDYA, Greenbow, boarding residence) but offer a similar nourishment. However, I must be mindful of promoting an essentialist view of these spaces. They are not always happy, protective spaces. Some participants spoke of the other side of the coin, the 'dark side' (Bourdieu, 1998; Halpern 2005) that can be an element of small, insular communities and bonding ties (Putnam, 1993) – experiencing gossip, bullying and exclusionary behaviour for example, as discussed in chapter eight.

This research has not found individualized notions of access (Mingus, 2011a) but on the contrary deconstructs the modernist myth of independence. In other words, it has found that resistance is facilitated through inter-relational encounters. I have repeatedly used the phrase ‘contours of inequality’ in this research. In doing so I am moving away from a discourse of ‘barriers’ as to use the language of barriers, I think, indicates a sense of no access whatsoever. However, as I have described, through agentic, creative strategies, deaf women navigated contours of inequality to access their intimate citizenship. Narratives of flourishing are deeply intertwined with the relational. To flourish is a collective, interdependent effort. However, how we want to flourish as a deaf woman is self-determined. I suggest that UCC can be considered as a critical tool and a form of Deaf Gain (Bauman and Murray, 2014). This is important as it highlights the need to move away from ‘targeted interventions’ that are imposed in a top-down manner upon groups, but rather outlines that, more broadly speaking, we must recognise the capacities within groups and look at this to promote and create the conditions for transformative change. This is connected to the notion of the politics of flourishing drawn out in the following section.

While continuing inequities must be recognised and challenged it is important to “also recognise the importance of growing individual autonomy and democratization…far from declining, new forms of social capital – associations, networks, emotional and cultural resources – are surely emerging” (Weeks, 2007: 172). As evidenced by participants, throughout all analysis chapters, emphasis on support through UCC and deaf networks in turn generates embodied deaf social capital, which is balanced with individual autonomy. UCC, deaf ties and an intercorporeal, relational way of living were consistently perceived by participants as providing an invaluable source of support and solidarity in both a practical and emotional sense. This speaks to Young’s conceptualisation of how we can move forward, which as Allen (cited in Young, 2011: ix) states is, “where individuals have not only the equal political rights of liberalism but also an equal right to flourish as social – and, as Hannah Arendt would say, therefore discriminating – beings”.

9.4.2 Resisting and displacing vulnerability discourses with flourishing

Participants' narratives drew out strong themes of resistance and flourishing sexual subjectivities constructed amongst competing discourses. These narratives were crucial in bringing together the complex story of claiming of intimate agency and positive sexual subjectivities in the face of audist/ableist contours of desexualisation, sexual normativity, discrimination and inequality. The narratives resist the vulnerability discourse, regarding deafness and sexuality, that has been revealed through the policy analysis and literature review. They also offer a powerful challenge to the ingrained knowledge/power nexus that has normalised and shaped policies and practices that contour deaf women's intimate lives. The danger of embedding the reductive vulnerability concept, as I have noted, is that it reproduces a false victimising, passive discourse, positions deaf women and their bodies as subject to 'intervention' and reproduces oppressive cultural assumptions. It also excludes an intersectional understanding of the dimensions of deaf women's lives in relation to sexuality; gender, age, class and so on. Moreover, and I think most importantly, participants find fault with the application of this concept to their embodiment. The perceived negative connotations it carries does not reflect their lived experiences. A view is being imposed upon members of a social group who reject this view. These stories speak truth to power to disrupt this knowledge/power dynamic, a dynamic that has developed problematisations from a starting point of audism/ableism. Deaf women are often conflated with disabled women and thus many policies contain silences in relation to deaf women, consequently rendering deaf women invisible within policies.

There is a clear need to shift from oppressive, uncritical ways of problematising issues in policy making. As Bacchi (2009: xi) states "the characterisation of the 'problem' is the place to start in order to understand how an issue is being understood". I suggest that the problem representation is that sexual health inequalities are tied to the differential embodiment of deaf women, as opposed to embedded structural inequalities. It emerges as strikingly clear that the intimate stories of deaf women belie the vulnerability problematisation etched across government policies. In shifting we can create better recognition and responses in policy making. I argue that this will contribute towards addressing the material effects of discursive structures outlined and support the achievement of flourishing for all – not just deaf women. I do not suggest that dismantling this problem representation within policy making is a panacea for all intimate inequalities deaf women encounter, as this representation is situated within larger social and power relationships and processes. However, policy is an important reproducer of cultural assumptions and it is an essential starting point to begin from and this will have broader implications for other groups also. We need to challenge taken-for-granted notions of assumed vulnerability and interrogate silences. This research has gone some way towards addressing the silencing of deaf women and the silencing of stories that do not align with dominant narratives on deaf women's intimate lives.

As such, this research has ascertained that the assumption of vulnerability embedded in policy is something to be *rethought* and displaced (Bacchi, 2009). I have outlined why this assumption needs to be rethought, as well as what the concept of vulnerability can be replaced with, that is the framework of flourishing. To advance flourishing is to advance a new political language, new meanings and new ways of knowing and inquiring into intimate lives with discursive and subjective effects. This moves away from the reductive nature of using the language of 'vulnerability', even if it is used to challenge the notion of vulnerability. This perpetuates limited ways of knowing and knowledge production.

Furthermore, this pathological, hegemonic representation at policy and discursive level has materiality. "It translates into real, lived experience" (Bacchi, 2009: xviii) and contours these lived experiences as evidenced in participants' narratives of encountering poor treatment and attitudes across a range of spheres related to intimate life. It is crucial to displace the concept of vulnerability and take a pluralist approach to developing sexuality-related policy that does not just recognise diversity but "values diversity as a good in itself" (Weeks, 2007: 123). As Weeks (2007) concludes – difference should be the starting point for thinking about constructing solidarity. Ideologies of normalisation should be challenged in this way (Baker et al., 2004; McDonnell, 2007) in order to effect change in structural inequalities. I contend that this will challenge a 'tacked on approach' in policy that addresses SHR access of disabled and deaf women.

Additionally, there is potential for a number of pragmatic steps to be taken and collaborations to be fostered by which the conditions for flourishing can be operationalised, as I have set out in recommendations in chapter nine. For instance, at a micro level, based on a three-week SHR workshop for young deaf women that I supported under the umbrella of IDYA and the feedback of participants in this research, – a strong need to create a deaf friendly sexual health toolkit has been highlighted. The IFPA, HSE, IDYA and NDWI present ideal organisations to partner with in this respect. Such an approach will also begin to dismantle and displace the dominant knowledge/power nexus evident at policy level in this research. One participant referred to the excellent example of good practice by Women's Aid who have created an accessible website and text service as well as committed to providing an ISL interpreter. This approach needs to be developed across other SHR spaces. These are small but important pragmatic actions in relation to quality of service and information delivery that are meaningful in their impact and demonstrate a commitment by service providers to be attuned to diversity, rather than expecting deaf women to fit into one model of service and information delivery.

In all this, my research CONTRIBUTES deaf women's ways of knowing and being in relation to intersectional intimate lives. These ways of knowing and being bring current ways of knowing AHEAD of ingrained 'deficit' and 'vulnerability' frameworks. I also use CONTRIBUTE and AHEAD to express that deaf people contribute an additional form of understanding intimacy and sexuality to the world and human diversity. There is wider application and CONTRIBUTION from this knowledge at a macro level. It advances knowledge and thinking, (brings thinking AHEAD), not just on deaf women in Ireland and the intersection between deafness and sexuality, but also on women occupying marginal spaces in Ireland. It illuminates ways by which resistance is facilitated to navigate exclusionary processes. In this way it highlights why the vulnerability label, more widely speaking, is not a useful discourse. It distracts attention from wider structural inequalities and frames groups in pathologizing ways that serve to constrain our thinking and our possibilities. Furthermore, this research contributes to wider discourses of resistance. Through the flourishing narrative and recognising patterns of resistance this research sets out a challenge to traditional problematisations which have stigmatised and marginalised women and restricted their access to intimate citizenship for so long. An additional key theme that arose here was lack of recognition and misrepresentation through the vulnerability narrative. I argue that this begins from problematising (Bacchi, 2009) through a normative lens which crucially must be challenged.

9.4.3 Uncovering the politics of recognition

This research showed how the public shapes and impacts upon the private and how deaf women in this research experienced their intimate citizenship on this basis. It demonstrates not a 'new kind of citizen', as Plummer (2003) originally refers to in his conceptualisation of intimate citizenship, but a citizen who was already there but without their choices, rights and needs being explicitly recognised. At present, deaf women are overall invisible within the policies I have explored and there are strong indicators that this non-recognition (Fraser, 2009) has materiality as evidenced through the findings. These processes of silencing and lack of recognition (Shildrick, 2009) contribute to a lack of parity of participation (Fraser, 2009) for deaf women which continues to reproduce and reinforce inequalities deaf women face in the arena of intimate citizenship. It is apparent that there is a connection between participants' deaf embodiment and their experiences of the public in the private.

This identifies the need for status recognition (Fraser, 2007) by first naming deaf women as a group and secondly, as a diverse group. This research has also evidenced the diversity of backgrounds that deaf women have and there is no one way to approach requirements on this basis. As Weeks (2007: 109) writes; "today we live in a plural world, a world of irreducible diversity and multiple sources of authority…yet it is also a world that is productive of creative efforts at coexistence". This hopeful note explicates that this plural world offers many possibilities, opportunities and acceptance of diverse forms of intimacy (Weeks, 2007). We must foster and normalise this – as explicated through the narratives, there are possibilities for further acceptance and celebration of diverse intimacies. A persisting need for a deep appreciation of diversity and more creative efforts at 'co-existence' to be fully reflected in our sexual/cultural imaginary and our policies and legislation still exists, as evidenced through the intimate stories shared in this research, such as Irene's and June's stories of encounters with their doctors. This research argues that, while forms of diverse intimate practices have become more accepted, this has yet to extend outwards to the perceived non-normative body and become normalised. This is especially illuminated in the narratives of mainstreamed deaf women.

Contemporary lives and intimate citizenship are contextualised (Lister, 2003) and lived in a multiplicity of ways. This must be reflected in our approach to policy making and conceptualising of the sexual being in order for the material specificity of diverse bodies to be addressed. Young (2011) refers to this as the ‘politics of difference’ – the need for explicit representation and rights via advancing groups’ rights through particular mechanisms in order to support participation and rectify the harm caused by exclusionary or oppressive social practices. However, this stance has been identified as problematic, raising critiques in terms of an essentialist stance on collective identities. Yuval-Davis (1997: 86) for instance notes that this approach reifies oppressive traps associated with identity politics whereby groups are perceived as homogenous and “with fixed boundaries”. This is an important point for this research. I am not advocating a move towards an essentialist, communitarian perspective that denies difference within and encourages a homogenous view of fixed positions of deaf people. Indeed, my findings would dispute that suggestion. Participants have discussed the complex, fluid and contextual relationships they have with their deaf embodiment. We see this across chapters five and six in particular. Thus, the difficulty associated with Young’s (1990) approach is that it moves away from an intersectional approach to social divisions (gender, age, class etc) that recognises citizens as multi-layered (Yuval-Davis, 2007). It does so by constructing particular interests, by subjects holding particular locations in a social group, as a given (Fraser, 2004) and representing the social group in its entirety (Yuval-Davis, 2007).

This is a pertinent concern in relation to participants who engage with culture, education and community in different ways – particularly for some who would not choose to be recognised on the basis of having a deaf identity (Beckett, 2005). Beckett comments that the further risk with this approach is in relation to those who do not seek to be recognised in relation to an identity category but are linked with those who do.

“For any groups, such as disabled people, where identities are often *embodied,* giving such a group representational rights on the basis of a purportedly shared identity/culture runs the risk of locking all members into an alleged shared identity which bears no relation to their own true sense of identity" (2005: 417).

Thus, some deaf people who would not choose to engage with their deaf identity are at risk of being subsumed within an overall narrative, which was an additional point made by some participants in chapters five and six.

In addition, it is queried whether Young's approach stretches far enough in tackling perpetuated injustices (Fraser, 1997). Thus, at this juncture, Fraser's work on the 'politics of recognition' emerges as most helpful (2004: 377);

> "what is really important is not the demand for recognition of a group's specific identity, but the demand for recognition of people's standing as full partners in social interaction, able to participate as peers with others in social life".

It is important to respond not solely to difference but to develop meaningful and appropriate mechanisms or ways of responding to difference and hold diversity as the standard so that all are recognised as "full partners".

9.4.4 The politics of flourishing

Linton (1998: 529) has summarised the basic position of the disability rights movement with regard to access; "society creates many of the problems disabled people experience and society has a responsibility to address them". Shildrick (2007: 54) has expressed concerns about this general position – she is not convinced that social constructionism and "the extension of socio-political recognition and regulation" is the answer. Informed by the findings of this research I agree with Shildrick that we must go further than such measures. As she contends, to follow Linton's suggestion is to expect more of the power behind legal and social systems than is actually possible in effect and to underestimate the power of the cultural imaginary in relation to disability. This is evident in this research through exploring the psycho-emotional impacts of normalisation on some deaf women. Tilley (1996) argues that many of the issues that disabled women encounter in healthcare access are rooted in prejudicial social attitudes, as well as discriminatory and exclusionary practices. Certainly, this point has been evidenced in multiple ways in chapter seven in the exploration of deaf women's experiences of sexuality related services and information.

Concluding her point Shildrick (2007: 64) reiterates a vital question by Shakespeare, "are we trying to win access for disabled people to the mainstream of sexuality, or are we trying to challenge the way in which sex and sexuality are conceived and expressed and limited in modern societies?". In my view, both. Legal recognition is not enough to dismantle social processes that produce inequality, result in lack of parity of participation and constrain the right of people to choose how they organise their own personal lives. Normalisation functions as a form of ideological power to limit and shape practices of intimacy. Some participants in this research articulated poor treatment and experiences in healthcare settings, their desire for better access to sexual health services and information in mainstream settings and the need for attitudinal change in these spaces. Some expressed a lack of recognition of them as sexual beings and the material inequalities that have consequently resulted – particularly in relation to maternity care. There is strong evidence that the specificity of deaf women's requirements is being overlooked and must be recognised and met to realise inclusivity.

Going forward, I suggest that adopting a more nuanced and reflective approach to problematising will be more meaningful and responsive to deaf women and create better opportunities for flourishing. As I have noted, this is a more useful approach than 'targeted interventions' – which, in my view, has weaknesses. It reinforces a pathological, vulnerability narrative and acts as a form of distributive justice that is inadequate for achieving equality (Young, 2011). Participant narratives suggest that the targeted and mainstream intervention approach promoted within many policies is inadequate for addressing structural inequalities deaf women encounter. Firstly, deaf women are still some way from experiencing conditions for flourishing in intimate lives, indicating this approach is not effective. Secondly, this approach promotes a notion of deviating from the norm that requires targeted intervention, rather than recognising structural inequalities that contour deaf women's experiences. Finally, it also fails to recognise capacities already present within groups, as drawn out through considering UCC and embodied social capital.

Participants' narratives speak to the need for developing both a structural system and cultural imaginary that recognises and embraces diverse sexualities and bodies. It also speaks to the specificity of the need for recognising deaf women and the plurality of deaf women and our diverse ways of being in the world, accessing information and using services. This has wider implications and applications also – it holds intersectional meaning. Beginning from diverse understandings of sexuality and bodies deconstructs the normative system that is exclusionary for many, not just deaf and disabled women. It considers how all women can flourish and how this can be supported through a more nuanced cultural imaginary and structural system.

There is also a question here of a 'politics of doing' (Bacchi, 2010) (which I am referring to as a 'politics of flourishing' in the context of this research) and in what ways policy responses should be engendered to ensure real transformational change. As I have noted, the purpose of this research, is not just to explore what 'flourishing in relation to intimate well-being' for deaf women looks like, but also *how* it can happen – to illuminate and suggest ways in which to move forwards. As Baker et al., (2004: 69/71) state, "if we believe that existing systems and institutions operate systematically to reproduce gross injustice, we have a duty to imagine structures that would work in a very different way: to imagine another world". I argue there is a need to simultaneously displace and reimagine the normative, ableist cultural imaginary. Along with this, pragmatic, material actions, such as greater and easily accessible funding for interpreters and policy recommendations that address access issues at primary healthcare level and beyond must be addressed. These recommendations are discussed in chapter nine.

Generating key conclusions led me towards the need to begin problematising, policy making and service delivery from a position of recognising and appreciating diverse bodies and diverse ways of being in the world. Systems have been constructed that maintain a lack of access and poor treatment of deaf embodiment. Such structural inequalities are gradually being dismantled by steps such as the passing of the ISL Act 2017. However, there are still further steps to be taken. At present I contend, there are problem representations embedded within policy and discourse that are rooted in the mythical norm (Mingus, 2011b) with added-in, special mention of those who divert from this normative ideal and a normative way of being in the world. As Davis (1995:

71/72) writes - “[a]n able body is the body of a citizen; deformed deafened, amputated, obese, female, perverse, crippled, maimed and blinded bodies do not make up the body politic”. We are not working from an accurate reflection of our, ‘body politic’ or service users. Shifting ableist perceptions and attitudes of the ‘body politic’ and deafness will lead to better approaches to policy making and towards better attention towards structural inequalities which is the ‘real injustice’ deaf women encounter (Fraser, 2007). This is important in order for transformative justice to be achieved for deaf and disabled women and for diverse bodies to be treated with value. As Mingus states;

> “We must…move beyond access by itself. We cannot allow the liberation of disabled people to be boiled down to logistics. We must understand and practice an accessibility that moves us closer to justice, not just inclusion or diversity”. Achieving justice is not simply about becoming part of the mainstream but dismantling systems of oppression and privilege and embracing difference”.
>
> (Mingus, 2011a: para 3)

Including processes of recognition by naming (giving representation to) deaf women and considering the specific lived experience of deaf women in relation to language, communication and culture for example, will assist with more effectively addressing structural inequalities that deaf women in this research have encountered, as opposed to focusing upon the need to develop mainstream and targeted interventions. We must move towards a starting point that recognises and embraces difference in a holistic way, not as deviation from the norm, but as the cultural imaginary. Embedding recognition of diversity and diverse representation within the policy making process will contribute towards increasing parity of service and information use. This will set us more firmly on a path toward achieving real social change. From this starting point there is the potential for transformation of patterns that have traditionally led to exclusion and marginalisation, towards the achievement of positive social change and developing a more diverse sexual and cultural imaginary.

9.5 Moving the story of flourishing forward

There are limitations to my research, as noted in chapter four, and my research has implications from this perspective. It offers some useful points of departure for future research. A potential avenue is connected with the experiences of mainstreamed deaf women and men. Participants in this research that had links with mainstream also had some links with the deaf community. As such they could be characterised as holding a liminal position – between deaf world and hearing world. It would be interesting to explore the experiences of mainstreamed deaf people who use English as their first language and who have few to no links with the Deaf Community. Approximately 78% of deaf children in Ireland (Mathews, 2017) are mainstreamed and thus this setting will continue to shape the experience of deaf people. Additionally, the sample presents limitations – four women identified as other than heterosexual. Therefore, the diversity of the sample in this regard was limited. Going forwards it would be fruitful to consider the intimate lives of deaf bi-sexual, lesbian and trans women in more depth.

Key issues were raised by participants around parenting which are important to further explore – such as fostering and adoption. Participants raised concerns about fertility treatments for deaf couples and making information and services accessible for both same-sex and heterosexual deaf couples. Lastly, in taking a gendered approach to exploring the intersection between deafness and sexuality, I have identified the ways in which deaf women experience their intimate lives. Participants identified that they felt research exploring deaf men and deafblind people's experience of intimate life is important. I did not include either group and this presents itself as an important avenue for future research, particularly in terms of exploring how gender has meaning and is experienced at the intersection of sexuality and disability for deaf men.

9.6 Flourishing as a researcher

My PhD journey has been disconcerting and nourishing (hooks, 1989), encompassing self-discovery and intellectual growth, from becoming immersed in feminist disability literature to the research interviews. It has demanded a critical and self-reflexive examination of my own responses to other research and to the research interviews. The first moment of this was when I read Pride against Prejudice by Morris (1991: 1), one of the first books I read starting into this research. My emotional reaction to Morris' writing was an insight into how the rest of the PhD journey might be and what I hoped it would be. As Morris says her identity "has been an increasing source of strength and liberation", a stance I also relate to.

My lens as a mainstreamed deaf woman with particular experiences of intimate life has shaped this research from start to finish - from the research aims, to the research questions to my engagement with research participants and my interpretation of and response to the data from research participants' narratives. Earlier in my research writing I discussed how I related to the writing of Bruggeman (1997: 647) on her reflection on "coming out" as a deaf person and how she used her doctoral research as a professional 'foil' to "make a personal journey to the centre of Deaf culture". I was interested in finding out what experiences and feelings were shared by other deaf women - what experiences were not isolated and individualised. In this way I had an impact on the research process and my subjectivity is interwoven with each chapter.

This research has been guided by feminist notions of researcher reflexivity - by my acknowledgement that the knower and known cannot be separated. While I have acknowledged this since my MA studies, it has taken me some time to become comfortable with writing myself into this research. I have always recognised it is unethical not to, particularly given the approach taken in this research, but taking the step to committing words to paper that others will read and getting past concerns of being viewed as simply navel-gazing has been a challenge.

Other deaf women sharing their stories with me, as well as my engagement with feminist, disability and deaf literature had profound impacts. One important aspect has been an exploration of my own deaf embodiment. I connected with experiences that other deaf women had – not just as a deaf person but as a woman and what it meant to strive to be as 'feminine' as I could to make up for my deafness. This research has also had an impact on me and a BENEFIT in that I feel closer to my deaf way of being and this has come about through the relationships I have been lucky enough to build in this research journey – my UCC and my embodied deaf social capital and DEAF-GAIN. This is also part and parcel of narrative inquiry (Clandinin and Huber, 2010). As I come towards the end of this stage of the research, I feel I have had the opportunity to flourish as a researcher, community worker and deaf woman in more ways than one.

I began this thesis with a powerful insight by hooks and I reiterate it as I come to the end of writing as hooks' message is integral to the core of my research and, to my sense, to my own research journey;

> "…The margin is more than a site of deprivation, it is also the site of radical possibility, a space of resistance…a site one stays in, clings to even, because it nourishes one's capacity to resist. It offers to one the possibility of radical perspective from which to see and create, to imagine alternatives, new worlds"
>
> hooks (1989: 20).

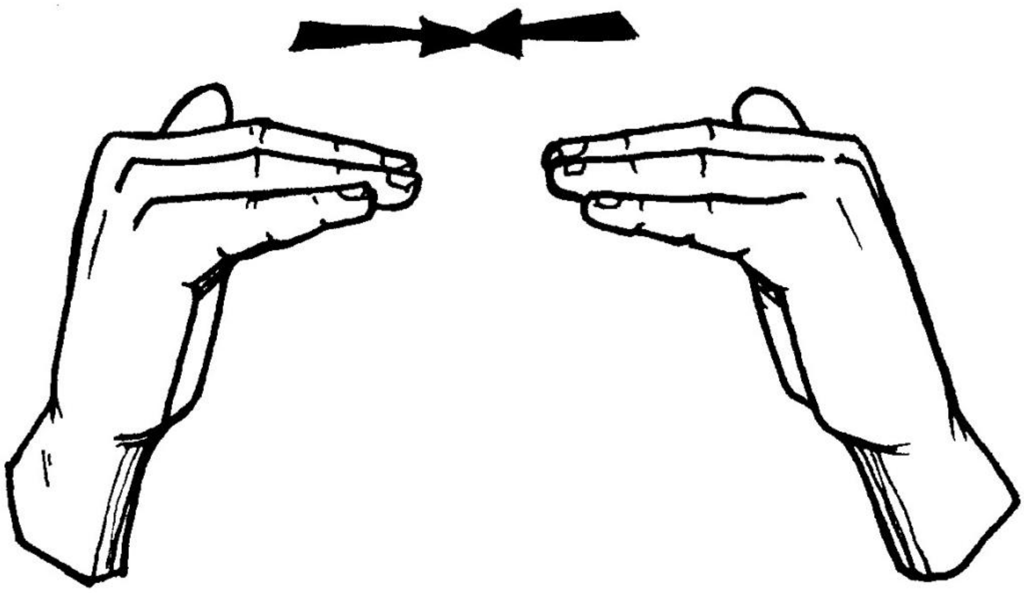

Figure 8: ISL sign for 'equality'

9.7 Recommendations

9.7.1 Recommendations for promoting flourishing across dimensions of intimate life

This research has centred the three dimensions of DEAF-GAIN. It contributes critical empirical evidence regarding deaf women's intimate lives in Ireland. It also troubles discursive and policy approaches that position deaf women as 'vulnerable' and contributes thinking that reimagines flourishing in intimate lives for deaf women and thus is AHEAD of common discursive and policy approaches. On this basis a number of recommendations and possibilities for going forward have been generated. These possibilities are drawn from the 'radical perspectives' of research participants, as well as context setting interviews and the critical policy analysis. Within this section I lay the possibilities out across key dimensions and contexts of intimate well-being.

Bronfenbrenner's (1977, 1979) social ecological conceptual framework is helpful here as it gives us gives us the opportunity to set out about how we can create the conditions for flourishing and where this can happen through the different contextual levels. Working from this framework I explicate where recommendations are set out at micro, meso or macro level within these recommendations. I have broadly set out what changes are necessary at macro level within chapter nine and concentration is given to the micro and meso level in this section.

9.7.2 Supporting sexual knowledge building

This section sets out recommendations regarding formal and informal ways of supporting sexual knowledge building. My research highlights that young and older deaf people turn to informal sources of knowledge that can be unreliable and can result in risky behaviours and negative outcomes. Thus, the need for improving formal pathways of sexual knowledge building across different dimensions of learning from menarche to contraception was identified. I outline how this can happen in the recommendations set out below.

9.7.3 Formal sexual knowledge building

As uncovered in the analysis chapters, at the meso level participants placed greater emphasis on informal ways of building knowledge, highlighted as a response to gaps at the formal level. Participants expressed the view that there were gaps in their knowledge that should have been addressed through RSE. This research corroborates findings that there is variability in the RSE module delivery. This parallels other discussions (Keating et al., 2018; Nolan, 2018) that note the implementation of the RSE and its content requires improvement.

The 2019 Joint Committee on Education and Skills Report on Relationships and Sexuality Education concurs with this. 54 stakeholders contributed submissions to the 2018 Committee review. The report of this was published at the end of January 2019. There was no deaf representation in this review. Some points correlate with recommendations from this research and are noted. The report is timely, and some of its recommendations can be extended to incorporate recommendations from my research.

- Firstly, the report notes that consideration should be given "to the methodologies chosen that will be most supportive and inclusive for students" (2019: 14). My research supports this and contends that specific consideration should be included for deaf people. It is important resources are deaf-friendly and use Clear English and ISL where appropriate.

- Secondly, Inclusion Ireland discussed taboos surrounding sexuality and intellectual disability which can impact on sexual education quality. Recommendation 11 in the report notes the need for "a specific curriculum for people with an intellectual disability that is accessible and appropriate" (2019: 27). This recommendation provides insight into the need to be inclusive of disability and sexuality. However, it is important not to overlook the needs of other disabled people. The specific sexuality education needs of deaf people should also be considered. On this basis recommendations from my research are; that RSE updates should be reviewed to include positive perceptions of disability and sexuality broadly – it should not just 'target' specific groups. Any further strategies and work emerging from Committee recommendations should include consideration of deaf people.

9.7.4 Menarche and Menstruation

- At micro level young deaf women should be supported in schools to understand menarche - their cycle, what is a regular cycle, using sanitary products, managing period pain, to seek medical support if necessary, to be aware treatment is available.

- At meso level deaf friendly, visual, age-appropriate resources with Clear English (books, pamphlets, online videos) should be available to parents and a range of professionals such as social care leaders, community resource workers and SPHE teachers to support information sharing.

9.7.5 Sexual health programme development - meso level

- Deaf friendly sexual health tool kit with visual resources and ISL videos urgently needs to be developed alongside RSE curriculum updates. Different types of contraception and associated side effects should be clearly detailed. This information should also promote a ‘sexual wellbeing approach’ with topics such as confidence, pleasure, agency and consent that dismantle gendered ideas of sexuality.

- There is no ‘one size fits all’ model regarding the intersectionality of deaf requirements and identity markers. General resources need to be available to be adapted for one-to-one and group work. Resources should include a range of different examples and experiences that can be adapted to meet the learning needs of different deaf young people.

9.7.6 Informal sexual knowledge building – micro and meso level

- At micro level a yearly workshop series should be provided for deaf people with clear discussion about a range of sexuality-related topics. This should be available to deaf parents as well as older and younger deaf people. For example, deaf parents expressed interest in accessing HPV vaccine information. The IDYA or Irish Deaf Society (IDS) and IFPA are ideally positioned to partner and support this. Funding needs to be secured for interpreters, workshop facilitator and resources.

- At meso level information must be made available online as well as through physical spaces. Information should be designed to meet a range of knowledge and learning requirements.

- At meso level, UCC and embodied deaf social capital has been found to be a mitigating factor for knowledge access inequalities. It should not be relied upon as an accurate source of knowledge. Deaf organisations that create spaces for deaf people to foster embodied deaf social capital should be supported. This is particularly pertinent for mainstream deaf people who should be supported to engage with deaf spaces from a young age.

9.8 Sexual health and reproductive (SHR) services

This research demonstrates that deaf women experience gaps in the area of SHR services from which a number of recommendations arise at micro, meso and macro level;

9.8.1 Family planning; meso level

- The physical and interpersonal infrastructure of family planning centres should be deaf friendly. Clients should be supported to make an appointment and access test results by email or text. Buildings should be deaf friendly and use a bell or intercom system with clear signage and a visual system, such as a green light, to indicate entry.

- Family planning centres, crisis pregnancy counsellors and abortion services need to make explicit mention that their services are accessible to deaf people and ensure they are prepared to book an interpreter.

- Booking and communication for all services should be easily accessible with an online booking system and possibility to get responses through text or email.

- It is important that family planning centres should be designed with diverse bodies in mind and work from this starting point.

9.8.2 Antenatal classes, labour, pregnancy, breastfeeding and post-natal support: micro and meso level

- At micro level interpreted antenatal one-to-one or group classes should be provided for all deaf women. Deaf women should be explicitly informed about their options at hospital appointments. Visual, Clear English resources should be made available to all expectant deaf mothers. Useful material has already been developed by the IDS and this should be updated and made available online.

- At micro level all deaf women should be supported to design a birth plan that addresses their communication needs as well as birth requirements. An interpreter must be provided for the labour if requested.

- At micro level a deaf partner should have access to an interpreter for full information access throughout pregnancy and labour.

- At meso level a comprehensive overview of topics related to pregnancy, breastfeeding, raising a new born, raising a toddler, new mothers' health and body should be developed in ISL and subtitled videos. This could be hosted on 'whatsupmum.ie'.

- At meso level 'Breastfeeding.ie' has subtitled videos but these should be translated into ISL. It is critical that deaf mums get one-to-one support in the hospital as breastfeeding support groups may not be accessible to deaf mothers without an interpreter.

- At meso level ISL resources should be made available explaining post-natal depression (PND) and support options. PND support groups are not accessible to all deaf mothers because of interpreting requirements. Deaf mothers should be made aware of other suitable options.

- At meso level partnership should be built between NDWI and HSE in relation to supporting interpreting of videos and resources suggested.
- At meso level deaf mothers should be supported to meet through online and physical spaces.
- At meso level healthcare professionals should be trained to provide appropriate supports for new mothers in post-natal wards and afterwards.
- At macro level maternity policies should be designed working from a starting point of diverse bodies.

9.9 Ways of Knowing and Responding to Deaf Women: macro level

9.9.1 Policy making

A critical interrogation using the WPR framework (Bacchi, 2009) reveals how policy contributes to particular, misleading ways of thinking about sexuality and disability through its problematisations. This indicates inadequacies in the policy making process and the need for reconsidering the process around problem representations. Speaking widely, policies need to be better informed from the ground up in order to ensure that the traditional construction of deaf women as ‘vulnerable’ and the wider exclusion of deaf women in policies is not perpetuated. Deaf organisations and representatives need to better contribute to policy making to create better understandings of deafness and sexuality and ‘what the problem is’, along with more appropriate responses. Policy making processes must rethink how problems are constituted in wider policies to reveal the problematising of deafness and sexuality. They should be enabling and empowering and should not start with the idea that deaf women are vulnerable. This links with the following recommendations;

- Deaf women should be specifically recognised in strategies and policy developments going forward, rather than subsumed as an add on under "vulnerable groups".

- Updates to the National Sexual Health Strategy 2015-2020 should be carried out with respect to including the information and service delivery requirements of deaf women and men.

- The research summary and recommendations emerging from my research could be included on the 'sexualwellbeing.ie' website. This would be a useful, direct way in which to inform best practice.

9.9.2 Research: macro level

This research demonstrates the value of inclusive methodologies that work to centre and privilege deaf women's voices. In doing so through a co-production of knowledge it contributes to an in-depth understanding of the intimate lives of deaf women and challenges the dominant normative construction of deaf women as 'vulnerable'. This research particularly demonstrates the value of narrative inquiry for achieving this way of knowing deaf intimate lives. Key recommendations that emerge for research are that;

- Research designs going forward must place value on inclusive and emancipatory methodologies that - what others might say allow for the 'hearing' of deaf women - but I prefer to say, centre and privilege deaf women's insights and does not "speak about you and for you" (Lynch, 1999).

- Research agendas must challenge problem-centric research approaches for understanding deaf lives and recognise how knowledge building creates conditions for flourishing.

- Exploring deaf women's sexuality in the future must build upon ways of knowing deaf women as flourishing intimate citizens

9.9.3 Media: macro level

- Deaf women should be included in awareness raising campaigns for women's health in order to give recognition and visibility to deaf women. This should be an empowering approach that does not portray deaf women as victims or vulnerable but entitled to equal care.

- Social media resources and campaigns should be designed to include young deaf people. Deaf people indicated they have more awareness of health topics through exposure to information campaigns shared on social media. This should be taken advantage of.

- Technology needs to be updated. Many laptops do not have DVD players anymore and information delivery needs to update in recognition of this.

9.10 Interpreters: meso level

- Maintaining privacy with interpreters is an ongoing concern for deaf people. It is difficult for a deaf person to use the same interpreter for counselling alongside employment and education situations. There is a need for ISL fluent counsellors as well as to increase interpreter numbers to afford deaf people more choice.

- Interpreter availability outside of urban areas is also an issue and the pool available needs to be increased in rural areas in order to accommodate the needs of deaf women accessing health and sexual health services in these areas.

- Interpreter cost is often cited by service providers. This distracts from costs to deaf person's mental/sexual/emotional health. This cost is non-negotiable – services widely need to recognise their obligation to become accessible. The attitude of service providers is key and the ISL Bill 2017 is an important tool for this.

9.11 Service providers: meso level

- Resources are available through the HSE library. These can be adjusted for deaf requirements and should be available to deaf organisation practitioners involved in sexual health.

- Service providers that were key informants in this research identified the need to respond to diverse needs and scenarios related to sexuality in their work. Opportunities for informal, as well as formal, information sharing with clients arise frequently and should be taken advantage of. To do this, providers need to feel confident through being equipped with knowledge through training. A system should be in place so providers can put service users in touch with another appropriate service provider. The deaf community is small and often professionals within the community have pre-existing friendships or relationships. There is a tension between the need to support information delivery and maintaining professional/personal boundaries. At the same time stigma should not be fuelled and it should be standard practice that all workers can access sexuality-related training and provide support.

- Mainstream providers should disability-proof their services to ensure staff members are aware of the communication requirements of deaf women. They should develop an awareness that some deaf women have limited sexual health knowledge and a need to cover basic topics as well as more complex topics. In tandem with the policy recommendations, service providers must also be cognisant of their own problematisations and provide empowering services that do not reify ideas of vulnerability.

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Appendix I: WPR Framework

‘What’s the problem represented to be?’ – WPR framework (Bacchi, 2009).

The ‘WPR framework’ is used in this research to identify and disrupt dominant representations of deaf women as ‘vulnerable’ within relevant policies as outlined in chapter two.

Question one: What’s the problem represented to be in a specific policy?

Bacchi (2009) contends in asking question one in the WPR approach; ‘what is the problem represented to be’ in a specific policy, that looking at what the suggested intervention is will give insight into how the problem or issue is thought about. It is a clarification exercise. There are usually a number of different proposals within a policy and thus identifying how problems are represented can be challenging Bacchi states (2009: 4). Using the WPR approach in this research project was to undertake the task of seeing how deaf women, or disabled women, are represented within national policies and what this might potentially mean for their sexuality-related experiences. Through examining the policies named in the preceding section it became evident that deaf women or disabled women are frequently labelled as ‘vulnerable’.

Question two: What presuppositions or assumptions underlie this representation of the ‘problem’?

Bacchi notes for the second question in the WPR process, ‘what assumptions or presuppositions underlie this representation of the policy?’ must be considered. In other words what is said and not said – what can we understand as the stances of the policy representations – the worldview or epistemological and ontological assumptions? How are issues conceptualised within the problem representations? This line of inquiry is acutely important in this research. This is the first step in a journey toward clarifying and illuminating what the values and thinking are that underpins problem representations. It is a fundamental step in understanding how problems and interventions are subsequently constituted. This requires an analysis of assumptions underpinning key concepts in the representation of deaf women in policy.

Significant for this research is the motivation behind this line of inquiry, a task which sets out to uncover and provoke explicit recognition of assumptions that may be consciously or unconsciously embedded within policy. In relation to policy, Bletsas and Beasley (2012; 22) outline that, "in this account policy is not the government's best effort to *solve* 'problems'; rather policies *produce* 'problems' with particular meanings that affect what gets done or not done, and how people live their lives". I use this account to uncover how particular knowledges produce particular meanings in relation to sexuality and deafness in order to understand the factors shaping the contours of deaf women's intimate lives.

Bacchi contends that the solution proposed about something gives insight into what is considered problematic – what needs to change. This change and the ways in which change is necessary may not necessarily be the views, desires or values of groups referred to within policy making[83]. How problems are conceived within the governing process is central to the process. "In effect we are governed through problematisations rather than through policies" (2009: xi) and these have particular effects upon people. It is considerably all too easy for the 'problem' to become the concern as opposed to the "shape and character of problematisations" that is embedded at its very core (2009; xi).

3. How has this representation of the 'problem' come about?

In the third question of the WPR process Bacchi encourages us to reflect upon, interrogate and trace the non-discursive practices, "specific developments and decisions" (Bacchi, 2009: 10) that lead to or contribute to this 'problem representation'. In tracing how problem representations are constructed the taken for granted convention that policy has naturally evolved is disturbed. From this it is possible to recognise that power relations are at play in the process of constructing problem representations. Importantly, it allows us to recognise that things could be otherwise.

---

[83] Policies have repeatedly been constructed for and imposed upon groups (such as Travellers, migrants, women and disabled people) without consultation and putting forward both the perceived problem as well as internally devised solution. This is particularly relevant to deaf people in Ireland in relation to the ideology and values of normalisation and oralism and policy of mainstreaming which had particular, deleterious effects on deaf people

4. What is left unproblematic in this problem representation? Where are the silences? Can the 'problem' be thought about differently?

Question four directs us to consider the above questions and carry out a critical analysis of the policies under examination. Here we ask, where are the missing questions, the missing problematisations – what is overlooked and how can we think differently about this problematisation? Importantly, we discover how limited thinking or misrepresentation constrains policies by how problems are represented. We also discover what needs to be illuminated.

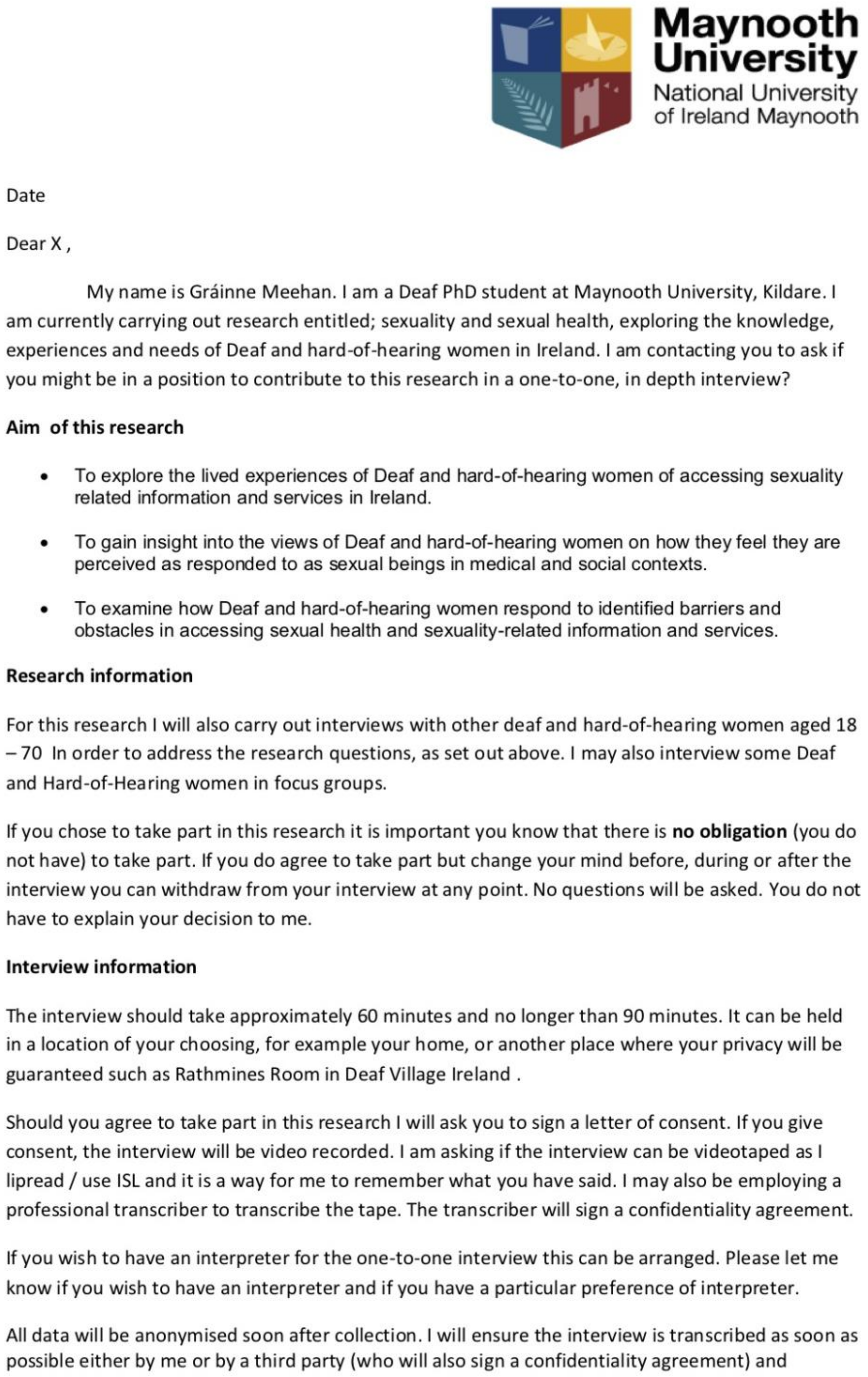
5. What effects (discursive, subjectification, lived) are produced by this representation of the "problem"?

Turning to question five probes the critical analysis further to examine the effects that incur from problem representations. As Bacchi (2009) notes this is not a typical evaluative or monitoring approach as is common in policy making. This requires probing for nuances to understand discursive, subjectification and lived effects and critically assessing these effects.

6. How/where is this representation of the 'problem' produced, disseminated and defended? How could it be questioned, disrupted and replaced?

In the final question in the WPR framework we consider what practices and processes ensure problem representations become and stay hegemonic and gather legitimacy. It also allows us to find spaces of resistance and ways of challenging these dominant representations.

Appendix II: Participant Information Sheet



Maynooth University
National University of Ireland Maynooth

Date

Dear X ,

My name is Gráinne Meehan. I am a Deaf PhD student at Maynooth University, Kildare. I am currently carrying out research entitled; sexuality and sexual health, exploring the knowledge, experiences and needs of Deaf and hard-of-hearing women in Ireland. I am contacting you to ask if you might be in a position to contribute to this research in a one-to-one, in depth interview?

Aim of this research

- To explore the lived experiences of Deaf and hard-of-hearing women of accessing sexuality related information and services in Ireland.
- To gain insight into the views of Deaf and hard-of-hearing women on how they feel they are perceived as responded to as sexual beings in medical and social contexts.
- To examine how Deaf and hard-of-hearing women respond to identified barriers and obstacles in accessing sexual health and sexuality-related information and services.

Research information

For this research I will also carry out interviews with other deaf and hard-of-hearing women aged 18 – 70 In order to address the research questions, as set out above. I may also interview some Deaf and Hard-of-Hearing women in focus groups.

If you chose to take part in this research it is important you know that there is **no obligation** (you do not have) to take part. If you do agree to take part but change your mind before, during or after the interview you can withdraw from your interview at any point. No questions will be asked. You do not have to explain your decision to me.

Interview information

The interview should take approximately 60 minutes and no longer than 90 minutes. It can be held in a location of your choosing, for example your home, or another place where your privacy will be guaranteed such as Rathmines Room in Deaf Village Ireland .

Should you agree to take part in this research I will ask you to sign a letter of consent. If you give consent, the interview will be video recorded. I am asking if the interview can be videotaped as I lipread / use ISL and it is a way for me to remember what you have said. I may also be employing a professional transcriber to transcribe the tape. The transcriber will sign a confidentiality agreement.

If you wish to have an interpreter for the one-to-one interview this can be arranged. Please let me know if you wish to have an interpreter and if you have a particular preference of interpreter.

All data will be anonymised soon after collection. I will ensure the interview is transcribed as soon as possible either by me or by a third party (who will also sign a confidentiality agreement) and returned to you. You may edit or change any part of the transcript as you wish. You also have the right to withdraw from this research at any point.

All data will be stored on a secure computer in my office in Maynooth University. It will be password protected and will only be accessed by me. Any information I have about you will only be kept while I am doing research. I will **delete all this information when I am finished** doing research. Any identifying information about you such as your name or your contact details is **not kept** with the interview transcript. It is kept separately so in the unlikely case the interview transcript is read by someone else they will not know who you are. It will be kept in a secure and safe locked cabinet in my office in Maynooth University. No one else can access this cabinet. Only I have a key for this cabinet.

I may also publish articles for other researchers to read. No information about you will be in these articles. It is Maynooth University policy that research (interview) data will be kept for 10 years and then deleted. The research data that will be kept is the information you share during the research process. I must keep this research data in case there are questions later about whether my research is accurate. I will delete information about the interviews in ten years' time. I will do this by deleting research and overwriting information saved on my hard disk drives using specialist software. Any hard copies I have will be shredded.

While every effort will be made to keep your research private, in very rare cases the courts can ask for this information. This is ***very unlikely*** but it is important I let you know it may happen. It must be recognized that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

After the interviews?

When I am finished the research I will make an ISL VLOG/give a presentation in Deaf Village Ireland and tell you about the findings. I will also make an information pack so other people in the Deaf Community can see what I found out. **No identifying information about you** will be in this research.

What would I like to know?

I am contacting you regarding your particular knowledge of being a deaf woman living in Ireland and I will be asking you questions in relation to the topic of access to information and services related to sexuality and relationships.

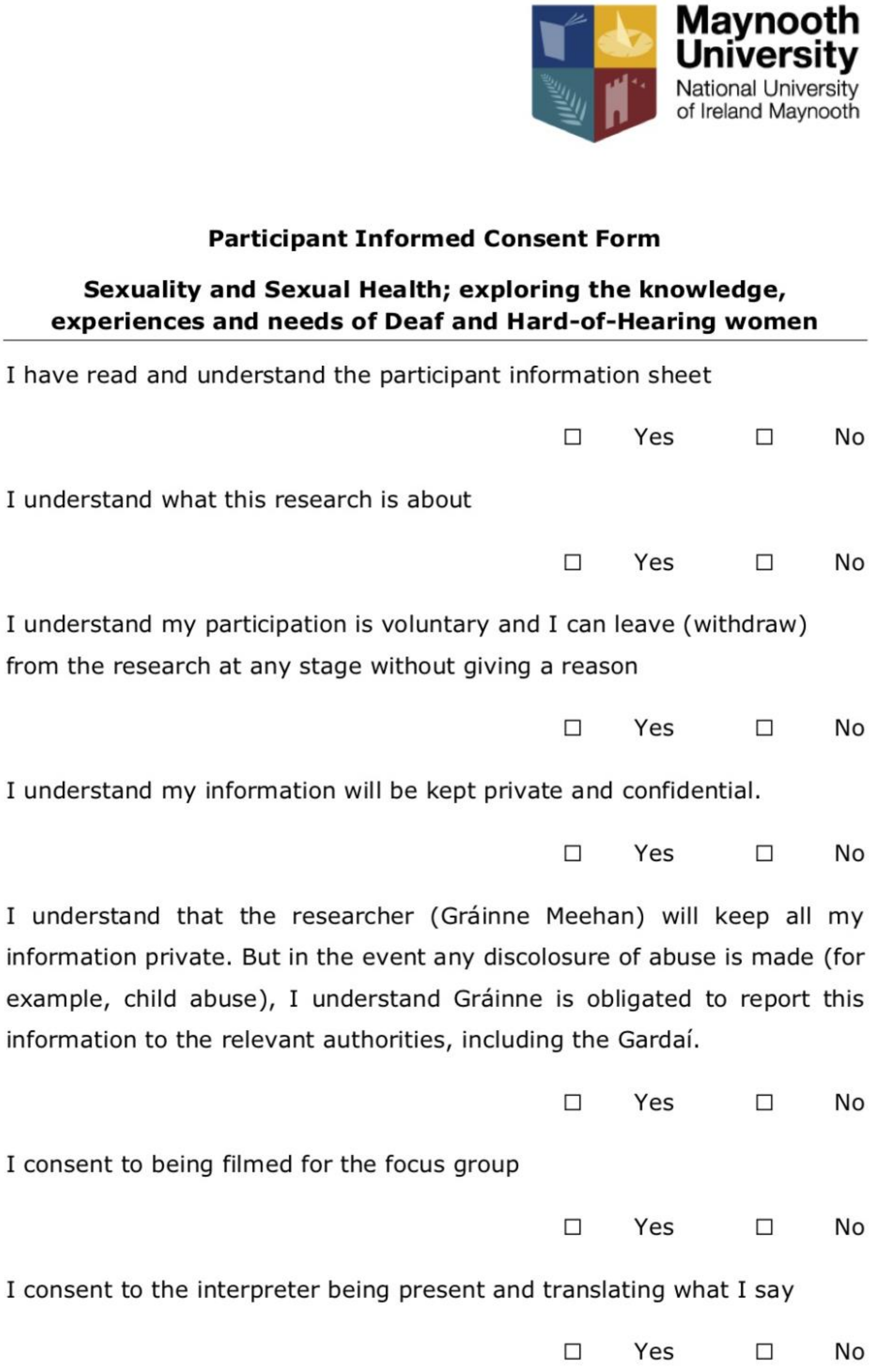
Your contribution to this research would be much appreciated. Please find attached a copy of a letter of ethical approval from Maynooth University. If you would like more information about my research I would be happy to meet with you for a discussion to help you decide if you would like to take part in this research or not. Please contact me by e-mail at your earliest convenience.

Maynooth
University
National University
of Ireland Maynooth

Yours sincerely, Grainne Meehan

Grainne.p.meehan@mumail.ie

Appendix III: Participant Consent Sheet



Maynooth University
National University of Ireland Maynooth

Participant Informed Consent Form

Sexuality and Sexual Health; exploring the knowledge, experiences and needs of Deaf and Hard-of-Hearing women

I have read and understand the participant information sheet

☐ Yes ☐ No

I understand what this research is about

☐ Yes ☐ No

I understand my participation is voluntary and I can leave (withdraw) from the research at any stage without giving a reason

☐ Yes ☐ No

I understand my information will be kept private and confidential.

☐ Yes ☐ No

I understand that the researcher (Gráinne Meehan) will keep all my information private. But in the event any discolosure of abuse is made (for example, child abuse), I understand Gráinne is obligated to report this information to the relevant authorities, including the Gardaí.

☐ Yes ☐ No

I consent to being filmed for the focus group

☐ Yes ☐ No

I consent to the interpreter being present and translating what I say

☐ Yes ☐ No

I consent to the interpreters voice and what I say being voice taped

☐ Yes ☐ No

I understand I will be able to access the transcript of the focus group when it is ready (when it has been typed up). I understand I will also be able to see the video of my focus group.

☐ Yes ☐ No

I understand I can make any changes I want to this transcript and any changes to what I said on the video will be recorded by Gráinne.

☐ Yes ☐ No

I agree to allow Gráinne Meehan to contact me with information for the workshop later this year. I agree that Gráinne Meehan can ask me to take part in this workshop.

☐ Yes ☐ No

I understand information from this research will be published as a PhD and may be published in academic papers.

☐ Yes ☐ No

I have read this form. I am over 18 and I am happy to take part in the study.

☐ Yes ☐ No

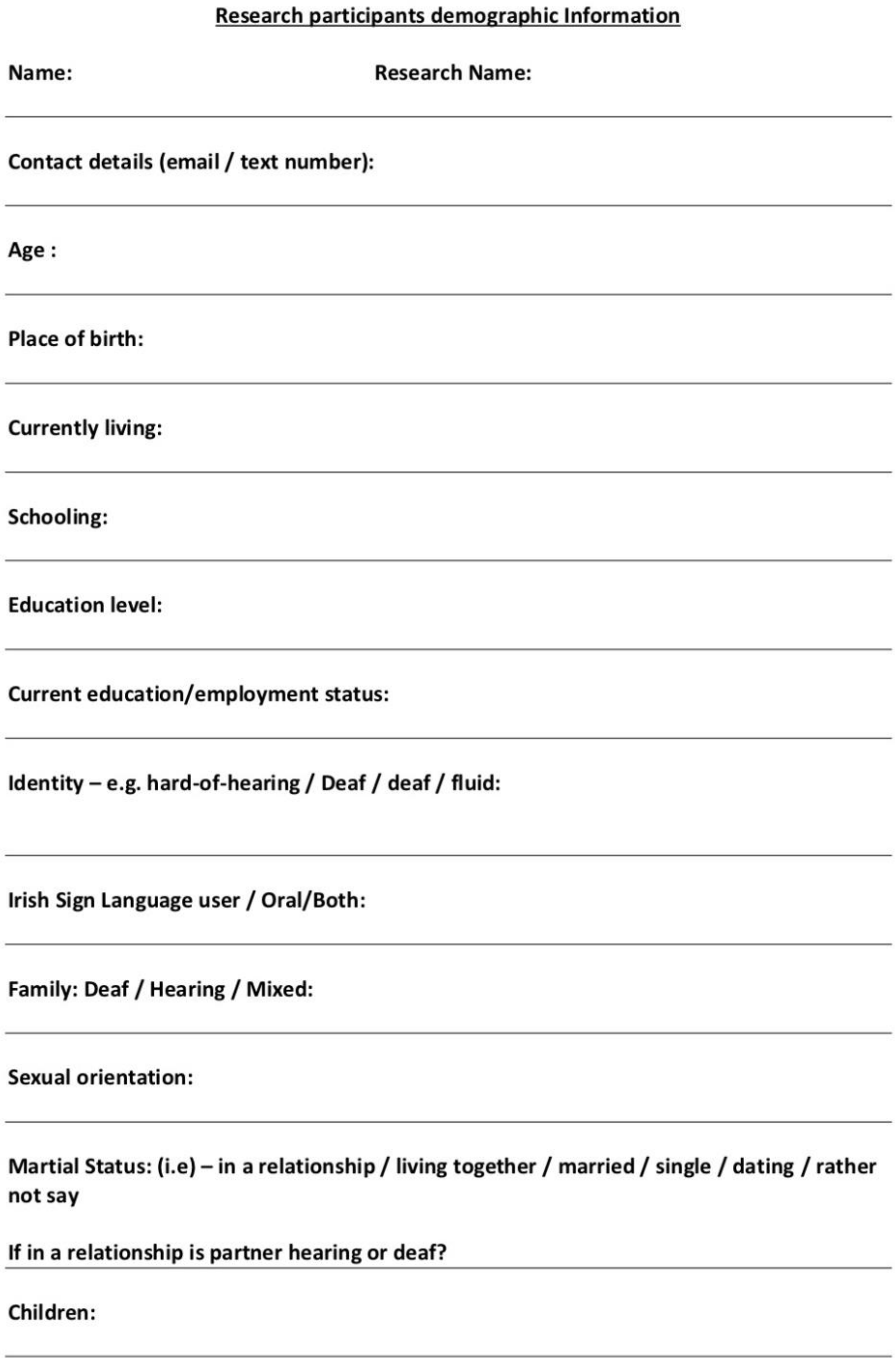
Maynooth University
National University of Ireland Maynooth

Signed: Date:

Thank you,
Grainne Meehan
Grainne.p.meehan@mumail.ie
Text number: 0863708141

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Appendix IV: Participant Demographic Information



Research participants demographic Information

Name: **Research Name:**

Contact details (email / text number):

Age :

Place of birth:

Currently living:

Schooling:

Education level:

Current education/employment status:

Identity – e.g. hard-of-hearing / Deaf / deaf / fluid:

Irish Sign Language user / Oral/Both:

Family: Deaf / Hearing / Mixed:

Sexual orientation:

Martial Status: (i.e) – in a relationship / living together / married / single / dating / rather not say

If in a relationship is partner hearing or deaf?

Children:

Appendix V: Participant Interview Guide

Introduction

Background as to who I am, what I am studying and why I am interested in this topic of understanding the meanings and experiences of deaf and hard-of-hearing women in relation to sexuality and sexual health.

Give reassurance that while this research does ask some sensitive and personal questions there is no onus on the person to answer anything they don't wish to and I will not probe any further if so.

Discuss the information and consent sheet and sign

Could you tell me a little bit about the:

- School you attended
- Where you are from
- Your family
- Work / education

Context setting: relationships and deaf identity

Could I ask what you think about this research topic? Is there a reason you decided to participate in this interview?

Could you tell me a bit about your identity as a deaf woman? How do you feel about it?

Could you tell me a little bit about some of your experiences of romantic relationships with a boyfriend / girlfriend?

(Probes: your first bf's or gf's/how did you meet / was it easy for you to meet/ what was it like dating as a boarder/ did you feel happy in those relationships?)

At that time how did you imagine your future in terms of a relationship?

(Probe: Did you hope or expect to have a long term partner / to marry / to have children? /
How did you develop these ideas – did you parents or house mothers influence these ideas?)

Could you describe your ideal relationship?

Probe: (how did you develop that view of relationships for example did you come up with that idea through your experiences – is your view now different to when you were younger?)

Is it important your partner is deaf and why if so?

Has being deaf ever been an issue for you when meeting people to date?

(for example in the club or online?)

Has being deaf ever been an issue in a relationship for example with a partner or their family or friends?

(How did that feel if yes? Did it affect your confidence in relation to dating for example are you reluctant to date as a consequence or are you concerned about other people's views of you being deaf for example your partners family members?)

Can I ask also how do you prefer to meet people?

THEME ONE: **Learning about sexuality and sex**
(information regarding different topics such as: relationships, sex, sexual health, questions about bodies etc)

Formal and informal learning about sex, sexual health and sexuality

How did you first start to learn about topics such as period cycle / menopause?

Probe: (Some people say that when they got their first period they were not prepared – they never knew about it – other people are prepared. What was your situation?)

How did you learn about sex and also safe sex / sexual health?

Probe: (What was it like to learn about that? Do you feel comfortable with your knowledge about HIV for example? Do you know the time of your cycle that your most likely to get pregnant at? Could you tell me about your sex education classes in school and what they were like? If poor why was this)

Were you taught about sexual feelings or emotions or relationships?

Did you ever have questions about these topics and how did you find answers to your questions?

If you had concerns would you use the internet / go to the doctor / speak to someone you know? / Was there anything about sex that you worried about? / How did you find answers to your questions? Did you prefer to go on the internet or to talk to someone?)

Could you describe how you find information to your questions related to sexual health now?

(such as the doc, internet, friends - how do you feel about understanding sexual health topics now? Could you elaborate on that?)

How do you feel about your experiences of accessing such information – was it easy or hard for example?

Did difficulty accessing the right information ever affect your health or you emotionally in anyway?

Probe: for example your relationships or being aware of how to avoid pregnancy?

Did you have any particularly good or bad experiences in relation to seeking information from a person that you remember? For example a person who was really willing to talk to you or a person who was dismissive of your questions?

How could your experiences of accessing information be better?

How do you feel policy could respond to the needs of Deaf and hard-of-hearing women?

THEME TWO: **Sexuality socialisation and how are deaf women perceived and treated when in social and medical contexts**

Influenced by - Gillespie-Sells, K., M., Robbins, B (1996) She dances to different drums: Research into Disabled Women’s Sexuality. London: King’s Fund – cited in Liddiard Kirsty (2011 – S(Exploring Disability).

What was it like talking to your parents or your other family members when you were younger about your relationships or sex or puberty?

Probes: (What kind of conversations did you have, how did they respond to you, could you speak to them about feelings and contraception?)

How did you feel about talking to the house mother / your teachers?

Probes: (What kind of conversations did you have, how did they respond to you?)

Were you and your friends open about talking about relationships / sex / romantic interests?

Have you ever gone to a sexual health clinic such as Well Women to talk about your sexual health in any way such as fertility testing, menopause, period management, sti testing and how was your experience of that?

(did you feel looked after or well responded to – how did you treat your communication needs?)

If you were going to a doctor to discuss birth control or using a sexual health clinic for a check-up for example would you/have you - bring/brought an interpreter with you?

Being deaf – has that ever affected how doctors or nurses treat you?

Attitudes towards sexuality / relationships

How do you view marriage / having children?

Can I ask what is your opinion about sex outside of marriage or people having children outside of marriage? How do you feel about one night stands?

Were you comfortable with the idea of having sex when younger?

(Is that something you felt you should enjoy / you do enjoy?)

How do you feel generally about sex now?

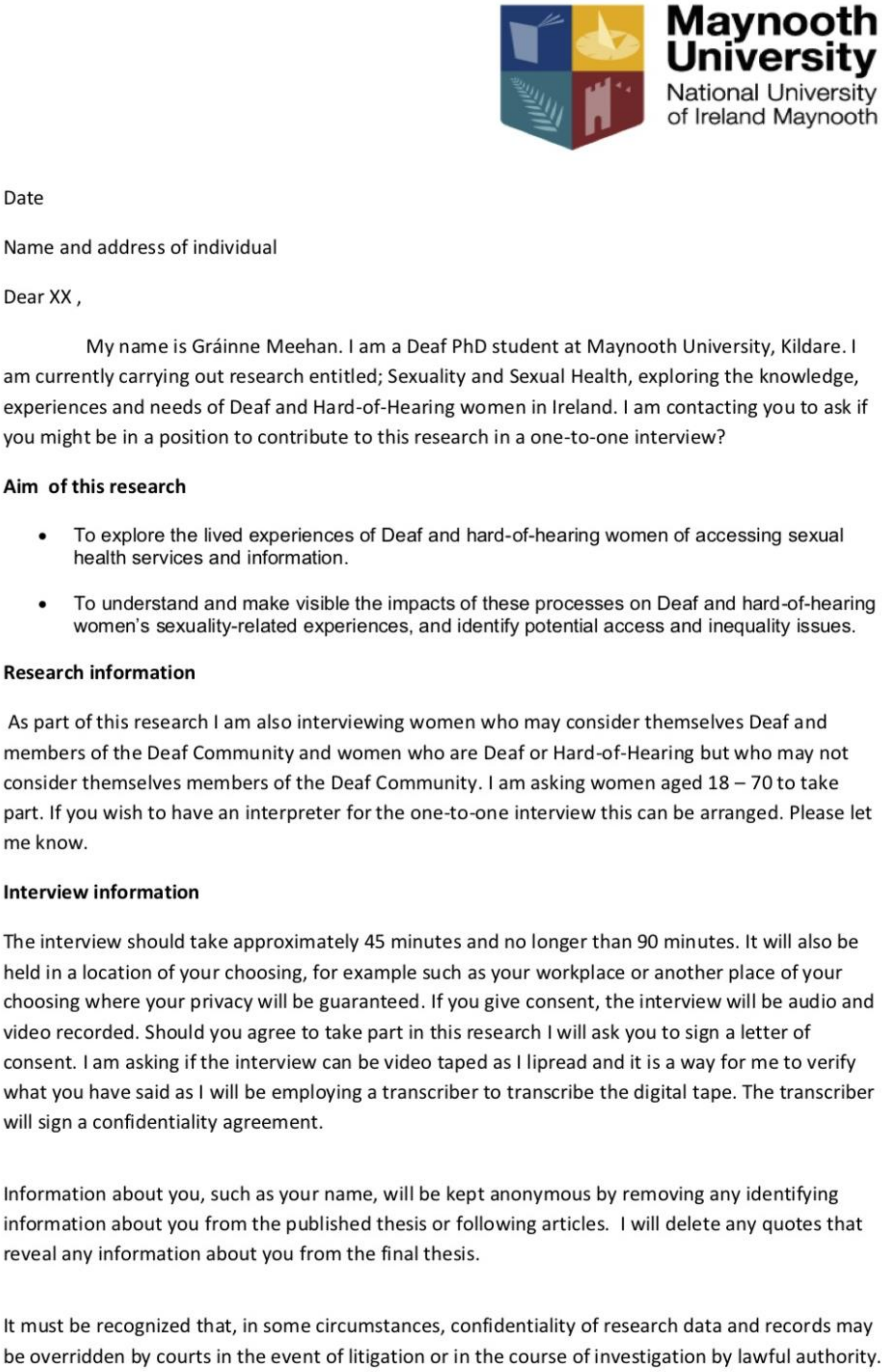
Emergency contraception / abortion

Closing up comments

Is there anything else you would like to add? / Any final thoughts?

Is there anything that didn’t come up but you would like to include?

Appendix VI: Key informant information



Maynooth
University
National University
of Ireland Maynooth

Date

Name and address of individual

Dear XX ,

My name is Gráinne Meehan. I am a Deaf PhD student at Maynooth University, Kildare. I am currently carrying out research entitled; Sexuality and Sexual Health, exploring the knowledge, experiences and needs of Deaf and Hard-of-Hearing women in Ireland. I am contacting you to ask if you might be in a position to contribute to this research in a one-to-one interview?

Aim of this research

- To explore the lived experiences of Deaf and hard-of-hearing women of accessing sexual health services and information.
- To understand and make visible the impacts of these processes on Deaf and hard-of-hearing women's sexuality-related experiences, and identify potential access and inequality issues.

Research information

As part of this research I am also interviewing women who may consider themselves Deaf and members of the Deaf Community and women who are Deaf or Hard-of-Hearing but who may not consider themselves members of the Deaf Community. I am asking women aged 18 – 70 to take part. If you wish to have an interpreter for the one-to-one interview this can be arranged. Please let me know.

Interview information

The interview should take approximately 45 minutes and no longer than 90 minutes. It will also be held in a location of your choosing, for example such as your workplace or another place of your choosing where your privacy will be guaranteed. If you give consent, the interview will be audio and video recorded. Should you agree to take part in this research I will ask you to sign a letter of consent. I am asking if the interview can be video taped as I lipread and it is a way for me to verify what you have said as I will be employing a transcriber to transcribe the digital tape. The transcriber will sign a confidentiality agreement.

Information about you, such as your name, will be kept anonymous by removing any identifying information about you from the published thesis or following articles. I will delete any quotes that reveal any information about you from the final thesis.

It must be recognized that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority.

In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.

All data will be anonymised soon after collection. I will ensure the interview is transcribed as soon as possible by a third party (who will also sign a confidentiality agreement) and returned to you. You may edit or change any part of the transcript as you wish. You also have the right to withdraw from this research at any point. All data will be stored on a secure computer in my office in Maynooth University. It will be password protected and will only be accessed by me.

What would I like to know?

I am contacting you regarding your particular knowledge of xxx and I will be asking you questions in relation to this topic.

Your contribution to this research would be much appreciated. Please find attached an abstract of the proposed research and a copy of a letter of ethical approval from Maynooth University. If you would like more information about my research I would be happy to meet with you for a discussion. Please contact me by e-mail at your earliest convenience.

Yours sincerely,
Grainne Meehan
Grainne.p.meehan@mumail.ie

Appendix VII: Interview Guide – Key Informant Interview Guide

- Could you tell me about your organisation and your role in particular?

- From your work what stands out for you as key issues related to deaf women (or men) and sexuality and sexual health?

- Do you do any pieces of work in relation to sexuality in your role? Can you tell me a bit about that? – how do you work with services users (groups/individually?).

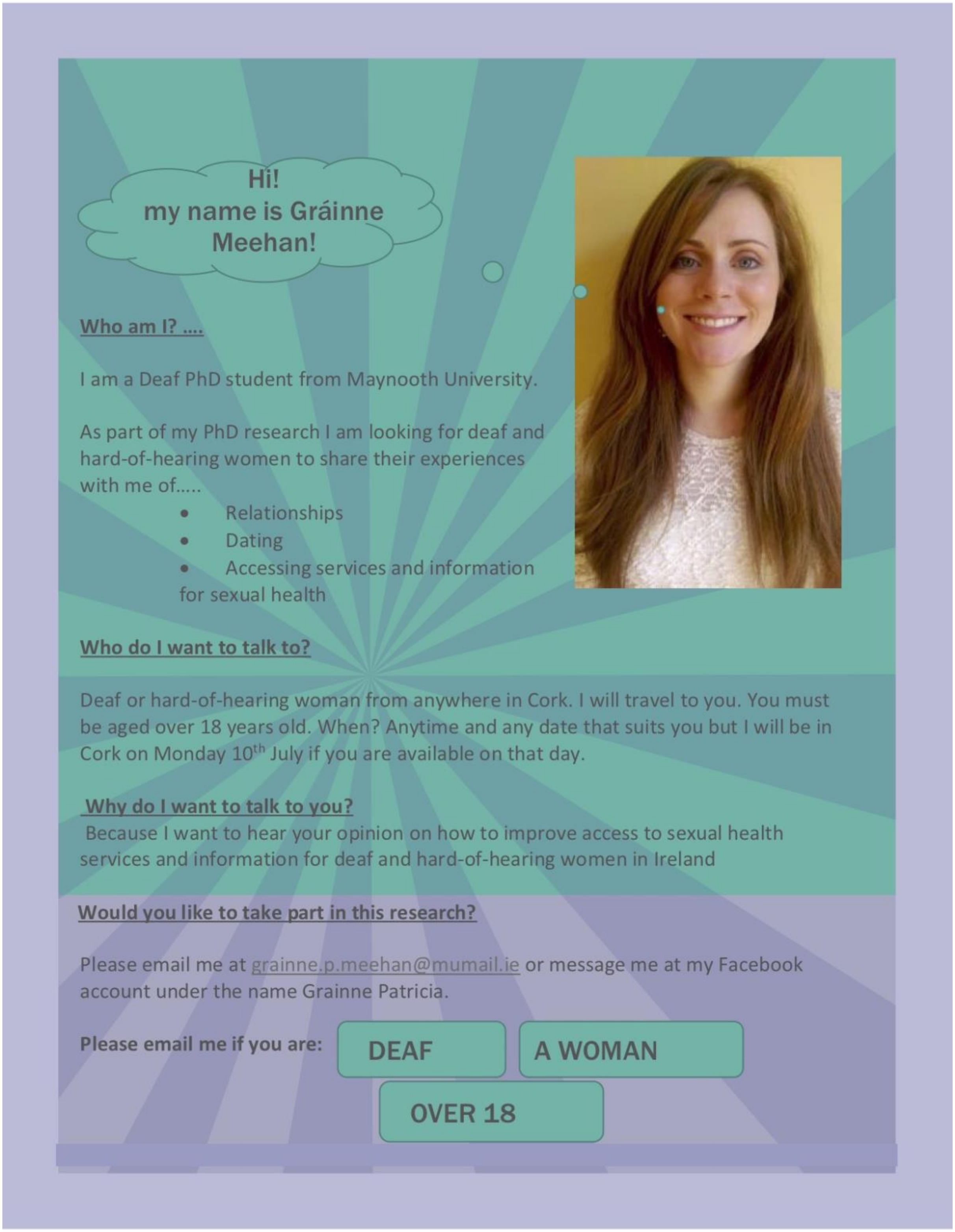
- Why did or how did this piece(s) of work come about?

- How do you feel about this topic – in terms of your training, your access to materials, your knowledge, your comfort discussing this with service users?

- Are there any key issues in relation to deaf women (or men) and sexuality that you could tell me about? I am particularly interested in access to services and information related to sexuality.

- What can deaf and mainstream services do to improve access and information?

Appendix IX: Research Poster



Hi!
my name is Gráinne
Meehan!

Who am I? ….

I am a Deaf PhD student from Maynooth University.

As part of my PhD research I am looking for deaf and hard-of-hearing women to share their experiences with me of…..

- Relationships
- Dating
- Accessing services and information for sexual health

Who do I want to talk to?

Deaf or hard-of-hearing woman from anywhere in Cork. I will travel to you. You must be aged over 18 years old. When? Anytime and any date that suits you but I will be in Cork on Monday 10th July if you are available on that day.

Why do I want to talk to you?

Because I want to hear your opinion on how to improve access to sexual health services and information for deaf and hard-of-hearing women in Ireland

Would you like to take part in this research?

Please email me at grainne.p.meehan@mumail.ie or message me at my Facebook account under the name Grainne Patricia.

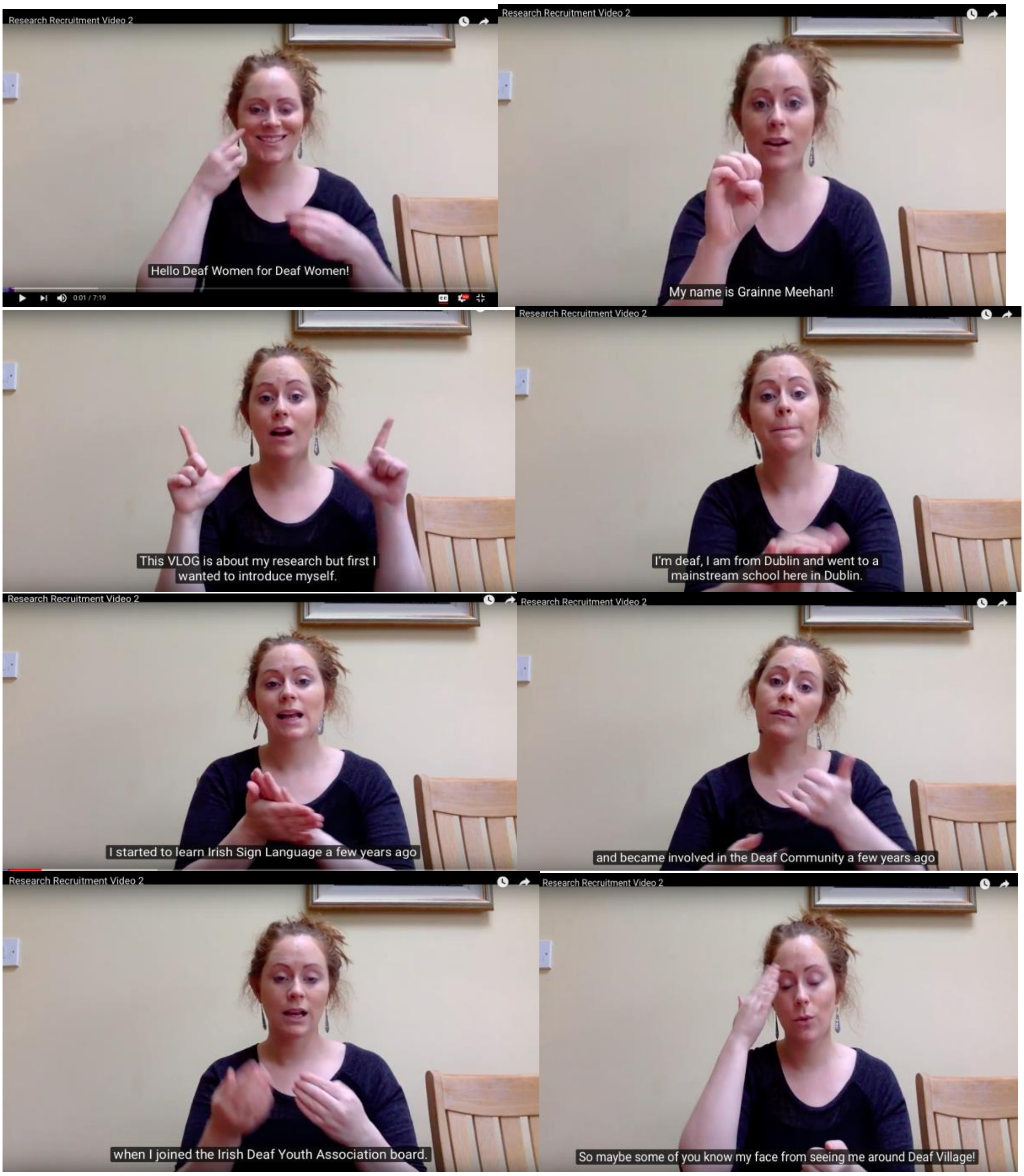
Please email me if you are:

DEAF

A WOMAN

OVER 18

Appendix X: Recruitment video screengrabs[84]



Hello Deaf Women for Deaf Women!

My name is Grainne Meehan!

This VLOG is about my research but first I wanted to introduce myself.

I'm deaf, I am from Dublin and went to a mainstream school here in Dublin.

I started to learn Irish Sign Language a few years ago

and became involved in the Deaf Community a few years ago

when I joined the Irish Deaf Youth Association board.

So maybe some of you know my face from seeing me around Deaf Village!

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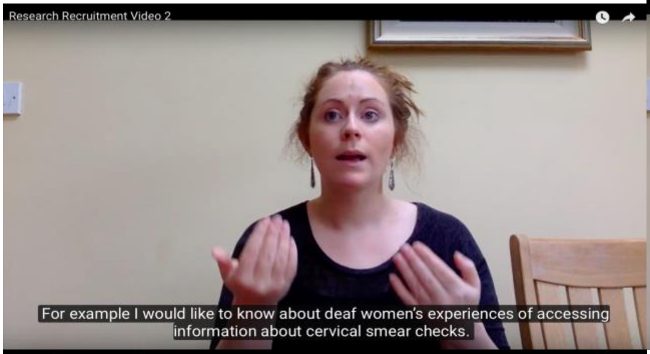
[84] Not every clip from the recruitment video has been included due to space restrictions.

Now I still live in Dublin and I am studying
for a PhD at the moment in Maynooth University

So what is my research about?

First, I want to find out deaf women's experiences of accessing information about sexual health and healthy relationships.

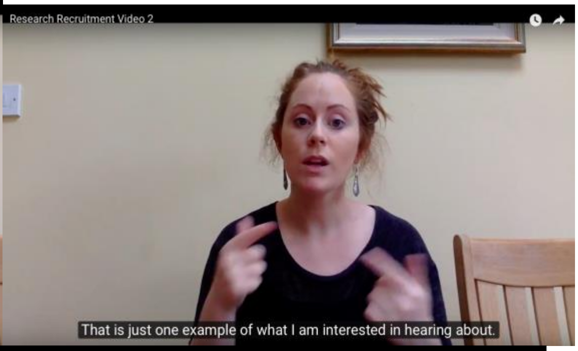
It includes a lot of topics!



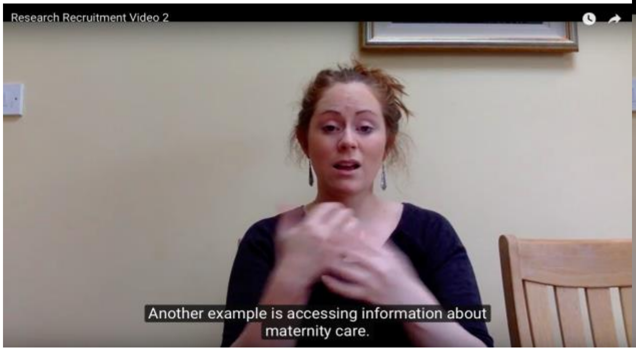
For example I would like to know about deaf women's experiences of accessing information about cervical smear checks.

How was your experience accessing that kind of information? Was the information clear to you or was it
difficult to access?

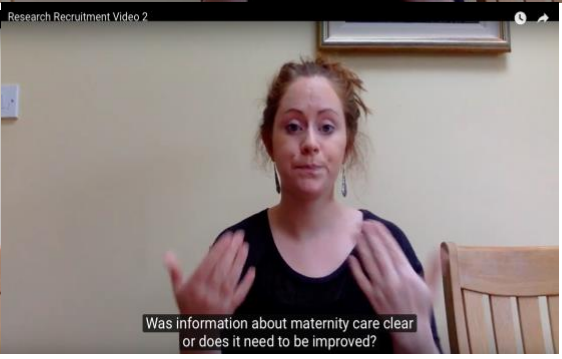
Was it confusing or does access need to be improved?



That is just one example of what I am interested in hearing about.

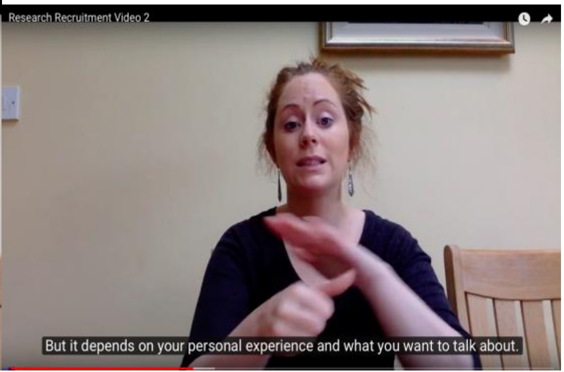


Another example is accessing information about
maternity care.



Was information about maternity care clear
or does it need to be improved?

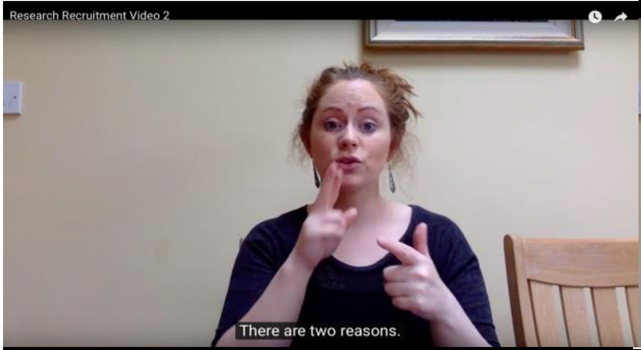
Another example is information about sexual health such as STD's and contraception.



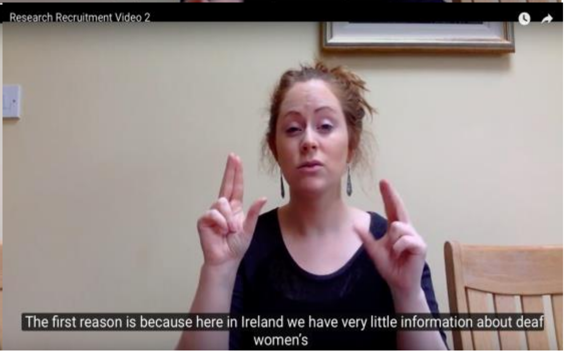
But it depends on your personal experience and what you want to talk about.

So there are a lot of topics but again it depends on what you want to talk about.

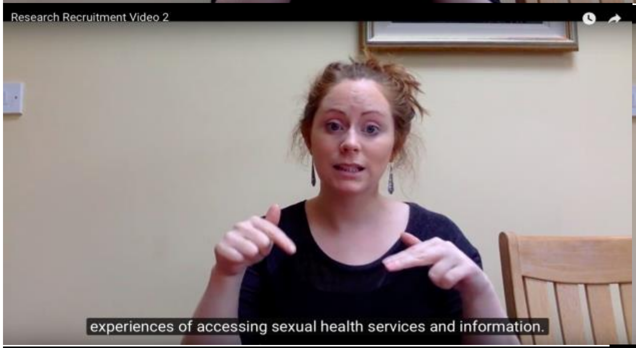
So you might wonder why I am doing this research?



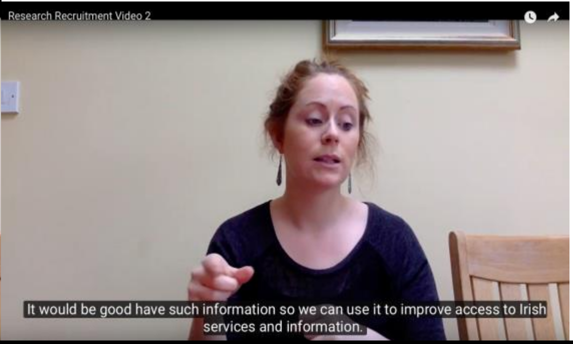
There are two reasons.



The first reason is because here in Ireland we have very little information about deaf women's



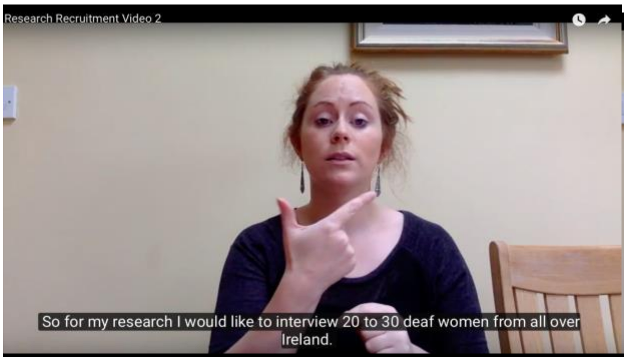
experiences of accessing sexual health services and information.



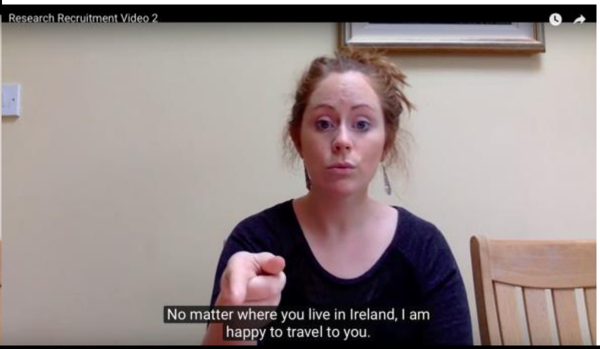
It would be good have such information so we can use it to improve access to Irish services and information.

We deaf women are strong, positive and empowered!

BUT, a lot of research focuses only on the negative experiences that deaf women have.



So for my research I would like to interview 20 to 30 deaf women from all over Ireland.



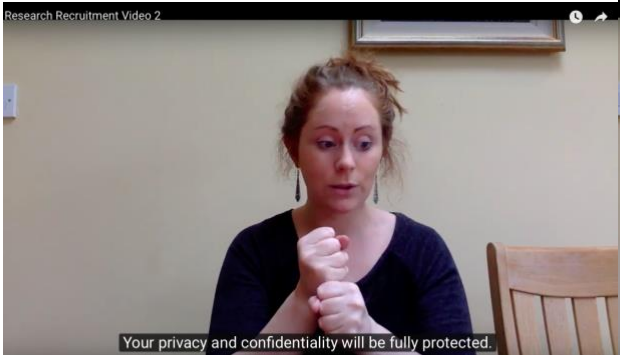
No matter where you live in Ireland, I am happy to travel to you.

I will use a video camera to record the interview.

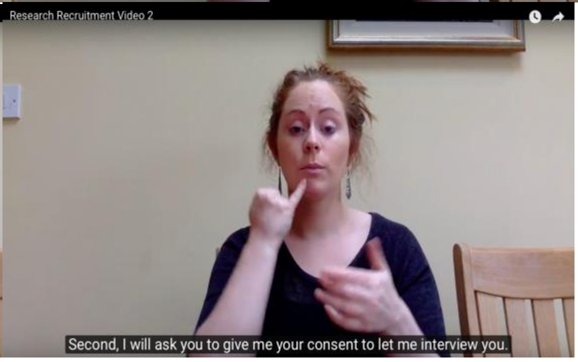
Last, I hope this research will help to show how access to sexual health services and information could be improved for us deaf women.

So you could help to make that happen by sharing your opinions and views for the future.

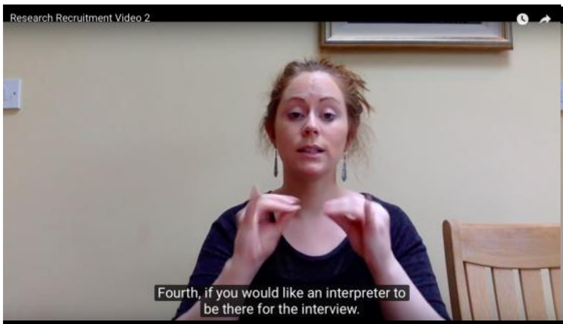
I will not use your name or any information about you in the research.



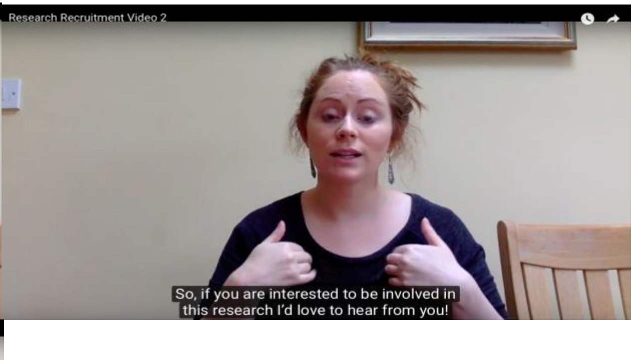
Your privacy and confidentiality will be fully protected.



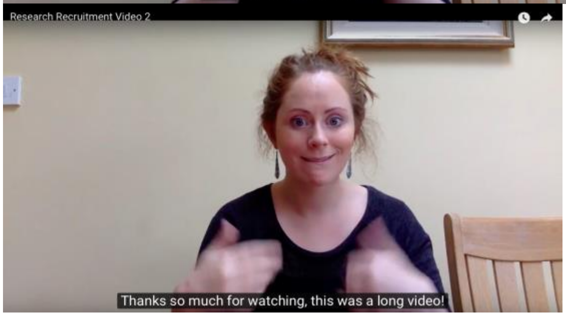
Second, I will ask you to give me your consent to let me interview you.



Fourth, if you would like an interpreter to be there for the interview.



So, if you are interested to be involved in this research I'd love to hear from you!



Thanks so much for watching, this was a long video!