The Case for Experts By Experience in Irish Mental Health Policy and Practice: A Qualitative Approach

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I still dream of Orgonon
I wake up crying
You're making rain
And you're just in reach
When you and sleep escape me

You're like my yo-yo
That glowed in the dark
What made it special
Made it dangerous
So I bury it
And forget

But every time it rains
You're here in my head
Like the sun coming out
Ooh, I just know that something good is gonna happen
I don't know when
But just saying it could even make it happen

On top of the world
Looking over the edge
You could see them coming
You looked too small
In their big black car
To be a threat to the men in power

I hid my yo-yo
In the garden
I can't hide you
From the government
Oh, God, Daddy
I won't forget

'Cause every time it rains
You're here in my head
Like the sun coming out
Ooh, I just know that something good is gonna happen
I don't know when
But just saying it could even make it happen

And every time it rains
You're here in my head
Like the sun coming out
Like your son's coming out
Ooh, I just know that something good is going to happen
And I don't know when
But just saying it could even make it happen

Ooh, just saying it could even make it happen

We're cloudbusting, Daddy

The sun's coming out

Your son's coming out – (Bush, 1985)

SUMMARY

This exploratory qualitative research analyses the concept and role of the Expert By Experience (EBE), and their relationship with Irish mental health policy and practice. Informed by a combined Foucauldian/Gramscian theoretical framework, the research critically analyses Irish mental health policy and practice through the lens of power-knowledge and hegemony (Gramsci, 1971). This critical analysis identifies how power-knowledge (Foucault, 1977) has traditionally been exercised in Irish mental health policy and practice, and which institutions and actors have been included in and excluded from its exercise. Power-knowledge is found to have primarily been exercised by the medical and statutory stakeholder spheres, through the functions and apparatus of the biomedical model of mental illness. The social model of disability and the biopsychosocial model of mental health are also found to be influential. *A Vision for Change* (Government of Ireland, 2006) espoused a biopsychosocial model of mental health, and is found to be the only piece of Irish mental health legislation not drafted from a biomedical perspective. A gap is identified in service-user inclusion in Irish mental health policy and practice. Through the parallel research strands of autoethnography and in-depth EBE interviews with five EBEs, the views, experiences, and insights of EBEs on Irish mental health policy and practice are gathered and thematically analysed. This analysis identifies a distinct journey taken by respondents in becoming EBEs, distinguished by the novel 'step' of 'individual professionalisation'. An EBE stakeholder sphere in Irish mental health policy and practice comprised of EBEs who possess the distinct 'dual' traditional and experiential expertise gained through 'individual professionalisation' is proposed to address the gap in service-user inclusion in Irish mental health policy and practice. The research's autoethnographical methodology, and its exploration of how individuals with subjugated knowledges have legitimised (Weber, 1922) their expertise, hold global implications for methodologies and knowledge generation.

GLOSSARY OF TERMS

AI	Amnesty International Ireland
EEAG	Amnesty International Ireland's Experts by Experience Advisory Group
ADMC	*Assisted Decision Making (Capacity) Act 2015*
APA	American Psychiatric Association
AVFC	A Vision for Change
CMHT	Community Mental Health Teams
CVNI	Critical Voices Network of Ireland
DSM	Diagnostic and Statistical Manual of Mental Disorders
EBE	Expert By Experience
IAN	Irish Advocacy Network
IMG	Independent Monitoring Group established under *A Vision for Change*
HVM	Hearing Voices Movement
MHC	Mental Health Commission
MHR	Mental Health Reform
STV	*Sharing the Vision*
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION TO RESEARCH

INTRODUCTION

The concepts of mental health and mental illness are contentious and contested (Pilgrim, 2017; Townsend, 2015; Whitley, 2015). There is limited consensus on what constitutes mental health, though the World Health Organization's (WHO) definition states: "Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community" (World Health Organization, 2022). There is continuing debate and disagreement between different stakeholders and thinkers around the nature, objectivity, and propriety of conceptualising the experience of mental and emotional distress as 'mental illness(es)' (Bertolote, 2008; Elkins, 2009; Galderisi et al., 2015; Ghaemi, 2018; Mechanic, 1999; Svensson & Hansson, 1994; Van Dyke & Hovis, 2014). This debate between stakeholders surrounding the existence and objectivity of discrete 'mental illnesses' is evidenced in the American Psychiatric Association's (APA) evolving diagnostic criteria for mental illnesses and disorders categorised in each revised edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), currently in its 5th Edition which was revised in 2022 (American Psychiatric Association, 1952, 1968, 1980, 1994, 2013, 2022).

These definitions and concepts surrounding mental health and mental illness are malleable, disparately agreed upon (Karlsson, 2012), and ever-evolving. Their varying manifestations and conceptualisations in Irish mental health policy have mirrored this malleability, as they have elsewhere (Goldman & Grob, 2006). Notwithstanding this, knowledge, policy, and practice have been evolving in this context of contention and contestation. Policy has often reflected ideologically current definitions at the time of policy development (Arts & Verschuren, 1999; Seidman et al., 2011). In the Irish context, as well as internationally, these definitions have historically ranged from conceptualising distress as 'lunacy', distress as 'criminality', distress as 'mental illness' resulting from a biomedically conceived chemical imbalance of the brain, and more recently, 'mental health' and 'illness/distress' as complex manifestations of biopsychosocial ("bio" = biological, "psycho" = psychological, "social" = social) factors which result in 'mental health problems' (Government of Ireland, 2006). This introductory chapter outlines the background to and rationale for the research, the autoethnographical approach to

the research, the gap in knowledge the research seeks to address, the research aim, objectives, the research questions, and the research design developed to conduct the research.

This autoethnographical research analyses Irish mental health policy and practice from the unique perspectives of Experts By Experience (EBEs), including the author's, who were each at different stages on their journey to becoming EBEs during the period of 2006-2020 when the Government of Ireland's third official mental health policy, *A Vision for Change* (AVFC) (2006), was active. As such, AVFC is the most pertinent piece of mental health policy to this research. The primary aim of this research is to investigate issues of EBE and service-user inclusion in mental health policy and practice discussed in the international literature (Beresford, 2007, 2010, 2012; Noorani, 2013; Tew et al., 2004), and in the Irish literature (Department of Health and Children, 2008; McDaid, 2009; The Health & Social Care Regulatory Forum, 2009). This investigation consists of primary research analysing EBEs' experiences of the policy's implementation in 'Chapter Five' and 'Chapter Six', and a review of the development of Irish mental health policy and laws from the early 19th century to AVFC in 2006. This critical review is presented in 'Chapter Three'.

The research's analysis of EBE perspectives on mental health policy and practice during AVFC's lifespan is located within the context of the laws, policies, and mental health strategies that preceded AVFC in the Irish context. AVFC was informed by and evolved from this mental health legislation, and is inextricable from it, as this research holds that ideologies presented as hegemonic knowledge are socially constructed, iterative, and historically contingent on one another (Foucault, 1980: 81-87). This contextualisation of the social, cultural, and political context of AVFC and the mental health legislation preceding it from which it is developed is presented in 'Chapter Three'.

BACKGROUND

AVFC constituted a radical ideological shift in Irish mental health policy when introduced. This shift in the policy was away from the institutionalised, paternalistic, and less service-user focussed mental health services operating under the biomedical model of mental illness that predated it (O'Sullivan & O'Donnell, 2007) towards a more service-user-focussed, community-based, and dignified suite of mental health services operated under a biopsychosocial model of mental health. Its implementation, however, has been criticised for apparent failures in meeting the promise it held during its development as a policy (Johnston, 2014). Research analysing its successes and shortcomings in implementation from the

perspective of EBEs contrasted against its potential as an ambitious policy document, such as the current research, is timely.

By analysing how AVFC's biopsychosocial provisions emerged in the context of Ireland's historically biomedical mental health legislation, and investigating whether its provisions materialised and/or significantly altered the existing mental health services for service-users from the perspective of EBEs who hold a distinct knowledge in this research area, it is intended that actionable recommendations for future mental health policy and practice can be proposed from the research findings. As the research is conducted autoethnographically and is primarily concerned with EBEs' and service-users' experiences and perspectives of Irish mental health policy and practice during the period when AVFC was official mental health policy, the research findings illustrate the gap that exists in Irish mental health policy and practice for service-user and EBE inclusion. These findings may enable future policy to be drafted with a more service-user-focussed and service-user respecting remit, informed by and including the hereto untapped expertise of mental health EBEs.

AUTOETHNOGRAPHY

The autoethnographical research is firmly sited within and informed by my own experience of the Irish mental health services as a service-user during the implementation stage of AVFC, and the process I underwent becoming an EBE. To this end, autoethnography serves as both a methodological approach and a primary research strand. Autoethnography is the primary lens through which this research is viewed and analysed, and it frames the work as a whole. Analytic autoethnography is woven throughout the thesis to reflect upon the iterative research process (Anderson, 2006; Berry, 2021a, 2021b). I utilise in-depth interviews with EBEs (Seidman, 2013) as a parallel research strand alongside the analytic and evocative autoethnography (Ellis & Bochner, 2016) research strand to form a robust, triangulated methodology that is inclusive of the EBE perspectives involved with AVFC (Denzin, 2012). This unique methodological approach and the form it took in practice are detailed in 'Chapter Four'. Authors such as Beresford and Tew note that the perspectives of EBEs and service-users are frequently under-represented in policy and policy research (Beresford, 2005, 2007, 2010, 2012; Tew 2002, 2005, 2008, 2011; Tew et al., 2012). It is this under-representation of these key stakeholders and this gap in our academic and policy research and knowledge that this study seeks to address by advancing understandings of the 'Expert By Experience', and demonstrating the potential of Irish mental health EBEs in informing mental health policy and practice.

RESEARCH AIMS, OBJECTIVES, AND QUESTIONS

The overall aim of this explorative, qualitative study is to investigate and analyse the processes through which service-users become EBEs in mental health policy and practice in Ireland by investigating their lived experience of Irish mental health policy and practice during the period when AVFC was the official government mental health strategy.

The research questions are:

1. What are the views, experiences, and insights of Experts By Experience on Irish mental health policy and practice?
2. What are the implications of Experts By Experiences' insights for the future development of mental health policy and practice?

ORIGINS OF MY INTEREST

This qualitative research builds upon previous qualitative research into the area of Irish mental health policy and practice I have conducted, focussing on the topic from a social policy perspective. The earlier research comprises two theses (Markey, 2013, 2017). The first thesis analysed whether modern Irish psychiatry and the biomedical model of 'mental illness' were instances of 'medicalisation' (Conrad, 1992, 2007; Szasz, 2007; Zola, 1972), finding that they were. This thesis was purely sociological, and was not anchored to policy. It employed an autoethnographical methodology coupled with in-depth interviews of service-users within the Irish mental health services.

The second thesis employed a wholly autoethnographical methodology, analysing the level of success of AVFC's implementation by contrasting my own lived experience of the mental health services as a service-user against the policy's provisions. That piece of research identified and explored AVFC's implementation gap.

Separately, I have conducted research on AVFC, along with earlier qualitative research concerning mental health in the Irish context, while working with Amnesty International Ireland (AI) and Mental Health Reform (MHR). These roles form a significant part of my experience working with mental health policy, and they have informed my experience as an EBE. The current research marries and expands upon my lived experience of AVFC as a service-user, my individual research, and research I have collaborated on with these organisations, and my lived experience as a mental health EBE, producing a study that is both

autoethnographical and demonstrative of the need for and worth of EBE input at all levels of mental health policy and practice.

RATIONALE

My previous thesis examining AVFC's implementation (2017) was limited to analysing the implementation phase of AVFC, and was based upon my autoethnographical data and policy analysis of AVFC alone. The current research expands upon this in scope with a critical chronological analysis of Irish mental health policy from its beginnings in 1811 (UK Parliament, 1811). This critical analysis is found in 'Chapter Three'. The robust understanding of Irish legislation's historical conceptualisations of those in distress and its provisions for them offered in this critical analysis provides the necessary context to expand understanding of EBE's experiences of AVFC described in the findings within their broader legislative and ideological background, rather than in the framework of AVFC alone. It also comprehensively demonstrates the presence or absence of service-user and EBE inclusion and representation in policy and practice from the beginnings of statutory interventions in distress through to AVFC. The research findings, enhanced by grounding them in their deeper legislative context, are indicative of more than EBE experiences and insights into Irish mental health policy and its implementation while they were becoming EBEs. The research findings are also illustrative of whether AVFC departed from existing mental health policy, ideology, and practice as envisaged, or whether hegemonic biomedical ideology and practice were maintained during this period.

Departure from original research topic

The original rationale for this research was to conduct an autoethnographical social policy analysis of AVFC to investigate its development as a document and its provisions, to identify and interview the actors involved in the policy's development, and to analyse the policy's implementation from the perspectives of both service-providers and service-users. The research aim was to represent the perspectives and role of each stakeholder sphere involved in AVFC's provisions and implementation. As detailed in 'Chapter Four', this research focus changed upon beginning my first stakeholder interviews. These interviews were with the EBE stakeholders. As this research was viewed and analysed through an autoethnographical lens, it became apparent to me as a researcher and an EBE that there was a series of key themes which were common across each EBE's interview. This was despite the fact that each EBE's story

was remarkably unique to them. Using autoethnography, I followed the research in this direction to focus on these significant emerging key themes.

The research rationale evolved from representing the perspectives and roles of each stakeholder sphere involved in AVFC, to solely investigating and developing the distinct story that EBEs detailed. This story describes the journey of the shared 'steps' respondent EBEs had universally taken in becoming EBEs, informed by their experiences of mental health practices operating under AVFC. The experience of becoming an EBE had not been the focus of the interview schedule, which had been drafted with open questions which would be applicable across each stakeholder sphere to be interviewed. Some of these questions would be specific to respondents based on the stakeholder sphere they were drawn from – service-user, medical, or statutory – but the questions were necessarily broad to allow the comparison of the data collected from each sphere during data analysis. In the interviews, open questions were posed regarding AVFC and mental health policy, with some specified to the respondents' unique role as EBEs. The story became apparent in EBEs' perspectives on AVFC, and in their lived experiences of its implementation. The journey EBEs detail also offers a definition of the 'Expert By Experience' as understood by EBEs themselves. This definition is characterised by an important 'step' which has not been accounted for in the literature surrounding the role of EBEs (Dings & Tekin, 2023; Noorani, 2013). This is the 'step' of individual professionalisation identified in this research. This definitive 'step', and the 'steps' that accompany it to form respondents' journeys to becoming EBEs, are discussed in 'Chapter Six'.

THEORETICAL CONTEXT

This research is founded upon a combined Foucauldian/Gramscian theoretical framework. This framework is influenced by and utilises Foucauldian post-structuralism, and his concept of power-knowledge (1977, 1980), at the micro and meso theoretical levels. Gramsci's concept of hegemony (1971) is the macro level theoretical influence in this framework. This framework, and the concepts central to it and the research, are outlined in 'Chapter Two'. Post-structuralism holds that there are no knowable 'facts', only conceptualisations represented *as* 'facts' through power-knowledge relations. Foucault (1980: 81) suggests the existence of 'subjugated knowledges'; the 'knowledges' held by marginalised groups that differ from the normative, accepted 'knowledges' and 'common sense' (Crehan, 2016) of powerful majorities (Rabinow, 1984). The knowledge held by EBEs represents a subjugated knowledge. Gramsci, a cultural and structural neo-Marxist, developed the concept of 'cultural hegemony' (1971) to

name and describe the means of ideological and cultural control, normalisation, and subjugation through which the dominant hegemonic group subjects the minoritised and their 'subjugated knowledges' to the exercise of power-knowledge (Foucault, 1977, 1980; Lukes, 2005; Visoka & Lemay-Hébert, 2022). 'Hegemony' consists of that which is taken to be natural or 'common sense' (Crehan, 2016; Gramsci, 1971; Lukes, 2005) at first glance in dominant cultural and institutional spheres. Foucault's concept of the 'subjugated knowledges' held by the minoritised which the dominant hegemonic group abnormalise and oppress through the exercise of hegemonic power-knowledge and processes of biopower (Foucault, 1976; Visoka & Lemay-Hébert, 2022), and Gramsci's concept of the 'hegemony' of normative ideologies, structures, and social mores held and (re)produced by the dominant hegemonic group (Gramsci, 1971; Lukes, 2005) are central concepts through which this research is understood.

By questioning the who, when, how, and why of that which has been presented as fact in Ireland's formative mental health legislation in 'Chapter Three', and proceeding to explore its effects on those with lived experience of them in the 'Belonging' and 'Chapter Six', the existence of different perspectives or 'knowledges' and the power-knowledge which underpins them in the area of mental health were brought to light in the research.

METHODOLOGY

This research employs an autoethnographical methodology. It is based on an explorative, qualitative research design. Two parallel research strands were employed in this methodology. These research strands were, as stated, autoethnographical analysis, and in-depth qualitative interviews with EBEs. Two methods were chosen to offer rigour to the research and its findings through triangulation. Triangulated methodologies for qualitative research studies were originally theorised by Denzin (1970), and later developed by Flick (2007), and Fielding (2009). They contain two or more research methods by default (Denzin, 2012). Flick (2007, 2012) states that triangulated methodologies add "breadth, complexity, richness, and depth to any inquiry" (Denzin, 2012: 82). This richness and complexity are also noted features of autoethnography (Adams & Herrmann, 2023; Ellis et al., 2011; Ellis & Bochner, 2016). These benefits, particularly the strong validity offered by findings corroborated or falsified across different modes of inquiry (Denzin, 1970), made a triangulated methodology, composed of two parallel research strands, the best model for the proposed research.

Autoethnography

Autoethnography is an approach to research that, at its core, consists of the inclusion of the researcher and their lived experience within the wider cultural and societal context that is being researched *in* the research. Ellis et al. define autoethnography as "an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)" (2011).

I chose autoethnography as a method for several reasons that benefit the research. Autoethnography allowed me to analyse data that I was assured, as a researcher, was first-hand and uncompromised. This autoethnographical data has internal validity based in the grounded narrative of my life's narrative as it pertains to becoming an EBE. Bleijenbergh et al. (2011: 145) note that qualitative data with internal validity, such as autoethnography, is best equipped to meet the research criteria of "verifiability, comprehensibility, and acceptance of the [research] results, as well as holism". Autoethnography allowed me to produce deep, "thick" analyses of the data in answering my research questions (Adams & Herrmann, 2023: 5; Geertz, 1973).

Autoethnography also enabled me to gather qualitative data from a second EBE perspective, coupled with those from the in-depth interviews with mental health EBEs. It allowed me to add my own voice to the choir of stakeholders invested in mental health policy and practice, particularly those whose lives were affected by mental health policy's provisions and implementation in practice. The method has been found to be positive when the researcher is investigating issues of health and illness, due to these topics' emotional and personal nature (Ellis, 1999; Foster et al., 2006). Given the scope of this piece of research and my own status as an EBE with both traditional, 'expert' legitimate knowledge and authority (Weber, 1922; French & Raven, 1959; Lukes, 2005), and experiential knowledge and authority (Noorani, 2013; Dings & Tekin, 2023), it was an ideal method to research the impact of mental health policy and practice with, and one that has yielded fascinating insights each time I have employed it in my research methodologies. The benefits of autoethnography as a method and methodological approach, and the valuable insights this approach can produce in research into health issues and social policy has been demonstrated in the Irish context by Farrell Delaney's ground-breaking 2021 research exploring her experience of living with Myalgic Encephalomyelitis (Farrell Delaney, 2021).

Autoethnography helped me to produce an interesting and dynamic body of research, and facilitated the shift in this research's focus. My experience with autoethnography has shown the method to be highly revealing for external critical readers, and for myself, both as a researcher and individual. It provides a greater insight into the cultural and social world that the policy being researched was drafted in and reflects, as the researcher is required to analyse their own experience of this cultural and social world, rather than solely interpreting somebody else's (Ellis & Bochner, 2016; Gergen, 2018; Witkin, 2014). The data collected through the method is vivid and detailed, and when used with the parallel research strand of in-depth EBE interviews, it made the findings surrounding EBEs' experiences of mental health policy and practice, and their potential as a stakeholder sphere, quite stark.

In-depth interviews with EBEs

To answer both research questions robustly, the perspectives and experiences of EBE stakeholders involved with mental health policy and practice from its development through its implementation were required. These were collected using in-depth interviews with EBEs. These interviews were intended to act as the first tranche of interviews to be conducted with respondents from the three service-user, medical, and statutory stakeholder spheres in line with the original research rationale. Due to the shift in rationale that followed these interviews, the in-depth EBE interviews constitute the complete data sample from this parallel research strand. These interviews and the form they took are described in detail in 'Chapter Four'. Respondent EBEs were initially approached using purposive sampling from a variety of groups who lobbied government or publicly called for drastic changes to the Irish mental health services at the time of AVFC's publication and implementation, some of which I was a part of at different points, which provided me with access to EBEs. These groups included the Critical Voices Network of Ireland (CVNI), the Irish Advocacy Network (IAN), and members of Amnesty International Ireland's Experts by Experience Advisory Group (EEAG), of which I was a member. This purposive sampling did not result in the necessary sample of respondent EBEs, and snowball sampling was employed to complete the sample. This process and the rationale behind it are outlined in 'Chapter Four'.

Reflecting the service-user experience was imperative for me in conducting this research. A primary personal motivator and a large part of my research rationale is to hear and reflect EBE experiences and knowledge, and to give voice to these experiences, such that the knowledge they hold can exist with parity of respect and esteem in mental health policy and practice

alongside the traditional perspectives of the statutory and medical stakeholder spheres identified in this research that, it is argued, have traditionally exercised power-knowledge over EBEs and service-users.

Five EBEs were interviewed across a total of six in-depth EBE interviews. At this point, theoretical saturation was reached, and with no new data emerging, the data collection from the in-depth interview strand was completed (Morse, 2004; Saunders et al., 2018). These six in-depth EBE interviews with five EBEs, and my autoethnographical data comprised of analytic autoethnography woven throughout the research, and my evocative autoethnography describing my own journey to becoming an EBE in 'Chapter Five', form the dataset for this research. The evocative autoethnography was written following completion of the in-depth EBE interviews, and it reflects upon the significant moments in my life that informed my becoming an EBE, informed by the key themes that had emerged in the interviews I conducted with fellow EBEs. The in-depth EBE interviews were thematically analysed, and their findings are presented in 'Chapter Six'.

THESIS STRUCTURE

The thesis is composed of seven chapters, with this chapter, 'Introduction to Research', comprising 'Chapter One'. The six remaining chapters of the thesis are sequenced and structured as follows. 'Chapter Two' is 'Theoretical Framework and Key Concepts'. This chapter considers the post-structuralist theoretical framework this research is founded upon, and the key concepts which are central to conceptualising the research topic. These concepts include: power, power-knowledge, hegemony, the biomedical model of mental illness, the social model of mental health, and the 'Expert By Experience' in the literature. 'Chapter Three' is 'A Critical Analysis of the Development of Irish Mental Health Policies and Legislation: From the Lunatic Poor to the Emotionally Distressed'. This third chapter demonstrates the socially constructed nature and different conceptualisations of mental health and distress in Ireland from the early 19th century to contextualise how Irish mental health policy arrived at AVFC in 2006. 'Chapter Four' is 'Methodology', which outlines the research design, the research methods used, and the process of conducting the research. 'Chapter Five' is 'Becoming'. This chapter is my evocative autoethnography which details the journey I took to become an EBE. 'Chapter Six' is 'Thematic Analysis and Discussion', which presents the findings of the in-depth interviews with mental health EBEs. This sixth chapter describes the journey these EBE peers took to become EBEs, and the 'steps' which define their journey.

‘Chapter Seven’ is ‘Conclusion’, which discusses the findings of this research, the gap in knowledge which it contributes to, and the form this contribution to knowledge takes, together with some recommendations.

CONCLUSION

This introductory chapter has introduced the wider research area this study investigated, while also detailing the discrete research topic it focusses on. The origins of my interest in this research and this policy area were explained in line with the autoethnographical nature and EBE focus of this research. The background to and rationale for the research were detailed. The theoretical context that underpins the entire piece, and the methodology I developed in line with it were explored. The two parallel research strands used in the research were elaborated upon, and the cohort of interviewees and their specific expertise as related to mental health policy and practice were examined, and an overview of the thesis’ structure was provided.

CHAPTER 2: THEORETICAL FRAMEWORK AND KEY CONCEPTS

INTRODUCTION

This chapter presents the research's theoretical framework, an exploration of the concept of power, a comparison of the dominant models of viewing mental health through which power has historically been exercised in Irish mental health policy and practice, and a consideration of the role of the Expert By Experience (EBE) in redressing issues therein. The concept of power is central to this research due to its focus on the lived experience of EBEs and their engagement with powerful medical institutions. A discussion and understanding of power, specifically from a Foucauldian perspective, is also important to frame the research's analysis of how power has historically been distributed to policy stakeholders by government in the Irish context. This power has traditionally been exercised through two distinct models of mental health. These are the biomedical model of mental illness, which has been the predominant model, and more contemporarily, the social and biopsychosocial models of mental health.

The chapter begins with an outline of the research's post-structuralist, social constructivist theoretical framework. The concept of power as hypothesised by key thinkers and theorists in the literature is then discussed. An exploration of power as it is conceptualised through this research's combined Foucauldian power-knowledge (Foucault, 1977; 1980) and Gramscian (1971) cultural hegemonic theoretical lens follows, with a consideration of Foucault's analysis of the history of madness and biopower (1965). The biomedical model of mental illness and the social model of mental health are then defined. The chapter concludes with a consideration of the nature of expertise by experience and the potential of an EBE stakeholder sphere to redress power imbalances present within Irish mental health policy and practice.

THEORETICAL FRAMEWORK: POST-STRUCTURALISM AND SOCIAL CONSTRUCTIVISM

This research is founded upon a post-structuralist, social constructivist theoretical framework and epistemology. This epistemology holds that there is no one knowable, objective 'truth', nor are there knowable social 'facts' (Foucault, 1977; 1980). From a post-structuralist perspective, there are many 'truths', 'facts', and knowledges developed and held by different social groups resulting from their unique experiences of the exercise of power-knowledge in

their society (May, 2012). Within a social constructivist framework, the 'truths' and 'facts' that a society recognises and accepts as 'true' are developed from observations made by learners and theorists, who proceed to construct knowledge from them based upon their own social and cultural understanding of the world. These theorists' understandings of the world are informed by their social world and the knowledge they have already learned and accepted from this specific social world through channels including language and culture, all of which are affected by the exercise of power-knowledge. As the process of power-knowledge is ongoing, knowledge developed from these 'truths' and 'facts' is (re)produced and constructed. It is not static. From a constructivist perspective, then, all knowledge is historically contingent and constructed (Foucault, 1980: 81-87).

Vygotsky discusses the interplay between culture and meaning-making by learners and observers. He gives an example which illustrates the socially constructed nature of knowledge: "A special feature of human perception… is the perception of real objects… I do not see the world simply in color and shape but also as a world with sense and meaning. I do not merely see something round and black with two hands; I see a clock…" (Vygotsky, 1968: 39).

POWER

Conceptualisations of power

Power is concerned with the capacity and strength an individual or group has to exercise their will. As it exists and is exercised between individuals and groups, power is relational (Dahl, 1957). Giddens defines power as "the ability of individuals, or the members of a group, to achieve aims of further interests they hold" (Giddens, 2006: 1029). Weber (1922) viewed power as exercised in society either legitimately, or illegitimately. Weber identified legitimate power as exercised in society through three distinct forms of authority. These were traditional authority (based on a society's established patterns), charismatic authority (exercised by individuals with force of personality), and rational-legal authority (based on power legitimised through accepted laws and rules) (1922). Weber classified power exercised outside of the three forms of authority as illegitimate, coercive control. Coercive control is illegitimate power exercised through the use of force, including threats of violence. It is not consensual. One notable form of coercive control exercised in society is that of domestic violence (Walby & Towers, 2018). This form of illegitimate power and abuse is exercised and facilitated through patriarchy, which is a key concept in feminist theory. Walby defines patriarchy as "A system

of social structures and practices in which men dominate, oppress and exploit women" (1989: 20).

Spicker (2008) identified three different types of power: economic, social, and political. Spicker's typology is greatly informed by Lukes' theory of the 'three dimensions of power' discussed below (Lukes, 2005). Though distinct from each other, Spicker's three types of power are interrelated. Spicker sees power as exercised by elitists or pluralists. Pluralists theorise power as widely dispersed or "diffused" in society (Bachrach & Baratz, 1962: 947). Dahl, a pluralist theorist, considered that political outcomes are decided upon through competitive relations between interest groups with different, unbalanced degrees of power (Dahl, 1961, 1967). Elitism, a critical response to the position of pluralists, holds that power is instead concentrated and held by a specific group who can access political and economic resources in a society. Elitism and pluralism are interconnected with the concept of class, which is fundamental to Marxist critiques of power. Marxism, specifically Instrumental Marxism, critiques an elitist approach to power. It holds that the actors exercising power in the state in an elite model come from their own class. They will bring their experiences and outlooks from this class into their exercise of power (Goldstein, 2004). As a result, the power they exercise and the policy and law they create will not be in the best interests of all, but instead it will further their own interests and concerns through nepotism and favouritism (Codato & Perissinotto, 2010; Poulantzas, 1967, 1968, 1978a, 1978b). This view of statutory power views laws as tools used by the elite to maintain their economic power and ideological power through cultural hegemony (Gramsci, 1971).

Lukes' theory of the 'three dimensions of power' holds that power has three dimensions or 'faces' (1974, 2005). The first dimension or 'face' is decision making, concerned with an individual's or collective's ability to determine a course of action based on an assessment of their situation, and successfully see it through. This action can be coercive or non-coercive on the part of the actor. This 'face' corresponds to a pluralist conceptualisation of power. The second 'face' is agenda setting, which describes the extent to which a person or group controls the boundaries of a discussion. In social policy terms, this refers to the extent to which a person or group can control the content of policy debates. This means that those who set the agenda can promote certain areas of the agenda by selecting them while silencing other areas that they wish to prevent from being furthered, influencing the outcome of the debate in their favour.

The third ‘face’ of power, according to Lukes, is ideological power. This ‘face’ is influenced and informed by Gramsci’s theory of hegemony (1971), and the exercise of power-knowledge described by Foucault (1977, 1980). Ideological power is exercised in the socialisation that individuals in a society undergo to accept the hegemonic ideology of the dominant social group, who have the most decision making and agenda setting power. This is often achieved without individuals even realising, such as through advertising, charismatic speeches by those who hold power, and the exercise of power-knowledge on our bodies through processes of biopower in schools, clinics, and prisons. Foucault introduced the concept of biopower in 1976, and Nail succinctly defines it as “political control over life and living beings” (Nail, 2016: 249). This third ‘face’ exists to prevent conflict and dissent. As Lukes notes “The most effective and insidious form of power is to prevent… conflict from arising in the first place” (2005: 27).

Biopower is the real-world application of Lukes’ ideological power, informed by Gramsci’s theory of hegemony. It is a method of normalising the dominant social group’s ideas, and functions to make these ideas seem natural. Biopower operates to further the interests and ideology of those exercising it, and produces Gramscian hegemony through normalisation and ‘abnormalisation’ (Visoka & Lemay-Hébert, 2022: 3). These concepts are discussed further on in this section. Hegemony, and Lukes’ third ‘face’ of ideological power, incorporate the minoritised and subordinate (Gramsci, 1971; Lukes, 2005). This incorporation alienates these minoritised and subordinated groups’ understandings of the world from them as the strength of hegemony and ideological power makes their place in society appear inevitable (Boggs, 1976; Joll, 1976). Crehan notes aspects of hegemony in her work exploring Gramsci’s stance on ‘common sense’:

> The narratives that become hegemonic are those that reflect the world as seen from the vantage point of the rulers rather than the ruled. Those that emerge from less privileged locations are forced to exist within the interstices of the dominant explanations; an ability to impose commonsense truths, which assume that existing power relations are the only ones possible, is a crucial dimension of any power regime. (2016: 51)

Gramsci considered the insidious nature and problematic implications of hegemony and ideological dominance when he discussed the problem of their expression in a society as ‘common sense’. For Gramsci, a society’s ‘common sense’ represents the dominant ruling group’s discrete ideology successfully becoming hegemonic, appearing ‘natural’. This ideology has been normalised so that it is not now recognised *as* an ideology or a political position any longer. It is simply ‘common sense’. As such, for an individual to critique it or

question it would be for them to critique or question the naturally occurring. This suppresses critiques, and is so pervasive as to almost be imperceptible. In this way, Gramsci's perspective on common sense is closely linked to Lukes' third face of power:

> Emerging out of a world structured by inequality, common sense's ever-shifting accumulations of disparate truisms are the precipitates of heterogeneous life worlds occupying quite different social and economic locations. The narratives that become hegemonic are those that reflect the world as seen from the vantage point of the rulers rather than the ruled. (2016: 51)

The subordinated understandings held by the minoritised groups' form Foucault's "subjugated knowledges" (Foucault, 1980: 81). Subjugated knowledges are those which do not form part of the normalised, hegemonic ideology or "common sense" achieved through ideological power discussed by Lukes and Gramsci.

Power and knowledge

According to Foucault's theory of power-knowledge (*pouvoir-savoir*), power is not something static that is 'held', it is something that is exercised by those who dominate the discourse (knowledge) (Foucault, 1977, 1980). This is a departure from earlier theories of power as something held by individuals, or *an* individual in the case of Hobbes' sovereign in *The Leviathan* (1651). Power and knowledge have a symbiotic relationship whereby they contingently produce and reproduce one another in an ongoing process (Foucault, 1977, 1980). This mutuality can be indicated by hyphenating 'power/knowledge' to become 'power-knowledge'. Such a post-structuralist understanding of power and knowledge is distinct from positivist understandings of power being solely a political phenomenon, or of knowledge being related only to epistemology or pedagogy.

Foucault's theory of power-knowledge posits that power and knowledge do not exist as two separate, discrete phenomena. They are two sides of the same coin. Through this lens, knowledge does not exist as one objective, universal understanding of the world. Power is instead something that is exercised. In lieu of one objective universal knowledge, different understandings of the world held by those who belong to minoritised or othered groups outside of the majority are developed into "subjugated knowledges" by these groups (*savoir des gens*), which are subjugated through the exercise of power and normalisation by those within the dominant social group (Foucault, 1980: 81).

When socially constructed knowledge developed by learners and theorists becomes accepted and established as 'truths' and 'facts' within their broader society as outlined above, this accepted knowledge is then reproduced through power-knowledge relations by the most powerful social and cultural group, and spreads further. The knowledge becomes dominant, and achieves normativity. The power and ubiquity of the knowledge in society makes it appear 'natural', rather than being one knowledge of many held by different social groups. In turn, this dominant social group is seen to be 'normal' through the process of normativity. In her analysis of Foucault's philosophy, May finds that:

> Although normalization lies deeply embedded in our conception of who we are, it does so only by means of its influence and by its inherence in so many of our practices. There are other ways we can be, ways that can be explored through the construction of new practices. Who we are now is historically contingent. (2006: 83)

Gramsci called the process of one social group's ideological and social dominance over others 'hegemony' (Gramsci, 1971). The dominant hegemonic knowledge subjugates and oppresses the knowledges and members of those in minoritised groups through the exercise of power. Foucault identifies this oppression as a defining characteristic of "subjugated knowledges": "By subjugated knowledges… I am referring to the historical contents that have been buried and disguised in a functionalist coherence or formal systemisation." (Foucault, 1980: 81).

Reflexively considering my own role in this research and this discussion autoethnographically at this point is important. As a learner and observer in my own social world, I am constructing knowledge through this piece of research. I am centring myself and my own lived experience firmly in this analysis. This is to acknowledge the socially constructed nature of knowledge, my reasons for conducting this research, and my history with the topic. I approach research to produce intellectually honest findings. Social constructivism does not inherently hold that knowledge, due to its unfixed nature, is unknowable. It does not lead to the conclusion that, if all "truths" and "facts" are constructed, then they are invalid or not worth pursuing. It is my own understanding and epistemological stance that when the researcher acknowledges that their observations, facts, and the knowledge they contribute are inalienable from their social world and personal experience ontologically and epistemologically, they site themselves in the work and produce a contribution to knowledge which is not intended to be definitive or to represent one universal "truth". Social constructivism and post-structuralism, through their

acknowledgement of different knowledges, encourage research to be conducted from the perspectives of those with "subjugated knowledges" (Foucault, 1980: 81). This research constitutes such a piece of research.

Epistemologically, the production of knowledge, particularly knowledge in the social or medical sciences, is contentious when it is presented in objective, normative language. Altman (2002: 317) summarises this as follows: "For those of us engaged in that broad range of disciplines usually summarized as encompassing humanities and social sciences, the claim to objectivity and science too often becomes… a form of intellectual dishonesty".

Biopower and mental health

Normalisation is a function in the exercise of power by the dominant social group, as normalisation offers their practices and ideologies legitimate authority. With this legitimacy, normalised social norms, mores, and roles can be institutionalised and replicated through the monitoring and control of individuals. This is done to identify that which is abnormal or deviant, to exercise power to correct it. Normalisation is carried out in practice using statutory apparatus and institutions where power-knowledge is exercised. Discussing the function of normalisation, Visoka and Lemay-Hébert argue that:

> abnormalization is constructed and sustained through knowledge production in the form of reports, metrics, and statistical analysis, which categorizes state performance across different scales. In short, the very act of normalization makes certain practices abnormal, which serves as the locomotive for justifying intervention and maintaining unequal power relations. (2022: 3)

Foucault noted schools, hospitals, asylums, and prisons as institutions that existed to fulfil this corrective social function of abnormality through their oversight and management of bio-power using examinations which create data from which levels of normalcy and performance amongst peers through averages can be measured. Regarding this process, Gutting explains "On the basis of these records, those in control can formulate categories, averages, and norms that are in turn a basis for knowledge." (2019: 86).

Biopower is a concept Foucault first discussed in his literary work in 1976's *The History of Sexuality*. He defined biopower during his lecture series at the Collège de France between 1977-1978 as such:

> By this [biopower] I mean a number of phenomena that seem to me to be quite significant, namely, the set of mechanisms through which the basic biological features of the human species became the object of a political strategy, of a general strategy of power, or, in other words, how, starting from the 18th century, modern Western societies took on board the fundamental biological fact that human beings are a species. This is what I have called biopower. (Foucault, 2007: 1)

From the mid-to-late 18th century to the present day, psychiatry has mostly been seen by the social majority as holding expert power (French & Raven, 1959) due to the training psychiatrists undergo and their distinct, expert learned knowledge. This has afforded psychiatry the ability to exercise legitimate power through the medical model of mental illness in the Modern Era. Foucault explored the history of madness in *Madness and Civilization* (1965) and the apparatus of the asylum as exemplars of power-knowledge and biopower in controlling deviance and that which was deemed abnormal (1965, 1976, 1977). The role of the asylum was to confine, discipline, punish, and control social deviants who demonstrated signs of madness (perceived abnormality):

> Everything was organized so that the madman would recognize himself in a world of judgment that enveloped him on all sides; he must know that he is watched, judged, and condemned; from transgression to punishment, the connection must be evident, as a guilt recognized by all. (Foucault, 1965: 267)

According to Foucault's critiques of madness and the clinic, the meaning of madness changed and evolved to represent the dominant ideology of specific epochs, from the Renaissance to the Classical Age, through to the Modern Era. In the Renaissance, those experiencing madness were perceived to hold a specific wisdom which reflected the mysteries of cosmic tragedy (Foucault, 1965). The 'mad', rather than being seen as lacking reason, were seen to have their own intellect with which they engaged with rational individuals. This view has some similarities to the views espoused by the Hearing Voices Movement (HVM), particularly related to individuals who hear voices or experience other forms of what would medically be seen as severe mental illness (Romme & Escher, 2011).

The HVM offers an alternative, holistic, and person-centred perspective on the phenomenon of voice-hearing. It suggests that the experiences of those who hear voices and the voices they hear hold a deeper meaning which should not be viewed as dangerous psychopathy. Higgs (2020: 133) notes that "The Hearing Voices Movement identifies these experiences as having personal, relational, and cultural significance". This has been embraced by many people in this

demographic as far more liberating and positive for their wellbeing and sense of self than the approach from which the medical model has traditionally led.

By contrast, and parallel to Renaissance literature and art's changing perspective of the mad as possessing a unique wisdom to demonstrating 'unreason' as per Foucault's analysis, the biomedical approach sees those who hear voices or hallucinations as experiencing psychosis or a schizoaffective disorder such as schizophrenia. These diagnoses have been seen as "constructs" by some in the HVM (Higgs, 2020: 134). Through the lens of the medical model, these conditions are chronic, physically-sited illnesses with uniquely negative outcomes when compared with all other mental illnesses (Lavretsky, 2008). They present an immediate problem to the individual suffering from them and, potentially, those around them and larger society, as they are indicative of dangerous unreason (Raine, 2006). The voices and hallucinations are something that the individual must view as a symptom of a physical sickness, devoid of any metaphysical meaning, which they should compartmentalise and treat (Häfner, 2002; McGlashan et al., 2010; Murray et al., 2005). This difference in perspectives between the progressive view of voice-hearers in the HVM and the traditional medical view of psychosis and schizophrenia, demonstrates the constructed nature and power over individuals and institutions that ideologies command.

For Foucault, (1965), during the Classical Age when reason and morality were the two dominant criteria through which a person's wellness and worth were measured, madness accordingly became a matter of unreason, insanity, and moral failings. With this conceptual shift began "the Great Confinement" in Europe, which marked the beginnings of the mass institutionalisation of society's undesirables. This Confinement began in the 17th century and progressed through the 18th century. This marked a turning point, with legal systems being created to permit systemic social control and containment of these undesirables (the insane, prostitutes, the blasphemous, etc.) in insane asylums and other institutions. This was done in order to separate these individuals and their moral contagion from decent society. In considering the Mass Confinement, Foucault (1965: 39) states the following about this institutionalisation of society's unwanted together, its true purpose, and the beginnings of psychiatric dominance and theories of mental illness:

> … this proximity [in the asylums] which seemed to assign the same homeland to the poor, to the unemployed, to prisoners, and to the insane. It is within the walls of confinement that Pinel and nineteenth-century psychiatry would come upon madmen; it is there – let us remember – that they would leave them, not without boasting of having "delivered"

> them. From the middle of the seventeenth century, madness was linked with this country of confinement [the asylums], and with the act which designated confinement as its natural abode.

As these individuals were considered to be suffering from the consequences of their moral ineptitude and failing, these institutions would impose systems of punishment, which the state believed would allow the deviants to repent and choose the correct moral path (Foucault, 2009). It was not for the inmates' wellbeing that this was done, it was to punish and control them through the exercise of statutory power. Discussing the rationale and function of one of France's first established asylums, *l'Hôpital général de Paris*, Foucault stated that "In its functioning, or in its purpose, the Hôpital Général had nothing to do with any medical concept. It was an instance of order, of the monarchical and bourgeois order being organized in France during this period." (Foucault, 1965: 40). This excerpt demonstrates the utility of the asylum as a novel means of controlling deviancy as defined by those in the majority societal group. With the asylum, those who held legitimate power physically manifested their hegemony in practices of confinement of those who did not conform to their normalised ideology of reason and morality, through biopower, within brick-and-mortar institutions and exercised on individuals' bodies. The legislative beginnings of the lunatic asylum in Ireland and its evolution and adoption of the biomedical model in practice through psychiatry is explored in 'Chapter Three'.

The Great Confinement of the Classical Age laid the groundwork for the psychiatric institutions of the 20th century and contemporary times, though they have drastically changed in their operation over time. Foucault reflects this changing nature of the institutions and their rationale and purpose based on the evolving meaning and ideologies surrounding madness in the final era he analyses – that of the Modern Era. The Modern Era began at the close of the 18th century, and signalled the era of asylums transitioning into mental institutions administered by medical doctors (psychiatrists). This medicalisation was undertaken due to the changing ideological stance which moved away from conceiving madness as a moral issue, or one of 'badness', to one of physical illness and malady. This new medical view of madness ushered in the age of the medical model, which views madness as mental illness, to be treated and cured.

For Foucault, this move offered the endeavour of institutionalising the mad away from the social majority a veneer of compassion and increased scientificity. The impetus now was on providing therapeutic interventions to those in the mental institutions, rather than solely confining them (Foucault, 1965). However, this latter function of confinement was still a

primary application of the admittance of individuals to mental institutions. This transition away from the language of asylum to that of the mental institution which Foucault describes is reflected in the policies and law corresponding to this timeframe within the Irish context, detailed in 'Chapter Three'. In considering where society's ever-changing constructed meanings of madness and the associated practices and means of engaging with the mad employed by the social majority had led modernity to at the time of his analysis, Foucault noted the following:

> … modern man no longer communicates with the madman: on the one hand is the man of reason, who delegates madness to the doctor, thereby authorising no relation other than through the abstract universality of illness; and on the other is the man of madness… There is no common language: or rather, it no longer exists; the constitution of madness as mental illness, at the end of the eighteenth century, bears witness to a rupture in a dialogue… The language of psychiatry, which is a monologue by reason *about* madness, could only have come into existence in such a silence. (1965: x-xi)

To understand the ever-changing social meaning of 'madness' in Irish mental health policy and practice, and how power has been exercised therein and by who, it is necessary to describe the two dominant models which Irish policy and practice have historically been founded on. These are the biomedical model of mental illness, and the social model of mental health. Both models have distinct ideological backgrounds, outlooks, and views on who has expert power which distinguish them from one another. The next section provides an overview of these two models.

THE BIOMEDICAL MODEL OF MENTAL ILLNESS AND THE SOCIAL MODEL OF MENTAL HEALTH

The biomedical model of mental illness (the biomedical/medical model) and the social model of mental health and disability (the social model) are markedly distinct from one another. The biomedical model is a model which views mental and emotional distress as manifestations ('symptoms') of discrete, physically-sited mental illnesses. These mental illnesses are understood to be the direct result of biological pathology, specifically pathologies in an individuals' neurochemistry (Deacon, 2013). This view of neurochemical problems as the cause of mental illnesses is known as the chemical imbalance theory (Ang et al., 2022; France et al., 2007; Lacasse & Leo, 2015; Moncrieff et al., 2022). An individual's subjective distress, therefore, only constitutes symptoms of an objective illness to be diagnosed, treated, and cured by medical practitioners, namely psychiatrists. The contents of the individual's distress are not

meaningful (Dogra & Cooper, 2017; Kenneth & Kendler, 2014; Thoits, 1999). This model has been criticised for over a century for its reductionism (Rocca & Anjum, 2020: 75; Rudnick, 2002). The social model of mental health and disability contests the biomedical model. It constitutes a direct response and counter position to that of the 'mental illness' espoused by the biomedical model, in the form of its conceptualisation of distress as a socially-sited and, in many cases, socially-rooted phenomenon (Davidson et al., 2016: 46; Goffman, 1961; Scheff, 1966). This section of the chapter will outline the rationale and central concepts of both models, as well as the effects they have had when put into practice in mental health treatment.

The biomedical model

Terminology and definition

The term 'biomedical model' is used interchangeably with the term 'medical model' in academic discussions of mental health and mental illness. As an EBE (Expert By Experience) conducting this research autoethnographically, I have used both terms when discussing the same phenomena throughout the research, as they are part of my lexicon. This is a result of the ubiquity of both terms' synonymity amongst EBEs when discussing their lived experiences. The EBEs who participated in interviews for this research similarly used both terms interchangeably. We do so unconsciously, and this use of language is an expression of our subjugated knowledge when discussing some of the most significant parts of our experiences relating to medical interventions in our distress.

'The medical model' is a term first coined by the influential critical psychiatrist, R.D. Laing, in 1969. He defined a medical model as a "set of procedures in which all doctors are trained." (Laing, 2018 [1969]: 39). Laing's defining characteristics of the medical model are succinctly outlined by Siegler et al. (1971: 84) as ""definition", "etiology", "treatment", "prognosis", "the rights and duties of the patient" and so forth, and they constitute the dimension of the model." This definition has applications outside of the field of psychiatry alone, encompassing all medical or medicalised fields of practice and inquiry. Its terminology and concepts have accordingly been enthusiastically adopted, refined, elaborated on and critiqued from different perspectives and disciplines. This widespread use has given the term its ubiquity in academic discourse and in public understanding.

Psychiatric applications of the medical/biomedical model

The biomedical model of mental illness utilised in psychiatric treatment is applied by diagnosing an individual's biologically-sited mental illness(es) from the nosology (classification of disease) of the Diagnostic and Statistical Manual (DSM). The DSM, which is currently in its 5th revised edition (APA, 2013, 2022), is sometimes called "the bible of psychiatry" (Horwitz, 2021; Paris & Phillips, 2013: v). It is produced by the American Psychiatric Association (APA). Kawa and Giordano (2012: 1) eloquently summarise the impact, implications, and applications the DSM has had:

> Translated into over twenty languages, referred to by clinicians from multiple schools, as well as by researchers, policy-makers, criminal courts, and third-party reimbursement entities, the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM) enjoys a nearly hegemonic status as the reference for the assessment and categorization of mental disorders of all types.

Once correctly diagnosed from the DSM through a psychiatrist's subjective evaluation (Fuchs, 2010; Nordgaard et al., 2013), the mentally ill individual is then treated using pharmacological interventions intended to target their specific illness(es). The aim is to cure the individual from their illness(es). Deacon (2013: 846) defines the biomedical model as follows:

> The biomedical model posits that mental disorders are brain diseases and emphasizes pharmacological treatment to target presumed biological abnormalities. A biologically-focused approach to science, policy, and practice… the use of psychiatric medications has sharply increased and mental disorders have become commonly regarded as brain diseases caused by chemical imbalances that are corrected with disease-specific drugs.

Psychiatry's widespread overreliance on psychotropic medications as the first, and often only, line of treatment deployed in the medicalised approach to treat perceived mental illnesses and their 'symptoms' is a key characteristic of the biomedical model. The efficacy and rationale for the use of these medications is a primary concern in academic discussions of biomedical psychiatry (Jobes & Chalker, 2019; Kaminskiy et al., 2021; Paris, 2015; Sedler, 2016).

The history and development of the psychiatric biomedical model

Laing had developed his definition of the medical model to explain the ideological move towards a biological understanding of most illnesses across all fields of healthcare provision that had gained momentum and power from the end of the 19th century through the 20th century

in the West (Laing, 2018 [1969]). This ideological and practical shift was a result of the profound impact of Germ Theory, developed in the 19th century by Pasteur, Koch, and Lister to explain the aetiology (the cause of disease) of a number of physical diseases. Emil Kraepelin synthesised this biological materialist perspective into his philosophy of mental and emotional distress by developing a nosology of physical, endogenous (internally-occurring and unrelated to external matters) mental illnesses (Kraepelin, 1899; Heckers & Kendler, 2020; Shorter, 2022). His nosology stated that the different categories of mental illness and pathology he identified were caused by biological and genetic factors (Kraepelin, 1899). Hoff (2015: 33) notes that "Kraepelin strongly advocated the view that different mental disorders are categorically distinct objects, "natural kinds" or, as he usually put it, "natural disease entities" *("naturliche Krankheitseinheiten"*)".

This Kraepelinian perspective, and the use of nosology to classify and medicalise mental and emotional distress would eventually expand, evolve, and become hegemonic (Shorter, 2022). Demonstrating that conceptualisations of mental health, mental illness, and distress have always been contended and contentious, it is interesting to note that psychiatric ideology had not entirely galvanised behind this purely biological explanation of mental illness during the early 20th century, although it was highly influential.

The early 20th century saw Freud's psychodynamic theory of psychoanalysis gaining influence in conceptualisations and classifications of distress. Freud's theories posited that human experience and distress are affected and shaped by external factors. Distress, from Freud's psychodynamic perspective, could best be resolved through psychoanalytical talk therapy exploring the individual's subconscious world to get to the root of their distress (Erdelyi, 1985; Thurschwell, 2009). This was reflected in the understanding of mental illness presented in the first and second DSM (APA, 1952, 1968) as having both biological *and* psychodynamic causes. Kawa and Giordano describe this:

> Psychodynamic theory gained rapid acceptance in both the clinical and academic arenas of psychiatry, and by 1946, was officially acknowledged as the leading school of thought by the American Board of Psychiatry. Respective of changing conceptualizations of mental disease, and a broadening of psychiatric clientele… the APA Committee on Nomenclature and Statistics sought to create a new classification system: the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-I). (2012: 3)

This understanding was influenced by psychiatry's growing scope in the early-to-mid 20th century, referenced in the above passage. Those seeking help for their distress now included

individuals experiencing distress in the community. These people were presenting for help with distress that was not severe enough for institutionalisation. Such functional distress was categorised as 'neuroses'. Discussing what a neurosis *was* at this time, and simultaneously demonstrating the expanding application of psychiatry as a tool of biopower functioning to control social deviance and define abnormality through power-knowledge, Horney (1939: 426) wrote that:

> The need to define a neurosis has developed only recently with the realization that psychic disturbances need not consist only of gross malfunctions, as was held in the latter part of the nineteenth century, but may consist of character trends of a particular nature, the sum total of which interferes with the individual's happiness… every neurosis is essentially a character disorder. This view introduces social viewpoints into a field claimed by medical psychiatry.

As the 20th century progressed, psychiatry's primacy as *the* field to identify and treat specific forms of distress under the typology of mental illness grew. The biomedical model grew with it, with the advent of the first psychotropic medications. These were hugely successful in furthering the acceptance of a medicalised understanding of mental illnesses as physical illnesses caused by chemical imbalances of serotonin, dopamine, norephedrine, and others, with an endogenous aetiology (Park & Ahm, 2009; Schroder et al., 2022). The chemical imbalance theory was adopted and normalised by modern psychiatry from the mid-20th onwards, with Leo and Lacasse (2008: 35) noting that "the idea that neurotransmitter imbalances cause depression is vigorously promoted by pharmaceutical companies and the psychiatric profession at large". Using the chemical imbalance theory as its scaffolding, psychiatry created a colossal nosology of classifiable mental diseases. This typology, enshrined as objective knowledge in the DSM, became the hegemonic ideology through which the seemingly enlightened and humane understanding of madness as physical mental illness was normalised. This came at the expense of the psychodynamic approach in psychiatric hegemony.

When Spitzer was tasked with compiling diagnostic criteria for the third DSM, DSM-III (APA, 1980), he approached the undertaking with "the formal operationalization of psychiatric diagnosis with established reliability and validity" (Surís et al., 2016: 5) as a primary concern. He sought to offer the already medicalised field, which was already dominant, increased legitimacy and scientificity through a more detailed and comprehensive nosology of mental illness. Surís et al. (2016: 5) discuss the profound effect this tactical ideological incorporation

of a wholly medicalised view of mental illness had on psychiatric hegemony and the legitimacy it afforded to the power-knowledge psychiatry exercised:

> The changes in the diagnostic criteria in DSM-III were highly controversial and contributed to a radical redirection of American diagnostic criteria for psychiatric disorders that represented a major paradigm shift. These advancements were part of a larger movement at the time in American psychiatry to re-medicalize psychiatry, grounding the field in empirical research. The new empirically-based and operationalized definition of mental disorders in DSM-III added legitimization to the field as a medical specialty.

The DSM-III was potentially the most significant edition of the DSM in terms of the impact it had. The diagnostic criteria presented in the DSM-III were used extensively in psychiatric diagnoses of mental illnesses as noted in the literature from the period analysing diagnoses from psychiatric and psychological perspectives (Craig et al., 1982; Maser et al., 1991). The legacy of the DSM-III in cementing biomedical psychiatric hegemony in practice has been studied by Decker (2013). She describes the DSM-III as "a path-breaking and revolutionary work—for good or ill…" (2013: xxi).

As such, the classification of disorders it described contributed significantly to the normalisation of mental illness as a biological illness, and the hegemonic conceptualisation and social acceptance of mental illnesses and how common they were. The biomedical model of mental illness had been finely tuned with the DSM-III. The model's legitimacy and authority as *the* means of understanding distress and responding to it in in policy and in practice was further expanded with the development and mass production of different categories of new psychotropic medications. Selective-serotonin reuptake inhibitors (SSRIs), in particular, were hugely influential in seemingly giving credence and legitimacy to the medical model, the chemical imbalance theory, and psychiatric nosology from the 1990s onwards (Moncrieff, 2008; Smith, 2014; Timimi, 2014).

In a significant, comprehensive 2022 umbrella review of meta-analyses and systematic reviews of the literature investigating the scientificity and existence of the chemical imbalance theory, Moncrieff et al. found that the chemical imbalance theory positing a deficiency of serotonin as the cause of Depression was unfounded, unsubstantiated, and false: "Our comprehensive review of the major strands of research on serotonin shows there is no convincing evidence that depression is associated with, or caused by, lower serotonin concentrations or activity."

(2022: 3253). Regarding the medical model and chemical imbalance theory's proliferation and success, they note the role that SSRIs played in popularising the theory:

> A link between lowered serotonin and depression was first suggested in the 1960s, and widely publicised from the 1990s with the advent of the Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants. Although it has been questioned more recently, the serotonin theory of depression remains influential… Surveys suggest that 80% or more of the general public now believe it is established that depression is caused by a 'chemical imbalance'. Many general practitioners also subscribe to this view and popular websites commonly cite the theory. (2022: 3244)

The objectivity with which psychiatry presents the medical model has been questioned by a growing body of people with lived experience, academics, and psychiatrists themselves critiquing the model (Elkins, 2009; Galderisi et al., 2015; Ghaemi, 2018; Mechanic, 1999; Svensson & Hansson, 1994; Van Dyke & Hovis, 2014). These critical perspectives have been presented since psychiatry and the biomedical model began to act with legitimate authority (Engel, 1977). Two of the most notable early critics of the biomedical model and psychiatry's increasing remit to include the treatment of 'neuroses' in wider society were Szasz and Laing. They were both psychiatrists who perceived the increased medicalisation of distress and psychiatry's growing scope as an exercise in normalisation and the social control of deviancy, and not of a medical enterprise seeking to ameliorate the suffering of individuals (Laing, 1960, 1969; Laing & Esterson, 1964; Szasz, 1961, 1970, 1973).

Szasz and Laing's initial critiques demonstrate that different knowledges and understandings of phenomena exist from different perspectives, even from within the field which is normalising and controlling deviancy. The conceptualisation of mental illness as biological and psychodynamic in the first 2 editions of the DSM further elucidate that the medical model is not innately objective or true: it is simply the model that gained the most legitimacy and power through power-knowledge with the production of the DSM-III. The conceptualisations and perspectives of groups with subjugated knowledges have gained traction and momentum contemporarily, leading to the wider critiques and rebuttals of the medical model which have in recent times weakened its hegemony and dominance (Elkins, 2009; Galderisi et al., 2015; Ghaemi, 2018; Mechanic, 1999; Svensson & Hansson, 1994; Thompson, 2018; Van Dyke & Hovis, 2014). Psychiatric doctrine itself now largely acknowledges that it is only *an* approach, amongst many (Biesta & van Braak, 2020; Fusar-Poli et al., 2018; Freeth, 2007; Hogan, 2019; Huda, 2021). These critiques have weakened the hegemonic acceptance of the medical model

as fact, and allowed alternative perspectives and models of mental health to exercise more power. The most significant of these alternative models within the Irish policy context is the social model.

The social model of disability: dimensions of mental health

Background and definition

The term "social model of disability" was first coined by Mike Oliver, a sociologist living with a disability, and disability rights activist, in 1983. He defined it as follows:

> This new paradigm [the social model of disability] involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations upon certain groups or categories of people… Adjustment within the social model, then, is a problem for society, not for disabled individuals. (Oliver, 1983: 23)

The social model of disability (the social model) can be traced back to the work of disability activists within the Disability Rights Movement in the 1960s and 1970s. These activists were a part of the larger civil rights movement of the mid-to-late 20th century.

These individuals questioned the nature of their exclusion within societies which were increasingly employing the medical model in policy and practice. The perspective of the medical model that it was an individual's difference itself – their disability – that was the cause of their impairment did not correspond to these individuals' lived experience. For them, it was social structures, infrastructure, and inadequate supports which impaired them, not their difference itself. These social phenomena formed barriers to their meaningful inclusion, which could have been facilitated by changes or adaptations to them.

From this perspective, people with disabilities are no less capable of social and economic inclusion than those without disabilities just because of their disability. They are rendered less able to participate meaningfully when society and its structures and infrastructures are not designed to include them. Reflecting this, Boxall and Beresford (2013: 590) note that "… the social model of disability… removes the causal link between impairment (functional limitation) and disability (socially imposed restriction)". This is in line with the aim of the social model "to switch the focus of attention away from the functional limitations of

individuals with an impairment onto the problems caused by disabling environments, barriers and cultures" provided by Oliver (2004: 21).

The social model has been expanded and elaborated upon in the years since. It has been adapted and adopted by other thinkers and groups who use the concepts of difference and social impairment to describe their experiences of barriers in society. Boxall and Beresford describe this conceptual evolution: "Although the social model of disability was originally developed in relation to people with physical and sensory impairments, later discussions included people with learning difficulties, mental health service users and older people." (2013: 590). Most notably for the current research, this includes those who experience distress, with the social model of mental health being used to describe their experiences in a different and opposing way to that of the biomedical model. The social model represents a direct response and counter position to the concepts of the 'disability' and 'mental illness' espoused by the biomedical model, as impairments and distress are understood to be socially-sited and, in many cases, socially-rooted in the social model (Davidson et al., 2016).

Oliver noted this essential distinction in his initial definition of the social model (Oliver, 1983). He distinguished between the 'social model of disability', which was characterised by 'impairment', and the 'individual model of disability' that the medical model represented, which was characterised by individual 'disability' (Oliver 1983: 15-26).

The social model is, at least partly, an EBE-developed model of conceptualising difference, disability, and distress. Developed to contest the tenets of the medical model by those with lived experience of its practices and their effects on their lives, the social model represents an example of a minoritised group challenging the legitimacy and true purpose of the power exercised by the majority over them and others (Brosnan, 2013). The social model is informed by these individuals' firsthand understanding of the best approaches to dealing with the barriers and difficulties they face, based on their own subjugated experience and knowledge. The model is supported by many academics and service-providers as a more holistic, humanistic, and person-centred approach than the reductionist, deficit-based, and disempowering medical model. Barnes (2019: 14) explains the impact of the social model by describing how until it was developed, "'disability' was viewed almost exclusively as an individual medical problem or a 'personal tragedy' in Western culture".

It is important to note that, although the social model represents a valuable corrective to the over-medicalised dominant biomedical model of mental illness, it is a model, and not a full

theoretical account of mental health. This has been noted as it relates to disability in the literature by key thinkers in the field, including Oliver (Cameron, 2015; Oliver, 2004). For example, Shakespeare (2006) has found that the social model fails to account for the pain some people with disabilities feel on the individual level – the micro level. As it is a challenge to a medicalised model which does seek to offer a full theoretical account of mental health, it is important that the social model itself is receptive to and inclusive of critiques which highlight its limitations. This is particularly important as the social model exercises its own power-knowledge as an eminent counter-model to the biomedical model. One of the social model's defining critiques of the medical model is the latter's inaccurate and harmful focus on the micro – that is, its focus on the individual in its conceptualisations of impairments and distress. The social model, as discussed, instead focusses on the macro – the societal structures and barriers to inclusion which constitute the impairments or create the 'mental illness' that individuals with disabilities or who experience distress face. As Shakespeare noted, this focus on the macro has detrimental consequences in failing to capture the fullness of the person with disability's experience at the micro level (2006). Its focus on impairments rather than disability has also been found to limit the social model in facilitating the emerging discourse around the concepts of ableism and disablism (Campbell, 2005, 2009; Nario-Redmond, 2010, 2019; Watermeyer, 2012). These concepts describe the discrimination faced by those who identify as disabled.

The concepts of ableism and disablism are applicable to those who experience distress, and their own experience of discrimination (Bogart & Dunn, 2019; Cech, 2023; Green et al., 2020; Young et al., 2019). Under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Ireland signed in 2007 and ratified in 2018, 'long-term mental health difficulties' are recognised as a disability (United Nations, 2006). The UNCRPD uses the social model of disability as its theoretical framework, and the language of 'psychosocial disability' is employed throughout the Treaty. Ringland et al. note that "Psychosocial disability involves actual or perceived impairment due to a diversity of mental, emotional, or cognitive experiences." (2019: 156). There are individuals who experience distress who may not consider themselves disabled, though they are protected as such under both national and international laws and treaties. Macro classification (statutory and international legal definitions), does not preclude the individual on the micro level (self-perception) from identifying themselves in the way that best suits them. Although issues of self-identification are an individual matter for each individual, reticence to accept a space in the discourse of disability and the rights of disabled people may reflect internalised ableism and fear of stigma on the part of those individuals who

do not identify as having a disability, or choose not to disclose their identity (Bril-Barniv, 2017). These are, of course, not the only reasons an individual may choose not to identify as disabled, or why they may choose to identify or not identify as a member of any other community solely because they have experienced distress. The author wishes to state, as an individual with long-term mental health difficulties, he recognises the right of each individual to identify in the way that is right for them, according to them. Identity is a complex and personal phenomenon, and it is a fundamental right for each person to define themselves. Language is powerful, and as Reaume notes "no term in the history of madness is neutral, not mental illness, madness, or any other term" (2006: 183).

The above limitations to the social model, and the need for any theoretical account of mental health to acknowledge the multitude of factors which influence it and contribute to or cause distress, have led to the development of a more holistic model. This model is the biopsychosocial model.

The biopsychosocial model

The biopsychosocial model is a hybrid, holistic model which understands mental and emotional distress to be caused effected by biological, psychological, and social factors. It does not focus solely on the micro (the individual), or solely on the macro (society). The model focusses on the individual from both biological and psychological perspectives, combined with a focus on the social factors which influence the individual's mental health. This makes the biopsychosocial model a meso theory of mental health and distress. Davidson et al. (2016: 13) describe the biopsychosocial model and its relationship with the biomedical model:

> … it would be a mistake to suppose that there are two camps at permanent war [the biomedical and social models]. In more recent times the two models have been partly merged and today most medical practitioners adopt a "bio-psycho-social" approach, taking biological, psychological and social factors into consideration when assessing any patient or client.

The 'biopsychosocial' model was the model and ideology that informed the Irish government's third mental health strategy, *A Vision for Change* (AVFC) (Government of Ireland, 2006). This marked the first time a model other than the medical model was the driving force and dominant perspective in Irish mental health policy. As such, the model's history and application in Irish mental health policy is quite limited and brief when compared to that of the medical model. Its inclusion and use as the framework through which mental health and mental health service

provisions were understood in policy constituted a significant challenge to the power-knowledge and hegemony of the biomedical model in the Irish State.

The social model and power

The social model posits that an individual experiences impairment and disability as a result of the disabling effects of normalisation in society, and not directly because of their individual difference(s) from the social majority. It is an individual's 'difference' from the social majority, whose exercise of power-knowledge and biopower in institutions have normalised their experiences and physicality, which categorises persons with disability and those who experience distress as 'abnormal'. This is the process of abnormalisation described by Visoka and Lemay-Hébert (2022: 3), who note that "the very act of normalization makes certain practices abnormal, which serves as the locomotive for justifying intervention and maintaining unequal power relations". As such, disability is not the direct result of an individual's physical, developmental, or mental difference(s) – the experience of being disabled results from how society is organised. 'Disability' is the result of the interaction between people living with disabilities, and a disabling environment (Boxall & Beresford, 2013; Davidson et al., 2016; Oliver, 1983, 2004).

Conceived of this way, there is a clear power imbalance which acts to other and pathologise those with disabilities and those who experience distress through the medical model of mental illness and disability (Allsopp & Kinderman, 2021; Handerer et al., 2022; Kinderman, 2014). Those who exercise power-knowledge through biopower decide upon interventions and treatments which are appropriate for the individual – the 'patient' – accessing services, as described in this chapter (Foucault, 1976, 1977, 1980). It is not a collaborative or democratic process between 'doctor' and 'patient', but a power imbalance which favours the former.

In the social model, however, the service-user is an active participant in their care and treatment. There is co-decision making between the 'service-user', 'client', or 'consumer', and the 'service provider' (Sugiura et al., 2020) The use of these different terms to describe the parties engaging with the services and those providing them itself is an expression of the social model's exercise of power-knowledge to correct the power imbalances of the medical model. McLaughlin discusses the importance of this language, finding that

> The language we use labels individuals in different ways and, in so doing, acts as both a signifier and an external social control. Whichever label we use—'service user',

> ‘consumer’, ‘customer’, ‘client’ or ‘expert by experience’—it is descriptive not of a person, but of a relationship. (McLaughlin, 2008: 1114)

A ‘consumer’, ‘client’, or ‘service-user’ has agency, rights, and choice; they are choosing to use or consume the service being provided by the service-provider. As described by Sugiura et al. (2020: 52), “The approach adopted by the social model recognizes that people with psychosocial disabilities have the same right to take decisions and make choices as other people, particularly regarding treatment, and have the right to equal recognition before the law.”.

The language of ‘consumer’ and ‘service-user’ was developed by consumers and service-users to retake the understanding of their engagement with medical and mental health services. This language does not serve to define the entire person by their need or decision to access a service. Vicariously, it does not define them by the ‘disability’ or ‘distress’ they are accessing services for (Cowden & Singh, 2007; McLaughlin, 2008).

This is a move from the dehumanising, deficit-based language of ‘the patient’ used in the medical model, which defines the person by their impairment and strips them of agency and power in their interactions with the ‘doctor’. The language of the social model is a challenge to the false objectivity and function of social control which the language of ‘doctor’ offers to psychiatric and medical practitioners within the medical model. It illustrates that these practitioners may have expert knowledge (French & Raven, 1959), but they do not have *objective* knowledge. This language supports the social model’s central concepts of autonomy, agency, choice, and mutual respect between service-user and service-provider. Keyes et al. find “the importance of relational autonomy, based on Tronto's framework, in realising service imperatives rooted in empowerment… beginning with the individual, rooted in dialogue and embedded in whole organisations.” (2015: 236).

The service-provider exists in a consultative role with the service-user, rather than a labelling, prescriptive role. Discussing the person-centred nature of such approaches to service delivery, Davison et al. reflect this collaborative aspect. They describe how the service-user is themselves the expert in their own experience: “The person is the expert in his or her own life. The person themselves should lead the therapy as they are the ones who have a natural tendency to move towards what they need to self-actualise.” (2016: 36). Power-knowledge is therefore exercised from the perspective of those with lived experience and their will and preferences in

the social model, as a correction and challenge to the perspective of the service-provider and their imbalanced exercise of power-knowledge practiced in the medical model.

Social model of recovery

The concept of 'recovery' as understood in the social model of mental health and disability is one of its most distinguishing components. Recovery in the social model is a service-user defined concept, which differs significantly from a medicalised understanding of what 'recovery' represents. For service-users, people with disabilities, and those who experience distress, recovery is not understood to mean being 'cured' of an illness or disease, though this is possible (Deegan, 1993; Secker et al., 2002: 410). It is not the desired end goal of successful medical treatment, and the eradication of the illness, or disease and its 'symptoms' that the 'patient' had previously been afflicted with, as it is understood to be in the medical model. Ridgway (2001) describes a key characteristic of the social model of recovery being the individual's journey from seeing their disability as chronic and hopeless to seeing their life as far more content and dynamic.

Pilgrim (2008: 296) states there is a distinction "between 'recovery from' and 'recovery in' mental illness. The former is based upon recorded longitudinal evidence of people with diagnoses of severe mental illness becoming symptom free and not returning to the patient role." From the 'recovery in' perspective, he states that "Mental illness is viewed as a long-term condition that the person lives with daily, and tries to make progress about, despite their vulnerability to relapse to various degrees or even despite the ongoing presence of symptoms."

Ragins (2002) identified recovery from 'mental illness' as having four stages (Ragins & Sunkel, 2023). The first stage is hope, which helps to motivate the individual out of despair. The second stage is empowerment, when individuals become attuned to their sense of power and their capabilities. The hope they have coupled with empowerment helps the individual to identify opportunities and make their own choices. They may require encouragement and the belief of others in their capacity at this stage. This demonstrates the elements of community which are intrinsic to much of the social model of recovery. The third stage of recovery is self-responsibility, which entails individuals who suffer with distress taking responsibility for themselves, letting go of anger and blame associated with their distress, learning from mistakes, and breaking unhealthy dependencies. Ragins notes this can be a particularly difficult step. The fourth and final stage of recovery for Ragins is a meaningful role in life. At this stage, the individual experiencing distress must seek out meaningful connections, roles, relationships,

and interests in their life that are not connected to their distress. This could be seen as being a wholly realised individual, rather than an individual who is focussed only on a medicalised understanding of needing to 'cure' their illness before they can proceed with their life. In a 2023 article with Sunkel, Ragins stated that:

> The recovery movement is very ambitious. It seeks to take us beyond treating illness, to focusing on helping people have better lives… While the mainstream of psychiatry seeks ever more successful illness treatments, the "outsider" recovery movement seeks ever more successful ways of promoting better lives. (Ragins & Sunkel, 2023: 1)

Recovery in the social model is understood to be the ability to live a meaningful life in the presence of 'symptoms'. 'Symptoms' in this understanding do not represent symptoms of a biological mental illness (Hogan, 2019). They are instead manifestations of an individual's mental or emotional distress, which the individual may or may not attach meaning to, as those within the HVM do to their benefit (Higgs, 2020; Romme & Escher, 2011).

It is an ongoing process which the individual is actively engaged in through the use of social and personal accommodations which enable the individual to live, work, and pursue their interests, rather than trying to 'cure' the individual so they may fit back into a social rubric that is disabling to them. Recovery may include the use of medications, if the individual finds them beneficial and chooses to use them as they help to alleviate their 'symptoms'. From this perspective, the individual is not necessarily anticipating that the medication will 'cure' them of a biological illness. They are informed, and know from experience and from the information provided by service-providers through the social model that the medications instead provide symptomatic relief for them. They are a tool that the individual uses in their ongoing recovery in this scenario. This is different to being prescribed medications by a doctor in the medical model, with the expectation that they will cure the disease the individual is presenting with, as described by Pilgrim above (2008).

More importantly than the use or foregoing of medication, however, recovery is comprised of and facilitated by those accommodations, interventions, therapies, and things in life that the individual has found beneficial in navigating and alleviating their 'symptoms'. It is values-based in this way. It involves interdependency in many cases, as the individual in recovery may have key supports who are a part of their ongoing recovery, and as such, recovery can be relational (Pilgrim, 2008; Ragins, 2008, 2012).

It is also defined by the acceptance of these 'symptoms' by the individual, and the adaptation of life around them to facilitate the individual's work, education, personal endeavours, and passions (Secker et al., 2002; Swords & Houston, 2021, 2022). Recovery involves an individual acknowledging when symptoms are present, and acting in the most appropriate way to help and resource themselves until the 'symptoms' ease or pass enough for the individual to return to their endeavours (Beresford et al., 2010).

Reflecting on my own lived experience autoethnographically, I can say that the social model's conceptualisation of recovery has certainly been the one which has been closest to my own experience of living with distress. Having pursued the 'cure' I had been assured of within the medical model through medication, finding it only to neuter my mind, emotions, and spirit, I found infinitely more truth and resonance in accepting that I was not biologically broken and capable of 'being fixed' with medication. This acceptance, that I experienced certain forms of distress to various degrees in an ongoing manner, but I also experienced vast other facets of emotion and life in an ongoing manner too, was crucial. It had been in focussing on only the distress from the perspective of trying to 'cure' it, at the expense of seeing or enriching the other parts of my experience, that I had become more lost and distressed than I had been in the first place. Seeing the whole picture – *the distress and the rest*, so the speak – the good and the bad, and accepting that this was my experience, but there were things I could do, resources I could draw on, and lines in the sand I could draw to protect myself when needed, has done me far more good than trying to cure my 'illnesses' ever did.

EXPERTS BY EXPERIENCE: BACKGROUND AND DEVELOPMENT AS A STAKEHOLDER SPHERE

It is necessary here to discuss the background and meaning of the concept of an "Expert By Experience" (EBE) and the EBE's development as a concept in academic discussion. This section will explore the concept of the EBE in the literature to inform discussions of EBEs' experience of the power-knowledge exercised in Irish mental health policy and practice throughout this research. The background and context of the need for service-user involvement in mental health policy and practice sited in the literature is considered. The concept of the EBE is key to this research.

The understanding of service-user and EBE voices as wilfully repressed, 'othered', and omitted from decision-making through hegemony and normalisation in Irish mental health policy through the exercise of power-knowledge by traditionally powerful stakeholder spheres is part

of the bedrock of this research. As such. It is important here to identify the two primary stakeholder spheres this research argues have exercised mental health power-knowledge in the Irish context. The first of these is the biomedical psychiatric sphere (medical), which exercises power-knowledge through legitimate authority granted by legislative provisions. The second stakeholder sphere identified is the governmental (statutory) sphere, as it is the sphere which legitimises and enacts the power-knowledge of the medical sphere through its legislative provisions. This is a result of the statutory development and production of mental health policy and law, and provisions for the mental health services.

A prospective solution to include service-users as experts and equals alongside these two spheres is suggested in the form of a distinct EBE stakeholder sphere in Irish mental health policy. This proposed stakeholder sphere is based in a discussion of the literature surrounding EBEs, with a definition of what constitutes an "Expert By Experience" in the Irish mental health context put forward.

Background of the need for an expert service-user stakeholder sphere

Beresford argues that service-user representative research is both necessary and absent from analyses of mental health policy (2007, 2010, 2012). From a Foucauldian perspective, service-user 'knowledges' and insights have historically been limited in Irish mental health policy, and Irish mental health policy analyses, as discussed by Johnston (2014). These unique subjugated service-user knowledges have, through the exercise of power-knowledge through the structures in place, not enjoyed parity with the traditional 'expert' knowledges (French & Raven, 1959) held by the two traditional stakeholder spheres identified within this research (the medical and statutory stakeholder spheres). Foucault's concept of power-knowledge (1977, 1980) is explicit and vivid within the distinctly unbalanced power dynamic which exists between those trained in and practising the 'traditional' knowledges with legitimate authority (Weber, 1922), and those in possession of the unique knowledges gained only through personal experience of the power exercised upon them by those *within* these traditional spheres (Foucault, 1977, 1980).

This research proposes the development of an EBE stakeholder sphere that would, it is argued, belong with the two current, traditional stakeholder spheres in Irish mental health policy and practice this research identifies. These two traditional stakeholder spheres are described in this section. The proposed EBE sphere is developed from a consideration of the literature surrounding EBEs, informed by the author's own experience as an EBE, and the views of the EBEs who participated in this research. The proposed EBE stakeholder sphere would go

towards addressing the identified deficit of service-user insights, knowledges, and input into national mental health policy detailed in 'Chapter Three'.

Defining the Expert By Experience

Within this research, EBEs are identified as a discrete subset of service-users who can be distinguished by their conversion of their lived experience into expertise. Through this process, service-users become EBEs, possessing their own 'expert' knowledge (French & Raven, 1959). Mental health EBEs, then, are service-users who have developed unique, applicable insights and knowledges regarding mental health policy and practice stemming from their own engagement with mental health services. These insights and knowledges can and should, it is argued based on a consideration of the literature (Beresford, 2007, 2010, 2012; Noorani, 2013; Tew et al., 2004), inform mental health policy and research. EBEs have reflexively analysed their lived experiences of this policy area, with particular reference to policy implementation, developing an expertise that is distinct from the traditionally recognised expertise held by medical and statutory 'experts'.

EBEs are defined by their self-identification as 'experts', with the name 'Expert By Experience' strongly tied to human rights movements (Amnesty International Ireland, 2010; MacGabhann et al., 2010; Happell et al., 2019; Javed & Amering, 2016). This self-identification is an exercise of power by those with a subjugated knowledge to legitimise their unique expertise. It is this self-identification that separates 'EBE' from 'service-user'. The position that the expertise and knowledges of EBEs' are complementary to other types of expertise and should have parity with the expertise provided by experts from the two identified traditional medical and statutory policy spheres is a defining aspect of this research, as the research examines contemporary mental health policy and practice through this unique lens. This position is informed by the ongoing academic discussion and theories concerning the existence of EBEs, their primary identifying features, and their capacities and potentials, which are considered below.

Distinguishing between 'service-user' and 'EBE' and their inclusion in policy

It is important to distinguish between EBE and service-user. Though I have outlined the criteria through which an individual becomes an EBE for the purposes of this research, Pilgrim (2005) and Noorani (2013) provide a succinct, if not entirely unproblematic, explanation of the

distinction in suggesting there exist "'co-opted' service-users on the one hand and activists or 'survivor' service-users on the other. The term 'survivor' refers to those who have survived not only their mental health difficulties, but also experiences of psychiatric services, and/or the accompanying general social exclusion… Pilgrim thus describes a tension between user involvement as *a management resource* and as a *manifestation of protest*" (Noorani, 2013: 50). This passage suggests, and I would agree, that there exists a cohort of service-users which has been tokenistically co-opted by stakeholders in the traditional spheres to occupy spaces on mental health and governmental bodies. This distinction is discussed as it appears in Irish mental health research in 'Chapter Three'. This tokenistic co-opting is identified as pervasive in literature analysing the nature and success of service-user inclusion across the spectrum, ranging from individual care plans, service planning, service delivery, research, to policy formulation (Domecq et al., 2014; Greenhalgh et al., 2019; McLaughlin, 2008; Morrison & Andy, 2013; Perkins & Goddard, 2004; Romsland et al., 2019; Snow et al., 2018).

The rationale behind this co-opting is to let service-users believe that the calls they and others make for their inclusion in mental health systems are being answered, when truly their inclusion holds little influence. Conversely, it suggests that there exist EBEs, who will not willingly be co-opted, and who see such efforts in this tokenistic light: "organisations carefully moderate service user authority, in case they claim more than the organisation is willing to grant them the power to claim" (Noorani, 2013: 55).

I do not agree, however, with Noorani's judgemental appraisal of service-users who occupy those seats in mental health systems without realising they are not equals with the other members, and his valorisation of those who do not, who to Noorani have more integrity over the former. This tone underlies the above passage. Iteratively reflecting upon this stance from the perspective of an EBE using autoethnography, I consider that it is no-one's place to judge service-users about the morality or righteousness of their choices to be included in whichever way they choose, or indeed, do not choose. In addition, it could be said that occupying spaces within the psychiatric services or governmental mental health bodies and feeling unheard or ineffectual may be a step along the road for an individual service-user in their journey to becoming an EBE, by giving them pause to reflect critically on such an experience. Noorani and Beresford's work are discussed further in 'Chapter Three'.

Current status of the EBE in the Irish mental health context

The rationale for this research's primary focus on the lived experience and expertise of EBEs is to highlight and elevate the wealth and potential of these individuals' subjugated knowledges (Foucault, 1977, 1980) of the real functioning – and functions, where they differ from those stated in the mental health policy – of the Irish mental health services in informing mental health policy and practice. These EBE knowledges have been subjugated through power-knowledge relations which have favoured more powerful and recognised knowledges in the exercise of mental health power-knowledge. The current research identifies two spheres which exercise mental health power-knowledge in the Irish context, the medical and the statutory spheres, which have been able to disregard EBE knowledges as being "beneath the required level of cognition or scientificity" through the process of subjugation (Foucault, 1980: 82).

This research is conducted by a researcher who is an expert both in the traditionally accepted, legitimate, 'expert' manner (Weber, 1922; French & Raven, 1959), and an expert by experience. I possess "global unitary knowledge" (Foucault, 1980: 82) – that is, accepted knowledge – in the area of Irish mental health policy through prior academic research analysing AVFC, and professional experience working with AVFC and other Irish policies and legislation related to distress and capacity in roles in NGOs. I also possess "subjugated knowledge" (1980) as an EBE. Based upon my knowledge of policy and personal experience of the systems in place, I disagree with the othering of an entire expert stakeholder sphere's expertise to the side-lines in mental health policy development through the exercise of power-knowledge to gatekeep access and subjugate their knowledge. This exclusion is inappropriate, as these experts' lives, rights, and wellbeing are the subject of mental health policy.

A recent study by Dings and Tekin (2023) philosophically exploring the role of the mental health Expert By Experience in mental health care is pertinent to the topics in this discussion, and offers a case study of an EBE sphere in practice. The study considers philosophical and practical factors concerning the definition and place of the Expert By Experience "*Exp*", and the Expert By Experience movement "*ExpEx*", seeking to connect philosophical discussions of "*Exp*" and "*ExpEx*" with their real-world inclusion in mental health care (2022: 2). Their findings regarding the practicalities of *Exp* experiences working as *ExpEx* in the Dutch mental health services are relevant to the current discussion.

Importantly for the current research, the realities of the Netherlands' comparatively cohesive and applied EBE sphere, "*ExpEx*", and its effects on their mental health services for service-

users and service-providers are discussed. This presents an example of a functioning EBE sphere. Dings and Tekin's insights surrounding this sphere, its role, characteristics, potentials, and limitations in real world mental health care application are informative for the current research's consideration of the role of the EBE, what defines them, and what form and function an EBE stakeholder sphere could take in the Irish context.

The authors state that the knowledge generated through experiential learning is "*unique*" "experiential knowledge" amongst "Experts-By-Training", the latter group being synonymous with the current research's traditional 'experts' and stakeholder spheres exercising power-knowledge. Borkman first defined experiential knowledge as "truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others" (Borkman, 1976: 446). This "experiential knowledge" includes a "*cathetic* [sic] dimension" which described the critical self-reflection an individual with experiential knowledge engages in, as well as their feelings about themselves (Dings & Tekin, 2023: 6).

This critical self-reflection is a key component of the journey a service-user takes in becoming an EBE, as outlined in this chapter. Dings and Tekin also note that having traditional 'expert' expertise and having expertise by experience is possible, and that the two forms of expertise are compatible (2022: 2). This reflects the position of the current researcher as possessing both accepted global unitary knowledge (Foucault, 1980: 82) and subjugated knowledge as an EBE. Interestingly, Dings and Tekin note that "At the macro level, they [*Exp*] are involved in co-design of policy", "…contribute to shared decision-making" (Dings & Tekin, 2023: 3), and "developing and coordinating policy making" (2022: 4). This policy-level inclusion of Experts By Experience has been found to benefit the institutions, treatments offered, and the policy itself in their analysis. Such findings are a positive evidence-base for the inclusion of EBEs as a stakeholder sphere in Irish mental health policy and practice. They note that "collective experiential knowledge" shared by *Exp*, a communal knowledge, so to speak, is a tool to be used in overcoming questions of the validity of *ExpEx* in practice due to perceived individual subjectivities (2022: 10-11). This reflects a need for cohesion amongst 'experts' with unique experiences to organise beyond their individual expertise by experience alone, and form a sphere which can legitimately exercise their subjugated power-knowledge.

This research has as an aim, therefore, the elevation of the EBE stakeholder sphere to an equal place in the policy process alongside the recognised global unitary knowledges of the medical and statutory stakeholder spheres, where it can enjoy parity of esteem.

The EBE sphere as necessary and equal

The above consideration of the important place of policy input from such a group as the proposed EBE sphere, one composed of expert service-user voices, developed from the theories put forward by Beresford (2002, 2007, 2010, 2012), Noorani (2013), and Tew et al. (2004) has demonstrated the place that exists for such a sphere. Inherent in the reluctance to recognise the equal worth and value of an EBE sphere by those exercising power-knowledge and biopower within hegemonic institutions is the expression of a recognition of the power of the input and expertise such a sphere would offer mental health policy, if it gained legitimate authority. This proposed sphere's input could prove deep, meaningful, and result in the development of policy provisions that better meet the needs of EBEs and service-users, filling the niche in service-user involvement in mental health policy identified by Beresford (2007, 2010, 2012) and Tew et al. (2004). This potential outcome echoes Noorani's work on EBEs (2013). He states that "the service user and survivor movement is able to draw upon an *experiential authority* that is rooted in practices of self-help and peer-support…" which he incorporates into a dialogue with "… a model of *traditional authority*." (2013: 49).

There are many parallels between Noorani's understanding of the potential space for the unique "experiential authority" of the EBE within the "model of traditional authority" (2013: 56), and the space the current research's proposed EBE sphere could occupy. Noorani's work shares a similar theoretical framework to the current research's conceptualisation of EBEs through a power-knowledge lens. Noorani's "experiential authority" is a component of the current research's "subjugated knowledges" of EBEs. His "traditional authority" shares a similar function to the hegemony's (Gramsci, 1971) "global unitary knowledge" (Foucault, 1980: 82). Noorani argues that:

> [W]e need to appreciate the positivity of the authority that is being produced in the service user and survivor movement, by connecting the capacities and techniques developed in the practices of living through distress and working upon experiences of mental distress in self-help and support group settings to the political potential of the emergent actors. (Noorani, 2013: 49)

This astutely captures the benefits that the collected expertise of EBEs in the form of their own stakeholder sphere could have on the development and implementation of policies which 'problematise' them (Bacchi, 2009), and the operations of systems and services with which they interact as clients or consumers, were they included on an equal standing with the medical and statutory spheres. The tools and capacities EBEs have developed in navigating their experiences of distress would be a valuable resource for policy concerning mental health provisions, protocols, and treatment options.

The experiences EBEs have in discerning what methods and tools have been beneficial or detrimental to their recovery in line with the social model constitutes useful intel on interventions which have been demonstrably effective in practice, as these interventions are shown to help those suffering in alleviating or navigating distress personally. This is a different, practical category of evidence to draw on in developing interventions than interventions founded on theory alone, such as the medical model's chemical imbalance theory and its medications (Ang et al., 2022; France et al., 2007; Lacasse & Leo, 2015). Such experiential evidence could suggest novel interventions in mental health policy and practice to better support people experiencing distress than those currently in place.

CONCLUSION

In this chapter, the research's post-structuralist theoretical framework informed by Foucauldian understandings of power-knowledge and Gramscian conceptualisations of hegemony is detailed. Key concepts that pertain to the research area are explored based in the literature and theories surrounding them, and their relevance to this research is outlined. These concepts are power, and the medical and social models of mental illness and mental health. Theses concepts' analysis is necessary to inform the research's investigation of Irish mental health policy and practice throughout. Though these concepts permeate each part of this research, they are particularly germane to the following analysis of Irish mental health policy and law in 'Chapter Three'. A potential means of redressing and rebalancing the power-knowledge exercised by the key two stakeholder spheres this research identifies in the Irish context, the medical and statutory spheres, is presented in the form of a proposed EBE stakeholder sphere. This is preceded by a consideration of the Expert By Experience in the literature.

CHAPTER 3: A CRITICAL ANALYSIS OF THE DEVELOPMENT OF IRISH MENTAL HEALTH POLICIES AND LEGISLATION: FROM THE LUNATIC POOR TO THE EMOTIONALLY DISTRESSED

INTRODUCTION

This chapter presents a critical chronological analysis of the development of Irish mental health policy and legislation from the 19th century to the present day. This serves two purposes. The first is to delineate the key laws and policies whose ideologies and provisions were significant in the founding of statutory institutions and interventions in the area of mental health, and how they functioned over time as they evolved into Ireland's contemporary mental health services. These institutions exercise(d) power-knowledge and biopower through either the medical model of mental illness or the social model of mental health, which are detailed in 'Chapter Two'. The critical chronology's second purpose is to illustrate the changing hegemonic conceptualisations of mental health which these laws and policies enshrined. This critical chronology does not include each individual piece of Irish mental health law and policy ever drafted. It focusses on those laws and policies that signalled and solidified cultural and legislative shifts in ideologies of mental health. These ideologies range from lunacy, criminality, biological mental illness, to mental and emotional distress ideologies – the 'mad', the 'bad', and the 'sad', respectively.

This critical chronology is needed to situate *A Vision for Change* (AVFC) (Government of Ireland, 2006) and its ideological framework amongst the laws and policies which preceded it, and from which it developed. AVFC was the active mental health strategy during the period that the current research analyses. This is the period when the author and the research participants were in the process of becoming Experts By Experience (EBEs). Table 3.1, page 90, illustrates each key ideological shift and their related laws/policies.

BACKGROUND TO LEGISLATIVE INITIATIVES

Ireland, like many nations, has a difficult history when it comes to our society's treatment of and attitudes towards those suffering from mental or emotional distress (Finnane, 1981, 1985; Kelly, 2016; Wright, 1997; Wright et al., 2008). Before the State intervened and drafted the first law concerning what were called 'the lunatic/the lunatic poor' at the time, the culturally accepted means of dealing with the mad were indicative of a fear of and disdain for that which manifested itself in its sufferers. Kelly elucidates this in his 2016 work, *Hearing Voices: The*

History of Psychiatry in Ireland, which provides a vivid account of Irish society's methods of to control mad people before psychiatry evolved as a discipline. One way Kelly notes families dealt with troublesome members who were unwell was by digging a pit in the ground inside their homestead, and proceeding to trap the individual in there, keeping them underfoot (2016: 2). Another was the practice of 'wintering' those perceived as mad. This practice consisted of admitting a distressed or troublesome family member to a workhouse during the winter months, releasing them during the summer when they could be useful to the family by providing manual labour on the farm, only to be admitted once again when their work was completed (2016: 3). Clearly, these interventions were not intended to care for or improve the circumstances of distressed individuals. They were, instead, forms of imprisonment and slavery, born of deep societal shame on behalf of the families, and fearfully held superstitions about the 'mad' and their potential links to demons, and the faeries of Irish lore (2016: 15-16).

Laying the foundations for institutionalisation of mental ill health

It is from this background that some attempts were made by more compassionate minds such as Jonathan Swift to ameliorate the fates of the mad, and to treat them more humanely. From the philanthropic efforts and calls for kinder treatment of those suffering from mental and emotional distress coming from Swift and others who followed in his wake, came the era of the asylums to house the 'lunatics', with St. Patrick's Hospital founded upon Swift's death using the capital he set aside for the creation of the facility (Powell, 1981). In the proceeding years, the overcrowding and appalling conditions of some workhouses which held a small number of cells for the 'lunatic poor' in Dublin, and the strain on Swift's hospital led to the conduct of inquiries by Parliament into the problem of the 'lunatic poor'. The findings of one of these inquiries, the *Report of the Select Committee to Consider the State of the Lunatic Poor in Ireland (1817)* (House of Commons, 1817), were highly influential in provoking governmental action on the issue (Skedd, 2015).

The result of this action was the drafting and passing of the first laws concerning the mad, who had hitherto been dealt with piecemeal by gaolers, mad-doctors, and the philanthropically-minded. Psychiatry, or 'mad-doctoring', is itself a relatively recent discipline and field, emerging in the 18th and 19th centuries (Scull et al., 1996) within this context of an undesirable social problem calling out for respondents to handle it. The advent of psychiatry does not mean that this call was answered, of course. The results of this governmental action were the *Irish*

Lunatic Asylums for the Poor Act 1817 (UK Parliament, 1817), and the keystone *Lunacy (Ireland) Act, 1821* (UK Parliament, 1821).

THE BEGINNING OF STATUTORY INTERVENTION FOR MENTAL HEALTH: LUNACY AND THE ASYLUMS

The *Lunacy (Ireland) Act, 1821*

In 1817, the UK Parliament passed the *Irish Lunatic Asylums for the Poor Act 1817* on the heels of the aforementioned Report into the lives of the 'lunatic poor'. This Act marked the introduction of the asylums, which were also known as 'madhouses' (Mauger, 2018), as it eventually mandated an asylum in each province of the nation to provide for the 'lunatic poor'. These institutions would in time become renowned and widespread (Malcolm, 2003; Mauger, 2018; Walsh, 2008). The place of asylums as institutions protecting the welfare of society through confinement of the mad (Foucault, 1963, 1965, 1976, 1977) was strengthened by the passing of the *Lunacy (Ireland) Act, 1821* and the subsequent *Lunacy Regulation (Ireland) Act 1871*, which was of a similar ideological composition. The 1821 and 1871 Acts, which framed mental health problems as 'lunacy' and 'insanity', remained the broad thrust of capacity law in Ireland until the introduction of the *Assisted Decision Making (Capacity) Act 2015* (ADMC), (Government of Ireland, 2015). The ADMC was amended by the *Assisted Decision Making (Capacity) (Amendment) Act 2022* (Government of Ireland, 2022), and commenced in April of 2023.

The *Mental Health Act, 2001* (Government of Ireland, 2001) and AVFC (Government of Ireland, 2006) introduced the framework of 'mental health problems/mental illness' and 'mental and emotional distress', while the ADMC introduced the concept of 'impaired/limited capacity' in lieu of 'lunacy/insanity'. The ADMC abolished wardship in Ireland and introduced a capacity-based framework, with a tiered system of decision-making supports to support the decision-making of an individual who has been found to be lacking mental or legal capacity (Government of Ireland, 2015). Under the ADMC, an individual can be supported through one of five kinds of decision support arrangements in exercising their agency (Government of Ireland, 2015, 2022).

Given how recently elements of the 1821 Act were still in place, it is perhaps unsurprising that the term 'asylum' has been ubiquitous and inseparable from terms such as lunacy, madness, mental illness, and other such terms denoting those in distress for almost two centuries. Even

today, the term ‘lunatic asylum’ evokes images of austere, looming Victorian buildings which sprawl, and seem to embody the cold and hardship. They were institutions exercising biopower which existed to confine, punish, and correct perceived abnormality (Foucault, 1963, 1965, 1976, 1977).

The history of the asylum, its role, and its impact on Irish society in the 19th and 20th centuries, has been discussed by authors including Barrington (1987), Dukelow and Considine (2017), Malcolm (2003), and Wright (1997), and from a social policy perspective. Discussing Ireland’s disproportionately high rates of institutionalisation in the asylums, Wright notes the important place the family played in committing family members. He refers to Finnane’s 1981 case study of admissions to an Omagh county asylum, which found 80% of those admitted to that asylum had been admitted by their family or a family member (1981: 132). Wright considers the unofficial judicial function of the asylums in the Irish context as driving their expansion and the ‘need’ for them which continued to grow:

> Clearly, there was an underlying residuum of violent admissions who had been apprehended 'at large' and, perceived as a threat, taken to the asylum; but as a percentage of admissions they became decreasingly important, a mere fraction of the thousands of admissions coming straight from the family. The expansion of asylums in the nineteenth century was thus driven by demand directly from families. (1997: 142)

Finnane notes this, stating that the asylums acted as the “arbiter of social and familial conflict” (1985: 135).

Lunacy in *Lunacy (Ireland) Act, 1821*: ill-defined social deviance

It is unsurprising that the 1821 Act does not contain a concrete definition of what a ‘lunatic/lunatic poor’ or ‘insane’ person is, unlike terms such as ‘mental illness’, ‘mental health’, and ‘capacity’ would in time. In fact, this lack of coherence surrounding the term perfectly reflects societal attitudes and understandings of ‘lunacy’ and ‘madness’ at the time: undefined, dangerous, external, and generally, something that someone would *know* when they saw it manifest; for example, in a beggar, or an individual seemingly speaking to no-one in particular. ‘Lunacy’, as a term, denotes those who were mentally ill, foolish (‘imbeciles’, which were legally differentiated from lunatics, as they were ‘foolish from birth’, as opposed to

developing ‘madness’ during their lives), people of poor moral standing (gamblers, alcoholics, etc.), and the dangerous (Riva et al., 2011).

The term ‘lunatic’ holds quasi-supernatural connotations regarding the condition of the sufferer, etymologically stemming from the Latin *lunaticus*, meaning “of the moon”, or “moonstruck” (Kelly, 2016; Lewis and Short, 1879). This shows the belief that the mad were affected by the phases of the moon, especially full moons. This again demonstrates the common belief that the ‘mad’ had something unnatural about them. In short, the term, and the laws that existed to control it, were the sum of society’s undesirables (Foucault, 1963, 1965, 1976, 1977). An important factor in their perception and within the 1821 Act was their inability to function as labourers and contribute to the economy, thus the term ‘lunatic *poor*’ (UK Parliament, 1821).

Introduction of involuntary detention in the *Lunacy (Ireland) Act, 1821*

Section 10 of the 1821 Act mandated the building of lunatic asylums and the transformation of gaols that had housed the ‘lunatic poor’ to same. Notably, section 17 of the 1821 Act introduced the lasting feature of involuntary detention for those in mental or emotional distress, allowing the courts to find a person “insane… and thereupon to order such person to be kept in strict custody, and to be taken care of, until the pleasure of the lord lieutenant shall be known” (UK Parliament, 1821). Though the language of and rationale for this provision has changed to reflect the ideologies of subsequent laws and mental health strategies, the reality remains the same today: an individual can be found, by functions of the state, to require institutionalisation (in the 1821 Act, due to ‘lunacy/insanity’, and in the *Mental Health Act, 2001,* due to suffering from a ‘mental disorder’). This individual can then be involuntarily detained for as long as is deemed necessary for their/others’ benefit by the statutory entity responsible for their detention, which typically takes the form of a public psychiatric institution. This function, which features in consecutive mental health laws and policies is one of its most powerful, controversial, and enduring features. It had been expected by many NGOs, advocacy groups, and stakeholders to be limited by the 2015 Act, but this was not realised in the final document (Mental Health Commission, 2013: 7; Mental Health Reform, 2011; Law Society of Ireland, 2011).

THE MAD AND THE BAD: LUNACY AND CRIMINALITY

The 1838 Criminal Lunatics (Ireland) Act

From the foundation laid in the 1821 Act, 'lunacy', 'insanity', and being an 'imbecile' were now recognised legal phenomena. This is a watershed moment in Irish mental health policy, as it is the first time that the government of the day introduced a conceptualisation, however thin, of distress. One which was actionable in the courts, and which would become culturally hegemonic – the first of numerous ideologies of mental health and ill health to become normative and reflected in our legal interpretations.

Subsequently, additional characteristics of madness, at this juncture still conceptualised as 'lunacy', would be recognised and realised by the law, adding new categories of 'lunacy' alongside that of the 'lunatic poor' legislated for in the 1821 Act. This addition came with the UK Parliament's *Criminal Lunatics (Ireland) Act* of 1838. This Act, just as its predecessor had done with asylums, would legislate for distress in a way that would create regrettably enduring beliefs about the mad. The lexicon and categorisations of the ideology being normalised through power-knowledge in this new policy area was developing.

In this instance, the belief was that 'lunatics' had an inherent capacity to become 'deranged' and commit impulsive violent crimes, such as intending to attack or murder individuals. This concept of the 'lunatic' becoming 'deranged' and violent illustrates the confluence of the ideas of the 'mad' and the 'bad'. As such, the 1838 Act legislated for a new subtype of 'lunatic' alongside the existing "lunatic poor"; that of the "dangerous lunatic" (UK Parliament, 1838). "Dangerous lunatics" were those individuals who were detained displaying unusual behaviour, or under circumstances which suggested that the individual was of "deranged mind". This differentiated the "dangerous lunatic" from the standard criminal. Discrete categories of abnormality were being honed and defined in legislation through the exercise of power-knowledge. Accordingly, two justices, with the advice of a physician, could imprison the "dangerous lunatic" in gaol, *or* transport the "dangerous lunatic" to a lunatic asylum (UK Parliament, 1838).

The moral underpinnings of 'mad' vs 'bad'

The provisions of the 1838 Act demonstrate starkly how the line that distinguishes asylums/mental hospitals as treatment centres from asylums/mental hospitals as detention

centres, no different from prisons, is at best questionable as a fixed border. The idea that mental institutions, prisons, schools, and other social institutions function to normalise the hegemony and power-knowledge of the dominant social group and to punish those who deviate from it, as espoused by Foucault, is evidenced here (Foucault, 1963, 1965, 1976, 1977, 2007). This is discussed in detail in 'Chapter Two'.

This questionable border was even more evident at the time of the Lunacy Acts, as the act of developing ideological categorisations to separate those who were 'mad' from those who were 'bad' was in its naissance. The 1821 Act demonstrates this, as it categorised a distinct subset from within the pool of those seen to be socially deviant in a general grouping of the 'mad' and the 'bad'. With the 1821 Act, an individual could now be both. In her research into the history of asylums in Ireland, Prior (2012: 2) provides statistics on the "lunatic poor" in Ireland from this time that demonstrate there was still uncertainty about which institution exercising power-knowledge should control the 'lunatics'. The breakdown of these statistics belies the conflation of those experiencing distress with those from other groups seen to be undesirable, mainly criminals and the poor. The effect of class in deciding a person's classification as 'mad' or 'bad' is also clear:

> … there were 9,286 insane poor in Ireland in January 1857. This number was made up of 5,934 'maintained at the public charge' and 3,352 'at large'. Of those in public institutions, 3,824 were in district asylums and the remainder were in workhouses (1,815) or in prisons (295). The commissioners deliberately omitted those from 'the wealthier class' from this number, as this would confuse the estimate for public provision. However, they did note that there were 459 patients in 'Licensed Houses and Benevolent Institutions' at this time.

At the most dubious end of this spectrum, the border between 'mad' and 'bad' could be seen to be a fabricated social distinction drawn by those with decision-making power to exercise the hegemonic power-knowledge of the society through processes of normalisation and abnormalisation (Visoka and Lemay-Hébert, 2022). This acts to neatly categorise the citizens that constitute that society for a sense of surety and comfort in the exercise of biopower. Gutting explains the function of recording statistics of those belonging to these categories for those exercising power-knowledge: "On the basis of these records, those in control can formulate categories, averages, and norms that are in turn a basis for knowledge." (2019: 86).

Velpry and Eyraud (2014), conducted a study into the similarities between the confinement employed in prisons and psychiatric units, and indeed, the struggle between the penal and

psychiatric systems to lay claim to the right to confine individuals. The rich debate about psychiatrists/asylums and mental hospitals as policers of deviance/prisons to correct social deviancy has notably been considered and researched in-depth by Foucault in his work, *The Birth of the Clinic* (1963), though it is a common topic in much of his work.

In the 1838 Act, that which separates the 'mad' from the 'bad' is not something tangible or something which has a quantifiable metric. It lies instead in the opinions and attitudes of those justices and physicians ruling on each case individually, as a *moral* question (Schirmann, 2013). Wright notes this initial adoption of morality as the rationale for confining people in the asylums by those confining others to justify their role and the endeavour of the asylums:

> In the early part of the nineteenth century there emerged a lunacy reform movement based on the premise that madness could be cured given proper institutional treatment. Originally associated with religious institutions such as the York Retreat, moral treatment was co-opted by an emerging group of medical men intent on creating national systems of public asylums under medical control. The period between 1800 and 1860 witnessed legislation enabling, and in some cases obliging, local authorities to provide for their insane poor. (1997: 138)

The rationale supporting confinement would, as this chapter explores, evolve ideologically over time as reflected in each law and policy that is analysed. The truth of the subjectivity of these 'experts'' decisions regarding the individual's status as either 'mad' or 'bad' is reflected in Otte et. al's 2017 study into the mental health of prisoners and psychiatric patients. The findings of their research suggested that both cohorts of prisoners and patients suffered from the same high levels of mental and emotional distress. We can see, then, that both cohorts could be argued to be one in actuality, and that the decision of which institution should receive each individual lies with those with the power to differentiate between the ratio of 'madness' to 'badness' of the act committed, and the character of the person who committed it. They are social constructs which seek to neatly categorise complex human experiences as discrete forms of social deviancy to be contained (Foucault, 1963, 1980, 2009).

ILLUSTRATING THE SOCIAL CONSTRUCTION OF THE 'MAD', THE 'BAD', AND THE 'SAD'

The synonymy between 'madness' and 'badness' continues today (Thompson, 2010). It is worth noting that this conflation did not find its origins within the 1838 Act. The Act's provisions, though they carried significant ramifications which survive today couched in

different language, just as involuntary detention has, did not create this damaging link. Instead, the Act legislated on that same link as it had already existed in peoples' minds for a long time. This link is not native to Ireland, and indeed it has haunted those in distress for time immemorial, as noted by Rössler in his 2016 article, *The stigma of mental disorders A millennia-long history of social exclusion and prejudices*.

As ideologies of 'madness' evolved throughout the 19th and mid-20th centuries, the biomedical model of 'mental illness' emerged. The origins of this model and its status as a powerful conceptualisation of distress are discussed in 'Chapter Two'. The biomedical model presents the 'sad' view of distress, joining the 'mad', and the 'bad' as potential reasons for perceived social deviance or abnormality (Visoka and Lemay-Hébert, 2022).

Race, criminality, and the 'mad', 'bad', or 'sad'

Contemporarily, the conflation of criminality with mental or emotional distress can be seen the moment there is a mass shooting carried out anywhere in the global West: if the culprit is a person of colour, the narrative is almost invariably one of terrorism – i.e., 'bad'. If the perpetrator is white, the narrative is almost invariably that of someone who struggled with their mental health, and who must have 'snapped' – i.e., 'mad' or 'sad' (Duxbury et al., 2018).

This is a clear example of the social construction of that which is 'mad' from that which is 'bad', and how the consensus reached about whether an individual is one or the other is decided on from a number of variables which relate to an individual's proximity to the majority hegemonic group ('mad'), or an individual's proximity to a marginalised, othered group ('bad'). In this case, that distinction is drawn on racial lines, demonstrating how our categorisations exist largely to help us make sense of the world around us in a way that reflects compassionately on the sympathetic "us", and punitively on the contemptable "them". The racialisation of mass shootings is dissected in great depth by Mingus and Zopf in their 2010 analysis, 'White Means Never Having to Say You're Sorry: The Racial Project in Explaining Mass Shootings'. While considering whiteness as the unquestioned, normal, and natural hegemonic standard for behaviour in society, the authors consider the work of Kimmel and Mahler, (2003: 1443), noting:

> Kimmel and Mahler… note that "as the shooters have become White and suburban middle-class boys, the public has shifted the blame away from group characteristics to individual psychological problems"" (Mingus and Zopf, 2010: 66)

In very sharp contrast to this, the authors, while considering how the racialisation of any ethnicity or identity that is 'non-white' affects the narrative of these shootings, and the lives of those who share or appear to share an identity with the shooter in respect of the Fort Hood shooting of 2009, write that:

> Before Nidal Malik Hasan began firing at Fort Hood army base in November of 2009, he reportedly shouted the words "Akbar", which translates to "God is Great." This phrase is known as the takbir and is used by Muslims to express a wide range of emotions. Although investigations concluded that the gunman acted alone, the incident prompted immediate accusations of terrorism… Little was said about the mental health of Hassan, a licensed psychiatrist. (Mingus and Zopf, 2010: 72)

Gender, criminality, and the 'mad', 'bad', or 'sad'

The question of whether an individual who carries out a criminal act which jars and disturbs the society that the perpetrator is a part of is 'mad', 'bad', or 'sad' has a gendered dimension, just as it does a racial one. Prior notes that there is a "parallel debate on gender and mental health, focusing on gender differences in society's response" to criminal behaviour (2005: 19). In the same manner that the phenomenon of mass shootings in the global West is highly racialised, the phenomenon of infanticide is highly gendered. The gendering of this specific crime explicitly illustrates the effect gender has on perceptions of whether an individual is 'mad', 'bad', or 'sad' (Easteal et al., 2015; Guilbride, 2004; Huckerby, 2003; Prior, 2005, 2012; Weare, 2017; Wilczynski, 1991, 1997). Women tend to be perceived as 'mad' or 'sad' by society and in legal proceedings, while men are typically perceived as 'bad' (Prior, 2005; Wilczynski, 1997). Wilczynski (1997) analysed the findings of a report investigating 48 cases of both fatal and attempted infanticide which had taken place between 1980-1990. These crimes had been committed by both fathers and mothers. Wilczynski's findings demonstrate this socially constructed differentiation between women ('mad' or 'sad'), and men ('bad') clearly:

> It was found that the criminal justice system responds very differently to men and women who kill their children at all stages of the legal process, in accordance with the view that 'men are bad and normal, women are mad and abnormal'. For example, women are less likely than men to be prosecuted; they also predominately use 'psychiatric' pleas and receive psychiatric or non-custodial sentences. Men, however, tend to use 'normal' pleas and receive prison sentences. (1997: 419)

Of course, gender does not preclude infanticide – or any – crime from also bring racialised. Gender and race intersect with class and the relationships with men in the act of categorising a mother who commits infanticide. The combination of these social categories further complicates the construction of the perpetrator as 'mad', 'bad', or 'sad', with those from non-white racial groups and/or lower socioeconomic class experiencing different interpretations of their crimes to their white counterparts. This is explained by Huckerby:

> [The] disparate coverage and treatment of criminal mothers stems from the fact that the concept of "motherhood" is neither innocuous nor universal, but pretends to be both. Motherhood is not innocuous, as it is given meaning by the core features of patriarchal ideology. It is not universal, because there are essentially three main variables which determine the value that attaches to motherhood: race, class, and the role that the father has in relation to both the child(ren) and mother… "Good Mothers" (white middle-class women) and "out-group" mothers (women of color, poor women, lesbian women) who cannot by definition be Good Mothers, and can, at best, hope to be Good Black Mothers or Good Asian Mothers." (2003: 152)

Huckerby comparatively analyses the treatment two mothers who committed infanticide received in the American context to illustrate how these factors impact a perpetrator's construction as 'mad', 'bad', or 'sad', and the strength of their claim to madness or sadness as the reason for their crimes. The two cases she analyses are those of "Andrea Yates as a white, middle-class mother with a supportive husband enjoys a higher moral claim to motherhood than Khoua Her, an immigrant mother with an estranged husband." (2003: 153). Huckerby notes the same pattern of mothers being treated with greater leniency and being seen as 'mad' or 'sad' in cases of infanticide that Wilczynski describes, however, her analysis demonstrates the role the interplay of different social categorisations including race and class can play on society's categorisation of mothers who kill their children, and the institutions that respond to their crime:

> There is a general pattern of "leniency" with respect to infanticidal mothers. However, within this general pattern of leniency, there are palpable differences in sentencing outcomes, depending on whether the defendant is classified as a "mad" or "bad" mother. This bifurcation is a manifestation of the general tendency to categorize criminal women as either afflicted by their hormones or by evil. Although invocation of "madness" as an explanation for infanticide does not guarantee exoneration, on the whole women who are perceived as being pathological are punished less severely than those who are deemed "evil." (2003: 158)

Though Wilczynski's and Huckerby's analyses are more recent than the period currently being discussed in this chapter, they are illustrative of the same gendered social construction of women and criminality identified by Prior. Prior's 2005 analysis is sited in the Irish context and investigates gendered attitudes to madness from the era of the asylums and the Lunacy Acts. Prior draws on the records of the Central Lunatic Asylum for Ireland in Dundrum, which exists today as the Central Mental Hospital in Portrane.

She notes that women who committed infanticide were perceived to be 'mad' as they frequently are contemporarily. The unique form their madness took was "puerperal mania" and "hysteria" (Prior, 2005: 25). This 'madness', which was what caused women to commit infanticide, was brought about due to their delicate nature, reproductive systems, menstrual cycles, and bearing children itself (2005: 24). The patriarchal construction of female madness, badness, or sadness, is evident in these accounts from both the 19th century the late 20th century to present day.

THE EFFECTS OF THE LUNACY ACTS (1811-1871) ON IRISH SOCIETY AND THOSE IN DISTRESS

The language of mental and emotional distress used in the laws and policy provisions drafted for their management remained couched in the prevailing concepts of 'lunacy' and 'insanity' for the remainder of the 19th century, and the beginning of the 20th century in Ireland. The asylums kept their place at the heart of detaining, confining, and treating 'lunatics', growing in number, steadily institutionalising increased numbers of individuals year on year, and cementing their place as a staunch, feared feature of Irish society (Malcolm, 2003; Wright, 1997, 2008).

The *Lunacy Regulation (Ireland) Act 1871* permitted the state, through the wards of court system, to sell a ward's ('lunatic's'/'idiot's'/person of 'unsound mind's') property and manage their estate without their consent (UK Parliament, 1871). The preceding *Marriage of Lunatics Act, 1811* had made it illegal for a ward of court to marry (UK Parliament, 1811). Therefore, it can be said that the advent of statutory intervention for those in mental or emotional distress up until this point was designed to protect society and the families of those with mental health difficulties through normalisation and power-knowledge, more so than it was designed to help those individuals.

By the beginning of the 20th century, the Acts which had been introduced could deny a person in distress, who were at that time understood to be 'lunatics', 'idiots', 'imbeciles', etc., their

freedom through involuntary detention in asylums or their incarceration in gaols as ‘dangerous lunatics’ (UK Parliament, 1821, 1838), their ability to make choices independently and marry (UK Parliament, 1811), and their ability to hold or manage their own property, estate, and capital (UK Parliament, 1871). The legislation in place following this first era of statutory intervention and subscription to a particular ideology of mental health and mental and emotional distress as a moral issue indicates an underlying motivation to define the parameters of ‘madness’ and social deviance, and efforts to confine and control it as something to be discouraged and disdained. It is from and within this context that the next paradigm shift we can identify in Irish mental health legislation’s ideologies would emerge.

FROM ‘LUNACY’ TO ‘MENTAL ILLNESS’ IN MENTAL HEALTH POLICY: ‘MAD’ TO ‘SAD’

Theories of mental health/ill-health, mental and emotional distress, and mental illness are in a constant state of contestation and evolution. This cycle, involving different ideologies of the phenomena falling in and out of favour, with old ones fading from prominence as new ones gain traction and become hegemonic, is not neat, clean-cut, or linear. We cannot say with any certainty when one ideology definitively replaces another. Ideologies are given legitimacy and normalised when they become hegemonic (Gramsci, 1971). This process is iterative, meaning conceptualisations taken to have the most verisimilitude change with the accepted beliefs of the dominant social group (Boggs, 1976; Crehan, 2016; Gramsci, 1971; Joll, 1976; Lukes, 2005). Hegemony and normalisation are discussed in greater detail in ‘Chapter Two’. It is not possible, therefore, to perform a dendrochronology of social mores and beliefs. It is, however, possible to identify paradigm shifts in these mores and beliefs as reflected in social policy and its ideologies.

It is worth noting that as different ideologies develop and evolve, they are informed by those that have come before them. They are in a constant state of flux. Remnants of formerly hegemonic ideologies are frequently present to a small or large degree in policies and laws reflecting alternative ideologies, which have been drafted after the former’s prominence has waned. This is quite clearly illustrated in the next law enacted in Ireland concerning mental health following the Lunacy Acts (1811-1871).

INTRODUCTION OF THE BIOMEDICAL MODEL TO IRISH SOCIAL POLICY

The Mental Treatment Act, 1945: Defining a Concept-Specific Ideological Departure

The first major piece of social policy concerning mental health in Ireland since the Lunacy Acts (1811-1871), *The Mental Treatment Act, 1945* (Government of Ireland, 1945), reflected the changing social and institutional attitudes and beliefs surrounding mental health and distress which had been developing for some time prior to its introduction.

These beliefs were founded in the theory that mental and emotional distress were literal, biological mental illnesses. This is the biomedical theory of mental illness, which is explored in 'Chapter Two'. Though the social model, which is also discussed in the aforementioned chapter, has challenged the biomedical model's hegemonic status in more recent years, the biomedical model is still a powerful ideology today, upholding powerful institutions. The concepts of mental and emotional distress as discrete and diagnosable diseases of the brain, as opposed to generalised 'lunacy', are crucial to this ideology. Though this is a markedly different, and at the time of the 1945 Act, a more humane conceptualisation of the suffering of individuals in distress than lunacy, the 1945 Act did not replace the Lunacy Acts (1811-1871). It built on and added to them, using a new theoretical lens to view the phenomena previously legislated for and to maintain the legitimate authority (Engel, 1977) afforded to these legislations' provisions. Compared to the vague and ill-defined terms used in the Lunacy Acts (1811-1871), the 1945 Act was a great deal more concept-specific, defining its terms from the beginning. This provides a premade lexicon with which to analyse the conceptualisations contained in the policy.

In the 1945 Act, the concepts of "lunacy", "imbecility", "dangerous lunatics", and asylums housing "(dangerous) lunatic/(s) (poor)" (UK Parliament, 1811, 1817, 1821, 1838, 1871) were changed to "mental disease", "private/public/temporary patients" receiving '"mental hospital assistance" in "mental institutions/mental hospitals" (Government of Ireland, 1945). The ideology of madness as 'lunacy', or 'badness' was replaced in the Act with the ideology of madness as 'sadness' caused by disease.

Psychiatric Ideology's Primacy in *The Mental Treatment Act, 1945*

This leap in the conceptualisation of distress and its reflection in the language used in social policy and by the 'experts' is significant. The language of the 1945 Act took Ireland from the Victorian era into an era of assumed 'enlightened' thinking regarding those experiencing mental and emotional distress. Asylums were not a suitable answer to the plight of those who were now thought to be 'sick' in this new theoretical framework; they were barbaric. These 'sick' individuals required medical treatment, which could best be provided by psychiatrists, as over the previous century, psychiatrists had progressed from 'mad-doctoring' the asylums, to developing a distinct knowledgebase of the various different forms of mental disease, and new and 'better' means to 'treat' them (Heckers & Kendler, 2020; Kraepelin, 1899; Shorter, 2022). This evolution of psychiatry and its scope to include experiencing distress outside of the asylum at this period in time is detailed in 'Chapter Two'.

The "lunatic" was now a "patient", receiving specialised medical interventions in "approved institutions" rather than "asylums" (Government of Ireland, 1945). The knowledge psychiatrists developed translated into a psychiatric expertise (French & Raven, 1959). This expertise held by psychiatry was acknowledged and cemented in the 1945 Act, which made the psychiatric institution the preeminent and legitimate authority on all affairs related to mental health and ill-health, and all actions to be taken regarding them. They became the most powerful institution exercising power-knowledge over those in distress. Imbued with this expert knowledge, psychiatrists could now exercise their power with more legitimacy (Engel, 1977; Weber, 1922).

In this way, the 1945 Act clarified and legislated for a lot of what was already the case in practice. Psychiatrists had already been the default authority and 'experts' regarding those in mental and emotional distress, beginning with the 'mad-doctors' recognised in the Lunacy Acts (1811-1871). Their role remained functionally the same as it had from the beginning of those Acts, though now what had been vague was refined, further developed, and turned into a specialisation with the 1945 Act. The lexicon and associated meanings evolved ideologically from the 19th century Acts, as did the lexicon surrounding suffering, but the role of psychiatrists was not drastically different to that of the 'mad-doctors', aside from refining the diagnostic criteria and treatment options they employed. This process of legitimising the biomedical model and its exercise of power-knowledge and biopower through a nosology of discrete,

classifiable ‘mental illnesses’, most notably the DSM, is detailed in ‘Chapter Two’ (Heckers & Kendler, 2020; Horwitz, 2021; Kraepelin, 1899; Paris & Phillips, 2013; Shorter, 2022).

INTRODUCTION OF FULL PSYCHIATRIC AUTHORITY OVER MENTAL HEALTHCARE IN *THE MENTAL TREATMENT ACT, 1945*

Given that psychiatry was unique in that it developed *from* ‘mad-doctoring’ in asylums, its practitioners fulfilled a social role that others did not wish to by default, until competing ideologies, such as that of social impairment introduced in the social model of disability (Oliver, 1983, 2004), challenged its hegemony as discussed in ‘Chapter Two’. As the default custodians and caretakers of mental healthcare in Ireland, psychiatrists were, at the time of the 1945 Act and contemporarily, stakeholders with very powerful input into the formulation of social policy and legislation surrounding mental health provisions.

Society needed and still needs somebody to ‘deal’ with the mad. Most people do not envy the position of caring for and treating the mad, as stigma towards the mad has traditionally been strong. Due to this stigma, madness and distress today remain something frightening to be covertly looked away from and controlled, just as they were overtly in Irish society before statutory intervention. Madness is something unseemly and threatening (Jorm et al.,, 2012; Pescosolido et al., 2019; Sowislo et al., 2017), and stigma is still present in contemporary society, as even the ‘sanest’ person subconsciously fears that the madness might be catching should they get too close to it (Corrigan, 1998; Corrigan et al., 2012; Corrigan & Rao, 2012; Del Rosal et al., 2021; Link et al., 2004; Pescosolido, 2013). In this collective societal desire not to directly engage with those in distress to the greatest degree possible, a void necessitating third party intervention opened, and psychiatry stepped in to fill it. This role was elevated to law in the 1945 Act.

Section 4 of the 1945 Act explicitly states who had authority over voluntary or involuntary patients, stating:

> 4.—In this Act, the expression “person in charge” means—
>
> (a) in relation to a district mental hospital—the resident medical superintendent of the hospital,
>
> (b) in relation to any other institution maintained by a mental hospital authority—the medical officer of the institution (Government of Ireland, 1945)

It was not the case that psychiatrists were no longer gaolers or 'mad-doctors', but with the cementing of the biomedical model ideology as *the* legitimate and hegemonic conduit of power-knowledge in the 1945 Act, they additionally became 'medical experts'. This socially constructed 'medical expertise' in social policy gives legitimacy to psychiatry's authority (French & Raven, 1959; Weber, 1922). It is a sanitised and, seemingly, humanising evolution of the role and the language that constructs it. One that makes it appear more specialised, and its more unsavoury normalising and social functions of detention, coercion, and decision-making power over individuals' bodies, which are and have variously been hallmarks of the discipline, seem acceptable to society. This is discussed further in 'Chapter Two'.

From "District Lunatic Asylums" to "District Mental Hospitals" in the 1945 Act

Part III, Sections 14 & 15 of the 1945 Act transformed the "district lunatic asylums" of the Lunacy Acts (1811-1871) into "district mental hospitals", with "local administrative authorities" monitoring their operation. The Minister for Local Government and Public Health replaced the Lord Lieutenant of Ireland. The creation of the administrative authorities is seemingly a step in the direction of monitoring and accountability for those specialists working in "approved institutions".

However, further augmenting and solidifying the primacy of psychiatric power-knowledge, and negating the agency of the administrative authorities, Part IX of the 1945 Act created the role of "chief medical officer/resident medical superintendent" for each district mental hospital. This superintendent would "exercise such control over the other institution as the mental hospital authority". Just as the *Assisted Decision Making (Capacity) (Amendment) Act 2022* (Government of Ireland, 2022), provides for advance directives which state a patient's will and preference regarding certain treatments and interventions that become invalid when a treating psychiatrist decides against them, negating any real agency, the 1945 Act's introduction of administrative authorities reads as progressive for the time, though in truth it is void of power or agency.

The sole resident superintendent had as much control over affairs in the district mental hospitals as the mental hospital authorities, which consisted of the entire County Council or Borough Corporation of the respective district hospitals, or in their absence, a Board. This illustrates vividly the allocation and weighting of power in the institutions awarded by the social policy and legislation of the era. This highly unbalanced affording of power and control to psychiatrists, guaranteed in the 1945 Act, would continue, and has arguably not changed

contemporarily. This is the legacy of the 1945 Act, just as involuntary detention remains, and the ward of court system formed part of the legacies of the Lunacy Acts (1811-1871).

Developing and Expanding Grounds for Involuntary Detention in *The Mental Treatment Act, 1945*

The features of involuntary detention and the wards of court system (ability to manage and dissolve a detained individual's capital and assets) remained in place, through appropriately updated terms reflecting the assumed 'enlightened' hegemonic biomedical ideology dominant in the 1945 Act. This is demonstrated in Part XIV, Sections 162-165 of the Act. These sections continue to refer to people "of unsound mind", but no longer mention "deranged lunatics". To involuntarily detain an individual, an "authorised medical officer" was required to write a "recommendation… for the reception and detention of such person as a person of unsound mind in such district mental hospital" (Government of Ireland, 1945).

The function of detaining individuals through the criminal justice system was retained, if "the Gárda Síochána is of opinion that it is necessary that a person believed to be of unsound mind should, for the public safety or the safety of the person himself… he may take the person into custody…" (Government of Ireland, 1945). This extract demonstrates another key feature of the assumedly 'enlightened' biomedical ideology of the Act. This is the concept of protecting a distressed individual's "best interests" (Government of Ireland, 1945, 2001).

The "best interests" principle was constructed as another justifiable reason for involuntary detention of individuals, alongside the explicitly societal function it was drafted for in the Lunacy Acts (1811-1871). This subtle addition to the rationale for involuntary detention is illustrative of the supposed humanity of the biomedical ideology. The provision no longer existed purely to protect *society* from people "of unsound mind" who may become "deranged" as per the Lunacy Acts (1811-1871). Now, it also functioned to protect the individual *themselves* in instances where they were unable to see that they required the help and treatment for their condition that was provided by the psychiatrists in the district mental hospitals and approved centres due to their 'mental illness' (Government of Ireland, 1945).

IRELAND'S FIRST TWO MENTAL HEALTH STRATEGIES: THE INTRODUCTION OF 'COMMUNITY CARE'

The next two pieces of social policy considered in the current analysis are the *Commission of Inquiry on Mental Illness: 1966 Report* (Department of Health, 1966) and *The psychiatric*

services - planning for the future: report of a study group on the development of the psychiatric services, (Study Group on the Development of the Psychiatric Services, 1984). Both policies are important for several ideological reasons:

i) They introduce the concept of the pillar of 'community care' in the management of mental illness, ending purely institutional psychiatric treatment.

ii) The policy uses the concept of 'community care' to call for 'deinstitutionalisation'. This process entailed heavily reducing reliance upon inpatient psychiatric treatment in district mental hospitals as the preeminent form of intervention for distress, in favour of outpatient care to be provided within individuals' communities.

iii) They mark a change in Ireland's policy approach to the issues of mental health from purely provisory laws largely based around 'who-treats-whom', to developing *mental health strategies* that consider the best practice around issues of mental health as enduring phenomena, and how best to provide for them moving forward. They consider the future as well as the 'now' that the previous policies and acts were drafted in.

Commission of Inquiry on Mental Illness: 1966 Report

The 1966 Report by The Commission of Inquiry on Mental Illness was the first to introduce the concept of "community care/community services" (Department of Health, 1966). The inclusion of another pillar in policy that was seen as both appropriate for and given responsibility for providing care to those in mental and emotional distress alongside psychiatry is important. In any instance, the inclusion of another perspective to the dominant biomedical psychiatric perspective inherently represented a challenge to the latter's hegemony. In analysing the 1945 Act, it was seen that the psychiatric perspective and approach to literal biological "mental diseases" was entrenched as the dominant and *only* valid policy approach (Government of Ireland, 1945). To recognise another approach or perspective beside psychiatry in social policy was to inherently state that the psychiatric approach alone was not, in fact, the only means of responding to the mental health needs of the nation. This innately recognises the existence of other knowledges and ideologies, even if tentatively, and this is important. The 1966 Report did just this less than 20 years after the 1945 Act cemented psychiatry as *the* 'expert' authority on mental health and "mental diseases" (Government of Ireland, 1945). This is clearly illustrated in the 1966 Report's identification of "the need to integrate psychiatry and general medicine" (Department of Health, 1966: xvii).

The 1966 Report, written by the Commission of Inquiry on Mental Illness, constitutes a significant shift in mental health policy ideology from the purely biomedical model to one that viewed the 'patient' in a more nuanced, whole-person manner. This step towards acknowledging the complexity of responding to mental and emotional distress, and the complexity of the lives of those who suffered from it, represents the first steps towards the "biopsychosocial" approach that would eventually be enshrined in *A Vision for Change* (Government of Ireland, 2006). The 1966 Report uses language that constitutes a notable departure from the purely biomedical, to what could be conceptualised as a limited version of the social model of disability in contemporary terms. Instead of existing to confine and control the mad as the preceding acts had done, the 1966 Report provided for the "complementary" use of "active treatment" in the community alongside inpatient treatment, which was now termed "residential care". Importantly, it strove:

> to ensure due respect for the innate dignity of the patient as an individual and the maximum opportunity for [their] rehabilitation" of individuals, particularly those with enduring mental distress, who were recognised in the language of the time as patients with disabilities. (Department of Health, 1966: xv).

Introducing the language of "respect" and "dignity" marks a watershed moment in Irish mental health policy, as it explicitly sees the "patient" as an individual outside of the patient role in the same sentence. They are more than their 'mental illness'. The suite of rehabilitative "community services" provided for in the Report were to be delivered by community GPs, social workers, and psychiatric nurses. With this, the 1966 Report simultaneously introduces other 'experts' from psychiatrists into the treatment and management of mental and emotional distress, which were conceived of as "mental illness" and "disabilities".

This would have the effect of diluting the power-knowledge exercised by psychiatrists amongst others with 'expert' knowledge (French & Raven, 1959) relating to mental health and 'mental illness' in practice. The Report provided for the establishment of psychiatric units in general hospitals, which could provide "short-term care" to those in distress in lieu of a long stay as an in-patient in a mental hospital, for example (Department of Health, 1966: xvii-xix).

These community services were to operate in tandem with the psychiatrists delivering in-patient, or "residential care" in the district mental hospitals. Regarding the district mental hospitals, many of which had previously operated as asylums, the Commission noted that there were "still too many barrack-like structures, characterised by large wards, gloomy corridors

and stone stairways. Too many… lack the purposeful activity and therapeutic atmosphere that are necessary in a modern mental hospital", which the Commission noted as an obstacle to "provide, in whole or in part, treatment in the home or in surroundings akin to the patient's normal mode of living [and] to provide adequate community services" (Department of Health, 1966: xiii). This language is critical of the existing psychiatric facilities and the institution itself, noting the danger that, should these hospitals not be modernised and operating alongside community services, "it would leave unbridged the gap between psychiatry and general medicine" (Department of Health, 1966: xiii). In acknowledging these characteristics of the district mental hospitals, the authors of the 1966 Report acknowledged something else. The district mental hospitals remained a physical representation that, though the hegemonic ideology, concepts of distress, and its surrounding interventions had evolved to maintain legitimacy over the years, the same physical structures of biopower created by the Lunacy Acts (1811-1871) were still the site for the same functions of normalisation and social control they were established for.

The policy choice to take treatment out of the district mental hospitals primarily in favour of siting treatment in the community to rehabilitate those in distress is a defining feature of the 1966 Report's provisions. Ideologically, the 1966 Report still largely conceives distress as "mental illnesses", not all together much different than the biological "mental diseases" of the 1945 Act. However, the 1966 Report is a great deal more person-centred, and inherently acknowledges the complex and uncertain factors that cause and affect mental and emotional distress by recognising the importance of the individual's dignity, and ability to live and function in their community, with "residential treatment" no longer envisaged as the primary site of treatment in the management of "mental illnesses" in favour of "community services" for those with "disabilities" (enduring mental distress). This represents a shift in government policy away from the core Foucauldian function in the exercise of psychiatric power-knowledge confining and removing the mad (the 'abnormal') from those in the dominant social group (the 'normal') (Foucault, 1963, 1965, 1976, 1977; Visoka and Lemay-Hébert, 2022). Accordingly, the numbers institutionalised in district mental hospitals following the 1966 Report fell steadily in the subsequent years, from the 18,000 public and 1,000 private hospital beds referenced in the 1966 Report (Department of Health, 1966: xiii), to the 11,906 noted in the 1984 Report (Study Group on the Development of the Psychiatric Services, 1984: 1).

The psychiatric services - planning for the future: report of a study group on the development of the psychiatric services (1984)

The 1984 Report further developed the ideological and practical move towards deinstitutionalisation from the mental hospitals introduced in the 1966 Report. Ideologically, the 1984 Report maintains the biomedical psychiatric hegemony cultivated and normalised in preceding policy. The 1984 Report can best be described as a bridging social policy document in the field of Irish mental health policy and practice between that which had come before it, and the sweeping holistic reforms to follow with its successor, *A Vision for Change* (AVFC) (Government of Ireland, 2006). Where AVFC called for a reimagined and restructured mental health service both in terms of conceptualising mental health as "biopsychosocial mental health problems" in lieu of the biomedical model, *and* providing multidisciplinary community-based mental health services, the 1984 Report only called for restructured community-based psychiatric mental health services provided through the biomedical model.

The 1984 Report maintained psychiatric hegemony and power-knowledge in the Irish mental health services, and the biomedical model as the appropriate lens to view distress and provide services through. However, the 1984 Report simultaneously recognised the impropriety of the mental hospitals as the primary site of providing psychiatric services to service-users. Barry Desmond, then Minister for Health, noted in his Forward to the 1984 Report that it:

> …contains a detailed analysis of our psychiatric service and provides guidelines for its future development as a community-based service meeting, in the most effective way, the psychiatric needs of the population (Study Group on the Development of the Psychiatric Services, 1984: iii)

In this quote, the underpinning ideology of the policy is clearly delineated. Mental and emotional distress remained the remit of psychiatry, and the needs individuals experiencing distress might have to ameliorate their suffering were classified as "psychiatric needs". The biomedical model is firmly reified. The Report does condemn the State's historic reliance on the mental hospitals as the primary spaces where individuals experiencing distress received treatments or interventions as in-patients or out-patients. The Report upholds the language of mental illness in labelling those experiencing distress as "mentally ill persons" and "mentally infirm". It also actively seeks to broaden the remit of psychiatry, calling for "a broadening in the scope of psychiatry to encompass a much wider spectrum of mental illness such as neurotic and psychosomatic disorders" (1984: 1).

This would further medicalise additional forms of mental and emotional distress and human suffering as "disorders" to be treated with psychiatric interventions. This would permit psychiatry to exercise even more power-knowledge through institutions and interventions of biopower, abnormalising more of the human experience. The biomedical model would be even more deeply entrenched and become even more hegemonic. The 1984 Report was published during the reification of the biomedical model of mental illness brought about by the DSM-III. This is discussed in 'Chapter Two', which may explain this policy direction.

The 1984 Report envisaged and provided for a more comprehensive community-based model of care for those in distress to that outlined in the 1966 Report, which does demonstrate a more whole-person centred ethos. The 1984 Report provided for multidisciplinary teams composed of a consultant psychiatrist as lead clinician, and psychiatric nurses, with access to clinical psychologists, social workers, occupational therapists, and a health administrator who would provide its community-based interventions (1984: 9). These teams are the "sector psychiatric teams" which were to be moved from the mental hospitals to the community in day facilities (1984: 14). This largely psychiatric multidisciplinary care team represents the first iteration of a community healthcare team provided for in Irish social policy. This model would be broadened to include a wider array of specialists and experts in *A Vision for Change*, with its provisions for community Mental Health Teams (CMHTs) in community mental health centres. The community-based psychiatric interventions were to be provided in the family home of the person experiencing distress where possible (1984: 1-3; 11-13). There was to be continuity of care, which is a notable departure from the deficit-based 'maintenance' of 'mental illness' inferred in the biomedical model. The 1984 Report recommended strong links between the sector psychiatric teams and primary care, and included provisions for housing supports for "mentally ill persons", and support for their families. Community services "of a high level", particularly day care services, mental health consultations, crisis intervention, and specialist out-patient clinics were recommended (1984: 14).

This entrenchment of community-based provisions presented a challenge to the purely institutional biomedical ideology which was hegemonically prevalent in Irish social policy before 1966. The change in policy provisions to include social supports for those experiencing distress while recognising their place within their communities moved the discussion in social policy further away from seeing the individual purely as "the patient", though not completely, as the language of "the patient" remains in the 1984 Report. The "patient" perspective, having been hegemonic for the better part of a century, had now begun to be problematised and

critiqued. Though the 1984 Report signals a continued progression of the more holistic conceptualisation of the individual introduced in the 1966 Report, it also sought to broaden the scope of psychiatry. As such, it could be said that the 1984 Report sought to physically deinstitutionalise psychiatry from the mental hospitals, and to foster it in the community instead. To what degree it represents a meaningful ideological challenge to the biomedical model, if any, is a matter for debate. The 1984 Report does note that the services had not, in practice, developed in line with the person-centred community care envisioned in the 1966 Report: "The hospitals were designed to isolate the mentally ill from society and this isolation still persists" (Study Group on the Development of the Psychiatric Services, 1984: xi).

The 1984 Report as a piece of social policy was informed by, or at least conscious of, these critiques and the developing discussions and alternative perspectives surrounding mental health and ill-health to that of biomedical illness. Ideologically, while retaining psychiatric centrality, it galvanised the importance of the community services pillar and deinstitutionalisation introduced in the 1966 Report. It further developed the suite of community services introduced in the 1966 Report to be the primary component of Ireland's mental health services instead of the psychiatric hospitals. These services were to consist of:

> prevention and early identification
>
> assessment, diagnostic and treatment services
>
> in-patient care
>
> day care
>
> out-patient care
>
> community-based residences
>
> rehabilitation and training (1984: xi-xii)

These services were to be delivered locally by the sector psychiatric team, who were responsible for ensuring that individuals/"patients" could transfer readily between them. The sector psychiatric team were charged with ensuring that these services were "integrated with general practitioner, community care and voluntary services" (1984: xii). This call for integration in the Report furthered links to experts and resources in the community outside of the purely psychiatric for those experiencing distress and signals another loosening of the biomedical model's monopolistic grip in policy provision, if not in ideology.

Regarding the mental hospitals and the psychiatric units provided for in the 1966 Report, the 1984 Report included a section on deinstitutionalisation that, on its own, demonstrates an extreme ideological and institutional departure, even from the 1966 Report. In full, it states:

> … in-patient facilities, whether located in a psychiatric hospital or in a general hospital, will cater for a designated catchment area consisting of a number of sectors. With the increasing availability of a wide range of community services, the majority of patients requiring in-patient admission will be discharged in a reasonably short space of time. However, even with the expansion of community facilities, there will still be a small group, usually described as "new long-stay patients" who, despite active treatment and rehabilitation, will need long-term in-patient care. To ensure that a time will come when the psychiatric hospitals are no longer needed, the psychiatric services in each health board area should begin to provide long-stay care in a more appropriate setting. (1984: xiii)

This section of the 1984 Report notes that there will, in effect, be no more need for mental hospitals or psychiatric units once the community services it provided for were in place to cater for those formerly in in-patient units, or those who might have been sent there under the remit of previous mental health policy. It considers the reality that despite its provisions, there would exist a cohort of individuals in distress who may still require more intensive, inpatient care, and allows for this. Incredibly, from an ideological stance concerning the confinement of the mad from society at large, it envisions “a time… when the psychiatric hospitals are no longer needed” (1984: xiii).

This sentence brought the ideology that underpinned the various Irish mental health policies from the Lunacy Acts (1811-1871), to the time of the 1984 Report concerning the institutionalisation and separation of the “mad” from the “sane”, full circle. The 1984 Report imagined a time when the institutions created in the Lunacy Acts (1811-1871), which had evolved, developed, been enshrined with the 1945 Act and upheld, even if challenged, through the 1966 Report would be relegated to the past. The era of the asylum and mental hospital would have passed, and a new era of mental health policy centred on community services would have been initiated in earnest. This constitutes a radical shift in the direction and ideology of Irish mental health policy which paved the way for its successor, *A Vision for Change*, in 2006.

On this point, it is important to note that, as with *A Vision for Change*, the degree to which the services and changing attitudes towards people in distress envisioned in the 1984 Report were

realised and implemented is a contested issue. Though there is no literature analysing the 1984 Report's implementation from which to draw conclusions, it would be remiss not to state that when mental health policy began to move away from the purely biomedical, psychiatric ideology of "mental illness" towards the more progressive, person-centred approaches introduced in the first national mental health strategy of 1966 onwards to the "biopsychosocial model" of AVFC, that the implementation gap between policy and realised provisions grew from a gap to a gulf. One that is complex, and which could not be explained or understood through a purely fiscal analysis of the policies' lack of implementation.

IRELAND'S THIRD MENTAL HEALTH STRATEGY: *A Vision for Change: Report of the Expert Group on Mental Health Policy* (2006)

The Government of Ireland's third mental health strategy, *A Vision for Change* (AVFC) (Government of Ireland, 2006), is central to this research. This is due to the policy's significance as a stark departure from the acts, reports, and mental health strategies that preceded it in terms of its explicit ideological standpoint, conceptualisations of mental and emotional distress and language surrounding them, and its provisions. It was the first piece of Irish mental health policy and law that was not founded upon the medical model. It was, instead, founded on the biopsychosocial model – a version of the social model of disability – which is discussed in 'Chapter Two'.

Combined with its importance due to this ideological departure from the biomedical model which challenged psychiatric biomedical hegemony, AVFC is the mental health strategy that was active while I was a service-user, and during the period analysed in the research's interviews and autoethnography. Both the author and the EBEs who participated in these interviews were in the process of becoming EBEs at the time AVFC was active.

The 1966 and 1984 Reports were significant for their ideological progression away from the "mental diseases" of the 1945 Act to their "mental illness"/"disability" and "patient" conceptualisations, respectively. They also introduced the concept and place of "community care" and deinstitutionalisation (Department of Health, 1966; Study Group on the Development of the Psychiatric Services, 1984). AVFC was distinct from the 1945 and 1984 Reports in that it went far beyond the incremental ideological progression within the established biomedical hegemony that they had. It instead constituted a paradigm shift and a radical departure from its predecessors in its scope and provisions, detailing a vision for a different and redesigned mental health system entirely.

This ambitious piece of social policy did not seek to build upon what existed already and what had gone before it in the provisions of its predecessors, it sought to entirely rebuild the mental health services and their remit upon a social model of mental health. It sought to do this by introducing the aforementioned "biopsychosocial model" of mental health (Government of Ireland, 2006: 4-5), which effectively and deliberately supplanted the institutionalised biomedical model of 'mental illness' which had thereto been a steadfast structural, legislative, and culturally hegemonic behemoth dressed in different terminology such as "lunatics"/"imbeciles"/"the mentally diseased"/"the mentally ill"/persons with "disabilities", depending on the piece of legislation and its corresponding cultural epoch (Government of Ireland, 2006: 241-242). AVFC reflected the contemporary understanding of mental health and distress as complex issues affected by a multitude of internal and external factors, which it understood to primarily be biological, psychological, and social ("biopsychosocial") in nature (Davidson et al., 2016). As a result, the language employed throughout the policy, significantly, refers to mental and emotional distress as "mental health problems" and "mental health difficulties" that "describe the full range of mental health difficulties that may be encountered" (Government of Ireland, 2006: 6).

The terms "problems" and "difficulties" in this regard are purposefully broad and are not limited to one ideology. They do not infer a singular, identified causal factor or pathology that is the remit of one sole, discrete discipline or group of experts to understand and respond to. This language at once eloquently rejects the supremacy of the biomedical model of mental illness in mental health policy and moves beyond the medicalisation of distress, while allowing for and acknowledging the broad spectrum of factors that can affect an individual's mental and emotional state throughout their life (Davidson et al., 2016). The terminology of the medical model is not entirely absent in the policy, with "mental illness" retained in the policy to refer to "specific conditions such as schizophrenia, bipolar disorder and depression" (Government of Ireland, 2006: 6). "Mental illness" is given clear parameters and boundaries and is used to refer to instances of enduring mental distress: what the 1966 Report labelled "disabilities" (Department of Health, 1966).

AVFC and the biopsychosocial model of mental health

AVFC introduced and enshrined a more socially-informed model of mental health, first introduced in the Irish social policy context in the 1966 Report detailed above. The 1966 Report introduced the concept of "community care" as a complementary pillar of care in the mental

health services to operate alongside the still-dominant psychiatric care (Department of Health, 1966). The 1984 Report furthered this position by calling for care in the community to be the primary mode of treatment delivered by service-providers who for the first time, would not be solely psychiatric in their expertise, to those with "mental illness" (Study Group on the Development of the Psychiatric Services, 1984). AVFC, however, entirely tipped this scale; it stated that community care was to be *the* primary and dominant mode and site of mental health care service delivery, and inpatient/institutional treatment overseen by and controlled by psychiatrists was to be a complementary, exceptional pillar of treatment reserved only for those who could not successfully be treated within their communities.

This policy's social model of mental health took the form of a "biopsychosocial" model of mental and emotional distress. This model understood distress to be the result of a complex interplay between biological ("bio"), psychological ("psycho"), and social ("social") factors (Davidson et al., 2016). The policy was explicitly "recovery-focussed" in its underpinning motivations (Government of Ireland, 2006: 4-5). This is a notable departure in the social construction of Irish mental health policy. It is a distinct move away from the motivations and role of the social policy and legislation that preceded it which had sought to protect society from the person experiencing distress – the 'lunatic' – and later, to protect the person in distress from themselves – the person "of unsound mind" – as per the 1945 Act (Government of Ireland, 1945).

Over time this had, as is explored in this chapter, become couched in the language of the "best interests" of the person in distress (Government of Ireland, 2001). The "best interests" approach presented the deprivation of a person's liberty and the denial of their will and preferences as situationally appropriate interventions necessary to protect individuals who were suffering as a new rationale to maintain the power of biomedical psychiatry and its institutions and insulate society from its undesirables. This approach was introduced in the 1945 Act, and reframed in the *Mental Health Act, 2001* (Government of Ireland, 1945, 2001). AVFC's "biopsychosocial" model of mental health and its "recovery-focussed" ethos, however, had been drafted with the wellbeing, agency, and choice of the person in distress at the fore, above the interests of any other stakeholders (Government of Ireland, 2006). The policy noted the primacy and importance of "psychological, and social therapies relevant to the needs of services users and their families" as equal to medicalised treatments or interventions (2006: 9).

Focussing on 'recovery'

The "recovery-focussed" nature of AVFC founded in its biopsychosocial model of mental health, which is informed by the social model of mental health, is another important evolution of policy thinking that differentiates AVFC from its predecessors. This is because the social model of mental health is one developed by service-users through their research into their own experiences and the structures those experiences took place within (Oliver, 1983, 2004). The social model, as detailed in 'Chapter Two', holds that distress is caused by events that individuals experience or are subjected to in society (Boxall & Beresford, 2013; Davidson et al., 2012; Oliver, 1982; Swords & Houston, 2021, 2022). Unlike the purely biomedical model, however, or the purely social model, the biopsychosocial model, which evolved from the social model, acknowledges that there are many different causes of distress, and it does not identify society or biology as the sole source or cause of distress. It takes a holistic approach to understanding an individual's distress, noting that it has no one causal factor, but many.

This move from a biomedical model of understanding distress to a social model variant of understanding distress in the "recovery-focussed" AVFC shifted the Irish mental health policy landscape from one that had been grounded in the containment of 'mental illness(es)' and the treatment of these 'illnesses' as literal physical maladies with biomedical psychiatry to one situated in a service-user developed model of conceptualising mental health (Government of Ireland, 2006).

Community care takes primacy

With this person-centred, holistic social model of mental health at its core, AVFC did not seek to protect society from the 'mad'/'bad'/'lunatic'/'imbecile'/'mentally ill' as Irish mental health policy had done in the past. It instead now sought to challenge the old misconceptions and social stigma reified in previous social policy and legislation's ideologies that such people were dangerous to begin with (Jorm et al., 2012; Pescosolido et al., 2019; Riva et al., 2011; Sowislo et al., 2017). AVFC provided for this by moving those in the 'asylum'/'district mental health hospital'/'psychiatric hospital'/'approved centre' back into their communities. Mental health services were to be provided in the community itself, primarily through general practitioners (GPs) in primary care (Government of Ireland, 2006: 60-69). Where specialist care beyond their remit was appropriate, GPs would refer individuals to their local multidisciplinary "Community Mental Health Team" (CMHT) which would be based in "community mental

health centres" situated alongside primary care centres (2006: 78-83). Deinstitutionalisation would be realised under AVFC, and the harmful physical and metaphorical separation of the 'mad' from the 'sane' in society would cease (2006: 9).

Each CMHT's multidisciplinary team would be comprised of experts from "psychiatry, nursing, social work, clinical psychology, occupational therapy, and clinicians with specific expertise – for example addiction counsellors, psychotherapists, creative/recreational therapists, speech and language therapists", with each CMHT having a catchment area of between 200,00 to 400,000 of the population. This broad array of experts who would provide the appropriate interventions to the person experiencing distress based upon their choices is in line with AVFC's use of the term "mental health problems"/"mental health difficulties" and its recognition of "the full range of mental health difficulties that may be encountered" (2006: 6).

Challenging psychiatric hegemony in AVFC: in theory and in practice

AVFC introduced two new national governmental oversight bodies to ensure independent oversight of the policy's implementation in line with the policy's social model, and to protect individuals within the system. The first of these bodies was the Independent Monitoring Group (IMG), which would oversee implementation and accountability in line with the policy's top-down system of governance. The IMG would produce annual reports on the policy's implementation. The second of these bodies was a Mental Health Service Directorate within the HSE. This Directorate was to be multidisciplinary in its membership, and not solely representative of one discipline or area of mental health expertise (2006: 27).

AVFC also provided for the establishment of a National Service-User Executive (NSUE). The Executive would act to represent the voices and interests of service-users in overseeing and monitoring the implementation of AVFC. NSUE would also provide a space for service-users to supervise the development and delivery of services by service-providers to service-users (2006: 26). This is a considerable provision and acknowledgement of the service-user in the context of the mental health policy that had gone before AVFC. The inclusion of NSUE was recognition of the place of the service-user in mental health policy. Though it was not transformative social policy as it did not imbue the service-user with any real power, nor did it resolve the deep-seated power imbalances or give service-users an equal place at the table, it was affirmative in that it was the first time service-users had been recognised as stakeholders in mental health policy in the Irish context.

Importantly, the psychiatrist would no longer – in theory – be the sole arbiter of what, if any, interventions or treatments the individual in distress would receive. They would form part of the multidisciplinary team of the CMHT along with the other experts, and their dominance and independence in decision-making would vicariously cease (2006: 14). This constitutes a major challenge to psychiatric power-knowledge in Irish policy.

The individual in distress was also to be informed of and feed into – and consent – to their care at every step of the way through the collaborative drafting of an individual care plan, further eroding the power imbalances of past mental health policy and practice, while safeguarding the individual's dignity and respecting their agency in their own treatment (2006: 39; 62; 64). There is a clear break between policy and practice here, as though AVFC as a policy provided for shared decision-making between all stakeholders in an individual's care, the policy assigned the psychiatrist in each CMHT to the role of "lead clinician" (2006: 80). This concession to the hegemonic power of the biomedical institutions that had formed Ireland's mental health services is crucial.

Though a leader amongst peers in theory, the psychiatrist, in practice, retained the agency to take the lead on an individual's case. They exercised the legitimate power-knowledge granted by their 'expert' knowledge which they exercised in biopower processes of normalisation and abnormalisation (Foucault, 1963, 1965, 1976, 1977; French & Raven, 1959; Weber, 1922). This retention of their role is a result of the legislative framework of the Government of Ireland's *Mental Health Act, 2001*. Section 4.(1) of the 2001 Act upholds the "best interests" principle of the biomedical model. This Section allows for the involuntary detention and treatment of persons against their will and preference, if it is deemed to be in their "best interests" in the opinion of the assessing medical practitioner to do so:

> In making a decision under this Act concerning the care or treatment of a person (including a decision to make an admission order in relation to a person), the best interests of the person shall be the principal consideration… (Government of Ireland, 2001: S. 4.(1)).

The 2001 Act, as a piece of primary legislation, took precedence over AVFC as a mental health strategy, and AVFC had to allow for the 2001 Act in its provisions. As a result, though AVFC is an explicit ideological departure from and challenge to the hegemonic biomedical ideology that predated it, it remained bound in practice to fit within the legal parameters of the time.

AVFC was active for 14 years, from 2006-2020. *Sharing the Vision* (STV) succeeded *A Vision for Change* as Ireland's fourth official mental health strategy in 2020 (Government of Ireland, 2020). This chapter analyses Irish mental health policy and its evolving conceptualisations and provisions chronologically up to and including AVFC, the active mental health strategy in the data collected. As such, STV is not considered in this research.

Academic, statutory, and civil society literature on AVFC and implementation

Though AVFC was a landmark piece of Irish mental health policy due to its substantial ideological evolution from the strategies and acts that preceded it, as well as the scope of structural and systemic changes in its provisions, there is little in the way of academic or policy analysis of the document or its implementation. One notable exception is Johnston's comprehensive 2014 analysis of the policy's implementation. Johnston finds that the policy was poorly implemented, and identifies the factors that affected its implementation using implementation theory, mapping the policy's implementation gap.

Johnston's work is a substantive exploration of the issues that caused AVFC to falter in realising its ambitious remit. Part of her research involved interviewing twenty-seven key stakeholders involved in the drafting of AVFC and its implementation to gather their perspectives on the strengths and weaknesses of the policy document and the policy's implementation. While these stakeholders found the policy document itself to be an excellent mental health policy, representing "a real step forward" as a "visionary and somewhat revolutionary policy" for a modern mental health service (Johnston, 2014: 53), they found that the policy was poorly implemented. Johnston identified three primary and four supplementary factors responsible for the policy's implementation gap in her analysis of the key stakeholder interview data. The three primary reasons were: the slow implementation of the policy, the implementation of the policy's provisions not being holistic but "piecemeal and haphazard", and the implementation of the policy being dependant on the Health Service Executive (HSE) (2014: 53). The four supplementary factors that hampered AVFC's implementation were: structural issues, lack of service-user involvement in implementation, cultural issues surrounding the policy and its implementation, and economic factors leading to inadequate resourcing (2014: 53-54). Johnston's work represents the only robust academic analysis of AVFC and its implementation.

From the statutory sphere, the IMG produced six annual reports reporting on AVFC's implementation in line with its mandate, releasing its final annual report in 2012. The IMG

stalled after this point, in the process becoming a failure in AVFC's implementation itself. In its final report, produced in 2012, the IMG conducted a meta-analysis of its six annual reports to that point. This meta-analysis found that there had been significant failures in resourcing the CMHTs across the country with the appropriate number of personnel. This lack of resources left the CMHTs critically understaffed, which undermined their ability to function and fulfil the provisions of AVFC. The IMG's 2012 meta-analysis identified insufficient capital investment and a lack of appropriate financing as significant contributors to the poor implementation of the policy's provisions (Independent Monitoring Group, 2012: 91-93). This is in line with Johnston's findings surrounding the role of economic factors and resources as a factor in AVFC's implementation gap (Johnston, 2014).

Civil society did produce some reports and snapshots concerning specific facets of AVFC, its provisions, and their implementation during the policy's lifespan. These pieces of research constitute grey literature and were primarily produced by the NGOs Mental Health Reform (MHR), and Amnesty International Ireland (AI). MHR produced a robust analysis of AVFC's implementation nine years after the policy's publication in 2015. It investigated the implementation of each of the policy's 168 provisions, finding problems with each one. This report used what sparse statistics were available combined with stakeholder interviews as its data to produce its findings regarding AVFC's implementation. One of the report's main findings was that service-providers in primary care, whom AVFC had designated to function as the most prominent providers of care to those experiencing distress within the community setting, still did not have adequate access to mental health professionals and specialists in CMHTs almost a decade after the policy was introduced. Compounding the issues surrounding implementation of the policy's primary care provisions, the MHR report found that many GPs still lacked the mental health training outlined for them in AVFC (Mental Health Reform, 2015: 19-21).

In a 2013 report commissioned by AI, it was found that adolescents were still being admitted to adult mental health wards and approved centres. This remarkably inappropriate and unsafe practice had been condemned in AVFC, but it was still taking place six years after the policy was published (Faedo & Charles, 2013: 36). AI noted serious concerns about the progress and pace of implementation of AVFC's provisions surrounding deinstitutionalisation in its 2009 submission to the IMG. It identified failures in the timely development of the community-based treatments that service-users were to access in lieu of institutional treatments, three years into the policy's implementation in this submission (Amnesty International Ireland, 2009).

SERVICE-USER AND EXPERT BY EXPERIENCE INVOLVEMENT IN POLICY DEVELOPMENT

Psychiatric hospitals and psychiatric units are still in existence and still receive many individuals each year in Ireland. Community and out-patient care, though they have evolved and have been expanded since 1966, leave much to be desired, even after three mental health strategies that have sought to cement them as the primary interventions for mental or emotional distress in Ireland. Prescriptions for psychiatric medications continue to rise year-on-year, while talk-therapy and other alternative therapies to the medical model remain underfunded, under-developed, and unavailable for many people accessing the public services. Psychiatrists are still the final decision-makers, as per section 4.(1) of the *Mental Health Act, 2001* (Government of Ireland, 2001), despite Ireland's adoption of the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) (United Nations, 2006) in 2007.

The decision of the "expert" psychiatrist is still final over the individual's, even in matters where an individual has written a legal document expressly to prevent the administration of certain treatments or medications, as per the *Assisted Decision-Making (Capacity) Act, 2015* and the *Assisted Decision Making (Capacity) (Amendment) Act 2022* (Government of Ireland, 2015, 2022). Involuntary detention is still a feature of our mental health policies and laws. Additionally, this feature has not been refined or updated to put the dignity and rights of an individual being detained involuntarily to the fore. The act of detaining the person is still carried out by An Gardá Síochána as per the 1945 Act and the 2001 Act (Government of Ireland, 1945, 2001). Though this is disheartening, it is fascinating to see how Irish mental health social policies and laws, which are reflections of the society and the times they were drafted in, began with 'asylums' and 'lunatics', developed into 'community care', and evolved into 'mental and/or emotional distress' contemporarily.

And it is the piecemeal mental health services that have emerged from these social policies and laws and their implementation gaps, the legacy of each contest and conflict between a policy's ideology and how the mental health services and those with vested interests and authority operating within them functioned in reality while that policy was in place, and the interaction of experts from different backgrounds within the mental health sphere that myself and the service-users/EBEs who participated in this research experienced and emerged from. The remainder of this chapter consists of an analysis of the available literature surrounding the interplay of service-users/EBEs with mental health policy in the Irish context. The language of

‘service-user’ will act largely synonymously with that of ‘Expert By Experience’/‘EBE’ in this section, as the existing literature on this topic in the Irish context uses the former term in discussing service-user involvement. There is scarce literature on this topic from the Irish context, but the important contributions that have been produced are discussed.

Academic perspectives on service-user involvement

A 2009 article by McDaid in the ‘Journal of Disability & Society’ analyses common factors frequently presented as barriers in discussions concerning service-user involvement in mental health policy. McDaid identifies four principal factors which those who hold decision-making power and social capital present for the lack of participation of service-users and their subjective knowledges within Irish mental health policy present as barriers to service-user involvement. These are namely: “the capacity of service users to participate, their lack of participation skills, the need for a positive organisational culture and the need for arenas of participation” (McDaid, 2009: 461). Her research problematises the legitimacy of these stated “areas of concern” as the primary causes of resistance to service-user involvement in Irish mental health policy using a participatory action framework methodology.

McDaid collected and analysed the perspectives of service-users through this participatory action framework to identify the barriers to involvement in decision-making that *they* experienced through the lens of Baker’s et al.’s equality of condition framework (Baker et al., 2004). This analysis found that service-users’ barriers to equal participation in mental health policy decision-making resulted from “unequal cultural, physical, mental and economic resources, time, power, ‘stigma’ (prejudice) and lack of respect for their experiential knowledge and emotional expression.” (McDaid, 2009: 461). These barriers contradict those touted by decision-makers in positions of power. They point to matters of poor recognition concerning service-users’ unique experiential knowledge and expertise, inadequate economic resourcing, power imbalances, and issues surrounding cultural and personal respect for service-users involved or seeking to become involved in mental health policy decision-making being the obstacles preventing service-user engagement. These variables are indicative of structural failures on the behalf of those in positions of decision-making power and authority, rather than the individual failures on the service-users’ behalf related to their capacity, skillsets, and attitudes asserted by those within the structures.

McDaid’s analysis concludes that the barriers to service-user involvement are structural in nature, and not the result of factors on the individual service-user level. She recommends that

accommodations be made on the structural side to facilitate service-user involvement in social policy on the individual level, such as appropriate policy training, breaks when necessary, and "flexible attendance arrangements" (2009). Though McDaid's analysis is not recent, it is pertinent to the current research, as it constitutes an analysis of service-user perspectives on their involvement in decision-making policy processes conducted while AVFC was the Government's mental health strategy. This data was drawn from service-users who were reporting on their experiences of engaging or attempting to engage with the policy process of AVFC. The structural barriers to their inclusion and facilitation in the policy process identified in this article are therefore reflective of the service-user experience of engaging with the policy that was in place during part of the period analysed in the current piece of research. McDaid's findings regarding structural barriers and her recommendations for structural accommodations may potentially be reified or reflected in current data analysis.

Brosnan (2012) conducted research into the nature of Irish service-user involvement in the mental health services from a sociological perspective. Her analysis critically analysed the contradiction and friction arising from the adoption of the concept of 'recovery', which originated and was developed in service-user discourses which were explicitly critical of psychiatry (Beresford & Wallcraft, 1997), in mental health policy and services. The article explored the reality of service-user involvement in the mental health services using Gaventa's (2006) "power cube" framework to explore the forms, spaces, and levels of power operating within the services through interviews with service-users (Brosnan, 2012: 46).

Regarding mental health policy, Brosnan notes that 'recovery', as a concept, was first introduced to the Irish policy landscape in a 2005 discussion paper concerning AVFC, produced by the Mental Health Commission (MHC). Analysing AVFC itself, she finds that there is a recovery ethos in the policy, but in parts; not holistically. In analysing the data, Brosnan noted respondents' expectations of 'recovery' in mental health policy as representing the availability of a greater choice of services and interventions as a major theme. This is relevant to the current research and its analysis of EBEs' expectations versus their lived experiences of the mental health services they engaged with.

A section of Brosnan's article surrounding the nature that service-user involvement should or could take in order to be most effective states: "… Recovery and service-user involvement are interdependent, if a service is providing choices it will include meaningful service-user involvement, and not just at an individual level." (2012: 48). This is a profound observation

noting the need for service-user involvement with the mental health services to take place on a collective, meaningful level. Service-user involvement on an individual level may be beneficial in some part for the service-user participating and the service they are involved in which benefits from the unique expertise the service-user provides, but meaningful service-user involvement requires collective involvement to be cohesive, and to succeed in achieving systemic change. This reflects the space which exists for the current research's proposed EBE stakeholder sphere in Irish mental health policy and practice.

Furthering this point, Brosnan considers Beresford's differentiation between the "consumerist" or "democratic" drivers for service-user involvement that he identified (Beresford, 2002). Brosnan finds that the consumerist driver is neoliberal in nature. Far from being transformative, it is affirmative in 'gifting' (Pilgrim, 2005) service-users representation. For Brosnan, services retain hegemonic power, and their inclusion of service-users can be tokenistic and invitational in consumerist service-user involvement. Swords and Houston (2023) have found this neoliberal co-opting of the concept of 'recovery' in mental health service provision to be a reality in the Irish context in their work. Their research investigating the concept of recovery in the Irish context (2020, 2021, 2023) indicates that hegemonic biomedical practices and ideology continue to be exercised, subjugating, diluting, and comingling the service-user conceptualisation of recovery as an individual, emancipatory experience to the biomedical, deficit-based view of recovery:

> The co-constructed meaning-making that is happening in everyday practice is not leading to any responsibility being taken by services, government, or society. The influence of neoliberalism and individualism also contributed to the need to ask critical questions in terms of societies understanding the difference between mental health challenges and mental illness. (Swords & Houston, 2023: 9)

Consumerist service-user involvement is exampled in Patton's 2013 article analysing the degree of service-user involvement in Irish acute admissions units. In this article, service-user involvement refers specifically to service-user inclusion in their own care plans, which is a requirement in AVFC for all individuals receiving care, the active policy at the time. His research is from the service-provider perspective, commenting on the experiences of 18 psychiatric nurses in facilitating this "collaboration" between themselves and the service-users they provided care for in acute mental health units. The nurses did not offer this collaboration to each of their patients, and their decision to do so was based upon their own privately arrived-upon criteria for the service-users who *should* be collaborated with. Patton describes this theme

in his article as "Heroic nursing", with the other substantial theme he identified being "Interacting with service users as people" (Patton, 2013: 389). This is in keeping with Pilgrim's (2005: 25) observation that in such consumerist instances, service-user involvement is "in the gift" of service-providers; they are not a given. Pilgrim echoes Beresford's (2002) position on the distinction between consumerist and democratic service-user involvement, using the language of "co-opted", and "survivor" service-users in his analysis (Pilgrim, 2005: 19).

The positive interpretation of the piecemeal adoption of one of AVFC's core provisions, that of individuals being involved in their own care, in Patton's 2013 article, which he notes is a result of the "modernization" of the Irish mental health sector since 1984's *Planning for the Future* Report and successive government policy since (2013: 387-388) is an example of Beresford's concept of consumerist service-user involvement in action (Beresford, 2002; Brosnan, 2012). Patton's article is not directly concerned with analysing service-user/EBE involvement in mental health policy, but it is an example of what 'service-user involvement' represented to a small cohort of service-providers mandated to engage in it by Irish mental health policy, at least. It also forms part of the limited research and literature which exists in this area. It provides a limited yet illustrative insight into mental health policy's implementation in Ireland at the time of its publication, from the service-provider perspective.

Beresford's (2002) "democratic" driver to service-user involvement differs to the "consumerist" driver substantially. It is founded in civil rights movements, which Brosnan notes includes the service-user movement itself, and it is based in ideas of autonomy, agency, inclusion, and self-advocacy (Brosnan, 2012: 49). Citing Beresford, Brosnan notes that "Beresford (2002) argues that the logic of the "democratic" approach is for "user-led" and "user-controlled" services, whereas the consumerist approach seeks to influence the provider-led approach to policy and services." (2012: 49).

This distinction is crucial for the current analysis, as a foundational belief of mine underpinning this research, in conceptualising that the role that EBEs and service-users should occupy in mental health policy and practice is one of parity with all other experts. The services, provided for service-users, should be monitored and implemented by them and with them in what Beresford labels "user-controlled" services (2002).

A key purpose of the current research is to demonstrate the place and worth of an EBE stakeholder sphere in Irish mental health policy and practice. This sphere, it is argued, should enjoy parity with the two traditional stakeholder spheres this research identifies: the biomedical

psychiatric sphere (medical), and the governmental (statutory) sphere. These are discussed in 'Chapter Two', and I feel it is important here to reiterate a position expressed in the same chapter. With that in mind, I feel it is important at this point in the discussion of "co-opted", "survivor", and "democratic" service-user involvement to restate that I do not believe it is anyone's place to gauge the worth of one service-user's involvement in mental health services over another service-user's based on their reasons for becoming involved. Service-user involvement in psychiatric mental health services or statutory mental health bodies is valid and should service-users engaged in this type of involvement feel they are unheard or unable to provoke change, this could give them reason to critically reflect upon the experience and form a part of their own journey to becoming an EBE.

Brosnan concludes her article by summarising the beliefs of her research participants, stating that "They believe service-user involvement can change the way services deliver care." (Brosnan, 2012: 63). This is a call from the service-user participants in the study for service-user involvement in Irish mental health policy and practice. This call is made from a service-provider, social-worker perspective by McDonnell (2015) in her analysis of service-provider attitudes to service-user involvement in the services. She finds that service-user involvement has increased since the publication of AVFC, noting that it is "widely recognised as important and beneficial, for the services and service users", with her data suggesting that service-user involvement in the services results in "a modern service where staff and service user work together to achieve mutual aims" (2015: 14).

Brosnan's analysis of service-user involvement, which she abbreviates to "SUI", is a comprehensive analysis of the power dynamics at play between service-providers and service-users, and the tensions and contestations which have existed in Ireland pertaining to both. It is a pertinent piece of research for the current analysis, as Brosnan contributes to the sparse literature surrounding service-user involvement in the mental health services (McDaid, 2009; Swords & Houston, 2020, 2021, 2023), from a service-user perspective. It resonates with the current research and with myself as a service-user in conducting the current research.

Distinguishing between mental health practice and mental health policy analyses

Building upon the analysis of her 2012 article, Brosnan's doctoral research is a thorough exploration of the concept of service-user involvement itself, its origins, the varying conceptualisations of SUI, issues of collaboration and co-opting, and the claims laid to SUI by parties with vested interests within the Irish context, analysed using Gaventa's (2006) "power

cube" conceptual tool. SUI is analysed in one Irish multidisciplinary mental health team. As such, the research is concerned with service-user involvement in service *provision*, and not service-user involvement in mental health *policy*. The research does note that SUI, from the perspective of the service-providers who participated in the research, is "a top-down policy encouraged by the MHS [mental health services], implemented at the discretion of local leader" (Brosnan, 2013: 397). This is certainly a comment on national mental health policy. McDaid (2009) calls for service-user involvement in mental health policy and mental health practice.

The current research explores the perspectives of EBEs, themselves service-users, and their process of becoming an EBE framed within the context of Irish mental health policy. It may, then, complement Brosnan's contribution to knowledge and literature, with the current research providing a contribution to knowledge surrounding service-user/EBE involvement in Irish mental health policy as well as practice, and helping to fill the gap in the literature surrounding service-users/EBEs and their experiences of Irish mental health policy and practice.

Statutory and civil society resources on service-user involvement

A comprehensive review of the work produced by Irish statutory agencies and civil society organisations analysing issues of policy implementation in the Irish mental health services identified a gap in the literature pertaining to service-user/EBE involvement in mental health policy. Several reports were produced by Irish NGOs and statutory bodies throughout the AVFC's lifespan, however they predominantly concern the implementation or lack thereof of the recovery principles enshrined in policy, as well as other failures in implementation from a service-based perspective.

From the statutory sphere, a 2008 report by the Mental Health Commission (MHC) provided a framework for delivering recovery-based services (Higgins, 2008). The IMG produced annual implementation reports as per its mandate in AVFC from AVFC's publication in 2006 until their final report in 2012 (Independent Monitoring Group, 2007, 2008, 2009, 2010, 2011, 2012). These pieces of literature analyse and report on the degree of implementation of AVFC's key provisions and recommendations relating to the 'recovery ethos' enshrined in the policy (Government of Ireland, 2006).

From the civil society sphere, MHR produced grey literature in the form of submissions to government, position papers, budget snapshots, and reports during the policy's lifespan. The reports and papers MHR produced investigating AVFC's implementation from a service-user

perspective focussed on the concept of recovery in analysing the policy's implementation (Mental Health Reform, 2011, 2015, 2017). These reports illuminate the service-user experience of the mental health services, but do not consider service-user involvement in mental health policy.

Statutory calls for service-user involvement in mental health policy

Two pieces of grey literature that were significant as they involve the inclusion of service-users/EBEs at the mental health policy level were identified in this review. The first is the *National Strategy for Service User Involvement in the Irish Health Service 2008-2013*, which was co-produced by the Department of Health and Children, and the Health Service Executive, with input from the Health Services National Partnership Forum. This was published by the Health Service Executive (HSE) (Department of Health and Children, 2008). The Strategy is quite progressive in the role it carves out for service-users. Differing from the reports discussed above, this 2008 strategy called for and detailed how service-users were to be included in policy and regulation as well as in the provision of services and their own care. The Strategy sought to bring practice into accordance with Government mental health policy, including AVFC (Government of Ireland, 2006).

The content of the Strategy that is of particular relevance to the current research concerns its objectives concerning service-user/EBE inclusion at the mental health policy and regulatory levels. The Strategy envisages a cyclical process of service-user inclusion and involvement, from individual care, through community service-level involvement, and crucially, to national policy development. At the national level, it aims to facilitate the development of "strategic policy informed through involvement of service user organisations in partnership with health care professionals." (Department of Health and Children, 2008: 9).

In supporting its ambitions for service-user involvement at the national and community policy levels, the Strategy notes several benefits provided by this involvement. They include addressing health inequalities, local services that are more attuned to the needs of their specific communities and more inclusive to lessen social exclusion, and reduced complaints and an increase in trust at the community level (2008: 10). The final outcome surrounding increased trust is interesting, as it implicitly acknowledges the lack of trust between service-users and the service-providers stemming from hegemonic power imbalances and individuals' negative experiences in the mental health services.

At the national level, the Strategy identifies four key organisational benefits of service-user involvement. Cost-efficiency resulting from improved service-delivery for service-providers is one. The remaining three benefits are significant to the current research. They are: "improved public perception and confidence in the health services", ensuring that "policies and service plans are informed, relevant, appropriate, and targeted", and fostering "Greater understanding of the links between health, lifestyle and the circumstances in which people live their lives" (2008: 10). These benefits all implicitly acknowledge the value offered by EBEs' unique expertise and perspective. The inclusion of their subjugated knowledges at the national policy level would contribute to the traditional, legitimately exercised expertise (French & Raven, 1959; Lukes, 2005; Weber, 1922) already in situ in the mental health services by addressing issues of the relevancy, appropriateness, and specificity of the mental health services.

By noting that service-user/EBE inclusion would be beneficial in alleviating issues surrounding the "public perception and confidence in the health services" (Department of Health and Children, 2008: 10), the Strategy further acknowledges that the mental health services, at the time still dominated by psychiatry and the biomedical model, did not have the trust of service-users. The Strategy's understanding that including service-users/EBEs at the national level and giving them a share of decision-making power in the process could help in addressing and correcting issues of trust, confidence, and negative public perception of the services demonstrates an implicit understanding on the part of the State that the services as they were, without service-user/EBE inclusion, were founded on unequal power structures that disadvantaged those accessing them.

The second piece of pertinent grey literature identified presents an even more explicit call for service-user/EBE involvement in mental health policy and of service-users and the public in the infrastructure of the State on a broader scale. This is the *Framework for Public & Service User Involvement in Health and Social Care Regulation in Ireland*, produced by the Health & Social Care Regulatory Forum in 2009. The Health & Social Care Regulatory Forum is a broad forum, whose membership includes many state agencies, professional representative bodies, and regulatory bodies. These include the MHC, and the Medical Council of Ireland.

The 2009 Framework which they produced is a more comprehensive, ideological document than the more practice-focussed 2008 Strategy produced by the HSE. The 2009 Framework considers the role of the public, consumers of mental health services and other public services, and the general citizenry in statutory regulatory instruments across all levels of regulation and

governance. It is noted in the Framework that "it is increasingly being recognised that a successful society depends on partnership - between citizens, civil society and the public service with respectful dialogue allowing the government, citizens and communities to seek the common good." (The Health & Social Care Regulatory Forum, 2009). The 2009 Framework cites the 2008 HSE Strategy in its recognition of the move towards stakeholder involvement across all spheres in developing regulation which was influential in government policy at the time (2009: 4).

The 2009 Framework considers AVFC, finding the policy's position regarding service-user involvement to be an exemplary example of the possibility for service-user engagement in mental health policy: "… the 2006 report of the Expert Group on Mental Health Policy, *A Vision for Change,* recognised that service users should be involved in implementing and evaluating mental health policy" (2009: 9). The Framework, not unlike the 2008 Strategy, describes what engagement from stakeholders should look like at five different levels: "communicate", "listen", "consult", "engage", and "partner" (2009: 18-21).

All stages should be part of any regulatory body according to the 2009 Framework, with the "partner" level occupying a similar conceptual and practical space as the "National" policy level described in the 2008 Strategy (Department of Health and Children, 2008: 10). The "partner" level of service-user engagement is described as:

> [Involving] introducing a public and/or service user representative to the inspection or review team of a regulatory body. Any public or service user representative is an equal member of the inspection team who brings his/her own experience to the inspection process. (The Health & Social Care Regulatory Forum, 2009: 21)

This describes what service-user/EBE inclusion in mental health policy, as well as the inclusion of other stakeholders in their respective spheres, should look like in practice. It is noteworthy for emphasising that the service-user must have parity of esteem with the other members of a review team of a regulatory body. In terms of the current research, this would take the form of EBEs being equal decision-makers in mental health policy as well as in practice through their own stakeholder sphere, with their unique expertise being recognised by the 'traditional experts' who have historically decided upon policy and service formation.

CONCLUSION

This chapter examines Ireland's evolving ideological trajectory of conceptualising mental and emotional distress in mental health policy, law, and practice. The cornerstone mental health policies and legislation that have enshrined or progressed a distinct conceptual model are examined. Conceptualisations of individuals experiencing mental or emotional distress have ranged from "mad" historically, "lunatics" in the *Lunacy (Ireland) Act, 1821*, "bad" in the *Criminal Lunatics (Ireland) Act (1838)* (UK Parliament, 1821, 1838), "mentally diseased" in the *Mental Treatment Act, 1945* (Government of Ireland, 1945), "mentally ill" in both the *Commission of Inquiry on Mental Illness: 1966 Report* (Department of Health, 1966) and *The psychiatric services - planning for the future: report of a study group on the development of the psychiatric services* (Study Group on the Development of the Psychiatric Services, 1984), and finally, experiencing "mental and emotional distress" in *A Vision for Change: The Report of the Expert Group on Mental Health Policy* (Government of Ireland, 2006). Each piece of legislation is analysed in the context of that which preceded it, and that which succeeded it chronologically, critically analysing each document and its conceptualisations, provisions, and implementation (where applicable). The literature surrounding these policies is explored, where it exists.

The policies and laws are analysed using the current research's combined Foucauldian/Gramscian theoretical framework, investigating the hegemonic ideology and exercise of power-knowledge, and those who exercise it, in each piece of legislation. Power is predominantly exercised through the medical model of mental illness or the biopsychosocial model of mental health. The latter section of this chapter reviews what relevant literature exists concerning the Government of Ireland's last mental health strategy, *A Vision for Change*, with a particular interest in scoping analyses calling for or considering service-user/Expert By Experience involvement in Irish mental health policy formulation, identifying two relevant pieces of grey statutory literature. The current research contributes to filling the gap which exists in this area by providing a working definition of a mental health 'Expert By Experience' in the Irish context, and the process individuals undergo in becoming an EBE. This definition is informed by the literature surrounding EBEs which is explored in 'Chapter Two', building upon the concepts therein from analysis of the data gathered through the two streams of research outlined in 'Chapter Four'. This data analysis is provided in the chapters 'Chapter Five', and 'Chapter Six'. The latter two chapters explore what the characteristics of EBEs'

unique expertise are, and demonstrate the potential for EBEs to occupy a space in Irish mental health policy and practice.

Table 3.1: Irish Mental Health Laws and Policies and Their Concepts of Mental Health

IRISH MENTAL HEALTH LAWS AND POLICIES	EVOLVING CONCEPTS OF MENTAL HEALTH
Cultural: **pre-legislation/policy**	'Wintering' the **'mad'** (Kelly 2016)
Lunacy (Ireland) Act, 1821	Regulating **'lunacy'** through asylums
Criminal Lunatics (Ireland) Act (1838)	Imprisoning the **'bad'**
The Mental Treatment Act, 1945	'Caring' for the biomedically **'mentally diseased'**
a) First government mental health strategy: ***Commission of Inquiry on Mental Illness: 1966 Report*****.** b) Second government mental health strategy: ***The psychiatric services - planning for the future: report of a study group on the development of the psychiatric services*** **(1984)**	Community care for the **'mentally ill'**: move from institutionalisation of distress to outpatient community treatment begins
Third government mental health strategy: ***A Vision for Change: The Report of the Expert Group on Mental Health Policy*** **(2006)**	Community care and service-user involvement for **'mental and emotional distress'**: **'mental illness'** still dominant

Source: created by author 2023

CHAPTER 4: METHODOLOGY

INTRODUCTION

This chapter discusses this research's methodology, with an exploration of the research's unique autoethnographical, Expert By Experience (EBE)-led framework. The study's qualitative research design is presented. The primary research strand of autoethnography, which is a reflexive, iterative research method and approach to research that centralises the self in all parts of the research, from inception to its completion, is discussed. The second, parallel research strand of in-depth qualitative interviews with EBEs is detailed. In-depth EBE interviews were chosen for this research to give a voice to the experience of these experts who this author argues, have been overlooked in Irish mental health policy and practice, as described in 'Chapter Three'. The two approaches of purposive sampling and snowball sampling used in data collection for these interviews are then outlined. The impact of the Covid-19 pandemic on the initial research design is discussed. The ethical considerations involved in researching a personal and sensitive topic such as distress and EBEs' journeys are expanded upon, including the informed consent, anonymisation of data, supports available to participants, and the data management procedure utilised. Using autoethnography, the chapter concludes with a reflexive consideration and account of the author's experience of the interviews as they took place. This involves the unanticipated impact that the transcription of these conversational interviews had on the author, and how this impact was managed.

RESEARCH DESIGN

This research employs an explorative, qualitative research design. It investigates areas of participants' lives that are deeply personal, nuanced, and in many cases, difficult to discuss and revisit. A qualitative methodology is the most beneficial for research investigating and analysing issues of mental health and distress from a lived experience perspective (Beames et al., 2021). Quantitative methods, such as questionnaires, are not equipped to accurately capture and portray the intricacies of lived experience, particularly in instances of chronic mental and emotional distress (Brazier, 2010: 348-349; Saarni et al., 2010: 386-394). As Taylor and Francis note, qualitative research is beneficial to research which seeks to "get to the core of human experience of health and illness to facilitate change at individual and governmental levels" (2013: 12).

This design uses the two parallel research strands of autoethnography and in-depth qualitative interviews with EBEs. These strands were chosen for their depth, quality, and authenticity (Denzin, 2012: 82). Seidman (2013: 9) notes that "At the root of in-depth interviewing is an interest in understanding the lived experience of other people and the meaning they make of that experience".

The primary aim of this qualitative research design is to explore and analyse the experiences and expertise of EBEs in relation to Irish mental health policy and practice using autoethnography and in-depth interviews with EBEs, with the goal of analysing the lived experience of these experts who were developing their expertise during the timespan that AVFC was the active government mental health strategy. This analysis should reveal areas where EBEs' lived experience aligned with or differentiated from the overarching goals, vision, and specific policy provisions of AVFC, which I detail in 'Chapter Three'.

This research captures the voice of people who have unique experiences of mental health policy and power relations from the service-user perspective, and from the perspective of an expert group who have historically been absent and not included in Irish mental health policy and practice. This was evidenced in 'Chapter Three'. This research will make a contribution to knowledge in its description of the journey to becoming an EBE in mental health according to these experts themselves, and in demonstrating the value of their unique expertise and place at the policy stakeholder table.

The design employs a triangulated methodology. Triangulated methodologies for qualitative research studies were originally theorised by Denzin (1970), and later developed by Flick (2007, 2012), and Fielding (2009). They have several benefits. Theorists have found that using a triangulated methodology offers rigour to the research and its findings. This is thanks to the corroboration or falsification of fundamental underlying hypotheses, evidenced within the data that emerges from unique strands of inquiry (Denzin, 1970, 2012). This increases the validity of the analysis and findings. Further to this, Flick (2007, 2012) argues that triangulated methodologies add "breadth, complexity, richness, and depth to any inquiry" (Denzin, 2012: 82). These benefits, including the increased validity of findings corroborated across different modes of inquiry (Denzin, 1970), make a triangulated methodology appropriate design for this research.

A triangulated methodology is composed of two or more research methods (Denzin, 2012). I employ the two research methods of autoethnography and in-depth qualitative interviews with

EBEs outlined above in my data collection and analysis. I proceed to outline the rationale for each method here.

AUTOETHNOGRAPHY AND INCLUDING THE SELF IN THE RESEARCH

This research is an autoethnographical study. Autoethnography is a research method and approach to research that exists across a broad spectrum. There is no one singular autoethnographical method, and autoethnography exists on a spectrum ranging from analytic to evocative autoethnography, which I describe further on. Ellis et al. (2011) provide a definition of the method that encapsulates it and its core principles succinctly:

> Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (*graphy*) personal experience (*auto*) in order to understand cultural experience (*ethno*)… This approach challenges canonical ways of doing research and representing others… and treats research as a political, socially-just and socially-conscious act (under 'History of Autoethnography', para 1)

Autoethnography centralises my lived experience as the researcher within this research. Using it, I reflect upon my lived experience of the Irish mental health services as an EBE while AVFC was active, and how this experience has informed my academic career and decisions as a researcher, as well as broader considerations of how it has influenced other areas of my life, including my professional career. There is also the more personal nature that is innate in autoethnography, and more so with evocative autoethnography, which is how the events and experiences I discuss using the method have shaped me as a person, outside of specific roles such as academic or the positions in which I have worked as a result of them. All of this is revealed through autoethnography, making it an emancipatory approach to research.

One significant component of my autoethnography is 'Chapter Five'. In this chapter, I employ evocative autoethnography (Ellis and Bochner, 2016) to tell the story and present the narrative of my life living with enduring mental and emotional distress. Regarding evocative autoethnography, Gergen and Gergen (2018: 5) note that "An evocative ethnography is designed not to constrain the reader's attention but rather to invite a richer and more expansive appreciation of the possible. For the evocative ethnographer emotionally arousing discourse plays a central role." I write about the experiences I had growing up, from early childhood to the end of my treatment in the Irish mental health services at the age of 22 in 2012. These parts of my life were fundamental in shaping me as an EBE, up to and during the timespan when AVFC was the active government mental health strategy. This timespan was the period of

analysis the initial research design and interview schedule was intended to investigate in the in-depth EBE interviews. The collected data ended up covering and capturing a far broader and more comprehensive timespan in the EBEs' lives. I followed the direction my EBE peers were leading me in and reported on these same themes over a similar timespan, beyond the lifespan of AVFC, in my own evocative autoethnography. For Polkinghorne (1995), this reflexive approach to producing narratives and following the data in conducting qualitative research, as I have done in this research, is important. He notes that:

> The analytic development of a story from the gathered data involves recursive movement from the data to an emerging thematic plot… As the plot begins to take form, the events and happenings that are crucial to the story's denouement become apparent. The emerging plot informs the researcher about which items from the gathered data should be included in the final storied account (1995: 16)

RESEARCH METHODS

1. Autoethnography

I have chosen autoethnography for several reasons that benefit the research. Autoethnography allows me to analyse data that I am assured as a researcher is first-hand, with internal validity (Bleijenberg et al., 2011). It allows me to produce deep, "thick" analyses of the data in answering the research questions at hand (Adams & Herrmann: 4).

Autoethnography also enables me to gather qualitative data from a second service-user *and* EBE source, coupled with those obtained from the in-depth EBE interviews, as I am an EBE, and also a former service-user. The autoethnographical method has been found to be positive when the researcher is investigating issues of health and illness, due to their emotional and personal aspects. This makes it well-suited to this research area.

Evocative autoethnography, such as my own, seeks to invite the reader to engage with the content emotionally as well as intellectually (Ellington & Ellis, 2008). Along with the singular piece of data presented in this research's piece of evocative autoethnography, the autoethnographical epistemology and methodological approach involves a continuing discourse with myself as the researcher *as* I conduct and shape the research. In this sense, it functions as both a narrative framework through which the research method of in-depth EBE interviews and the data collected from them are viewed and described, as well as an ongoing part of the research itself. It is a thread that runs through each part of this research.

The research, like the person using autoethnography, is an evolving, iterative thing, and as such, it has not remained static as it has unfurled and taken shape. The research's nature and form have changed and morphed as I have undertaken it and followed the data I collected through interviews, as well as my own evocative autoethnography, where they led me. The end destination is different to the envisaged destination when I commenced this research. The dynamic, fluid nature of autoethnography has been fundamental in facilitating this research's changing focus, and in allowing me as the researcher to adapt to it and reflect and report upon it in the written thesis. Berry (2021b: 31) notes this iterative nature of doing and writing autoethnographical research, and following through reflexive practice as it evolves: "Practicing reflexivity within evocative autoethnographic research and writing practices also creates the conditions through which autoethnographers co-constitute (i.e., creatively make and remake) our-selves within this inquiry.".

As a research method and approach to doing research, autoethnography exists on a spectrum from extremely fluid and artistic in its nature, including journal entries, art, poetry, journals, and dance as creative methods on the creative end (Bartleet & Ellis, 2009), to extremely analytical on the opposite end (Tullis, 2013: 245). Witkin (2014) notes that when it is reduced to its most fundamental parts, autoethnography can be defined as belonging to one of two strands: evocative autoethnography and analytic autoethnography. Anderson (2006: 375) notes that the analytic strand is concerned with "improving theoretical understandings of broader social phenomena". Ellis and Bochner (2016) describe how evocative autoethnography is concerned with revealing the subjectivity of the person doing autoethnography as they exist within the social and cultural world they are exploring through a "personal, vulnerable, reflective, self-conscious, self-reflexive, narrative voice" (Ellis & Bochner, 2016: 51). My approach to autoethnography employs tools from across this spectrum, with evocative autoethnography, which is artistic and creative, and more analytic aspects of autoethnography used in this research. It is used to iteratively reflect upon the nature the research took, how it changed, and how it was *allowed* to change due to my use of the method in the analytic strand in my writing.

Previously, there had been some debate in the field of autoethnography regarding the perceived merits of one strand of the method in lieu of the other, with some believing analytic and evocative autoethnography to be mutually exclusive. However, contemporarily, there is more agreement amongst thinkers (Hayler, 2013; Sparkes, 2020; Winkler, 2018) that such blending and combining of both strands of autoethnography is not only possible, but beneficial and

fruitful for researchers engaged in autoethnography who weave them together (Sparkes, 2021: 268). This has been my experience when using autoethnography in the current research, as I marry evocative autoethnography with more traditional academic inquiry through a post-structuralist lens.

I believe the research's autoethnographical approach also demonstrates the strength of EBE knowledges in informing more traditional knowledges, such as those prevalent in academia. As autoethnography is a reflexive and iterative methodological approach and process, the EBE data collected through the in-depth interviews informed me as a researcher and in reflecting upon my own journey when it came to conducting my own piece of evocative autoethnography. As I thematically analysed the data and noted the main emergent themes from the interviews as I conducted them, the direction that the data was taking was consistently moving in certain key areas away from the direction I had expected from my initial research focus towards something else (Polkinghorne, 1995). This diversion was away from what I had anticipated based upon the broad questions and areas I had included on my interview schedule, concerning EBEs' perspectives on AVFC, to revealing that the larger and more consistent themes EBEs were reporting told the tale of their journey to becoming EBEs. Autoethnography by its reflexive nature allowed me to follow the data and my peers in this unexpected direction, and to share my own experiences surrounding these themes in the interviews as participants discussed them. As a researcher, I knew I should analyse the data based on the themes that had arisen so consistently across each of the six total interviews with five EBE participants instead of focussing the data analysis on participants' perspectives on AVFC as a policy. The explorative nature of this research also facilitated this refocussing.

Telling the story of how they became EBEs during the policy's lifespan was more important to me as a fellow EBE. It also addressed the original research's goal to analyse the implementation of AVFC, as participants' journeys to becoming EBEs were all significantly influenced and impacted by the treatment they received from the Irish mental health services during AVFC's lifespan. This makes their journey a reflection of the degree of success of the policy's implementation.

I consider that autoethnography is particularly suited to this study as it allows me to produce an interesting and dynamic body of research in line with the post-structuralist perspective of this study. Having previous experience conducting autoethnography, the method is remarkably revealing for 'me' as a researcher, as well as 'me' as an individual. It provides a unique depth

of insight into the cultural and social world that the social policy being analysed was drafted in and reflects, as the researcher is required to analyse their own experience of this cultural and social world, rather than solely interpreting somebody else's (Witkin, 2014). The data collected through the method is vivid and detailed, notably data collected using evocative autoethnography, which I employed in 'Chapter Five'.

2. In-depth interviews with EBEs

This research seeks to gather and interpret the perspectives of EBEs concerning their lived experiences of the Irish mental health services, as operated under the remit of government mental health policy (namely AVFC), to describe their experiences of these services and the impact they had on them in their process(es) of becoming EBEs. To answer the two research questions — i) What are the views, experiences, and insights of Experts By Experience on Irish mental health policy and practice? ii) What are the implications of Experts By Experiences' insights for the future development of mental health policy and practice? – the firsthand perspectives of EBEs regarding their experiences are needed. Such perspectives from EBEs on what makes them an EBE from their lived experience, distinct from the academic discussions surrounding their characteristics, will provide an important contribution to knowledge surrounding the reality of being an Expert By Experience in practice as compared to the Expert By Experience as has been theorised in the literature. These EBE perspectives will also be crucial in the theoretical formulation of an equal EBE stakeholder sphere in mental health policy and practice. In defining the role of the EBE in "the concrete social world" (Pokinghorne, 1995: 19), and the common journey undertaken by the EBEs who participated in this research, the perspective of these EBEs is the richest and most appropriate source of data available for the current research.

ETHICAL CONSIDERATIONS

This research and its methods are directly concerned with the sensitive issues of mental health/ill health and emotional distress, and individuals' deeply personal experiences of them gathered through primary data collection. It is therefore imperative to consider the fullness of ethical considerations and obligations to ensure that the research constitutes the lowest possible risk of causing distress to participants and researcher alike. Individuals' dignity, which may not have been recognised by third parties in the histories they shared, has been respected at each stage of data collection and analysis, and their anonymity has been safeguarded and

protected. These ethical obligations are especially pertinent in conducting research that involves the individual being interviewed describing potentially abusive relationships they were a part of, defined by a power imbalance weighted against them. Such relationships are frequently a defining characteristic of the relationship between individuals who have undergone psychiatric treatment and the psychiatrists who they saw, as they had been in my case (Markey, 2013, 2017). I describe the measures that were taken to ensure the ethical rigour, protections for all participants, and safety of all participants here.

Informed consent and supports

All individuals who have agreed to participate in the interviews were provided with an information sheet detailing the research, its purposes, and the data collection and retention period. This information enabled participants to either give informed consent or to decide not to continue with their participation. The potential risk posed to them was detailed, with the primary risk being the potential for the research to trigger emotional distress for participants during or following the interview. A list of supports that were available to participants should this occur were provided. The participants were also reminded that, due to the discursive nature of this research, they could contact me with any concerns they had following the interview which we may have been able to allay together, and which may otherwise have resulted in a knee-jerk withdrawal from the research on the part of the participant.

The participants were informed that they could withdraw from the research at any time, before, during, or after the interview, without the need for explanation or justification. It is equally if not more important to me as a researcher to ensure that research has not resulted in harm for participants who may decide to withdraw from a study, as their withdrawal may signify emotional distress triggered by the research. The current research's design included the following contingency plan should such an instance occur. Participants would be made aware of the supports available to them in a non-invasive manner consisting of a once-off email from me. This approach was intended to protect against imposing upon any individuals who may have decided to withdraw for a myriad of reasons other than distress, while simultaneously making room for individuals who may have withdrawn due to distress to open up a dialogue with me to assist them in finding the appropriate support for their current mindset, should they wish to have done so. This scenario did not occur during the research collection.

If the participant agreed to continue with the interview following receipt of this information and the information sheet, they were then provided with an informed consent form to read and

sign. This form stated that the participant had read the information sheet and was happy to participate in the research as described. It stated that the participant was entitled to a transcript of their interview should they wish to review the discussion, that they were aware of the potential risks and the supports available to them in case a risk was encountered, and that they understood and were satisfied with the measures that would be taken to anonymise their identity and their data.

Anonymisation

The information sheet explained that any information participants provided would be anonymised to protect both the participants, and those who may be implicated in their interview. Anonymity was achieved by initially using initials to denote those participating in the research in my rough interview notes, and those mentioned or potentially identifiable in their interview in all notation, and coding conducted during the data collection phase. In 'Chapter Six', discussing the findings, no pseudonyms or identifying factors were employed, relying on specific accounts given by participants without reference to them individually where possible to ensure anonymity in the written thesis. Specific locations and places, as well as clinics/hospitals/treatment centres/businesses, etc., described by participants were anonymised by replacing their names with their functions, i.e., '[INSTITUTION]', or '[HOMETOWN]' in transcription, coding, and notation, along with any other identifiers that come up.

A sample of the information sheet and the informed consent form is found in Appendix A.

Data collection and management

The primary data collected for this research using the outlined research methods were managed and are stored in line with Maynooth University GDPR guidelines. The key-informant interviews were recorded using a portable, password-protected digital voice recorder. The device's functions and contents can only be accessed using a password that only I know, and which there will be no written record of.

Following the conclusion of each interview, the data recorded on the digital voice recorder was transferred to a laptop which has been fully encrypted by Maynooth University IT Services. Only I can access this laptop, which requires the encryption key that only I know, and a password that only I know. No physical record of the key or password exist. Once the interview

file has been transferred to the encrypted laptop, it was destroyed from the digital voice recorder.

From the encrypted laptop, the data was uploaded to the Maynooth University Office365 OneDrive Server immediately. The data was then destroyed from the encrypted laptop. With these steps taken, the collected data will now exist solely in my University OneDrive on the encrypted Maynooth University Server. This is accessible only by me, through a two-step verification process that strengthens protection. This two-step verification is comprised of a password with no physical record, known only by me, and a unique sign-in code generated at each log-in which is sent to my mobile phone. My mobile phone is both biometrically-protected and passcode-protected. The unique access code is time-sensitive, and access cannot be gained to my OneDrive without it. The collected data will be retained and destroyed by me after the period designated by Maynooth University policy.

Autoethnographical approach to interviews

In considering the format of and schedule for in-depth interviews with EBE from a post-structuralist perspective, I needed to consider the role I would occupy and 'take on' during the interviews and after them in making myself available to participants for further comment, or retraction of their participation in the research without the need for explanation. In such an instance, I would follow the ethical guidelines described herein to fulfil ethical and moral obligations to ensure the participant has not been distressed by the research process, and if they have, to act accordingly to assist the participant insofar as my role allowed, or to aid them in identifying the most appropriate support available to the participant.

Interview sample

To collect these EBE perspectives, the current analysis' methodology features a research design that includes in depth qualitative EBE interviews as a complementary, parallel research strand alongside the autoethnography. I planned for interviews to take place using purposive sampling, with EBE interviews taking place until the collected data ceased producing new results, resulting in theoretical saturation. As described by Morse (2004), this is the point at which data collection ceases returning insights, no new themes are emerging, and the themes which have emerged have been described thoroughly. Data collection can then be completed. Saunders et al. (2018: 1893) note that "… in one form or another it [theoretical saturation] now commands acceptance across a range of approaches to qualitative research. Indeed, saturation

is often proposed as an essential methodological element within such work.". I achieved theoretical saturation following completion of data collection from the in-depth interview research strand with the fifth participant EBE. In total, five EBEs participated, with six interviews being conducted.

The primary identified sources of potential interview participants from the EBE sphere are service-user and mental health advocacy groups who lobbied government or publicly called for significant changes to the Irish mental health services at the time of AVFC's development as a policy document, and reforms to its implementation once published.

These groups are the Critical Voices Network of Ireland (CVNI), and the former Expert By Experience Advisory Group (EEAG) facilitated by Amnesty International, Ireland (AI) which I was a member of. As such, these groups and their members/participants were approached using purposive sampling.

The CVNI was selected as it is a network of service-users, people with lived experiences, EBEs, academics, and practitioners who are critical of the biomedical model of mental illness and current mental health practice in Ireland. They host an annual academic conference in Cork, where individuals from these varied backgrounds present on issues of lived experience, their own research, and the research of others being conducted into areas critical of the status quo in mental health policy and practice. This annual conference serves another key function for many attending service-users and EBEs, myself included, as well as those close to these individuals such as family, friends, and allies. It provides a sense of community, belonging, and being in a place where, for a few days out of the year, their 'subjugated knowledges' are the global unitary knowledge. It is a collaborative network, and invitations to members from researchers who are part of this community are welcome. As such, I contacted one of the two organisers of the CVNI via email to introduce myself and my research area, and to request their approval to send a blanket BCC email to the Network explaining my research, and to seek participants. They were happy for me to do so. I sent a blanket email to the Network in the summer of 2021 with a brief introduction to me and my research, the purpose and aims of the research, and attaching the Information Sheet for those wishing to learn more and potentially participate. This avenue of recruiting participants did not return any direct interviewees for the research. Interestingly though, it turned out that the five EBEs I did interview were all members of the CVNI and commented that they had read my email and Information Sheet and had been interested in the

research. In this way, the information regarding my research shared amongst the CVNI laid some of the groundwork with interview participants.

Members of AI's former EEAG was approached for interview as the EEAG was a group of 11 identified EBEs which I had been a member of. The EEAG was the steering group for AI's national mental health campaign which viewed mental health as a human rights issue. It was established in 2008, and completed its brief in 2013, when AI finished their mental health campaign. I became a member in early 2012. The EEAG had many functions. These included producing snapshots and critiques of the Government's handling of AVFC's implementation. The EEAG also fed into government policy, giving our feedback to Government on behalf of AI regarding then-proposed legislation which was being developed at the time concerning capacity and decision-making. This avenue of recruiting interviewees successfully returned a number of participants.

Though I had anticipated that I would recruit the required number of interview participants using these two channels, this did not eventuate. Previously, when I had conducted research into the service-user experience, each of my interview participants had been sourced from the CVNI using a similar blanket email. Reflecting on it, this change indicated to me that the nature of the CVNI may have changed, along with its membership, in the intervening years.

The remaining interview participants were recruited using snowball sampling. I asked the participants I had recruited from the EEAG if they knew of any other EBEs who might be interested in taking part in the research. They had several individuals in mind. I asked them if they would approach these individuals via email or phone to inquire as to whether they might be interested in participating or not. I asked them to do so only if they were comfortable doing so. They were happy to, so I requested that they approach these individuals and tell them about the research with as much or as little information as they wished about what the interviews entailed, as they had just undertaken them. If these individuals indicated they were interested or happy to know more, I gave the participants permission to provide my contact information to them, and to let them know I would be happy to hear from them. I insisted that these participants not give me any contact information for these potential participants, as that would be unethical and not in keeping with GDPR guidelines. It was crucial that, if any of these individuals were interested and wished to continue a conversation with me, that it be on their terms, initiated by them.

Using this snowballing approach, one interested individual contacted me leading to an interview with them. This individual was the third EBE I interviewed. They then suggested the one individual they thought may be interested. Using the same approach outlined above, I asked them to contact this individual if they were comfortable doing so. This individual contacted me and became the fourth EBE I interviewed. They also had somebody in mind who may be interested in participating in the research. This person then contacted me and became the fifth and final EBE I interviewed.

The sense of community and interconnectedness that I have always felt amongst other service-users and EBEs was clear to me through this process. My approach using a blanket email to a vast network had returned no direct interviews, but personal connections to EBEs from a professional body we had been members of together (the EEAG) did. These, in turn, had personal or professional connections to other EBEs who I did not yet know, showing how vast this somewhat hidden network of experts is. These EBEs were intrigued to participate in the research, knowing it was being conducted by a peer, and having had the process discussed with them from those with lived experience *of* the process, as they had just undergone interviews themselves. More knowledge was shared this way and further personal connections made between myself and other EBEs, stemming from community and an innate sense of wishing to help other EBEs in their work, knowing that the shared goal is to make an impact and to try to improve mental health policy and practice through whichever professional medium that EBE is using to do so.

Interview location and impact of Covid-19

In the initial research design, I intended to conduct the EBE interviews in person. The interview participant would sign their consent form in advance. I would leave a week's cooling-off period between the submission of their consent form to me and the interview taking place. This would be to allow for any change of mind to take place, and for the participant to have enough time to inform me should a change of mind occur. I would then travel to a location that the EBE being interviewed would choose so they would feel as comfortable as possible, and so as not to impose a power imbalance by picking the venue for us. I would audio record the interview using a digital recorder, and there would be no other recording of the interview.

I had chosen in person interviews due to the deeply personal nature of the research area, and the potential topics that might arise and be discussed between the participant and myself. When research is being conducted on sensitive, emotive, and difficult topics, it is best where possible

to conduct this research face to face. This allows for connection, compassion, and where necessary, support and guidance to other appropriate supports for the interview participant should they become distressed and require specific assistance. It is human, empathetic, and given the nature of this research, allows for the conversational nature of the interview to unfurl naturally between the interviewer and the interview participant.

The Covid-19 pandemic made the conduct of in person interviews impossible, however. It was necessary to change the research design accordingly, and all six interviews with the five EBE participants took place online, using MS Teams on my secured, private laptop. MS Teams is Maynooth University's permitted software suite for digital interviews in line with its security protocols. I planned the interviews around the participants' availability and preferred time of day. Some preferred morning, while others preferred the evening. They chose where to situate themselves for their interviews. I conducted each of the six interviews from my home, and ensured I was the only person in the house while they were taking place to protect participants' privacy, and to make sure I would have no distractions that could pull my attention from the participants' and their histories.

I audio recorded each interview using a digital recorder, using my laptop's in-built audio recorder as a backup. This was a precaution in case the audio captured on the digital recorder was distorted due to it coming from the audio being given out by the laptop.

Once the interviews were completed, I transferred the audio files from the digital recorder and the laptop to my Maynooth University OneDrive account and deleted the files from the digital recorder and laptop in keeping with ethics protocols.

The interviews

The interview with the first EBE took place in October of 2021. There was a pause between the first interview and the remaining interviews, as I deferred a semester. The second EBE interviewed required two interviews due to time constraints, and the iterative nature of what we were discussing moving away from discussions around AVFC to their experience of being and becoming an EBE. These two interviews took place five days apart in June of 2022. The interview with the third EBE took place in August of 2022. The interview with the fourth EBE took place September 2022, and the final interview which was with the fifth EBE took place in October 2022.

These interviews were conversational discussions between peers, who both had the shared experience of being through similar life experiences. With that comes an innate camaraderie. This camaraderie fits with the autoethnographical nature of my methodological approach to these interviews, as I could share my own story with these EBEs where we had similar experiences. This allowed for compassion, collaboration, and the natural evolution of our conversations. There was no sense of a power differential, which was an important ethical requirement of mine going into these interviews. Having experienced negligent or abusive treatment as a result of being on the powerless side of a power imbalance within the medical model, I did not wish to impart any feeling of a power differential between me and others who may have experienced similar treatment insofar as possible.

As these interviews were to follow an interview schedule which was not rigid, I had no anticipated mean duration for them. I was still somewhat surprised and pleased at how the conversational nature of the interviews allowed for them to develop so thoroughly and broadly beyond the interview schedule; the interviews ranged in duration from: 3 hours and 25 minutes at the longest; 3 hours and 8 minutes; 2 hours and 6 minutes; 1 hour 51 minutes; 1 hour and 25 minutes, and finally, 53 minutes at the briefest.

The 53-minute interview was the first of the two interviews that took place with the second EBE, and it was ended due to time constraint. The second interview with this EBE lasted 2 hours and 6 minutes. This means that their total interview time also came to just about 3 hours.

Personal impact of interviews

Conducting the interviews was a great opportunity for me and the EBEs I spoke with to feel a sense of belonging, mutual understanding, community, and mutual respect that comes with knowledge exchange between EBEs, from experience. Though there was much to be heartened by, these interviews were also intensely emotionally laborious.

It was difficult to for me, as a researcher and as a peer, to listen to some of the extremely distressing things participants had experienced in their lives, and some of the life-altering traumas they had encountered. Though the interviews were conversational and very much peer-to-peer, I did need to remain the overseer and pilot of the conversation at times as the researcher who was responsible for participants' wellbeing. This meant that I could empathise, sympathise, and discuss these topics with participants, but I still needed to remain balanced and unwavering. In this way, I had to suppress a lot of difficult emotions and reactions to some

topics discussed during the interviews for the participant. Given the duration of the majority of these interviews, this meant that when they had concluded, the full weight of them would sometimes hit me. This was especially true of the first interview.

I discussed this with my supervisors, who were understanding and directed me to some emotional and psychological supports I could avail of while undertaking this data collection. I realised that I needed to space out the interviews due to their content in order to protect my own wellbeing, ensure I had enough emotional resources to assume the unwavering, empathetic role required of me during the interviews, and as such, to ensure my integrity and ability as a researcher so participants could feel appropriately supported during their interviews and I could continue the research while safeguarding myself. I had thoroughly considered the potential for the impact any potential distress the interviews might have on the EBEs being interviewed in planning the research. I made every effort I could identify as a researcher and a fellow EBE to minimise the possibility of distress occurring, and developing a distress protocol to respond to any distress interviewees might encounter. These minimisation efforts and the distress protocol I developed are outlined in the 'Ethical considerations' section of the Methodology.

This was an important observation and demonstrates the iterative nature of this autoethnographical research, as in order to protect the research participants, the research itself, and myself as the researcher, I needed to adapt to meet what I felt was required of me for the interviews based on my own expertise by experience and my own mental health needs.

Transcription

I had begun transcribing the first interview once I completed it, but due to the emotional impact the material had on me, I found it difficult to listen to the content repeatedly to correctly transcribe it. I realised I needed to step back from this interview in particular due to the themes that came up and how they resonated with me. I successfully transcribed the second interview, and began transcribing the third. However, I faced the same obstacle in the form of the emotional impact due to how much the themes resonated with me. This stalling and starting had the potential to become an obstacle to the successful transcription of the interviews. In order not to jeopardise the research as a result of time constraints, as well as to protect my own wellbeing to continue the research, I had the remainder of the transcriptions completed by a secure transcription service. They had been used by several of the faculty of my Department, and I could trust their services. I detailed how sensitive the nature of these interviews was to the transcriber when consulting with them initially, and they assured me of their GDPR

compliance, strict privacy enforcement, and their destruction of the audio files individually as they were completed.

I thematically analysed the interviews. They were all remarkably vivid, and due to their emotional impact, I remembered the details of each interview and each EBEs' history. I took notes of the key themes that had arisen during each interview immediately after they each ended. I then listened to each individual interview in the days following their respective undertaking. I thematically analysed them, taking further and far more detailed notes on the themes and content that were emerging, and relating them back to the other interviews that had taken place. Though the common themes were already quite clear to me, this process elucidated them further, and allowed me to develop subthemes related to each major theme. I kept these themes in mind while conducting each successive interview, and would ask further questions and discuss matters outside of the interview schedule if these themes emerged during the next interview. This led to clearer data coming from the interviews on the themes and subthemes, with more detailed accounts related to them. I continued this process through to the last interview, at which point no new data was emerging.

Once the interviews were complete, I listened to each interview again, and thematically analysed them. My already completed rough thematic analysis provided the foundation for this, and I did not need to conduct much more analysis. I tied together the themes and noted the discrete ways they had appeared for each EBE and what their experience of each theme was. These formed my data points I would bring forth into 'Chapter Six'.

Reflecting the service-user experience and voice is a fundamental dimension of this research. A significant component of my rationale and aim is to hear EBE experiences, analyse how they relate to mental health policy and practice, and to give voice to these experiences in the research findings. Making space for their representation as a stakeholder sphere is crucial for two reasons. The first is to give an equal voice to the often tokenistic, fetishised, and/or voiceless experiences of service-users in social research (Domecq et al., 2014; McLaughlin, 2008; Morrison, 2013; Romsland et al., 2019; Snow et al., 2018), and to place them on a level analytical foundation beside the two 'traditional' medical and statutory stakeholder spheres. The second reason is to contrast service-users' experiences against EBE experiences to demonstrate and elucidate the differences that distinguish these seemingly very similar spheres from each other.

LIMITATIONS

In conducting this exploratory study, it was not possible to capture the diversity of EBE experiences across the broad spectrum of identity. All EBE respondents were Irish, white, and cis-gendered. It was not possible therefore to secure a depth of insight into the intersections of gender, ethnicity, different cultural backgrounds, LGBTQ+ individuals, and the EBE role. The limitations of this study in representing these EBEs' unique experiences could be overcome by building on this research in time with further study purposively delving deeper into the experiences of EBEs from each equality strand to gain their insights.

CONCLUSION

This chapter details the methodology used in this research. It explores the research's unique autoethnographical, EBE-led framework. The qualitative research design developed for this research is presented. I discuss and expand on the primary research strand of autoethnography. This includes consideration of the unique approach to research autoethnography presents, including the method's theoretical and epistemological foundations. I then explain how autoethnography is employed as a method in this specific piece of research, utilising methods from across its spectrum, including analytic and evocative autoethnography. I lay out the form that the second, parallel research strand of in-depth qualitative interviews with EBEs took. The approaches of purposive sampling and snowball sampling used in data collection and the reasons for their use in conducting the interviews are detailed. I note the impact the Covid-19 pandemic had on the shape of the initial research design and the data collection. I then reflexively analyse the interview process, including the unanticipated impact that transcription of these conversational interviews had on me and how I adapted the research to accommodate this. Finally, the many ethical considerations involved in researching a topic as person as mental and emotional distress, the informed consent, anonymisation, and supports which were available to participants, and the data management are taken into account.

CHAPTER 5: BECOMING

Rationale, motivation, and form

Living with mental health difficulties that are often debilitating is hard. Conducting doctoral research is, notoriously, hard. So, what type of masochist decides to combine both of these incredibly difficult things together, conducting autoethnographical doctoral research on the area of mental health? Me. Somebody with enduring mental health difficulties – an Expert By Experience. And why have I decided to do this? **Because** I am an Expert By Experience. And for me, a fundamental part of being an Expert By Experience is the drive and commitment to make something of my suffering, lived experience, and all that I have learned about navigating it and finding ways through seemingly dire and insurmountable mental and emotional states. To share that which I have learned helps me, and that which I have learned does not, in the hopes that it might be of benefit to someone else. To anyone.

Because having experienced the depths of that which my psyche can torture me with, I want to do anything I can to assist anybody else that might be experiencing something similar. Or to let them know that that they are not, despite what they may be thinking, 'insane'. And more so, that they are not alone. And that they are the experts in their own distress. That those providing help to them should do so in a collaborative way that honours their wishes, will, and preference. And that no one person, ideology, or means of intervention aimed at ameliorating a person's distress is *'the'* way of understanding or navigating distress. They are all just approaches, with pros and cons. No one ideology should ever be institutionalised or hegemonic, and they certainly should not be institutionalised at the expense of the sufferer, dressed up in the garb of objectivity to give them legitimacy.

This feeling that one is isolated in a madness that others would or could never understand lives in the darkness, and without the support of others who know this feeling to be founded on fear and lies that our minds assures us are true, it can all too often drag the sufferer into the darkness with it. I want to shine light on it. I want to make a contribution to the chorus of voices of those who live with these difficulties, and who sing out to ease the pain of those who are new to the choir, and who are scared. We have valuable knowledge, comradery, reassurance, community, and warnings to share with them. These are resources that cannot have been learned or acquired through formal education, but which were instead imparted and imprinted from bitter and beautiful experience.

With this motivation to add my voice, combined with my need to be entirely intellectually honest by not hiding myself as individual and researcher within the text, and the desire to share my own history and experiences in this area along with those who have shared theirs with me as part of this research, this autoethnographical chapter will detail the experiences I have had in my own life that have formed and informed my identity as Expert By Experience.

You may notice my style of writing is less formal and more fluid in this chapter than it is elsewhere in this research; this is a natural part of the way I 'do' autoethnography. I am writing what I am thinking and feeling as I reflect on my formative experiences as an Expert By Experience, without being overly censorious, or too concerned about run-on sentences, etc. This is how I write, uninterrupted. It is not quite stream of consciousness, but it is not too far removed. Autoethnography as a creative research method permits me to write in this voice, as it is authentic to me and part of my critical reflective process. And authenticity is something that is very important to me, particularly in my work. So, with that in mind, I will stop explaining the ins and outs, and the hows and whys of autoethnography, and show you autoethnography instead.

Going back

I have always struggled with Obsessive-Compulsive Disorder (OCD) and Anxiety. Long before I knew those terms – OCD or Anxiety. Back when I was a toddler and a young child. When it was just fear. Pure, unbridled, heart-shaking fear. And long before my lifetime of expertise gave me the knowledge about what it was and where it came from. Long before I learned that, contrary to my belief and feelings, this was *not* how everyone else felt. And I was *not* just weak, or unable to cope with what I presumed were normal parts of everyday life. I would feel sick to my stomach when unspeakable, worrisome fears came to me: "what if I'm not **good**?"; "what if I do something that upsets Mammy or Daddy?"; "what if I'm bold in class and the teacher is disappointed in me?". As I grew and matured, so did the fears and the 'what ifs'. They became more elaborate and abstract as my mind developed.

I was raised practising Catholic. This meant that I was taught each Saturday evening about the many, many ways in which I could be, would be, and was already sinning. Doing bad things. To my horror, one of my worst intuitive feelings was said to be true by the Priest: thoughts *could* be bad. And just as harmful as actions. The same thing, in fact. And they were sins!

They were also proliferous. So much so that we confessed to all of these sins at the beginning of each mass. This meant that even if I had done my best all week, I must never have gotten it right, as I still had to confess "… I confess to almighty God and to you, my brothers and sisters, that I have greatly sinned, *in my thoughts and in my words*, in what I have done and in what I have failed to do…". I was – rightfully, in my estimation – bound to go to Hell. I was already failing so badly at being good.

I would sometimes feel anger, for example. Unforgivable. I might think badly of someone. A wave of nausea would hit me with the panic and shame. I sometimes even thought *not terribly nice things in my head*. I was unfixable, and should only ever feel guilt, shame, and the heavy awareness of how much I was failing at what I once again presumed were things other people had no struggles with. Other people were all intrinsically good. Pure. Honest. Everything I could not be enough of to quieten my conscience or make God forgive me.

At bedtime, I would pray, and pray, and pray for forgiveness for each perceived sleight against God. Every 'bad' thought. Every 'bad' feeling. I would apologise to Him profusely. I would do this over and over again until it 'felt right'. Like I had punished myself enough and in the right way. And still, I was usually left so panicked that I could not get to sleep. Or at least not for several hours. I would lie there awake, with a slideshow of all the terrible things I had thought or felt reeling in my head at breakneck speed, and me reeling in my bed. All the proof of how bad I was. And new worries and 'sins' would be committed while I lay there. Because I would feel sick with guilt, worry, and shame. And I might, in a moment of weakness, wish it would all stop. And that was a sin. Because I was simply feeling the pain I should feel, I thought, in response to the terrible person I was. To wish for relief from it was selfish, and generous with a mercy I did not deserve.

I kept all of this to myself. After all, what was the alternative – to tell somebody what a horrible person I was? I didn't understand what I was experiencing to be suffering. I understood it to be the natural and correct emotional and mental response to the awful person I was. I could never share what I was experiencing with anybody else, least of all my parents or loved ones. I would have rather been struck dead than to let everybody down so completely with the truth of what a failure I was.

Without the benefit of any other perspective on what I was experiencing that I might have gained by telling somebody what I was going through – someone to tell this frightened child that they were not all of these awful things they thought they were, that an omnipotent,

omniscient creator did not hate them – that this was *not everybody else's experience*, and that they did not deserve to feel that way – I was in the dark. And I would stay this way into adolescence, with the sophistication and layers of my fear, guilt, and shame continuing to mature and grow with me.

Hard lessons to learn

The move from primary to secondary school was not one that was particularly easy for me. I found it very difficult to navigate this new, much larger and much more complex social structure than I had before. I had been bullied in primary school for being a goody-two-shoes, for being a geek (because I compulsively did well in school), and for being 'different' (read: gay) before I even knew I was 'different'. But secondary school presented 12 year old me with a stark contrast to that which I had known. I was a morally scrupulous, overly honest, and remarkably naïve person, and I assumed everybody else was, too. Again, other people were all intrinsically good, pure, and honest in my estimation. But the different types of people I met immediately upon entering secondary school demonstrated to me that this was not the case.

Some of these people were overtly *mean*. They were cruel. They would say things to me, and others, that were devastating. And for seemingly no reason other than they – somehow – found doing so funny. This was a very disturbing discovery for me. I could not reconcile the world I thought I knew with this world I was now thrust into every day, and I soon entered a deep depression. According to that voice inside my head that blamed me for everything, this depression was simply another sign of how I was weak and unable to cope with the everyday stresses of life that I thought other people simply strode through with ease. I went in on myself even more. My world got very small, and I felt like I was on an island, unable to communicate with anybody in a real way, and I did not have many friends in school yet.

I was still able to keep the mask on and ensure I was *doing* everything right, because my actions were something I could still meticulously control. This avoided arousing suspicion from family or anybody else that anything was wrong, and that was key. It was **still** critical that nobody find out what a weak, sinful, broken person I was. I had to keep the pain and shame inside, because if I couldn't be good on the inside, I could at least behave *perfectly*. By this stage, I was only 12. And the walls were closing in.

> It occurs to me to pause here to reflect upon the journey I have undertaken throughout my life when you consider this tortured child whose worst fear was anybody finding

> out what a monster (he thought) he was by revealing his thoughts and emotions, and contrast him with the adult who has been sharing his experience with mental health difficulties with the world for more than a decade in the hopes of bringing about positive change. It strikes me as a very clear example of how the role of Expert By Experience is an iterative and reflexive one that I am always in the process of becoming.

I eventually reached the stage of wanting to end my life at this point. I could no longer take the suffering and the bullying – even if it was just and deserved in my estimation. I confided how I was feeling in a friend, who I genuinely did not think would care, because I did not care about myself. They, rightly, told their parents, who in turn showed up at my door to speak with my Mother. I happened to be the one to answer the door, and I remember the bolt of terror and 'This is it. The ruse is over. *You're outed*.' that struck me like lightning when I saw who was standing at the door, and I went to get my unaware Mother for them to talk to. I sat in my room in a cold sweat, with what felt like my world crumbling down around me. Worst fear, realised. My shame and sadness would be known. And by my parents. The people I wanted to let down the least in the entire world. However, I broke down with confusion and guilt when my very clearly upset Mother came out of the room they were in to approach me about it, showing nothing but concern and compassion. I had not expected that anyone, let alone my parents who I could *never* disappoint, would treat me this way upon 'finding out'. It was a difficult day, and I cried more than I may have ever before that point. So did my Mother. We had an hours-long cathartic conversation about how sad I had been, how bad the bullying in school was, and how I did not like myself very much. I absolutely did not share anything about the fear, dread, and terrifying thoughts/sins I was bombarded with. I had been outed about feeling suicidal, but I was not going to volunteer something that, to me, was *definitely* unforgivable.

My parents suggested counselling to me, as had been suggested to them by my friend's parents – I immediately shut this idea down by saying something close to '**NO.** I'm fine now, we've talked it out, and I'll *NEVER* feel that way again; I'm not crazy! And I don't want to talk about this anymore'. I was, more than anything, ashamed. And, in a sense, I was in damage control more so than I was accepting the difficulty of what had just happened. I was shocked I had not been met with rejection and disgust, which I had anticipated and thought was the appropriate reaction. This was in 2002, and I held the prevalent stigma of the time surrounding mental health difficulties – then almost universally referred to as 'Depression', regardless of the nature of the difficulties – that Irish society embodied. To struggle with 'Depression' – a dirty word – was to be crazy. They were synonymous. And I was not willing to accept that shameful title.

My cup was already overflowing with shame. I now also knew that to confide in friends was dangerous: I had risked it, and it had gone severely wrong for me. Wouldn't be doing that again in a hurry. Fear that vulnerability = danger incorrectly validated, and lesson learned.

Door ajar

Now that my parents knew about some of what I had been feeling, they were a lot more emotionally inquisitive. They had always been there for me to talk to, but there were limits surrounding this for me. Namely about outing myself as a dirty, unsalvageable sinner and failure. And I had so much guilt about making them feel the way they had, and for scaring them like that. Still, it was nice to know that there were (certain) parts of the things I found difficult I now felt I could talk about with them, and it made me feel less like I was on an island. I felt safer. But this was all a very lucky fluke: they had been gracious, and it was out of the goodness of who they were as people and a sign of how pure, honest, and good they were that they had met me with love instead of reluctantly rejecting me. It was not because that is what most any parent would feel for their child, that they would want to help them, and that they would desperately worry and want their child to share anything troubling them that they could help with because of a primal love they had for them; it was my luck to have saints for parents. And I could certainly never, ever, ever share the fear (I still did not have a name for it, and just believed it to be the universal condition for bad people) and crimes of thought and feeling I so wantonly committed with them. That would be taking the piss entirely, and they would obviously know me to be mad and in need of locking up at that point. So the door was ajar, with a sliver of light getting into the darkness I was living in. But I was not being fully honest about the troubles I encountered by a long stretch. With my parents, myself, or anyone else. This is how it would stay until I was fifteen.

Fifteen

My fifteenth year was the worst of my life up until that point. And it remains one of them to this day. Just as autoethnography is an iterative and reflexive process, so is life. We are constantly undergoing psychological and emotional processes of holding things in, repressing them, coming to realisations, trying to heal, and having our hearts broken and patched up by the brutal, necessary nature of that healing. These processes become something else entirely and get amplified for those who have lived through significant trauma, in a way that cannot be holistically understood by those who have not experienced such things.

Post-Traumatic Stress Disorder (PTSD) can be described in clear, concise academic or medicalised language. We can read the symptoms of the condition, and imagine what that experience might be like rationally; academically. I wish I were one of the people who only understood it academically.

This year, 2023, has been a particularly difficult part of my experience that has affected my life in many ways, and vicariously it has very much impacted my experience as an Expert By Experience. I am, today, as I have been for the past number of years, in the process of unpacking things related to the events of my fifteenth year, and the effects they had on me that are still becoming clear to me from behind the mental shutter my brain put in place at the time in response to the trauma to protect me from the pain of the event and to allow me to survive.

Fifteen was the year I had my first nervous breakdown. The year I finally told my parents about my internal world. The year I did the unthinkable and spilled the truth about everything I had been convinced I had to keep hidden my entire life. About all of the things I had always believed they would be forced to disown me over, only for my Father to hold me while I sobbed and begged to be locked away because I felt I deserved to be. He just kept holding me, and holding me, and showing me love. Fifteen was the year I went to a doctor about all of this for the first time, and was reassured that this was *not* how everybody else felt all the time, and that it was in fact an enormous amount of suffering to have to contend with. Fifteen was the year I first saw a counsellor, who confirmed the suspicion that I had held for some time that I had OCD. The year I realised I was not the monster my mind and feelings had always screamed at me that I was.

And after all of those horrible, awful, painful, necessary, emancipatory experiences that made me feel like I was actually living like 'me' with my loved ones for the first time ever in my life, fifteen was the year I had my first sexual encounter, when I was sexually assaulted by a peer.

Fifteen was the year this news leaked into the wider social group myself and the perpetrator were both part of. And then the broader circles. And then to people I did not even know. Fifteen was the year I learned with utter revulsion and despair that those lessons I had learned about how some people behaved in secondary school were not only true, they were inalienable. The year that I was firmly disabused of my underlying belief that other people were innately good.

Because fifteen became the year I learned that people would happily and without conscience gossip about what they thought they knew about one of the single worst, most damaging things that has ever happened to me. Something that has affected me, my relationships, and my ability

to trust or relax, just as soon as they would gossip about who had kissed who at a party at the weekend.

And I learned in a baptism of fire that the truth is not always enough for some people. Even when you should not have to share or justify the truth. Because the truth was subjective to other people, and my devastation was their plaything. The young man who had only ever believed in being honest, to the point of it being a diagnosable mental illness, was now having to contend with the fact that some people (and I did not who or how many) thought I was a liar. And that I was lying about something so, so unspeakable. To think that anyone could or would lie about such a thing would have been unfathomable to me in my naivety up until this point, because that would be sick. And now, the irony was that I not only knew other people believed people could do or did do such a thing for some reason – I don't know what their reasoning was in my case – which was disturbing in and of itself, but they believed it about me. And to make it worse, they were doing so casually. It wasn't even important to them. It was just another piece of gossip.

Fifteen was the year I first learned to open up, and the year I then firmly learned to **shut up.** I had made the mistake of telling a concerned friend who had noticed I seemed extremely jumpy and not myself in the days after the assault, and it had gotten out. This was not the result of some malicious gossip on the part of the concerned friend, but still: trusting other people with anything emotional was dangerous. Trusting people at *all* was dangerous. Speaking about things was dangerous.

Fifteen was the year I split into two people: the Paul who was privately going through a hell he had not thought could exist beyond that which he had already lived in for 15 years, and the Paul who was around other people. Always hoping to god that my friends who had never brought up the assault around me either did not know, believed me, or thought I did make it up, but had decided to stay friends with me anyway. And so, this second Paul existed in a superposition in which he was both deeply wounded and silently seen, not seen (the best of the three), or a liar who had been granted a reprieve. This Paul was in the room with everybody I knew from school – including my closest friends – for many years. Until I would eventually broach it with each individual friend when the time felt right over the course of many years.

For insight into how much I shut down and learned to never, ever mention this assault to anybody from that time period, I told the last two people who are important and close to me from that time in my life two years ago, at 31. 16 years after it happened. And when I did, there

was no-one left for that Paul who had been in the room with them and all of those who had gone before them to stay around for, and he was no longer needed. Now, what remains for me to do is to continue to work of lifting fifteen year old Paul out of that hell he entered.

Letting more light in

Throughout my later teens, I was beginning to realise that I was gay. I tried desperately to change or 'fix' this through prayer (in my earlier-to-mid teens, when I was still spiritual in a Christian way. When god was still God), correcting my attractions and convincing myself that I liked girls, and accepting a 'worst case' scenario where I *may* be bisexual, but would not act upon it. There was a lot or repression and self-hatred here. I knew deep down that none of the things I tried to tell myself about my sexuality were true – I liked other boys. This was another one of the unacceptable things my parents would be forced to disown me over, in my estimation.

Yes, the previous unacceptable things had all been accepted by them, and with love no less, but these were always just flukes to me. Intense luck that would not be repeated again. Still, when I finished secondary school, I had accepted that I was gay. I did not think I could ever tell my family, but I thought I might have to. And in the end, I did. I told my parents first, as I did not want to tell friends in confidence, only for it to get out and get back to them without me having told them (the echoes of the assault at fifteen reverberating here).

I respected and loved them, and I wanted them to hear it from me. They were both absolutely accepting and loved me just the same (and it did not come as a surprise to them, anyway!). I was beginning to recognise that every time I was convinced that to tell those I loved something I was afraid or ashamed of would be the end of me, it had never been. And it had always been immensely difficult, but unfathomably rewarding in terms of relief, and feeling closer to freedom in the form of living authentically. I may not yet have trusted that this would be the case in these situations, but still, the evidence was mounting that this was usually the outcome. There is a nascent expertise by experience in this realisation.

Freshly out of the closet – and out of the closet on my own terms – and out of secondary school, which had been something I never thought would actually end due to how traumatic it had been, I was elated: I was now living the most authentic life I could live as a young gay man who could leave behind the social environment where the *bad things* had happened. I was going to study in Trinity College, Dublin. I could now make new connections with people without

worrying about whether they believed I was a heinous liar, a victim, or just *me*. I could just be me. Superposition Paul not required.

And I could tell people about having OCD and Anxiety, and being gay, and the person who had hurt me so badly. The latter, finally in a way where I felt I could let out and realise the pain and anger I carried about what I had gone through without the worry of preconceptions from the new friends I shared it with, which might have been there had they known the perpetrator, as my friends from school had. I still did not necessarily trust people, but the stakes were not there in this social bubble.

I began to come into my own, in a way. I was upfront about having an anxiety disorder, and OCD, and I had no issue correcting people's misconceptions about how 'quirky' OCD was, or how they were 'a bit OCD, too!'. These were all signs of my confidence developing, which was something I had never had. I was developing little bits of it here and there, mainly when it came to owning the things that I had hid away in the dark for so many years due to the devastating misconception that were anyone to find out about them, they would justifiably be repulsed by me and run away. Owning it was a way of disproving that belief and letting more of the light in; and one that is clearly still invaluable to me as I sit here writing this. I was starting to build up my expertise in realising what helped and what hindered in terms of living with my specific challenges.

For example, I also started to see a counsellor in the College on and off about my mental health difficulties, as I now recognised talk therapy to be the helpful tool that it is and that it has continued to be for me. I had not had the opportunity to see a counsellor or therapist since my limited sessions with the woman who had helped me so much when I had my breakdown at fifteen. She had explained intrusive images, compulsions, how anxiety worked, and that I was **not** insane to me – and all of that had felt like an impossible dream made true. This journey of my perceptions of therapy is an example of developing my expertise in my own experience in an ongoing manner. 18 year old Paul was certainly a long shot from my 12 year old self.

I was still plagued with crippling Anxiety and intrusive images of awful scenarios OCD convinces its sufferer are real and inevitable, no matter how preposterous, but I wasn't hiding this anymore. And that made all the difference. I was learning the value of openness, and discarding some of the shame that came from internalising it all, where overthinking and judgement by my ruthless moral scrupulosity turned my worries and fears into undeniable and unforgivable truths, as they always had done. My expertise was continuing to develop.

It was also a delightful shock and a complete antithesis to what I had believed for so many years to find out that people not only weren't repulsed by me, but that they actually *liked* this gay ball of nerves, and wanted to be his friend. Go figure.

Stumbling

While I was living my life in this new, more open way throughout my years as an undergrad, I was learning as I went. This meant that, like anybody else, I learned what worked for me and what didn't by trial and error. And I also had the usual obstacles to overcome that most do in their late teens and early twenties – arguments, falling out with friends, making up, falling for people, university deadlines, and the rest. As any of us will remember if we think about these coming-of-age moments, beyond the point at which we blush, we might remember they often seemed far bigger than they actually were at the time. Sometimes, they felt insurmountable. And sometimes, they of course were. Friendships thought to be forever, gone. Those we thought would be less consequential, still going strong. All of these events take their toll on us emotionally, mentally, and spiritually. And I was certainly no exception. I had my own fair share.

There had been a source of severe distress to me which had been going on for the first two years of my college experience in my personal life. I have chosen not to share this, as it is not my story to tell. But it had deeply affected me mentally and emotionally. I was in the darkest place I had been in since I was fifteen, and I was punching against my weight and fighting with the tools I had – therapy, and as much openness as I could allow. I was about to learn that those would not be enough in some circumstances. I felt so very lost without a compass to guide me, thinking I was doing everything I could to stay well, but somehow failing, and I could see no way out in the immediacy, because I did not yet know of other healthy ways to help. But I had found one way of helping that was decidedly unhealthy.

I was so filled with anxiety at all times that I could rarely sleep, and I had very frequent panic attacks. I felt like I was stuck in a dark room. I was depressed, but trying to just keep myself going. I thought that keeping going – keeping functioning – would get me out of it, as it had done in the past. I was so consumed with the things around me that were out of my control but which were wreaking havoc on my wellbeing that I caught every illness going for about a year and a half. My immune system was worn out. But I kept going, as I didn't know what else to do. I did not yet know to stop, intervene early, and avoid things reaching crisis level. And so, I

increasingly used the traditional college night out in town that I had once a week with my friends as both a release, and a whip.

Alcohol provided a few hours' relief from the unbearable anxiety and emotional distress I was living in, and from which I felt there was no escape. These were the only few hours out of the entire week when I felt something approximating relaxation. I knew what would await me for the next 3-4 days after a night out drinking, but that was somewhat the point. You see, for those of us who experience OCD and Anxiety, alcohol is a terrible thing. It provides those few hours' relief from symptoms I just described while you're drinking it, but the moment you wake up the next morning, you pay the price tenfold.

The moment I would open my eyes, my heart would already be in my mouth. The intense, blinding intrusive images were now amped up to the nth degree and increasingly fantastical but *more* terrifying regardless of their illogic. The alcohol acting as a performance-enhancing drug for them. The physical anxiety rendering me immobile from fear, frozen in place, sweating profusely, and shaking. Any blank or fuzzy spots in memory from the previous night that came from drinking too much would be greedily filled by intrusive thoughts with every conceivable scenario in which I could possibly have done the worst, most unspeakable thing imaginable. With my mental defences down, sometimes I would be fighting off thoughts which insisted I had committed multiple heinous actions at once. In short, alcohol was poison that felt like medicine, but only when I was taking it. And I was aware of this. I believed I deserved the 'punishment' that came in the days following a night out. So I got the few hours of relief, but at a cost I willingly paid because I thought I owed it and more besides. It was a form of ritualistic self-harm, poorly disguised as me just taking part in the same fun as everyone else my age. I don't think it was a terribly convincing act.

The big one hits

While all of this had been going on, a new intrusive thought hit me one night while I lay awake in bed, too anxious to sleep. It hit me like a bolt of lightning, seemingly without context and out of the ether. This intrusive thought was simple: I had AIDS. Not HIV, AIDS. It didn't matter whether this was likely, unlikely, or entirely fantastical. The instant terror I experienced was some of the strongest and most insurmountable I had felt since I had fought my first severe intrusive thought (before I knew what intrusive thoughts were, or that I had OCD and they were a defining feature of it) alone at fifteen for six months before having my first breakdown.

I knew this new intrusive thought was going to be the straw that broke the camel's back, but I slipped hard into my pattern of misbelieving that this one – ***this*** one of all ones – was one thing my parents and family would never, ever be able to come back from. And it did not matter how many times I got tested for HIV, which had become my newest compulsion.

If the test was negative, which it invariably was, my mind would invent an excuse as to why that was incorrect: the clinic had mixed up the vials; the window of exposure must have been a day or two off, during which time the virus had developed, which the test couldn't detect; I must have stepped on a syringe on the street, which had punctured through the sole of my shoe enough to break my skin but *not* enough for me to feel it or to spot blood, and I had contracted the virus that way. OCD is creative. And it doesn't matter how illogical and clearly nonsensical the reasons and flimsy rationales for its warnings are to the sufferer. Knowing it was all nonsense and understanding its mechanism of action did not stop me from feeling the feelings, or from having OCD. The duality of being a logical, rational person who has a mental disposition that causes everything and anything improbable to become something that is **definitely happening to me right now** whenever it hits, no matter how much I know that isn't true, is just another layer of the psychic anguish of living with OCD.

There was no relief, and I needed relief. I had panic attacks so frequently they became the norm. I visited my doctor about my mental health for the first time since I was fifteen or sixteen at this time, and was prescribed some Valium and sleeping tablets for the first time, which provided incredibly welcome short breaks from the physical experience of the panic and extreme distress. Talking with him and (unintentionally) breaking down and sobbing in his office before apologising and saying I would leave so he could 'get back to people who are really sick' helped me immensely, but I did not want to visit him frequently so as not to bother him with what I thought were 'not real enough' problems. I also did not have the money to do so. I was still seeing the counsellor in College biweekly or so, but it was far too little to pull me out the tailspin I was in. This entire period lasted for a year. And I can still not readily revisit that mental space, except to wish I had had more compassion for myself back then, and that I knew what I know now.

Of course, I would not know a lot of what I know now had I not gone through this desolation, as in many ways, it was the culmination of everything that had come up to that point. My OCD. My crippling Anxiety. My episodes of deep Depression. My lack of self-respect, self-worth, and self-compassion. My always wanting to please other people, frequently at a cost to myself

and my own needs. My assault, and the undiagnosed PTSD I had been experiencing since it. The interplay of coming out and dealing with shedding my religion – and the very damaging and lasting effects of Catholic guilt on a young gay man.

On one of my weekly Friday nights out in town with my friends, just after I turned 21, I was raped. I pushed it down and pretended it didn't happen. My brain dropped the same shutter to protect me from the trauma as it had when I was fifteen, and it would not lift for almost 2 years.

This precipitated my second, and worst, breakdown in February of 2011.

The plunge

I won't delve into the anatomy of a breakdown, because it feels like something that I do not need to share. As I do this autoethnography, I must listen to my gut when it says that certain things are off limits, or are simply too painful to describe with a blow-by-blow account. Besides, it is the treatment I received during and following this breakdown that is significant in discussing what has made me an Expert By Experience.

It is enough to say that one day, I simply broke. I couldn't do it anymore. There was nothing left inside except pain, and I could not function in any capacity. I cried, and cried, and cried. Just as I had when I was fifteen. And my Father once again hugged me, and met this pain with love. As did the rest of my family, who I had been trying to hide my deteriorating mental health from. I knew I needed a higher tier of intervention and treatment than I had accessed up until that point, and I had an emergency appointment with the out-of-hours GP, as it was a Sunday. I could barely explain what I was experiencing, and I just continued to cry. It felt like everything inside me had fallen apart. She referred me to a mental hospital for assessment, which I was in some ways relieved by, as in my mind, that would be the right place for me in that state. I imagined it as somewhere nobody wants to be, obviously, but somewhere I would be able to get help, and to recover and rest.

This assessment was the first time I had ever met with a psychiatrist.

I had a preconceived notion of what a psychiatrist did, largely subconsciously formed through their representations in predominantly American mass media that I had absorbed throughout the years. I thought that they were effectively like highly specialised counsellors, who could pinpoint what was happening for someone suffering and help them through it with therapy sessions and the correct medications, where appropriate. I think many of us think that is what

the discipline is: the right people intervening to pull people out of their darkest moments, and help them understand what is happening in their lives and how best to ameliorate their suffering. This is a nice idea.

I wish it had been accurate.

I was bawling my eyes out, and in a state of extreme distress. I wanted to vomit. I could barely get breaths in between my sobs, and I was shaking. The psychiatrist entered the room, paused, looked me up and down and said "Relax; we've seen worse than *you* before". They then proceeded to interview me for close to an hour with questions that seemed invasive beyond the point of information they might need to diagnose my distress.

I was asked what my sexuality was from a list of straight, gay, or bisexual. I responded that I was gay. This piqued their attention (they had come across as bored, somewhat irritated, and put upon up until now). They h looked at me bemused. It was as if they wanted to make sure I had understood the question given the state I was in. They reiterated "Gay?". I was now confused by this reaction. Even in the state I was in, it read as wrong to me. I repeated, "Yes, I'm gay". They responded "Gay?! Does your Father know?", which was a question pregnant with the expectation that if he knew, he must be disappointed. I said he did know. Then the psychiatrist laughed. Once they were finished, they continued with the questions.

In the end, the psychiatrist decided not to admit me to the hospital, instead telling me they believed I would be ok with outpatient treatment, and that I was explicitly in need of "direct psychotherapeutic intervention". At the time, I felt a sinking hole of despair at this decision. As though I had just gone through this intensely invasive assessment while in the worst state I had ever been in so I could get help, only to have that help denied to me. Like I had done what I was 'supposed' to do, and had gone to the right people, but I would not be receiving the care, understanding, and healing that I imagined waited for those admitted. Sure, I knew it must be a rough go of it in there, and the stigma was still enormous, but I was at the place where I needed what I believed, at the time, was provided in such a facility. I now see it as a great mercy that I was not admitted to that mental hospital.

I was sent on my way with my Father and Sister who had driven me to the hospital and who were comforting me, and telling me that everything would be ok. I had done the hard part now, and I would be able to get help. Specifically psychotherapy, which I really wanted, as I had already benefitted from counselling. The psychiatrist had prescribed me some tranquilisers to get through the next two or three days, as they had assured me that I would hear from the team

at the hospital by that point, who would be telephoning me to detail my outpatient treatment plan to me. I clung to this for those three or four days. I told myself that I would still be getting the help I needed. I just had to hang on and keep breathing until they called me. The call finally came, and I couldn't answer the phone quickly enough. To my horror, I was told that my address fell outside of the catchment area of that particular hospital, and they would not be involving themselves with my treatment. I was reeling. I asked if this meant they would instead be referring me to their counterpart within my catchment area, as at least this would mean I would still hopefully get help quickly. They told me that this was not the case. My assessment and whatever reference they might have would be sent to my GP, who I should contact in the coming days to speak with them. My GP would then have to refer the psychiatrist's referral on to their counterpart in my catchment area. This makes as much sense to me now as it did then, and it presented the terrifying fact that I was on my own to survive for an unknowable period of time.

I ended up waiting a month and a half or so, which I now know is actually remarkably quick within the public mental health system. My GP, who was an enormous support to me, met with me every three days or so to check on me throughout this time. They would always ask if I had any thoughts or feelings about hurting myself, and I would answer that I did not. I had no intention of giving up. The reason I eventually saw the psychiatrist in my catchment area was because as time had dragged on over that everlasting month and a half, I had been deteriorating, and in the last meeting I had with my GP before seeing the psychiatrist, I realised in the moment that I could not honestly say I did not feel like harming myself when asked. I just burst into tears. My GP called the psychiatric outpatient clinic immediately and forced an emergency meeting with them for later that same day. I consider myself very lucky to have had such a dedicated care-giver and advocate.

As I made my way to the clinic, I felt like I was now going to get the help I needed, and things would start to improve. I felt a bit of hope, which was invaluable. I imagined that I would meet with a new psychiatrist who would have read through my interview which had been sent on by my GP, and who would be able to help me. I also presumed that the psychiatrist I was to meet with that evening would remain the same for the duration of however long I needed their help.

I waited with my Mother in the waiting room, and when I was called in, I met with a nicer psychiatrist than I had the first time. A good start. But then I was subjected to the same hour-long interview again. Out of panic at the thought of going through that process again, I asked

if this was really necessary, as I could see the file containing my completed interview sitting in front of the psychiatrist on their desk. They said they wanted to hear it from me rather than read it. And so, I did it again. I was immediately diagnosed with OCD, Generalised Anxiety Disorder (GAD), and Depression. This felt accurate. Then, I was prescribed 200mg of a selective-serotonin reuptake inhibitor (SSRI) antidepressant called sertraline, Valium, and sleeping tablets. Nothing was said about psychotherapy, and the psychiatrist had not themselves asked me any questions of a therapeutic or personal nature.

I had previously been given this SSRI by my GP at a dose of 50mg for a short period, which I understood to be the more regular dose – 200mg sounded like a lot to me. The psychiatrist explained that that was the dose required to treat OCD. I was not (yet) familiar with medication, and I asked them explicitly – hopefully – 'Will this get rid of it?', to which they casually responded 'If it doesn't, you'd be the first!'. The instant wave of relief I felt crest over me was indescribable. I had been given the silver bullet! This whole time, a medication had existed that would cure me. Mental illnesses could be treated and eradicated with medicine, just like physical illnesses! And now I had the specific *names* of my illnesses. I knew the enemy! Yes, I was irked and concerned about the impersonal nature of the meeting, the fact I needed to redo that devastating interview when it sat in front of the psychiatrist completed, the lack of any questions about my wellbeing or anything going on in my life that might be causing me distress (of which there was a lot), and having had no discussion about the psychotherapeutic intervention which I had been referred there for in the first place, but those were nothing compared to the relief I now had from my belief that it was all going to be made better with this medication.

Labels. Medicine. It boiled down to that all along. What had seemed so complex and nuanced and human was actually so remarkably simple. Imagine.

The spur

I have written about my experience as a psychiatric outpatient in previous research, when I was at different stages in my life and my career. But, with a decade now having passed between my first piece of research that included an autoethnographical component reflecting on the experience and this current piece of research, the importance of this psychiatric treatment as a catalyst in my life has never lessened. It is the time I spent as a patient (a term I am using in the context of the power-knowledge of the institution of biopower I was then in and the role it and its innate power imbalance imposed upon me, and one which I reject wholeheartedly) that

was so impactful and life-altering that I have dedicated my energy, passion, and my career to date to working to change it. This has been in roles as an academic, a policy-worker, an expert (both by experience and qualification), a consultant, an advocate, and an activist.

It lit a fire in me to use the tools I had and the opportunities I was presented with to investigate the history, sociology, and characteristics that define this institution, and to critique it in the hopes of contributing to discussions about its nature and what it should or should not be. But I do this work primarily to try to improve things for other people in distress who may be entering this system without knowing what they may be getting into. Even if I don't achieve much success in doing so. To try to move the dial to make it more like what they might reasonably be expecting it to be – a system that exists to care for them when they are at their worst, to provide them with help, and to empower them to move forward and live their lives. Because unfortunately, this is not what I experienced.

Considerations

I will give a briefer outline of what my treatment consisted of and its most important milestones than I previously have in my research on this topic, as it is not the sole focus of this autoethnography as it previously was. Coupled with this, recounting this experience would involve far too much emotional labour in an instance where its telling constitutes only one part of a holistically emotionally intensive autoethnographical excavation. When conducting any interview, a good researcher must always recognise the wellbeing of the interviewee as the most important part of the process when it is taking place. Reasonable boundaries must be kept and respected. And this is no different when the researcher is interviewing themselves.

So, rather than a blow-by-blow, here is the trajectory of my treatment which lasted from February 2011 – June 2012 described by the snapshots and details that are etched into my mind, and which have remained the most significant through innumerable retellings of my experience over the years, and which naturally come up for me as I write this. In this way, they are the same as any answer I would give on the subject were I being interviewed about it by a third party.

(Mis)Treatment

I went back over for my first appointment after that emergency one around a week or so later. I had assumed I would be meeting with the same psychiatrist who had interviewed me and prescribed me the antidepressant. Not so. It was somebody entirely different. I was surprised and confused, and was about to become more disheartened when this psychiatrist disconnectedly asked me what I now call 'the five questions' – 'Have you had any thoughts about harming yourself or others in the past week? How has your mood been in the last week? How many times in the last week have your cried? How has your sleep been in the last week? How has your appetite been in the last week?' – and didn't expand beyond that. The appointment lasted all of around two minutes. There were no questions about how I was, what I was feeling, or any mention of the psychotherapy I had been referred to the service for in the first place. And more so, there was no *room* given to discuss these matters, or anything else, with the psychiatrist. I got the distinct message that this was not a dialogue between care-provider and care-receiver, this was a questioning of very limited scope. Elaboration beyond those questions was, in the kindest wat of putting it, not expected, and in the more felt sense, actively discouraged, unnecessary, with the act of doing so feeling somehow vicariously dangerous.

With those five questions, this person who had never met me before, had not engaged in any conversation with me, had scarcely looked at me, and had dispassionately noted my responses to their five shallow questions in my file, could apparently decide what treatment I should get for my mental illness(es), which they could also identify from these five questions. They had also added another medication to my prescription. A drug classified as an antipsychotic. I was told 'You do not have psychosis, but it will help you sleep'. I wanted to sleep as I was starved of it, but this drug sounded worrisome to me. Still, I had to trust that this person knew what they were doing. I didn't want to take more medication, but if the psychiatrist were right, then this would help. No side effects (or effects, really) were described, which I would learn in quick time was par for the course. As was the ever-changing psychiatrist. And the minimal, power-imbalanced two minute appointment.

Whenever I had an appointment, it was usually with somebody different to who I had met with the previous time. A stranger. And they would come up with their own conclusions/new diagnoses if they felt so inclined after asking me the five questions. What is important to note here is that when a psychiatrist would give a different name to a previous psychiatrist's existing

diagnosis in my file, or casually elaborate upon one by adding what I would call an elaborative mental illness (noting their new finding/descriptor/illness of Social Anxiety Disorder to the existing Generalised Anxiety Disorder diagnosis in my file), they were never in contest with the existing diagnosis. It was not a second opinion or contrary diagnosis to challenge the existing one, so to speak. It was in addition. Just like medications, new diagnoses were added, but *never* taken away from my prescription or file, respectively.

I always felt worse after an appointment. Like I would build up a bit of hope in the week or two weeks between appointments that maybe I would meet a nice psychiatrist the next time who would actually ask me about *me*, or let me at least talk a little about the things in my life that were, to me, so very obviously impacting my mental health and my chances of feeling better. Everything I had been through, the experience of having a breakdown and having to withdraw from University in the last semester of my final year because of it when I was so close to the finish line, the sudden disappearance of a lot of people I had considered my closest friends when I had my breakdown; any of it. But you see, this would never happen. Because these things were antithetical to psychiatry's underlying ideology, at that time, at least, and antithetical to the way psychiatrists were trained to treat patients.

None of these things matter in the treatment of a patient's mental illness(es). They are superfluous.

The illness(es) are caused by a chemical imbalance in the brain; potentially serotonin or dopamine, or norephedrine. Regardless, the patient will incorrectly perceive events in their life such as traumas and struggles, existential dilemmas, or relational issues to be the context in which these illness(es) have emerged, and the reason for them. Given that this underlying hypothesis is incorrect and they know no better, they will try to speak about them with you in appointments. You, not being a therapist, but a doctor – a person of science – can recognise their concerns as noise that has no bearing on the illness(es) being suffered. You must discourage them from thinking that meeting with you is a space where that is going to happen or that it is, indeed, appropriate, and you must tune them out: you are not there to treat the person, with their misbeliefs about why they are suffering – you are there to treat their *illness(es)*. When you do that, the patient's illness(es) will improve. And then, they will stop complaining. Dehumanise, label, and medicate. Rinse and repeat every two to three minutes when another patient enters the room.

This was the system, and I was now in it. And increasingly, it felt less and less like I had agency within this system. Like I was free to engage with it, or say 'this isn't for me' and leave. I would go to my appointments when scheduled, be it weekly, fortnightly, or monthly, and as ever, it would usually end up being with a person I had never me before. There was no continuity of care, no cohesion. Just somebody asking me the five questions, and depending on their level of dispassion or interest that day, lackadaisically giving me an entire new name for my distress from their perspective, which became another illness diagnosed and label written down in my file. Another one for the pile. All describing the same person presenting with the same issues, as interpreted by different strangers. I have found it quite funny since I left the system to try to get the tongue-twister of a diagnosis I would have if I combined all of the different ones that were mentioned to me correct, so here goes: I am a Depressive (NOTE: to be a 'Depressive' is not the same as having 'Depression') with Obsessive-Compulsive Disorder, Generalised Anxiety Disorder, Depression, Dysthymia, Social Anxiety, Panic Disorder, and Insomnia. And what's funnier to me now as I write this is that I know I'm forgetting some there. That used to take up about two full sentences!

In the same way, depending on their level of dispassion or interest during any given appointment, new medications would be added to my prescription, or doses of others already on it would be increased – but doses were never reduced, nor were medications taken away. They were only ever increased or introduced.

Again, I had gone there seeking psychotherapy, which I felt would help me a great deal and was the only part of the conclusions the psychiatrist who had assessed me that first time in the hospital I thought made sense. All I was getting was medication. In every appointment I would ask what the situation with that psychotherapy was. When I would be getting it. Where in the process of getting it I was. They would usually respond by telling me they didn't know if the previous psychiatrist had referred me on yet, but they would do so. This never seemed to happen. And with the lack of continuity that would have been provided by seeing the same psychiatrist each time, or at least having some sort of ongoing account of what referrals had been or had not been made – a treatment plan – it was impossible to actually know if I had been referred with every different psychiatrist. I was growing frustrated inside.

But in the beginning, and up until things tilted so that that frustration in my gut saying 'This isn't working. It doesn't feel right. Why are you feeling worse? Why do you have even less hope?' went from something I almost considered an intrusive thought to an alarm, I put my

faith in holding out for the psychotherapy, and presuming the medication must be helping. It *must* be. I was a broken person, who had no fight left, no emotional or mental energy, and a vast chasm inside me that left me vulnerable. I was at my lowest possible point. I needed help.

These people *were* that help I had been socialised to consciously and subconsciously recognise as legitimate experts, and to seek out. They must be giving help the way it was supposed to be given (I would later find out this was very much not the case as per the provisions of *A Vision for Change*). So the feelings of disconnection, dehumanisation, isolation, worsening mental health, and despair I was having must have been part of my mental illnesses. In hindsight, this was my expertise in my own experience trying to make itself known. I just didn't know that that's what it was yet, so I fought it and followed the hegemonic ideology of mental illness instead. I kept going with what I believed *must* be going to help me eventually. At some point, the tide would turn. I thought this must just be how bad my illnesses were. But the tide wasn't turning, and the water was getting deeper, and I was now very much struggling to keep myself afloat.

Six months passed in this way, and by that stage, I was on so much medication that I could not feel. I could not think properly. Everything was muffled and blurred. I had been looking forward to returning to University in September of 2011 to redo my final year, which was something that was incredibly important to me. But by the time it came around, I went to a few classes in the first week, and immediately realised I could not function in the world. I couldn't connect to anyone or anything around me. I felt the same way I do in dreams where I try to speak, but can't get anything out, and the dreamscape around me is nonresponsive to me as a result.

I remember trying to do the reading for a tutorial over and over again, because I couldn't make the information make sense. I couldn't retain a sentence long enough to conceptualise it. I was heartbroken by this. I told the psychiatrist I met with at that time about this, and to my surprise, they took it in. They told me with a degree of certainty that I would need to take six weeks off, and then I would be fine to go back. This was just the effect of my illnesses. They also increased the dose of the antipsychotic, which I was now taking three times daily instead of solely at night, to 8mg. This may not sound like a lot, but I later found out the highest recommended dose of this incredibly powerful drug, classified as a major tranquiliser, was 6mg. And that was a lot. This was only supposed to be for a few weeks to get my baseline steady, and then it would be reduced.

It was never reduced.

Resignation

At the time, I was happy to be told by this psychiatrist that they would be seeing me on a regular basis from now on. They told me that they were sending on the referral for psychotherapy right then and there, and assured me of it. I felt a spark of hope, because I would be able to see the same person, and I felt like the ball was actually rolling on the psychotherapy front. My family were increasingly upset at the difference in me. How severely medicated I was, and how deeply dissociated I was as a result. My Mother kept asking me "Where are you, Paul?", to which I would say "I'm here, Mam. I'm here"; "No, you're not, Son".

I didn't know what else I could or should do. I was doing what I was told was the right thing by the doctors we are told are the right ones to see in this situation. Everybody knew that. It's why I had sought this help. I felt increasingly more siloed, more trapped. I couldn't understand how, because I didn't think things could disimprove any more, but they continued to.

I felt – well, I felt nothing. I felt nothing and everything all at once. It's an impossible feeling to describe, and one you can only know if you've ever had the misfortune of experiencing it first-hand. A chemical lobotomy that leaves you entirely unable to feel your own feelings, or to even access any of them, while you stay fully aware that they're all there, raging beneath the concrete lid that has been slammed over them. All the pain, all the suffering, all the joy, all the happiness, all the *anything* you might feel, simultaneously there and not. Silently screaming. And none more so than the pain and suffering that you have been trying to improve and which you sought help for in the first place. I hated how upset I could see my condition made my family, because I didn't want them to hurt. But, I couldn't mess with my treatment, because if this was how bad I was feeling *on* all of these medications that were supposed to be helping, I couldn't imagine what hell I would be in if I stopped taking them. If this was me at my best thanks to treatment, then whatever version of myself existed off the meds was not somebody who would survive.

In these instances, it was not that the medication wasn't working, or indeed that there was far too much of it. No, it meant something far more individualistic and terrible. My illnesses were treatment-resistant: I was so mentally ill that the *best* medications used to treat them weren't helping much. Which confirmed the feared outcome I had of staying on the medication and just existing as I was. And with that, the last tiny shred of hope I had went out the window.

This was at the end of Autumn/beginning of Winter in 2011. I resigned myself to this life. This was my best possible outcome. To not die, but not live. To exist so I wouldn't upset my family and those who cared about me more than any other outcome would. I saw absolutely no way out, and I gave up inside.

College was a write-off. Those six weeks had come and gone, and I had only gotten worse and less connected to everything through my deepened sedation.

Side effects and tuning in

One of the medications I was put on at this time had caused me to suffer sudden and crippling suicidal ideation (I did not know this was the cause when this ideation started, and would not realise until later). I had experienced suicidal thoughts before, but I had always seen them as a sign of how badly I was feeling, and they had spurred me to talk to people and to fight harder to get out of the place I was in. But these were different. They weren't coming from a place I recognised. Everything was such a comatose mess inside me, but I knew these were not coming from my despair. They felt different. There was no reasoning with them. They were **constant**. This terrified me even more. I did not want to kill myself. With these suicidal thoughts came another suite of thoughts that I had, up until this point, not been particularly familiar with. I could not stop thinking about harming myself. I had never self-harmed before nor was it something I had struggled with in terms of ideation, but now, it was as ever-present as the suicidal ideation. And it also felt like it wasn't coming from me organically.

I lay in bed, wrestling with these thoughts over and over, and telling myself I did not want to do any of them – the part saying that was the part that felt like me. That was the bit of me kicking up from my gut to sound the alarm again. My expertise and better self. But it was so muted by all of the medication that it was extremely faint. One afternoon while I lay there, I had a horrible experience. Even though I was entirely sedentary now, I realised that I was getting out of my bed. It was like an out of body experience. I could tell what I was going to do, even as the alarm inside me went as loudly as it could that I did not want to do this. That it wasn't me. I was terrified to not feel like I was in control of the situation. Like it was involuntary. And the next thing I knew, I was sitting on the side of the bath in the bathroom, cutting into my thigh over and over with a nail scissors. I looked at myself doing it from outside myself, equal parts shocked and devastated. I returned to my bed afterwards, and knew this was a watershed moment.

I spoke to my Father about what I had done and what I was experiencing after he inquired after a few more of these instances, noting I seemed somehow even more disturbed. He reassured me, as ever. And I felt awful for burdening him with the blow of a further deterioration. But the little part of me that was still me, very deep down and being smothered by all of the medication and the tract I had been fed by psychiatry about the nature of biological 'illnesses' I was suffering from, was just loud enough to get through to me, and for me to realise a correlation between a specific medication and my newfound suicidality and self-harm.

It had been roughly four weeks since I had been prescribed and had begun taking a new antidepressant on top of my existing one (and alongside the five other medications I was on by this point). This one was an SNRI (serotonin-norepinephrine reuptake inhibitor), which sought to alter the reuptake of serotonin and norepinephrine in the brain. Different in nature to my existing antidepressant, which was an SSRI (selective-serotonin reuptake inhibitor).

One of the reasons for prescribing this specific drug to me was that it was supposed to help with sleep. By this point, I had been on sleeping tablets and Valium for so long that they no longer worked in getting me to sleep. And sleep was the only thing I had. Sleep was the only escape I got from the hell my life had become. Knowing it was waiting at the end of the day made waking up at the start of each new day bearable. There would be a temporary pause. A break. So when I stopped being able to get to sleep due to being sedated all of the time anyway, I would have done anything to get it back. To that end, even though being prescribed another antidepressant felt beyond extreme, and like the hole being dug around me was just getting deeper and this meant there would be even less chance of a way out, I was immensely relieved when it did get me to sleep for a few hours each night after taking it.

For two or three weeks, I slept at night again. Not through the night, admittedly, but four or five hours was worth its weight in gold. 'At least this one is actually doing something helpful', I thought. At around four weeks, the suicidality and self-harming hit. And after feeling totally helpless, that bit of me that was still 'me' helped me through critical analysis: four to six weeks is how long it takes for antidepressants to become "clinically effective" (how long it takes for them to build up enough in your system to kick in and have whatever effect they are going to have, if any). I knew that one of the primary side effects of antidepressants was suicidal ideation and self-harm, and I realised that this was a possible cause of these terrifying new aspects of my distress.

I felt relief and hope! I explained to my Dad that I thought I might have found a cause for what was going on, and I made an emergency appointment with the psychiatrists to discuss this. I reckoned that because this was probably just an issue with a medication and not my mental illnesses, they would be willing to hear me out and – perhaps – be pleased that something going wrong in my treatment had been identified and could be course-corrected. After all, that was the end goal, wasn't it? To help me get better? I wasn't talking about anything happening in my life as a cause, or going beyond their preferred purview of medical reasoning. I was inquiring along these lines to find out if, in fact, one of the treatments may just be causing a common and widely known side effect to harm me, seeking their permission to cease taking it (what this in and of itself says about my own agency at the time, and how very assimilated into the system I had become on the wrong end of a power imbalance is deafeningly loud).

I explained for perhaps five minutes, genuinely and with as much enthusiasm as I could, that this suicidality was terrifying to me, that it was uncharacteristic, that I had felt suicidal before, but it had never felt like *this*, like it wasn't coming from *me*, how it had hit so suddenly and intensely at the same time as the SNRI would have become "clinically effective", and that I wanted to wean off of it to see if it things would improve. After all, if I were wrong, I thought, what was the worst that could happen? I stay suicidal, and they just increase the dose again because reducing it didn't help. It was simple from my perspective. Looking back at this whole dialogue now, it had the same feeling as though I were a teenager desperately putting forward my best pitch to a parent to convince them that if they let me get a pet, I would take really good care of it. This was my body. My wellbeing. It should have been my decision to make without the need for anybody else's permission. But it wasn't.

I was told that that particular drug was a *wonderful* drug, that I was by no means to stop taking it, and that they were going to increase the dose of it.

This would end up being the first time I went against the treatment given to me and acted against the power-knowledge being exercised over me. The first time I felt like I was breaking the rules, because *I* knew better. The first time in a long time I would take the risk of trusting my *own* expertise over the expertise of the psychiatrists, and stop taking this medication regardless of their instructions. And the only reason it felt like a risk was not because it felt as though something bad might happen to me physically or emotionally in terms of withdrawing from the medication; the risk came from fearing that the psychiatrists might ever find out, and that I would be in trouble.

I stopped taking the medication, and within three days, my suicidal thoughts had weakened substantially. They got weaker and weaker with each day, until I was no longer bombarded with them. I was so, so immensely relieved. They continued to dissipate, and I stopped self-harming within that week. Yes, sleep was an issue again now, but I was just going to have to find another way to deal with that. I had been right to trust my inner wisdom. And this fed my soul, reminding me in a felt way that there were always other ways to do things, and other perspectives.

Sleep and waking up

It's slightly ironic to me that all of the medications prescribed to me, ostensibly to improve my distress, would trigger the low point that did, in fact, lead to an enormous improvement in my distress. Because this low point made me come *off* all of the medication, cold turkey.

Sleep had continued to be an issue in the weeks following my cessation of the SNRI. I had taken to doubling the dose of sleeping tablets at night, which would grant me three to four hours' quasi-sleep until they wore off. Then, I would be lying in bed from four or five in the morning, heavily sedated yet unable to rest or get any relief. And I really needed that rest and relief. After a few weeks of taking double the dose of sleeping tablets, they once again stopped working, as my body was so tolerant to them at this stage. I was entirely dependent on them now. So I started to take three a night, along with the Valium, beta blocker, and antipsychotic. My GP told me later that I was technically overdosing on sleeping tablets every night. And then three sleeping tablets stopped working. I was at a dead end.

This insomnia and reliance on medication to get me to sleep which was no longer working would lead to an act of desperation which would save me around January or February of 2012.

I realised that I must still have the SNRI in my drawer somewhere, and I decided to try an experiment. The SNRI had worked amazingly at getting me to sleep for four or so hours, and I was desperate. I would take a *small* amount of it – much lower than the dose I had been taking when it was prescribed – to see if I could find a loophole whereby the drug would help me sleep, but would not bring the horrible side effects that it had the last time. I reasoned that I knew the side effects it caused me, and as harrowing as they were, I could be assured that if they did in fact hit me again were I to take the drug, I would know what they were this time, and I could stop the experiment, safe in the knowledge that any suicidal ideation would pass as the drug eliminated itself from my system. And so, I made a very, very ill-advised decision out

of a place of paradoxical apathy and desperation that would, ironically, end up being the making of me.

I tested out my theory and launched my experiment. I began taking a small amount of the drug at night, and it worked as I had hoped it would. I slept. I cannot express how invaluable this was. For a week or so, this continued, and I slept. But after just over a week of this, I woke up one morning and was immediately bombarded with the familiar screech of 'Kill yourself, kill yourself, **kill yourself**' looping in my mind. 'Shit'. It hadn't worked. 'Fuck. Right, well, time to stop the experiment. Just ride this out, it will pass in a few days. You haven't even been taking it that long this time, so it shouldn't take more than a day or two'.

But after three or so days, it had not passed. The thoughts were still as loud and terrifying. And this is when everything changed for the better through a very painful process of realisation and action. It was a Monday afternoon and as usual, I was dissociated in bed. I was being assaulted by the thoughts of suicide, and then something scary happened. In the same manner as I had felt a very disturbing disconnect between myself and these thoughts and impulses as I had watched myself rise from my bed to harm myself for the first time, I realised that I was opening my bedside table's drawer where I kept my mountain of medications. I felt the same desire to stop whatever was happening, but I no longer felt like I was in control of this moment. I then watched as I tipped out each of the different vials of medication and counted them all. This will sound strange, but the only way I can describe what happened next was hearing myself think 'Hmm, I don't think there's enough here to kill me. That will just land me in the hospital'. It was the apathy of the thought and action, and the entire mundanity of the affair, that shocked the 'me' part of me from its coma. I realised what I was doing. And I did not want to do it. I quickly put all of the medications back, and tried to think of the right thing to do in this situation. What the right support would be. I was trying to resource myself, which was coming from listening to my inner voice that knew this wasn't right, and that it wasn't me. My expertise and gut were trying to save me.

I decided to get up and go to my GP to discuss this, because I knew how dangerous it was to be actively suicidal. It was too important to worry about what the psychiatrists might say or do. I had to survive it, I could deal with the aftermath of that survival afterwards.

I got no farther than my bedroom door and into the hall of my house before my Mother and Sister both saw me, and immediately knew something very wrong was happening. 'Shit. Shit, shit, shit.' I couldn't tell them exactly what was going on, but they could see it. They were very

clearly worried and trying to reach out to me to find out what was happening. I tried to play it off, and said I was just going to go to the doctor's because I needed to check in about my mental health. This was not unusual, as by this point, my doctor saw me twice a week to check on me. They knew this time was different. What followed was an incredibly raw, vulnerable, everything laid out on the table conversation that frankly, I would not be here today without. It was an on the spot intervention.

My Mother and Sister told me from a place of genuine terror, love, and concern, that they did not think all of this medication was helping me. That it was making me much, much worse. That I had disappeared into myself, and that I was not there. That they wanted me to have a life, and to get better, and that this was not working. This was not the way.

I tried to explain that I had to keep doing this, because I had been told over and over that this was the way to recover from my illnesses. That the *experts* were giving me all of this medication, and that this must be the best possible outcome. That without the medication, I would be even worse, and I couldn't deal with that. I didn't know how I could.

They told me they didn't believe that.

This was mind-blowing. I had been so indoctrinated into the hegemonic ideology and institution of the psychiatric system that I had almost entirely forgotten how to hold other perspectives. To think critically. To decide for myself. Which was reified through the very evident power imbalance between 'doctor' and 'patient'. I was not so much being treated in an effort to help me, as I was being controlled by *those who knew best*. They could not be wrong. But with this conversation from two people I love and who love me, I realised that might not be true. Their words had weight. I am eternally grateful to them both for having this heart to heart with me, which was so hard for all of us, but so essential and cathartic.

I called my GP to tell them the state I was in. That I was feeling suicidal. The GP agreed that I didn't even sound like myself over the phone, and I could sense the concern in their voice. By this stage, it was late evening, but my GP sent a letter on to the nearest mental hospital for me to be assessed immediately. I felt sick at the gravity of what was once again happening to me, but I knew that something powerful was happening all the same. Somehow, this was make or break. I could feel that. Something had to change, because the situation had become entirely unsustainable.

My Sister drove me to the hospital and waited with me, out of concern and not want**in**g me to be left alone. She then swapped with my other Sister when she needed to go home. When I was called in after a few very stressful hours, I was somewhat surprised to see that the attending psychiatrist happened to be one who had treated me in my local outpatient clinic. I thought this might be a good sign, as they at least had a passing familiarity with me. My Sister joined me in the meeting.

I explained to the psychiatrist that I was feeling actively suicidal. I told them about my experience earlier that day. I started to explain my concerns and frustrations about all of the medication, to inquire as to whether they could be exacerbating any of my distress. They said it was not the medication. My Sister jumped in, and by holding the social capital of 'sane person' in this scenario, she was listened to in a way that was notably different than the way I was.

There was a respect shown to her by the psychiatrist that had not been shown to me. She was not less than. She voiced my family's concerns about me, she told the psychiatrist about her Brother, and how he had changed and gotten much worse with all of the meds, and that this was not who he was. It felt so strange to see someone challenge a psychiatrist; I had felt immediate panic once my Sister started talking to the psychiatrist, as if she was putting herself in enormous danger in a situation she didn't understand. Like she wasn't respecting authority. Like I wanted to tell her to stop talking to protect her. Only to realise, as she continued talking, she was safe. She was not seen like I was. This was eye-opening.

The psychiatrist asked me outright if I had plans to end my life, or felt that I was a danger to myself. I responded that I was afraid of leaving the hospital, because I did feel like I was a danger to myself, and like I wasn't safe. Which was all very true. I was incredibly scared, as were my family.

The psychiatrist told me "By the grace of God, you will not do this. Because you are a ***good*** boy".

They then prescribed another sedative to take that night, alongside all of the other medication, so I would sleep, and they told me they would meet me in a few days' time at my next appointment.

My Sister was visibly stunned.

That was it. This encounter shattered the illusion entirely. The emperor wasn't wearing any clothes. This psychiatric treatment was a dead end. I realised how many chances I had given it, and how deep down the rabbit hole I had gone without realising it, and I snapped back into myself and decided that this was going to be the end of it. I had tried it, and I was now suicidal and taking seven different medications, totalling 18-23 tablets a day. I was already at rock bottom, so it was time to try going a different route. My family supported this wholeheartedly.

I woke up the next morning, and I only took the SSRI I had initially been prescribed. The reason I did not stop taking this one was because I knew that while this medication fundamentally altered the chemistry of the brain, the majority of the other medications were all effectively various different classifications of sedatives. Heavy duty tranquilisers.

I cut out every other medication. I went from 18-23 tablets to two. **I do not advise this or endorse it as a fix for anybody in a similar situation**. Abrupt cessation of medications should always be avoided, as it can have deleterious effects on the person doing so. It is always, always, best to wean off of medications slowly and at your own pace with the oversight of a trusted professional, where possible and applicable. For me, I was already suicidal and bedridden, and it was unfortunately a do or die decision that I felt had to be made.

And thank god I did make that decision. Even though I was hurled into a severe physical withdrawal from benzodiazepines, sleeping tablets, and the other medications. I didn't sleep for at least three weeks. I could not rest. I could not breathe properly because of the intense withdrawal and the re-emergence of adrenaline in my body. My heart felt like it was going to explode. My body was sounding the alarm and trying to right itself and adapt to a remarkable sudden shock to the whole system. I was shaking all of the time. I felt pain throughout my body. I sweated through the sheets every night as I lay there, agitated and waiting for the morning, because at least then I would be going through the withdrawal with other people and life happening around me. I felt like I was going to vomit literally all of the time for the first week.

One night, while I was lying in bed sleeplessly, I projectile vomited across the room and all over my bed. I hadn't slept in at least four days by then. I had to get out of the bed, and change the sheets and clean up the mess, while dripping sweat and shaking violently at around three in the morning. It was, simply put, torture. And yet, I would gladly endure this withdrawal, knowing it would eventually stop, than continue experiencing the soul death the medication caused.

I knew it was the right thing to have done because, within two days, I could smile again. I was able to actually participate in conversations with my family. I was able to access my feelings more than I had in months. I actually laughed on the Wednesday – I laughed! And, to my great relief, I could even cry! I could *feel* my feelings, rather than just being aware of them stagnating and heaving underneath a concrete lid of chemicals. I could walk again! I went for walks, and pumped out all of the sweat that was coming with the withdrawal, while listening to music that I could suddenly connect to again. That felt amazing.

My muscles had atrophied quite a bit from being bed-ridden, and a good walk would leave me feeling like I had done a heavy gym session, but I was so very glad of it. I had the motivation to walk again, and the desire to feel, and that was worth all of the withdrawal in the world. I was **present**. My family could see the change in me, and they were so relieved to be able to talk to me again, and not just go through the motions of a conversation with somebody metaphysically absent. It was so healing. And I could not have gotten through all of it without their belief, support, encouragement, and help.

Connecting to others is something the medication had fundamentally denied me, and that is particularly cruel, as it is one of the most important factors in the journey to healing possible that I have been reminded of again and again through my experience. I am eternally grateful to my family for all they did for me, and what they taught me about the importance of trusting myself in the process.

Saving grace

By this time, I had finally gotten to start appointments with the psychotherapist I had been referred to the services for in the first place just before Christmas of 2011. At last!

For the first few sessions, nothing happened. I wasn't present or able to actually connect, feel, or do any of the work due to my medicated stupor. But once I ceased the medication, I was happy to meet with the psychotherapist and to actually *feel* what we were talking about, and to be able to access the issues deep inside me we were working on (the very issues I had known were the obvious things impacting my wellbeing when I sought help in the first place, but which psychiatry had rubbished as irrelevant to my 'illnesses').

We got cracking on some difficult therapy for OCD called Exposure-Response Prevention Therapy (ERPT). This involves facing the feared intrusive thought or image head on (the 'Exposure' part). In this case, this meant listening to a recording of myself stating the fears as

fact in the present tense over and over for 45 minutes each morning, and not responding to them or partaking in any physical or mental compulsions (the 'Response Prevention' part). It's as hard as it sounds, but it genuinely helped me to face the gut-wrenching health OCD I had, as well as some other intrusive themes, and to loosen their grip on me.

The psychotherapist was kind, professional, and dedicated to helping me build up my tools to battle OCD and Anxiety. Their help was invaluable to me, and I will be eternally grateful to them for the work we did together. Above all else, the psychotherapist treated me with the same respect and humanity as they would anyone else on the street. I was not seen as 'less than' by them, as I felt I was with the psychiatrists. I was not 'ill'. I was just there for some help.

Framed in my development as an Expert By Experience, my knowledge that talk therapy and Cognitive Behavioural Therapy (CBT) were extremely useful and effective for me in working through my distress and finding new ways to resource myself was reinforced by this treatment.

I was now beginning to move fully into what felt right for me, what was making me feel closer to myself, and what made me feel more present than I had in a very long time. I was moving towards my values, trusting my own innate sense of what was a good or bad fit for me, and owning my expertise in my own experience over the opinions of some other experts.

In the same way, I was becoming aware that things rarely had a one size fits all, objective solution: and certainly not things as deeply complex and layered as the human experience, the mind, emotions, and suffering. No one institution, discipline, or ideology should claim to offer such a solution, and claim it as objective, scientific truth.

Affirmation

Now that I had made this decision to think outside of psychiatry, and I had taken these steps to cease medication, I knew they were the right ones for me. My GP, though naturally not thrilled to hear the choice I had made about the medication due to the severity of it and the potential dangers that come with sudden cessation of such heavy drugs, respected it as well-reasoned, with me already showing signs of improvement in my outlook when I met with them a few days into my withdrawal. They later acknowledged that I may have been overmedicated.

This was an affirming moment.

Just the thought of stopping or even reducing the dose of any one of these medications had seemed mortally dangerous to me up until I stopped them. And now I had at once grappled

with and accepted the harmony that came with remembering other perspectives and options existed outside of the singular, hegemonic one I had been subscribed to, and I had decided to trust one in a very all-in, risky way. And it had worked out amazingly. I felt deep gratitude that I had done what I had done. I could see my life ahead of me now, where before, I just saw existing in an agonising grey void in my bed in perpetuity.

Everyone around me told me how delighted they were that I was back. My friends admitted they had not seen how I would get out of the dark place I had been in, but they had hoped I would and believed I would find a way. It was surprising to me how many of those close to me opened up about how they had felt disturbed by the zombie I had become, and how it broke their hearts to see me like that on the rare occasions I would effort to meet with them. But they too had felt like it was not their place to question the efficacy of the expert treatment that was leaving me that way. Now, they were overtly critical and, in some cases, palpably frustrated at those who had been in charge of caring for me. They felt safe to voice these feelings now as they rightly guessed that, had they shared them with me while I was still going through the motions of the treatment in that state of resignation and stagnation, I would have just felt more hopeless and like I did not have their support.

I, too, was getting angry now.

Danger

I knew all too well that I would have to speak with the psychiatrists about my decision to cease medication. I wanted to reclaim my agency and power, and I planned to make an appointment to see them, so I could tell them I had ceased the medication, that it had had a profoundly positive effect on my mental and emotional state and wellbeing, and that I now saw a way forward in my life and a future for myself. I was about a week off of the medication at this point. Unfortunately, when I tried to make this appointment, I realised that the choice was no longer mine to make.

A third party within the multidisciplinary team had informed the psychiatrists of my decision and actions without informing me. A reminder of who held the power in this structure, and whose agency mattered.

I asked the psychiatrist for an appointment to discuss something. This happened to be the same psychiatrist who I had been seeing fairly consecutively since we first met, back when they referred me to the psychotherapist and increased the antipsychotic past its advised maximum

dose. They also happened to be the lead psychiatrist in the clinic, so they were remarkably powerful. I did not get past the initial request for an appointment before the psychiatrist shot something close to 'Oh, there's already an emergency appointment to see ***you*** tomorrow. We *know* what you've done' at me. The last part, spat at me seemingly just to rob me of the chance to tell her myself and to denigrate my choice.

I went from feeling empowered and planning to arrange an appointment on my own terms where I would clearly present myself as being in a much better place than I had been in many months, with a positive outlook, to quickly being brought back down to earth with a thump. I was still not in control in the eyes of this psychiatrist. And this meant that I was very objectively not in control of what would happen to me from this point because of the nature of the psychiatric field and the powers granted to it by law. I was not entitled to make decisions about myself. And now, I was in very serious danger: the only difference between a voluntary and an involuntary psychiatric patient is the patient's consent and compliance with the treatment given by the psychiatrist – the expert.

If I decided to stop a certain treatment as I had, this was not because I was free to do as I pleased, as one would expect with any other branch of medicine.

A cancer patient can be advised to follow a course of chemotherapy by an oncologist, assured that there is a very high likelihood that if they do so, they will survive. They can be told that if they do not undergo this treatment, they are likely to die. These treatments have a wealth of scientific data to prove their efficacy and legitimacy. The patient can choose not to, and have that choice respected. Even if it can be argued that they have effectively refused life-saving care, and will die from their illness.

A psychiatric patient can be told to follow a course of medication that is speculated improves an illness it is hypothesised exists and from which they suffer, for which there is no medical testing, and which is subjectively ascribed to them by a psychiatrist based on their estimation of the individual's mental state. There is no scientific data supporting the model of illness they are diagnosing from, and in fact, there is a wealth of data disproving it. There is also a wealth of data describing the inefficacy or total failure of these medications to improve the condition of the individual being told to take them. If they refuse to take the prescribed medications, they can be detained for involuntary treatment(s) for as long as is decided by the psychiatric system. The individual is stripped of their human rights to liberty and dignity, amongst others, in the process.

Psychiatry and the health of women and birthing people are the only two fields of medicine that have the authority to force treatment on patients without their consent, or explicitly against it. They can and do disregard and trample on individuals' bodily autonomy. And both fields are deeply entrenched in patriarchal norms, normativity, and biopower.

And I was now in the firing line of a psychiatrist who was openly irate and frighteningly angry at me when I spoke with them because of my decision to go against their treatment orders. I was absolutely terrified, and this time, it was not due to an irrational fear. It was due to a fear that, I would argue, *ought* to be irrational in a modern society, but which is not due to the policies and laws still in place.

Getting out

In my case, I hoped that, though the psychiatrist had been overtly angry and frightening when we had spoken, they would have had time to ground themselves, and would approach our appointment from a more open-minded perspective. I was terrified, but I tried to soothe myself with this notion as I prepared to meet with them the next day. That was a long night spent in anxious anticipation.

When I met with the psychiatrist the next day, I instantly sensed the mood. It was very, very off. They seemed to be trying to speak to me calmly, but their anger was palpable. I did not offer any resistance, and instead plaintively explained my decision to cease the medication, when I had done it, how I had improved mentally and emotionally in leaps and bounds, and how I was getting very good work done with the psychotherapist that was helping me immensely with the initial problems I had presented to the Clinic with.

I came from an authentic place, seeking to communicate my progress without any air of confrontation. I reasoned that, if the psychiatrist's mission and desire was indeed to help those they treated and see them get well, then they might see past whatever anger or frustration they were harbouring to realise that this is exactly what had happened for me. And that they would be satisfied, if not pleased, that I, as their patient, had improved.

This was not the case. The moment I finished speaking, the psychiatrist spoke with a measured tone that was barely concealing their ire. Not responding to any of the things I had just spoken about, they instead said what they must have been waiting to say the whole time I had been talking. They asked me if I would stop taking my insulin if I had Diabetes. I said that I would not, as Diabetes is a physical illness and insulin is a proven, effective treatment. I barely got to

say that I did not think my distress and Diabetes were comparable conditions before I was cut off. I was told in an extremely angry and loud voice that in three months' time, I was going to go so far downhill that not even *they*, the psychiatrists, would be able to help me.

I was surprised when I automatically defended myself by saying I would take that chance rather than take the medication again.

There was a moment's silence that was pregnant with tension and, to me, danger. Stunned by the psychiatrist's outburst, and by what they read as my defiance. I shut up, realising I was definitely not going to speak unless I was spoken to now.

After a few moments that felt like an eternity, they reassumed their faux calm demeanour, and began writing in my file. They told me that they were recording in the file that I had had an adverse reaction to coming off all of the medication. When I interjected to say that hadn't been the case, I was once again cut off to be told furiously that **I** didn't *know* that.

I shut up again. I was not going to contest this. I felt the danger I was in. I felt their rage at my decision. This decision somehow represented a reprehensible disobedience on my part to the psychiatrist that, by virtue of not having been done at their dictate, was a personal insult to them.

I realised that they were writing what they wanted the case to be, and not what the case actually was, in order to lay the groundwork to support a narrative whereby I would suffer a sudden deterioration, should the psychiatrist wish to make use of such a situation in the near future. Should I continue to be a problem. Should they need to have their treatment – and more importantly, to have their choices about what I was to do, and their *orders* that this treatment represented respected – implemented by force through involuntary hospitalisation.

I was very, very frightened.

I waited until they muttered the date of my next appointment to me after finishing writing in my file without glancing up in complete silence, preparing a fresh prescription for all of the medications I had been on for me to get back on (which I would never fill).

I left the Clinic, and had a panic attack once out of sight of the place. I tried to reassure myself over the next few days that my fears about the psychiatrist wanting to involuntarily hospitalise me for going against their orders were irrational. That they were coming from my Anxiety and OCD. That I was reading too much into the situation, and given how extreme a measure

involuntary hospitalisation would be with no medical reason to justify it, as I was not a danger to myself or anybody else, nor was I lacking in capacity, there was no way the psychiatrist could seriously have considered it.

This was until I spoke to my GP about the appointment during our next consultation. They were bemused, and a little stunned, by what I disclosed, but they seemed to have a face that indicated the situation I had just described to them to be elucidating. They shared with me that they had received a letter from the psychiatrist following our appointment, and then the GP read it to me. It was sternly written, and clearly not intended for me to see – the tone was that of one medical expert to another. In it, the psychiatrist complained at large about me ceasing taking the medication. They clearly assumed they were writing to someone who would be of the same mind as them on this issue, which my GP was not. They were just as surprised as I was by the psychiatrist's dogged, single-minded focus on correcting this wrong I had committed at the cost of actually seeing me as I was. That is to say, to critically analyse my condition and reason that it was much improved in every conceivable way. My GP was sharing this letter with me because, in direct opposition to the assumption evident in the letter, they viewed *me* as a peer in my treatment, and an expert in my own wellbeing. And they was just as startled by the psychiatrist's reaction as I was, frankly.

Then the letter got to the part that confirmed all of my fears about the situation I was now in. After explaining how reckless what I had done was and venting to someone they assumed was a confidant, the psychiatrist shared the following, as if to answer a question my GP might naturally arrive at about a possible option in getting my treatment back on track, and to break the bad news to them. This was that I was unfortunately not admittable under the Mental Health Act, 2001, as I didn't pose a risk to myself or others.

The psychiatrist was disappointed that they could not have me sectioned. That they could not involuntarily hospitalise me. They *had* considered it, and, to their disappointment, they had not found a feasible reason to go ahead with it. Because their reason for wanting to go ahead with this was not for a medical reason, or out of concern for my wellbeing, but because I had disobeyed them, and in doing so, insulted them, and they would not be disrespected like that. I would yield if they had their way. If I would not comply willingly, I would comply by force. I can't believe I need to be grateful that this psychiatrist could not find a reason to lock me away for doing what was right for me, but I do.

Think about that for a moment. Imagine you are a psychiatrist: unfortunately, you conclude that a patient of yours is presently lacking mental capacity, or poses an active risk to themselves or somebody else and needs, in your opinion, to be involuntarily hospitalised for a period of time. That may be how you would imagine involuntary hospitalisation should be decided upon.

Instead, my psychiatrist worked *backwards* from a desire to exercise power over me, without any coherent reason for me to need hospitalisation. So they sought to find a reason to justify doing so. The conversation surrounding deductive versus inductive reasoning is not one that belongs in scenarios where you are seeking to actively deprive somebody of liberty and violate their consent and bodily integrity, in my opinion.

And so, I now knew I was right to be terrified. I was in a very dangerous and precarious situation. I could not discharge myself from the Clinic, I needed to **be** discharged by a psychiatrist (another example of how the psychiatric endeavour functions to ignore individuals' agency, and is an institution that exercises power-knowledge and biopower over those subject to it). So I had to occupy the role of a good patient and hope it would all work out. In a very overt, socially performative way.

For five months or so, I attended my scheduled appointments. I would answer the five questions honestly. This meant that it was noted in my file with each appointment that my sleep had improved, my appetite was healthy, that I had not had any thoughts of harming myself or others, that I was crying more or less often, and that my mood was good with a positive outlook overall. But the *how* of these improvements (the changes I had made in my life, and my work with the psychotherapist) was not noted, thanks to the lack of room to expand upon these subjects that characterised my appointments. I was now very glad of that particular idiosyncrasy. I believe the psychiatrists I was seeing assumed I was back taking all of the prescribed medication again, which kept me safe from any potential retribution.

To my immense relief, this sudden and remarkable improvement in my condition, as noted in my file by different psychiatrists, led to my appointments being spaced out more and more. Thankfully, this meant that even though I would not be discharged for close to another six months, the appointments I was so afraid of in case things went south were now far fewer and further spaced apart than they had been when I was 'ill'. I was finally discharged from the psychiatric services in June of 2012, and I felt a huge weight lift off my shoulders. It was like my probation had ended, and I was no longer under scrutiny. I was back to being as free as I had been before I entered that system. And I have never, ever gone back to it. Even when I

have needed help acutely. Because my experience was so roundly horrifying that I am loathe and terrified to ever put myself in the position of having my freedom qualified, or to be given treatment that actively makes my distress much worse, but which I am not entitled to stop taking, or to request alternative treatments to. No matter how hard things have gotten at times since then.

And I do believe that there may well be beneficial treatments in that system for many people, myself included. The psychotherapy I received, that I had been referred for explicitly but did not receive for the guts of a year, was absolutely invaluable to me once I could engage with it. I also do not believe for a moment that there are not good people in that system. I know there are caring, compassionate people in different roles within the mental health services, and that people in distress benefit from their help. Unfortunately, aside from my psychotherapist, I only met with psychiatrists. And without hyperbole, all of the many ever-rotating psychiatrists I met with were not simply unbeneficial, they were harmful, negligent, and abusive.

I now know through very intensive experience several treatments, approaches, and methods of intervening that did not work for me to improve my distress. I had instead, largely, learned of several that actively made my distress *worse*. From this, I have been able to build upon my knowledge of what improves my distress, and to be less rigid in believing one practitioner, discipline, or approach holds the correct or 'best' means to help in ameliorating distress.

I have developed critical skills with which I question who the information, advice, or treatment I am receiving is coming from, what their biases may be, what their qualifications are and what they mean, and crucially, to see beyond the authority we award to those who carry titles such as 'doctor' to the person behind the title and who *they* are. I have learned how to resource myself by *not* being led by titles, positions, and 'expertise', but instead, to try things and see what works for me, trusting my gut, which got me through everything that did not help, but instead harmed me so much. And with that knowledge, which is always developing, I have learned how best to resource myself and advocate for myself in times of strife, and what supports are the most helpful and appropriate and when.

That is what expertise by experience gives you on an individual level.

CHAPTER 6: THEMATIC ANALYSIS AND DISCUSSION

INTRODUCTION

This chapter analyses the data collected from the in-depth interviews with Experts By Experience (EBEs), which were conducted to gather and interpret the perspectives of EBEs on their lived experience of Irish mental health policy and practice. These interviews form one of the two complementary research strands outlined in 'Chapter Four', with the other strand being autoethnography. The thematic analysis of the in-depth interviews in this chapter is complemented throughout by autoethnography. The process of thematic analysis entailed taking note of significant themes and issues that arose during each interview as they took place. By doing this, I was able to identify some initial key themes and concepts which were coming up in different forms in each interview, and to begin seeing consistencies and patterns emerging across individuals' experiences. I then listened back to each interview after conducting it to further familiarise myself with the data. The interviews were then transcribed. With the broad themes and concepts that had arisen in the interviews mapped from my initial analysis, notes, and familiarisation to guide me, I performed a deep thematic analysis of each transcript. This process is described in greater detail in 'Chapter Four'.

These broad themes arose in a pattern which was replicated in each interview. Though their specific manifestations naturally differed and varied from person to person, when they were analysed, these themes indicated and delineated a map of respondents' experiences throughout their lives, consistent with each major theme forming a 'step' on the respondent's journey to becoming an EBE. Though this research is not exhaustive due to its limited sample size of five interview participants and the author's autoethnography, it strongly suggests a uniform timeline of key milestones in a mental health EBE's life which, though different in their manifestation for each individual, consists of the same 'steps'. The respondents' data, as well as my own autoethnographical data, also indicate certain characteristics that all EBEs interviewed possess which drive them. This chapter will analyse the data, outlining each 'step' on the journey that EBEs undergo, by exploring the key themes which emerged *as* they emerged in EBEs' lives.

The three key themes or 'steps' that emerged from the data and are explored in this chapter are, in order: alienation, psychiatry and the biomedical model of mental illness; discovering alternatives to the biomedical model of mental illness; community; and, finally, the individual professionalisation undertaken by EBEs. This individual professionalisation was undertaken to

elevate EBEs' unique expertise, and to facilitate their work in careers where they seek to make changes to hegemonic systems which were harmful to them. These are the 'steps' on the timeline of our journey to becoming an 'Expert By Experience', as demonstrated in the data.

Subthemes which are recurring and interwoven throughout the analysis are: the reflective critical cycle; help-seeking and self-resourcing; identity; self-actualisation; empowerment; and social justice and injustice.

ALIENATION, PSYCHIATRY, AND THE BIOMEDICAL MODEL OF MENTAL ILLNESS

Alienation

Alienation was a broad experience and theme that arose in every interview, and in my autoethnographical data. It took different forms depending on the respondents' unique life circumstances, but the essence of it was internally consistent in its manifestation. Those who I spoke with went through a period of initial isolation and alienation upon experiencing the first onset of their mental and emotional distress. Respondents experienced this isolation and alienation internally, as they wrestled with trying to understand and manage what they were experiencing. In some cases, they also experienced this isolation and alienation within and from their communities and families, as they too struggled to understand and accept respondents' distress once they became aware of it. This finding reflects how the alienation of an individual in distress from their community is informed by social stigmatisation and lack of understanding surrounding mental and emotional issues. The effects of stigma on those who experience mental and emotional distress have been discussed in the 'Critical Analysis of Policies and Legislation', and 'Chapter Two' (Corrigan, 1998; Corrigan et al., 2012; Corrigan & Rao, 2012; Del Rosal et al., 2021; Link et al., 2004; Pescosolido, 2013, 2019).

The alienation and isolation respondents experienced from their communities upon their discovery of respondents' distress echoes society's desire to separate and control the abnormal which is reflected in the provisions and functions of Irish mental health policy and law, beginning with the Lunacy Acts (1811-1871). These functions have variously been fulfilled by the gaolers, mad-doctors, and psychiatrists, who have traditionally separated the 'troublesome' or undesirable mad person from their sane peers or family through exercises of biopower and control which reify normalisation and abnormalisation (Finnane, 1981, 1985; Foucault, 1965; Kelly, 2016; Visoka and Lemay-Hébert, 2022; Wright, 1997; Wright et al., 2008). This is

discussed in more depth in both the 'Critical Analysis of Policies and Legislation', and 'Chapter Two'.

Kelly (2016) has documented Irish society's historical mistreatment and stigmatisation of distressed – or 'troublesome' – individuals, particularly on the part of these individuals' family members. Prior to the first Irish legislative interventions into madness, the Lunacy Acts (1811-1871), Kelly notes that one way in which families confined and controlled their 'mad' or 'troublesome' family members was by placing them in pits dug into the floor of their homesteads (2016: 2). With the advent of the asylums, families would 'winter' their socially deviant family members in the asylums, discharging them for use as labour on the family farm during the summer months, and re-admitting them to the asylums when winter came back around (2016: 4).

The isolation and alienation felt by the interview respondents invariably gave way to help-seeking. The initial port of call in seeking help was a GP or psychiatrist for all five respondents. This demonstrates the cultural and institutional hegemony of the biomedical model in Irish mental health policy and practice during this time period when *A Vision for Change* (AVFC) (Government of Ireland, 2006) was the active mental health strategy, as outlined in 'Chapter Three'. Respondents' alienation and isolation from their communities and from themselves illustrate Foucault's theories of power-knowledge, normalisation, and biopower (Foucault, 1963, 1965, 1976, 1977, 1980, 2009; Gutting, 2019), which are explored in 'Chapter Two', in "the concrete social world" (Pokinghorne, 1995: 19).

Through the treatment given to respondents by these practitioners of the biomedical model of mental illness, which was medication in the case of all five respondents and myself, the majority of respondents (four of five) experienced an even deeper isolation and alienation. This biomedical alienation arising from seeking help for mental and emotional distress, which compounded the isolation and alienation respondents already felt as a result of their distress and its reception by those close to them, was the first major theme and 'step' on the journey to becoming an EBE which emerged from the data.

Respondents experienced a period of secret suffering while they struggled with trying to figure out what their distress was, and why they were experiencing it at its first onset. One respondent recalled that, upon experiencing their first major mental health episode during their early twenties, they suffered alone and kept it to themselves for months while self-medicating with

alcohol before seeking help. This hesitancy stemmed from the respondent's family history of mental and emotional distress, and their fear that they had inherited it.

The period between respondents' first onset of mental and emotional distress and them 'coming out' and seeking help – or others intervening and seeking help on their behalf in one instance – differed depending on the nature of the distress suffered. Most (four out of five, as well as myself), experienced a discrete or acute episode of suffering which triggered them to seek help of their own volition through the hegemonic biomedical service-providers. One respondent, however, had a different route to psychiatric treatment. They had been experiencing visual and auditory hallucinations for a number of years after finishing their undergraduate studies, and when these visions and voices intensified, they were sectioned under the sections of the *Mental Health Acts 1945-2001* in place at the time (Government of Ireland, 1945, 2001), and involuntarily detained for treatment in 1996.

This respondent was from a rural Irish Catholic family within a small and very closely-knit community. Within this community, there was a great deal of social capital and importance placed upon families' reputations, achievements, and appearances. In situations like theirs, the way the individual's isolation and attempts to conform to normativity, their community's hegemonic practices, and to assimilate to their community are broken not by the individual themselves, but by those close to them, is an even more distressing scenario. The 'sane' discovering the sufferer's secret, and the truth of their 'madness' – their deviancy and abnormality – confirmed by the need for those closest to them to seek help and intervention from community figures or mental health practitioners on their behalf (Foucault, 1965). In a sense, it was as though this respondent had 'failed' in some capacity on a personal level to fit into the normalised mould that had been made for them:

> I came back from third level [education] in Scotland, it was early-90s… I started seeing visions and hearing voices… it went on for about 3 or 4 years and got steadily worse... and I kind of froze. I was frozen. I was really ill – I would call it ill - because I was back then, like… about '92. My behaviour in the context of the community was, you know, *out there* [their emphasis], you know, whatever they want to call it, like… 'normal' – I don't think there's a such thing as normal but… at the end of the day, I was living at home in a village, small village in [names place], and my mother, my family, you know, they were at their wits' end. My community – like, I had been 'eligible'. I had been one of the few guys to go to university – to third level, I think – back in the late 80s, only 4% of school leavers went to third level, you know?

This respondent's community, when seeking help for them, were trying to make sense of the individual's experience through the lens of the religious and cultural beliefs which were dominant in their community. The choice of people this respondent's community initially sought help from reflects the social construction of conceptualisations of madness and mental and emotional distress discussed in 'Chapter Two'. They viewed the respondent's distress through a different lens than that of the biomedical model, and one which conceptualised this respondent's distress in a way that would have had more social capital than that of abnormality and deviancy which distress is conceived as in the biomedical model.

> "Somebody left me over to this monastery, and they thought they would take me in as some sort of holy madman or something."

The respondent's community thought that this EBE might be experiencing a religious, supernatural phenomenon. This at once demonstrates Foucault's analysis of past understandings of the 'mad' as having a unique wisdom and reason which reflected the mysteries of cosmic tragedy (Foucault, 1965), and his observations that due to the iterative, ongoing nature of power-knowledge, all 'truths' and 'facts' that a society hold are historically contingent and constructed (Foucault, 1980: 81-87). The previously hegemonic understanding of distress as a spiritual phenomenon still reverberated in this rural, religious community, but the religious figures the respondent was brought to for help deferred to the contemporarily hegemonic understanding of distress as illness:

> But the monks… just took me straight up to the psych unit, and they were like – they had tried to put me in the psych unit a few months beforehand, but the psych unit just said 'Oh, there's nothing wrong with [them]. Let [them] go'. But then they got me second time round. I did need help for something and I was accepting… I knew I needed help.

The social construction of how we understand and conceptualise distress is further illustrated by the monks immediately recognising that they were not the people best suited to help this individual. Instead, they reasoned using the more hegemonic understanding of the time, that the respondent was suffering from mental illness, and needed psychiatric treatment.

All other respondents came to seek help from medical-psychiatric practitioners through the more normative route of seeking support for distress from a medical professional due to the hegemony of the biomedical model of mental illness. This route, like the route of the respondent brought to a religious site for help, is socially constructed and reflective of the dominant understanding of mental and emotional distress held by the culture and society the

distress manifests in, and the hegemonic institutions exercising legitimate, ideological power (Gramsci, 1971; Lukes, 2005) and power-knowledge which exist to intervene in this distress within that society (Foucault, 1977, 1980). The biomedical model has become so entrenched as fact in Western societies that usually, until people such as the interview respondents have a personal experience with it, they are not aware that it is simply one of many different models of conceptualising mental and emotional distress, and that other models, such as the social model, exist.

Through ideological power (Lukes, 2005) and hegemony (Gramsci, 1971), the biomedical model and its institutions appear to be natural and inevitable in society (Boggs, 1976; Crehan, 2016; Joll, 1976). The development and evolution of the biomedical model of mental illness and its exercise of power-knowledge through psychiatry is discussed in detail in 'Chapter Two'.

Voluntarily or involuntarily, all respondents found themselves engaging with the medical and psychiatric systems in an attempt to relieve their suffering when their distress first manifested or became severe enough for them to seek help. As this was their first time encountering these systems of care, they did so with the hope that they would find support and help for what they were experiencing within them. This was the correct course of action they should take to seek help according to social norms and beliefs. Four out of five respondents, along with myself, then had experiences which were negative and which they found damaging for several common reasons I will detail further on in this analysis. Through these first-hand experiences, respondents' alienation deepened. From this alienation, the process of becoming an EBE began.

Respondents engaged their critical reasoning skills and began to develop them to critique the medical treatment they were receiving for their distress from their GP and/or psychiatrist, and how it was impacting them. From this critical space, they then reflected upon which interventions they were finding helpful, and which interventions they were finding unhelpful – or, indeed, harmful. They were then able to use their critical reasoning and nascent experiential expertise (Dings & Tekin, 2023; Noorani, 2013) to consider and deduce what *could* be helpful for them to ameliorate their distress, based upon what they knew helped them, did *not* help them, or harmed them. This reflective critical cycle is integral to becoming an EBE, and it is a recursive process which is iterative and ongoing. It strengthens with time, as the individual's own expertise and confidence in it strengthen.

But it begins with this first experience of seeking help, and it is triggered by the nature and quality of the interventions received by the individual *as* help. I will describe respondents' experiences of these interventions now.

Psychiatry and the biomedical model of mental illness

The interventions respondents received upon seeking help through the medical model were initially accessed and delivered by GPs in three cases, and by psychiatrists in two cases. In all five cases, respondents progressed to receiving treatment from specialist psychiatric services. They did so while either remaining linked in with their GP, or only receiving treatment from their psychiatric practitioners. I myself followed this trajectory, initially seeking help for my distress from my GP before escalating to psychiatrists further on in my journey. As I describe in 'Chapter Five', I – crucially – remained linked in with my GP. In the two cases where psychiatrists preceded GPs as the first service-providers respondents encountered, the respondents were experiencing mental health crises that were so severe, they required an immediate intervention. This intervention took the form of psychiatric assessment in hospital under the medical model.

Respondents, either soon after initially engaging with the mental health services or more slowly over time, described experiences with the medical model which were, with certain exceptions, such as the receipt of talk therapy through a GP, roundly negative. Reflecting on their experience seeking help through the psychiatric services, one respondent described their overall experience as follows:

> "It was a checklist, tick-box, like, 'find the problem', deficit-based, eh, like, yeah, there was... There was no solution/strengths-based visions of recovery; link people in with somebody in the community you could talk to…"

The first feature of this which was universal amongst respondents, as it was with me, was the immediate response to respondents' distress with medication by the treating GP/psychiatrist. In most instances, this was usually quite a lot of medication. Respondents were not informed of their GPs'/psychiatrists' rationale for prescribing their specific medications to them. They were not informed of the degree of efficacy of these medications. They were not informed of the potential side effects of these medications. They were not informed of the potential withdrawals which could arise from ceasing taking these medications, and they were not informed that taking these medications was a *choice*. They were not made aware of any other

options or alternative interventions to these medications for their distress, such as talk therapy. They were simply given the medication. This is something that deeply impacted some respondents:

> So my first mental health issue was around 2004/2005… I accessed support through my GP… So I never hit mental health services at that stage, which was great. Yeah, just with my GP: drugs – lots of drugs. No knowledge about coming off the drugs. Coming off the drugs was a disaster.

This same respondent later elaborated:

> … we [society] don't have a conversation about what drugs can do to people as well? And I am biased in this, now, but I'm biased on the foot of, I suppose, the evidence that's out there, and my own experience with medication as well. Like they're – some of the drugs are dirty, like, you know? And they're damaging to your heart… Some of the drugs are like two and a half decades less in life [expectancy].

Another respondent who had sought help from their GP upon experiencing the onset of a period of Depression succinctly illustrated the immediacy of this medicalisation as a response to distress, and further highlights a key facet of respondents' negative experience of taking these medications suggested by the respondent above. That is, that they do not work for many people:

> But yeah, like my GP was pretty good, but it was just the medication was not helpful at all. It just didn't, it didn't help. The treatment was, at the beginning, it was Prozac, and then quetiapine as well on top of that. So it [quetiapine] was actually a very strong, old [names antipsychotic: classified as a major tranquiliser].

These respondents' experiences shine light on how the alienation experienced within the medical model of treating distress develops and progresses. The individual is at a low point in life, and is usually already experiencing the alienation and isolation stemming from their distress and the loneliness of trying to make sense of it described previously. They then seek help from the signposted sources they have been socialised through cultural hegemony to seek such help from. When they receive this help (in the form of medications), they frequently find that it does not improve their distress or make them feel better. It can, instead, have effects and side effects which cause the individual to feel even worse than they did before commencing medication. This deepens the alienation and isolation individuals feel, as it ignores and disregards – and instructs the individual in distress to ignore and disregard as irrelevant

(Häfner, 2002; McGlashan et al., 2010; Murray et al., 2005) – the inalienable life events, trauma, and social factors that are impacting their distress.

This is due to the medical model's conceptualisation of distress as the 'symptoms' of discrete, biological 'mental illnesses' presenting, which will improve for the individual once they are on the correct medications to treat their illness (Ang et al., 2022; Deacon, 2013; France et al., 2007; Lacasse & Leo, 2015). This ideology can cause a deeper alienation of the person within and from themselves spiritually, emotionally, and cognitively, as their suffering and all of the reasons it is happening is reduced to an illness. Unlike the social and biopsychosocial models, which emphasise the centrality of personal and social factors to an individual's experience of distress (Davidson et al., 2016: 46; Goffman, 1961; Scheff, 1966; Oliver, 1983, 2004) the content of an individual's distress is understood to be meaningless from the biomedical perspective (Dogra & Cooper, 2017; Kenneth & Kendler, 2014; Thoits, 1999). The reductionism of the biomedical model, and the schism it causes between what the individual in distress feels and believes about their distress (Rocca & Anjum, 2020: 75; Rudnick, 2002), is discussed in more detail in 'Chapter Two'.

When the person experiencing distress believes that the biomedical model is correct, at least in part, and takes the medication prescribed to them with the expectation that it will improve their illness, they can come to believe that *they* are at fault on an individual level for not having a positive response to this treatment. This happened in my case.

This can be especially true when the medication being taken causes the individual to appear physically subdued, sedate, or docile. To those around the individual, this can seem to signify or correlate to an improvement in the individual's condition. It is also often taken as confirmation of such by biomedical practitioners, as it is considered an amelioration of 'symptoms' of the individual's mental illness(es). However, the individual frequently feels no better internally. Their mental and emotional distress may still be as present as it was when they sought help, if it has not become even stronger, though they may now be more physically tranquilised and therefore less emotive in affect. One respondent illustrated this phenomenon during our interview:

> So, I think the medication kind of makes people docile… There's a guy called [name], he's an expert, Expert By Experience in [names place]. And he was saying the same. Like, he was having huge hallucinations, voices, the whole thing. They tranquillised him, and

> he said he was sitting on the bed and people thought he was doing much better; he said he was in hell.

It stands to reason for the individual being treated this way, in these instances where they are waiting for their treatment to 'work', that if this help is the (presumably) medical grade, objectively effective treatment that they have been told to seek in such circumstances, and it is not helping them, the issue must be internal and personal. From the medical practitioners' perspective, the sufferer may be deemed 'treatment-resistant', as I was towards the end of my medicalisation. For as long as the person experiencing distress believes that the treatment they are receiving *should* be working, but it is not, as they and they are an exception, they experience an increase in despair about 'what is wrong with them'. It is not until they begin to engage in their own reflective critical cycle, considering other perspectives to this medicalised outlook, that they may begin to realise they may not be the defective element of their ineffective or ill-effective medical treatment. Demonstrating this, one respondent stated:

> Yeah. I think you need people who actually believe [that] you know yourself. You know what you need. That you're not... you're not just a medical condition – you're more than that, I suppose. Like, it's just so... it's such a weird lens [the biomedical lens] to be looking at people from, isn't it?

The individual then begins questioning their understanding and perception of their experience of distress and its causes. They begin to consider alternative rationales and reasons to explain why they may be experiencing their mental and emotional distress, outside of the medical model they have been operating within. They begin to reject the medical model as objective fact.

This process endows them with a developing critical lens through which they may critique established social systems and institutions that they have not previously had reason to question in a broader sense, and they may begin to analyse their own place within these social systems and institutions. Recounting their encounter with a psychiatrist as they sought help for their distress, one respondent shone a light on this process in action.

This respondent, who is a survivor of childhood sexual abuse and incest, had seen psychotherapists and previously consulted with medical model practitioners in their search for services or interventions that worked for them. Accordingly, they had experience of the power imbalances that often come into play between the treating practitioner and the 'patient' seeking help, and how the practitioner can gatekeep access to care based on compliancy with and

adherence to the medical model by the 'patient' (Allsopp & Kinderman, 2021; Foucault, 1976, 1977, 1980; Handerer et al., 2022; Kinderman, 2014).

The encounter this respondent described shows that they were already engaging in the reflective critical cycle, and viewing the medical model through the lens of structural critique. Further, it demonstrates the comprehension of alternative causes of distress to the medical model of mental illness sited in the individual's lived experience and social life, such as trauma, which develops and is fostered by EBEs once they begin engaging in this reflexive process:

> I was denied care, because I wouldn't submit to a doctor. He made me feel very uncomfortable, very unsafe, and, and had no – he had no appreciation for where my trauma was coming from, that, you know, abusive men weren't really conducive to my mental wellbeing… Somebody who thought his first name was 'Doctor'. And I think I annoyed him because he just walked into the room and said, '[says only their first name]?', and I said, 'Yes';
>
> 'I'm Dr [surname]'.
>
> 'Oh, hello, [first name of doctor], it's nice to meet you'.
>
> Because my rule is that, you automatically assume that you can call me by my first name, then I would automatically assume that you're fine being called by your first name… [He] really did not like it, didn't like being addressed by his first name. And again, it's a power thing. But I was wise to all of that bullshit at that stage. I don't really know what you're trying to do. You're trying to tell me that you're the dominant person in the room? Because your first name was 'Doctor'?... it was like, you will do what you were told, and I will bend you to my will. And if you will not do what I tell you to do, then you will not get you won't get your own way. And it's like, I will break you one way or the other, you will not challenge me.

Another respondent, when considering their initial encounters of help-seeking within the medical model, further demonstrates the sense of alienation and isolation arising from the clash between what they believed they *should* be feeling according to the medical model and their treating doctor – namely, an improvement in their distress – and the fact that they were *not* feeling any improvement in their distress, despite taking their prescribed medications. They were, however, experiencing quite a few side effects from the strength of the medication they were prescribed.

This respondent applied for a role within a community programme operating for those who experience distress, and they were appointed to the position. This, for them, was the moment their perspective and outlook began to change. It is represented an important milestone for this respondent on their journey to becoming an EBE, one experienced universally by each EBE interviewed in their own unique way.

This is the milestone of finding, experiencing, and reconnecting with community, one that is all your own, which highlights the dejected alienation that trying to conform to the medical model caused for the individual who had been experiencing it. The individual may then feel a sense of belonging, and empower themselves through their experience of distress by actualising it and using their experience and knowledge as an asset, as this respondent did. This is demonstrative of the "experiential authority" described by Noorani (2013), and the "experiential knowledge" observed by Dings and Tekin in mental health practices where EBEs are employed (2023).

This respondent had sought to apply for this role in the community programme specifically because of their experience of distress. This facet of EBEs' individually professionalising their expertise and experience and utilising it is explored further on in this chapter as another of the key 'steps' on our journey.

Upon meeting and speaking with other people experiencing distress within the community programme, this respondent began to experience a reconnection with a sense of community that was all their own:

> And at the bottom of the advert, it said we would… encourage people with mental health issues to apply and at the time, I was on quite heavy medication. And I remember sleeping before the interview, getting up doing the interview. Can't really remember a lot of it because, you know, the way you're hazy when you're on drugs? Then going home, exhausted and back into bed, wrecked! And so, I managed to get it! But, it was around 2-10 [2010] when I started talking to people who attended [community programme], like, pieces started to come together, you know? Like, that this medical solution or this, you know, chemical imbalance, like was all you know, very – it could come apart.

This part of the process is one component of the next 'step' on the journey of becoming an EBE, where the individual begins to be exposed to alternative perspectives to the medical model of mental illness, either through intentional searching, as in my case, or through circumstance, as with the above respondent. The other component of the next 'step' is finding

your community and reconnecting with people in a way that feels honest and authentic for the individual, as opposed to the time spent feeling disconnected and out of place which preceded it for them. There is a sense of belonging that comes with community and relating with peers that is vital for any individual's mental health and well-being. The irony of it being taken away from the individual who is experiencing alienation within the medical model is stark. Belonging and community are not something any person should be deprived of, let alone something to be deprived of while being systematically gaslit into believing this deprivation is a by-product of the 'help' they are receiving, but which they are not responding well to.

Discovering alternatives to the medical model of mental illness and finding community interweave as processes to form the next 'step' on the journey of becoming an EBE. I will now explore how these processes manifested in the interviews.

DISCOVERING COMMUNITY AND ALTERNATIVES TO THE MEDICAL MODEL

The discovery or acceptance of alternative conceptualisations of and approaches to responding to mental and emotional distress outside of the medical model of mental illness was an important and highly influential factor in respondents' journeys managing their distress. Hearing different people discuss differing perspectives exploring the nature of and reasons for the human experience of distress also served to bolster respondents' confidence in the place their own reflective critical cycle existed to occupy, the fact that they were engaging in this cycle, and to inform this cycle. The existence of entire ideologies founded on principles that run contrary to, or that overtly challenge, the medical model's tenets, such as the social model (Oliver, 1983, 2004), serves to reify the need for such critiques to those who have already begun questioning the veracity of the medical model as a result of their own experience of it. Exposure to different conceptualisations looked different for each respondent.

It is worth noting that respondents did not state that they subscribed to one alternative ideology or perspective of distress, or believed in one specific theoretical model of mental health that they were exposed to in rejecting the biomedical model. However, out of the various existing conceptual models of mental health, the alternative perspectives and ideologies of mental health that respondents described to me could all best be classified as falling under the umbrella of the social model.

One respondent held a degree in psychology, a discipline in the same genus as psychiatry. They held an 'expert knowledge' in the area as a result (French & Raven, 1959). When their

experience with the psychiatric practitioners responding to their distress and suicidality was negative, due to power imbalances and a lack of connection between the respondent and the practitioner, the respondent already had a strong, germane intellectual knowledge base to draw on due to their legitimate expert knowledge (French & Raven, 1959; Weber, 1922).

This expert knowledge, along with previous lived experiences of power imbalances, imbued the respondent with the ability to contextualise their experience through the sociological lenses of patriarchy, cultural and religious insensitivity, dominance, and gendered medicalised beliefs regarding how distress manifested which were not true for the respondent experiencing them. This respondent continued to critique their future interactions with medical practitioners from this position of knowing, intellectually, that there were other 'versions' of what medical practitioners were telling them. The respondent could then use this intellectual knowledge to test the truth of what they were being told based on the new emotional, experiential knowledge (Dings & Tekin, 2023; Noorani, 2013) they were gathering from these experiences as they happened.

They could then accept or reject the psychiatric practitioners' interpretations of their distress, and their suggested interventions in it, based on their own comparative analysis of their 'expert', intellectual knowledge, and their experiential knowledge. They could discern from their intellectual knowledge that though it may have appeared hegemonic, objective, and factual, the medical model was only one theoretical approach to their distress. The respondent therefore knew they were correct to question what felt like it fit and what felt like it did not for them by comparing this intellectual knowledge against their newfound experiential knowledge going forward in their journey:

> I was disagreeing with him [the psychiatrist] about - he was saying that nobody wants to die, nobody wants to die – I said 'Well, I fucking do', and he said, 'No, that doesn't make sense'. And I said, 'I'm glad it doesn't make sense to *you* [their emphasis]. Because that means you're not in this place. And you have never felt so bad that that is what you have wanted for yourself, to actually just be dead'. I said, 'But I'm telling you that this is my reality'. And I was speaking like this [measured tone]. And I had a degree in psychology, and I *told* [their emphasis] him that I had a degree in psychology, just by way. And the fact that I was not, you know – this idea of, you know, 'But then once you're dead, it's over'… I said, 'No, no, no, because there's reincarnation. And… that is one of my core beliefs' – He didn't like that at all. He thought that was that was a form of madness; 'What

> are you even *talking* [their emphasis] about that? What are you talking about, 'you come back'?'…
>
> I said, 'The soul will come back to do whatever work it is the soul needs to do', I said, 'But *I* [their emphasis] need… a rest. All of it [physical body and soul] just needs a rest. You can't press pause. And I can't press pause. So, this is the only way to do it'. And I was logical, and I was calm. And this affronted him… he hasn't forgotten me…
>
> I was told by a psychiatrist that I had Borderline Personality Disorder, which I don't know about you, but I just think that's the greatest load of crock. I mean, it is it is the 20th century Hysteria, 'cause it's mainly women, and it is *always* [their emphasis] women with histories of trauma… I've written about that as well… I went through the DSM, and I said, 'These are the things that you *'have'* [their emphasis], these are the symptoms of Borderline Personality Disorder, and *these* [their emphasis] are the symptoms of trauma. Do you see where I'm going with this? It's the same fucking thing! [emphatically]'.
>
> But if we *medicalise* it [their emphasis], if we pathologise your normality, we can give you drugs for it, and we can *invent* new drugs for it [their emphasis], and we can make money out of it. Talking therapy? Yeah, not so much.

This excerpt is necessarily lengthy, as it comprehensively highlights and illustrates several key themes that arose in my analysis of the interviews at once. It demonstrates this respondent's reflective critical cycle in action. It also displays the EBE's intrinsic acknowledgment of their need to advocate for themselves and in some regards, to protest the narrative and perspective delivered by the medical model practitioner *within* the medical setting. It showcases their ability and drive to do just that; to advocate and protest, as well as their ability to provide their own, alternative understanding of what is happening for them, and to evidence the reasoning underpinning their understanding.

It also touches on core fundamental characteristics and personal motivators that drive the EBEs I spoke with. These are a strong intolerance for social inequity, social injustice, disparity of respect and esteem, and a motivating desire to use their own experience and unique individual abilities to confront, challenge, and insofar as possible, ameliorate these social ills where they encounter them.

The impact that learning of alternative or contrary perspectives to distress than that posited by the medical model had on respondents was illustrated very starkly in one respondent's case. Their understanding and experience of their own distress and hearing voices changed in a way that affected their entire life upon being exposed to ideas about them that were different and

new to them. Their discovery of different conceptualisations of what distress is or could be, what affects it, and what different factors aside from biomedical ones might contribute to it, was so impactful that it entirely changed their beliefs around their own and others' distress.

When this respondent first began accessing mental health services, they were treated by psychiatrists operating using the medical model. The respondent accepted the medical model as fact, as it was all that was presented to them. Its ideological power, hegemony, and its normalised exercise of power-knowledge are evident in this (Foucault, 1977, 1980; Gramsci, 1971; Lukes, 2005). This respondent had experiences of hearing voices, as well as experiences of mental and emotional distress.

They explained that the psychiatrists they had seen over the seven years preceding their discovery of alternative models had never informed them of their diagnosis, which was Schizophrenia. The respondent only gained contextual insight into their experience, and received some conceptual frameworks to place their experience within when they met other EBEs for the first time.

This individual had been heavily medicated and compliant with their psychiatrists' treatments. They attempted to reconcile, understand, and site their experiences within the medicalised setting and framework they were being treated in. But their treating psychiatrists had never given them the diagnosis they had decided upon, making this attempt at reconciliation even more difficult for the respondent. This again demonstrates the internal alienation from the self that the medical model of mental illness can cause, by othering individuals from their own experience and understanding. The psychiatrists gatekept all information about their understanding of the respondent's 'illness' from them.

The psychiatrist who had diagnosed this respondent with Schizophrenia upon their entry to the hospital did, however, share their diagnosis with their mother at the outset. The respondent was a fully grown, legal adult at the time of diagnosis. This is an example of how disempowering and paternalistic the biomedical model can be. It reflects the respect and open-mindedness my sister was met with when communicating her concerns and frustration about my treatment to my assessing psychiatrist, described in 'Chapter Five'. By virtue of being 'sane', the family members of those with lived experiences of distress are often treated with the respect we are denied, as we are perceived as 'less than' them (Corrigan & Watson, 2002: 16-20; Malla et al., 2015).

This respondent's experience of receiving treatment further shows the painful infantilisation and disregard for their rights and consent that typified their treatment. The respondent experienced the internal alienation described earlier in this chapter as a result of this, combined with stigma and alienation coming from within their rural community. This demonstrates just how real the effects of stigma against those who experience distress noted in the literature can be (Corrigan, 1998; Corrigan et al., 2012; Corrigan & Rao, 2012; Del Rosal et al., 2021; Link et al., 2004; Pescosolido, 2013). The treatment of this respondent by their community became so negative and harmful that the respondent moved away from their hometown:

> … it was very hard from – about [period up until] the hospitalisation, was tough. They [psychiatrists] put me on Chlorpromazine [a typical antipsychotic], all the heavy stuff, the old stuff, the Haloperidol [a typical antipsychotic]. They gave me ECT [electro-convulsive therapy]… very heavy treatments. They threw the book at me, basically. They gave me everything that they could - that they were allowed to give me… I was out of it on Chlorpromazine or whatever, it's just like – in a black hole, that stuff.
>
> And as far as I can remember, they gave me – they put a form in front of me [to consent to hospitalisation and treatment], and he just asked me to sign, *they never even told me what it was*… It wasn't informed consent, no… I was in hospital for five months… It was a pretty horrendous experience… I had a long period of very tough recovery [from the treatments and their physical impact] for 10 years… I knew nothing about what I'd gone through. They told me absolutely nothing. They told my mother the first day I went in to the hospital… your son has Schizophrenia – I hate that word personally… it's just, like, just morbid with terror, you know?... they [psychiatrists] didn't tell me anything, and I was living at home first, and it was tough, because we were getting a lot of abuse… I did get beaten up a couple of times, but I also got a lot of, kind of, emotional abuse, you know? Like people like, you know, they thought it was really… 'mess with the dangerous', you know, 'the dangerous lunatic' sort of idea… so I eventually moved out of the village. – [Emphasis added]

The respondent knew nothing about their diagnosis, the nature of the strong medications they had been prescribed, the intended effects of these medications on their 'illness', or the potential side effects of these medications. They continued to live without any meaningful theoretical framework or ideology to conceptualise their experience over the next seven years. They learned of a conference taking place in a national university in the early 2000s which was being hosted by academics and activists who were critical of the medical model of mental illness, and they decided to attend.

The effect that attending this event had on the respondent was profound. Up until this point, they had been fully submerged in the language of the medical model, yet not able to use it to speak about their own experiences due to their treating psychiatrists' gatekeeping their diagnosis and information from them. Upon attending this conference, they felt like they finally understood their experience within the broader context of those who experience distress. They met other 'mad' people, and with that came a sense of community and camaraderie that they had been missing since their experience of distress began.

> … [names mental health advocacy group] had – they were just forming at the time – it was the beginning of, kind of like, mad activism, around the Millennium, and eight different people – [academics from Irish university] and people, different people [names figures in the field of mad activism]. So, I went to the Conference in [year], and that was a Eureka moment. Like, it was in a room full of people like me. And they were saying, 'These are the conditions. This is the medication they use', they just were chatting all about mental health. And that was the beginning of my journey to recovery.

Seven years of purely medicalised psychiatric treatment had not improved this respondent's mental or emotional distress. It had deepened it, as they had experienced the painful metaphysical alienation and isolation from the self as a result of biomedical treatment, and their physical alienation and isolation from their community that came from stigma (Corrigan, 1998; Corrigan et al., 2012; Corrigan & Rao, 2012; Del Rosal et al., 2021; Link et al., 2004; Pescosolido, 2013).

Meeting with peers who could relate to their experience, and could share their own, all while discussing their experiences from different theoretical perspectives for the first time, however, immediately gave them a sense of understanding and hope. The information shared freely at the Conference also endowed this respondent with the language of the medical model that had been gatekept from them for so long. These things – the sharing of experiences and perspectives with peers, learning different ideologies outside of the hegemonic around a subject area, and enjoying a sense of community are intensely powerful:

> That was a eureka – that was like, 'BANG!', you know? 'This is it!', like. 'This is what I'm going through', like. 'This is a whole thing... wow, this is just like, fucking amazing!', like, you know?... It was just amazing to have that, to be at that conference. So I just felt a belonging, you know?

As the respondent notes, encountering peers, different ideologies, and feeling a sense of community started their journey to recovery, understood from the perspective of the social

model. The concept of recovery as understood in this way is discussed in ‘Chapter Two’ and ‘Chapter Three’ (Pilgrim, 2008; Ragins & Sunkel, 2023; Ridgway, 2001; Secker et al., 2002).

It could also be argued that these things this respondent and the other EBEs I spoke with noted as crucial in their recovery – sharing similar life experiences, different ideas and ideologies, and exchanging knowledge while building community with peers – are simple things. Things that those in the social majority might not be given reason to stop and consider at all, unless they were to be deprived of the ability to engage in them freely, as myself and respondents were.

It is interesting, therefore, that something that is so commonplace for the social majority – the free sharing of ideas and experiences with others – can be, as it was in this respondent’s case, not encouraged, or even gatekept and withheld by those exercising power-knowledge over them within the hegemonic, socially accepted biomedical institution which exists to exert biopower over the individuals who it isolates (Foucault, 1965, 1976). This gatekeeping and withholding of information from individuals by those exercising biopower over them to control and maintain their hegemonic power-knowledge reflects Lukes’ observation that “The most effective and insidious form of power is to prevent… conflict from arising in the first place” (2005: 27).

One respondent had a more positive relationship with their treating psychiatrists and psychiatric nurses over the years they were receiving treatment than the other respondents did. The psychiatric practitioners had been respectful and accommodating of the respondent’s insights and preferences. Their treatment plan had, however, solely consisted of medications. During one hospitalisation, they described being on so many medications at once that they considered themselves a “polypharmacy”.

When the psychiatrists wished to introduce another medication to the respondent’s existing regiment, the respondent decided they did not wish to continue on this treatment plan any longer. This decision was respected by the treating medical practitioners. The respondent was referred to a rehabilitation centre at the end of their hospitalisation to discontinue their medications safely, as they were taking so many of them. The respondent had learned from their experience while seeking out help to ameliorate their distress over the years that these medications, which were the only treatment that had been made available to them, did not work for them.

They decided to seek out and try alternatives to medications. In doing so, the respondent discovered a local community programme catering to people who experience distress. After years of trialling different medications, they found that this was the first thing that ameliorated their distress:

> What helped was… when I joined that – so the first program was [names community programme and location], and that's [a] walking, talking, listening, you know, group?... it's a place you go – you have your tea, toast, whatever – coffee. There's a different walk… then there will be an afternoon session – one hour session. So that could be mindfulness. It could be a diary. It could be – it's always group activities, could be art therapy… But, being in there, I came across people... who were at different places in their recovery? And, people weren't medicated, people who were living with distress and wanted to accept their distress and wanted to *tolerate* [their emphasis] their distress so that they didn't have to take medicine. So I got ideas from that. And I got ideas for those groups and from mindfulness and some talks about the unhealthiness [sic] of medication and, maybe, more alternative ways of doing things and stuff and nutrition. We have nutritionists come in to talk about nutrition and, you know, how the gut relates to the mind. So you know, things like *that* [their emphasis], that's when I started to get an awareness of that – that's when I started to *learn* [their emphasis] about mental health.

This experience of finding a sense of community, or finding 'your people', so to speak, is another defining characteristic of the journey taken by the EBEs I spoke with during my data collection. The experiences described by respondents in the interviews reflect Ragins four faces of recovery from 'mental illness' from a social model perspective, which community is innately a part of (Ragins & Sunkel, 2023). This specific point in respondents' experiences, when they begin to find peers and community, corresponds with Ragins' first face of hope, and his second face of empowerment. Crucially, it correlates to Ragins' observation that during the empowerment stage of recovery, individuals may require the belief and encouragement of others. There is a mutuality to EBEs' recovery in this regard.

It is through this community, and the networks that form between us, that we garner an invaluable sense of belonging, of worth, and of empathy. It is also through this community and network that we engage in knowledge-sharing and knowledge-formulation of our subjugated knowledges. We exchange ideas, and share knowledge with each other rapaciously, which further develops and expands each of our own individual expertise. It is an example of the way many minoritised communities share their subjugated knowledges with each other outside of the dominant power-knowledge (Aparicio & Blaser, 2008; Parker, 2009; Nicholls et al., 2011).

This aspect of being an EBE – the compiling of our subjugated, communal knowledges and resources which we can all draw from – is integral to the role, and to our own wellbeing. It can be a component of our recovery, which one respondent noted in considering what they have benefited from in managing their distress:

> It helps to know exchange of knowledge and experiences. That experience [exchanging knowledge and experience] became a part of my experience in recovery, you know, being around people – people's lived experience – informal; it was all very informal, of course…. It was like, getting to know about mental health. Taking some of the mystery out of the stuff that was happening to me, and seeing that other people – being around other people who had it [distress] made me realise it's not just me. These are the type of things that help more than any kind of medicine could possibly – for me, and in my experience, you know? It was that being around peers and, and actually having some space to recover, and the time.

This 'step' of EBEs discovering alternatives to the medical model of mental illness, rejecting it as an ideology along with much of its practices, shedding their sense of isolation and alienation upon (re)discovering community with peers who inform each other's recovery and expertise, is the penultimate 'step' that emerged unilaterally across the collected data.

The next and final 'step' on the journey to becoming an EBE that emerged from the data was the EBEs' individual professionalisation of their experience. This 'step' encompasses the way in which the EBEs I spoke with were so motivated and shaped by the impact their journey has had on them that they decided to pursue careers or educations pertaining to it. All of the EBEs I spoke with have undergone or are continuously undergoing individual professionalisation in order to do what they can at an individual and a collective level to help others who experience distress, and to attempt to challenge and alter the systems and institutions that they found harmful. I include myself amongst them in this experience. Individual professionalisation is the final 'step' on the journey to becoming an EBE as it emerged in my thematic analysis.

INDIVIDUAL PROFESSIONALISATION OF EXPERIENCE

The concept of 'professionalisation'/'professionalization' exists in the literature (Evetts, 1999; Fournier, 1999; Gough & Neary, 2021; Reed et al., 2019; Stone-Johnston, 2014; Weeks, 1988). In this literature, the concept describes the processes by which a whole discipline or field of work, such as accountancy (Dyball et al., 2007), or academic administration (Gornitzka &

Larsen, 2004), itself becomes a legitimate profession, with barriers to entry and bespoke accreditations for those who wish to be considered a professional within it.

'Individual professionalisation'/'professionalisation', on the other hand, are terms I use in this research to describe the 'step' respondents took to pursue careers influenced by their lived experience of distress and the varied treatments and interventions they encountered in help-seeking. In this sense, individual professionalisation differs from professionalisation as it is currently conceptualised in the literature. Individual professionalisation describes how a person chooses to professionalise their lived experience by marrying their own unique, individual talents and strengths with their experience to inform their professional careers and life paths. It is professionalisation on the micro, personal level, rather than professionalisation at the macro, structural level, which 'professionalisation'/'professionalization' usually refers to in the literature.

Individual professionalisation is not limited to one discipline or field of work, but rather is unique to each individual, sited within their own experience and expertise. Individual professionalisation describes how an individual with lived experiential knowledge (Dings & Tekin, 2023; Noorani, 2013) is aware, using their critical reflective cycle, and driven, through a myriad of factors, including their desire to challenge social injustices, that to make changes to the structures of power-knowledge and biopower in place, they must acquire the necessary accreditation and qualifications to operate within those spaces. This represents the EBE's understanding of and appreciation for the legitimate authority granted to those who hold a traditionally recognised expert knowledge (French & Raven, 1959; Weber, 1922). This expert knowledge can be developed and utilised to complement and further the function of the individual's experiential authority (Noorani, 2013) and experiential knowledge (Dings & Tekin, 2023) in their endeavours.

The career each respondent pursued was unique to them. They ranged from academic, public, private, and community careers. Their career choices were influenced by what had impacted and motivated the respondents the most from their lived experience, and what they took from it.

In this way, individual professionalisation is a deeply personal experience. It reflects the EBE's internal experience and history of becoming an expert in their distress, while also reflecting factors such as social class, education, urban/rural background, gender identity, age, and sexuality which influenced each EBE's unique experience(s) and their treatment by those

exercising power-knowledge over them. Vicariously, the different fields the respondents chose to pursue reflects which of these factors may have impacted them the most strongly during their own help-seeking and receipt of interventions – both helpful and harmful. A significant motivator for respondents' desire to individually professionalise was finding a productive outlet for their righteous anger arising from their own negative experience of help-seeking through the biomedical model. One respondent noted:

> I was very angry [about their experience in the mental health services], I suppose. So, anger would have been my main thing, you know, for years. Very angry at, just, how things – the way this [their treatment] had happened. So like, I suppose, getting past that anger and turning it 'round and working in services … that's when things started to change.

Three respondents have held or currently do hold positions within the public mental health services or private mental health sector. Of these three, one is an accredited peer support worker who works privately in his community, but not for profit. One is an occupational therapist (OT) within the mental health services. One is a worker in a community mental health project which receives governmental funding.

Each of the five total respondents, as well as myself, is educated to at least master's degree level. The discipline each respondent holds their master's degree in relates directly to their lived experience and their interests pertaining to it. They range from law to community and youth work, and psychology. Two of the respondents I spoke with, along with myself, were pursuing PhDs to further their individual professionalisation and to upskill. Each of us doing so is researching an area in a discipline that is directly related to or inspired by our expertise by experience, and the careers we have already built in our processes of individual professionalisation.

This is not an exhaustive list of the many roles each respondent EBE occupies, or their accreditations. One is also a lecturer in a national university, among other roles they are actively engaged with around their expertise by experience. They hold this position in a school that teaches about the concept of recovery in mental health, and the different ideologies and problematisations which exist around it. This includes the concept of recovery as understood through the lens of the social model of mental health (Pilgrim, 2008; Ragins & Sunkel, 2023; Ridgway, 2001). Some of these ideologies and their problematisations are discussed in 'Chapter Two' and 'Chapter Three' of the current research. This academic position is one the

respondent was approached to apply for specifically because of their expertise, both professional and experiential, in the area.

The process of individual professionalisation is an important aspect of becoming an EBE, as it represents a fundamental counter-argument and challenge to those who conceive of EBEs' knowledges as '*less than*' compared to the knowledges held by traditional experts who are perceived as legitimate, as they hold a recognised 'expert knowledge' (French & Raven, 1959; Lukes, 2005), which enables them to exercise power-knowledge. Foucault notes that this relegation of subjugated knowledges, such as those held by EBEs, is done by those exercising hegemonic power-knowledge on the basis that such subjugated knowledges fall "beneath the required level of cognition or scientificity" (Foucault, 1980: 82). As EBEs individually professionalise and attain an 'expert knowledge' (French & Raven, 1959) which holds legitimacy to complement their experiential expertise (Dings & Tekin, 2023; Noorani, 2013), the position held by those exercising power-knowledge and upholding hegemony that EBEs are '*less than*' in this way is no longer legitimate itself.

The arguments which suggest affording EBEs less legitimacy than traditional 'experts', put forward by those *in* the majority, where the traditional 'experts' are, is It is a form of gate-keeping undertaken by those operating as 'experts' through exercises of biopower and power-knowledge to protect their ideological and institutional hegemony (Foucault, 1963, 1965, 1976, 1977, 1980, 2019) This argument and ideological position are inherently disproven, and their underlying presuppositions and biases against those who have experienced distress recognised, by the process of individual professionalisation and by those who engage in it.

This is because EBEs are not *only* experts in the capacity of their own lived experience which grants them a unique experiential expertise. By pursuing and attaining qualifications and accreditations, they also become 'experts' in the traditional, legitimate sense (French & Raven, 1959; Lukes, 2005; Weber, 1922). They become 'experts' in the same way and through the same recognised channels as those 'experts' exercising power-knowledge within hegemonic institutions who consider EBEs as holding a lesser, experiential expertise (Foucault, 1980). By undergoing individual professionalisation, EBEs could be said to be *more* qualified, and as operating with more legitimacy in the roles they occupy in many instances than those qualified solely as traditional 'experts' (Dings & Tekin, 2023). This is because EBEs hold a dual expertise: a traditional, professional expertise, the same as those held by the legitimised 'experts' (French & Raven, 1959; Weber, 1922), and a lived, experiential expertise that cannot

be taught or learned without first-hand experience (Noorani, 2013; Dings & Tekin, 2023). One respondent, who is both an accredited professional in trauma-informed practice and an EBE, described the feedback they received from participants in training they provide to service-providers as a professional with an expert authority and experiential authority. Their example demonstrates the strength of this dual expertise:

> I know that when I'm giving training… I gave training in trauma-informed practice to the entire staff of a [service for victims of violence]… the whole lot [entire multidisciplinary team], you know what I mean? From the clinics to the – everyone had to do this training with me. And I was kind of going, 'That's a broad audience'… and the feedback again, was that the bits that stuck with them, and the bits that made most impact, were when I spoke about my own experiences of domestic violence.

EBEs are conscious of the subjugating biases and underlying presuppositions entrenched in the hegemonic social institutions and academic spaces where they undertake their individual professionalisation. They are equally aware that these biases and presuppositions are held and reproduced in the exercise of power-knowledge by solely traditional 'experts' without experiential expertise within them.

In the instances where respondents individually professionalised to work in the public and health sectors, they were working directly with and within these hegemonic institutions and, sometimes, working with the very individuals who had imposed a power imbalance and exercised the power-knowledge and biopower over them that they had found harmful. EBEs are acutely aware that they must attain these accreditations and qualifications to claim to be 'experts' equal to the solely traditional 'experts' already exercising power-knowledge in these institutions (Foucault, 1980; French & Raven, 1959; Weber, 1922). The power-knowledge exercised by the solely traditional experts conflicts with the subjugated knowledge(s) held by the EBEs, which the EBEs wish to introduce to these hegemonic institutions in their efforts to challenge or change aspects of them. EBEs are motivated in part to purse qualifications and engage in individual professionalisation to offset and challenge their subjugation within these institutions, and to negate the position that they do not hold the necessary expertise for their inclusion in the spaces they wish to occupy in mental health policy and practice (Foucault, 1980).

One respondent recounted how they and a colleague of theirs with lived experience debate this point, while also showing their motivation and awareness of the need to continue their own

individual professionalisation to strengthen their expert knowledge in areas they wish to develop:

> Myself and [names colleague] argue on this. And we [they and their colleague] argued in an interview panel… he was like, you know, 'What is it about the lived experience role that you're applying for?'. Like, 'Why is it important?'. And I'm going, 'It's important, but you need other stuff [qualifications] as well!'. And he's like, '… there is an importance on that lived experience on its own without the other [other qualifications for role]. And like, I could see now where he was coming from, but at the time, I was going, 'Sure there's feckin' no way you'd survive in a lived experience role *unless* [their emphasis] you've got other skills as well!', you know? 'You'll just be seen as, you know, less than and already magnifying what's, you know, people think'… [reflecting on areas they would personally like to develop] human rights is kind of something I really need to kind of, you know, get more of a handle on – language around disability, I suppose, would be a big one, you know; power-literate; evidence-based policy – all of those kinds of things like are important, you know? Calling out injustices. You know, like, it's a skill.

This aspect of the motivation that EBEs have to begin the process of professionalisation is demonstrative of their reflective critical cycle, and their defining characteristic of wishing to challenge social injustice. Their cognisance of the means through which they have been/are being subjugated by social institutions, and their knowledge that this subjugation may be used as a barrier to delegitimise their efforts to challenge these social institutions, displays an innate awareness on their behalf of othering, social capital, and the importance of labels such as 'mentally ill', or 'expert' and the function they play in abnormalising and legitimising or delegitimising individuals from the exercise of power-knowledge (Foucault, 1977, 1980; May, 2006; Visoka and Lemay-Hébert, 2022).

Utilising their reflective critical cycle, EBEs discern that though they are already 'experts' in a way that is different to traditional 'experts', they must undergo further training or education to thoroughly legitimise their claim to the title of 'expert', and to do the work they wish to do. This makes the process of individual professionalisation a radical act in some ways, as it is an acknowledgement of and challenge to the social injustice and minoritisation which hegemonic power-knowledge engenders through the process of normalisation (Crehan, 2016; Foucault, 2019). As May (2006) observes, acknowledging normalisation and the distinct hegemonic power-knowledge being exercised enables people to recognise that that which is hegemonic is not static. It is constructed, historically-contingent, and pliable, as power-knowledge is

constantly socially (re)produced (Foucault, 1977, 1980). Those with subjugated knowledges, in this case EBEs, can influence the (re)production of power-knowledge by exploring other ways society and its hegemonic practices can be, "through the construction of new practices" (May, 2006: 83). By engaging in individual professionalisation and introducing different practices to institutions, respondent EBEs are challenging the hegemony that they are built upon (Gramsci, 1971).

While discussing their trajectory into individually professionalising, one respondent demonstrated this awareness of injustice, both personal and systemic, which is characteristic of EBEs. They highlighted how the act of upskilling and working in the mental health services as a qualified OT and specialist peer group facilitator has been something they have needed to stick with, despite initially facing systemic barriers to their inclusion. Their individual professionalisation has also provided them with a productive means of processing their righteous anger around their lived experience:

> I was volunteering for voices groups [peer groups for those who hear voices] at the start of the voices groups, like, I think around 2007 or 2008. And I volunteered for that. I met [names individual], the OT Manager here… And she brought me in to the Programme… I had to work for 2 years for free while we figured out how to get me paid, but I was getting bits and bobs from comfort funds and stuff like that. I really wanted to get into the mental health service, because I was angry. I said, part of our thing with [names prominent mad rights activist] and various people was like, 'We're gonna change this from within. We're gonna get into the service and change it from within'. And I was like, 'Yeah, I'm gonna do that'… and I was banging my head off a wall for years, but I eventually got the door open. Somebody opened the door for me. It'd be difficult for them to move me now! [laughing]

Some of the EBEs I spoke with also found the process of attaining their qualifications empowering, noting the process to be an aspect of their recovery. This is indicative of Ragins' second face of recovery from 'mental illness' mentioned above, which is empowerment (Ragins & Sunkel, 2023). Ragins' four faces of recovery are discussed in 'Chapter Two'. I myself have found my own individual professionalisation to be empowering.

My individual professionalisation began when, using my reflective critical cycle, I utilised the skills and the outlet I had at my disposal to research the Irish psychiatric services as an example of medicalisation for my undergraduate dissertation. This was within a year of my exit from the psychiatric services in 2012. At this time, I was invited to become a consultant for Amnesty

International, Ireland as a member of their Mental Health Expert By Experience Advisory Group (EEAG). The EEAG steered Amnesty International, Ireland's mental health campaign. We also produced reports and feedback for government concerning legislation being drafted at the time – primarily, *The Assisted Decision-Making (Capacity) Act 2015*, (Government of Ireland, 2015). From here, I began working as a Policy Intern for Mental Health Reform (MHR), Ireland's mental health coalition.

Engaging with my reflective critical cycle, I then reasoned that, alongside my activism, my knowledge of and work with social policy represented the area where I could do the most good as an EBE at that time. As such, I pursued an MSocSc in Social Science (Rights & Social Policy) to gain the accreditation necessary to work as an EBE in the way I thought I could be most useful, bolstered with the traditional 'expert authority' the accreditation would provide me with in the policy arena. My Master's dissertation presented another opportunity for me to produce work from my EBE perspective in attaining another qualification with a legitimate, 'expert' authority (French & Raven, 1959; Lukes, 2005; Weber, 1922). In this instance, I researched the Government of Ireland's mental health strategy, *A Vision for Change* (2006), which was active from 2006-2020. I was also appointed to Tusla's Independent Research Ethics Committee (REC) as its mental health expert in 2020. The REC reviews all ethical applications for research involving children and young people that are submitted to Tusla for approval. I also speak publicly about my experiences of medicalisation, and have been the subject of a long-form interview documentary about my experience. Lastly, undertaking this research and pursuing a doctoral qualification constitutes another aspect of my professionalisation.

A primary motivator for EBEs pursuing careers in their chosen areas was to do what was in their individual power to improve their particular area for other people experiencing distress. The desire to make things better and improve outcomes for others based on the knowledge the respondents gleaned first-hand from what they had found harmful or unhelpful when seeking help for their own distress inspired each EBE I spoke with to pursue their unique careers. Speaking about what motivates them, one respondent stated:

> But for people who have no fucking *idea* [their emphasis] what it's like to self-harm, or to be abused, or to hate yourself, or to want to die, or any of these; for people who don't have these experiences, through the way that I write, and the way that I speak about them, get an understanding of that, and kind of, 'Okay: *now* [their emphasis] I see why they

> need X, Y, and Z; *why* [their emphasis] they need other support; *why* [their emphasis] medication isn't good enough'.
>
> So that is what transforms me, from somebody who'd had had a really shit time of it, into somebody who'd had a really shit time of it, but was suddenly described as an expert, because I was able to, and *willing* [their emphasis] to discuss my experiences… and therefore… I could perhaps help other people because it *does* [their emphasis] come back to that. I decided – or realized – many, many years ago, that what I wanted to be when I grew up, what I wanted for myself, was that I would be the most useful person that I could be. And that is my goal in life – it has been for about 25 years.
>
> I *just* [their emphasis] want to be the most useful person I can be. And if me having a chat with you right now is going to be useful to you, or to somebody else, then great: let's do that. If me talking to a bunch of students in [names country], which I'm doing… about how to compose an ad campaign to raise awareness in the community around child sexual abuse, and talking about that, as somebody who has been abused, if that's helpful, great: I want to do that. [They describe a national awareness piece they participated in that involved them being photographed] But you know, because I was interviewed about [subject of photograph], and I spoke about how it was a response to self-harm… I thought, 'If somebody else reads that and understands their own pain, then good. I've been useful.'

The final aspect of EBEs' individual professionalisation that emerged from the data analysis was EBEs' own ideas and concerns around the concept and functional role of the 'Expert By Experience' itself. This aspect is a meta example of the reflective critical cycle which EBEs engage in, as respondents were considering the underlying principles and requirements that they thought could be necessary to underpin any actionable definition for an EBE stakeholder sphere on the collective level. Respondents shared interesting perspectives on what they felt differentiates a service-user, or a person with lived experience, from an 'Expert By Experience'. The concept of the 'Expert By Experience' as theorised in the literature, and the difference between a service-user and an 'Expert By Experience' is explored in 'Chapter Two'.

One respondent engaged in their own comprehensive consideration of this differentiation while we spoke, and described how the category of 'Expert By Experience' can itself be further divided into two camps. The first camp this respondent described is composed of EBEs with lived experience who have *not* undergone any individual professionalisation. This first camp more closely approximates the 'Expert By Experience' as conceptualised in much of the existing literature analysing the need for EBE inclusion, which largely conceptualises the 'Expert By Experience' solely in terms of their experiential expertise (Beresford, 2002, 2007,

2010, 2012; Dings & Tekin, 2023; Noorani, 2013; Tew et al., 2004). This literature is explored in 'Chapter Two'. The second camp this respondent outlined, which they felt is different from the first, is defined by the additional expertise afforded to its EBEs by the process of individual professionalisation they have engaged in. This second camp of EBE describes each respondent I spoke with who participated in this research. The respondent noted:

> … I do have to say that that my further definition of an Expert By Experience is – an expert [is] somebody who is experienced, and an expert *only* [their emphasis] in their own experience. And I think that that is a subtle, but important, designation to make. Because more and more, I find as the social sciences – and *rightly* [their emphasis] so – embrace the notion of the Expert By Experience, and welcome the voices of Experts By Experience, I think that we need to realise that those experts are still only experts in their own experience, unless and until they have other training or other ways of knowing that they can talk about...
>
> … 'Parity of esteem'; I think it's a lovely term, but I don't know if Experts By Experience should have the same parity of experience who have – [describing who they are defining] 'Experts By Experience, *and also* [their emphasis] training in'. I think that you and I, as Experts By Experience, but who also have *training* [their emphasis], [who are] researchers who have degrees in the social sciences, with full awareness of different models, I think… our expertise is more than *just* [their emphasis] being an Expert By Experience. *We are both.* – [Emphasis added where not otherwise stated]

A belief that was common amongst all respondents was the existence of limitations around the role of 'Expert By Experience' itself. Perhaps reflecting their negative experiences when initially seeking help and engaging with a medical system and model which purported to be definitive in explaining distress, respondents shared the sentiment that they are each individually experts in their *own* experience, and not experts in other people's. There is a need for a collective EBE stakeholder sphere which would provide consistency to the expertise EBEs offer:

> [Without] progress[ing] beyond your own experience, Experts By Experience are only experts in their *own* [their emphasis] experience. And their own experiences are absolutely valid, and… we can learn from them. But in terms of policymaking or policy changing… We need to take cumulative experiences. We can't change policy based on one person's experience. The same way that you don't make case law based on one, one person's experience, you know? That's not how it works.

One respondent recounted their internal conflict in accepting the title of 'Expert By Experience':

> "I really rejected it for about... four years? And the only way I could say it is that I'm an expert of my own experience."

Each respondent I spoke with had occupied the role of 'Expert By Experience' and had been practising in their professional roles for many years. This gave the respondents a lot of first-hand experience of how EBEs, even when they are individually professionalised as they all were, are treated by and compared against other solely traditional 'experts' who are perceived to exercise legitimate authority through hegemonic power-knowledge (French & Raven, 1959; Lukes, 2005; Weber, 1922). Respondents' experiences indicated that they were treated differently to, and with less professional courtesy than, their traditional legitimate peers who do not possess expertise by experience.

Respondents' experiences indicate that, over the past decade or more in Ireland, the concept of 'Expert By Experience' has gained social capital and esteem in hegemonic social institutions that are involved in providing treatment and interventions to those in distress, and academic institutions involved in the training or teaching of traditional 'experts' who work in areas relating to mental health. These institutions exercise significant power-knowledge in informing and (re)producing the ideologies and practices of other hegemonic institutions where power-knowledge and biopower are exercised on individuals, such as the mental health services, as well as in social policy formulation.

The esteem coming from hegemonic social and academic institutions has expanded as far as recognising the worth that those with lived experience *of* these institutions have, which they can provide by speaking about their lived experience in spaces they are invited to *by* those within these same institutions. This esteem has not usually, as respondents noted, expanded beyond this recognition to EBEs being adequately and equally respected or compensated for their work, time, or expertise *by* those institutions or those seeking their input. This type of engagement that EBEs described is an example of Pilgrim's (2005) concept of the consumerist form of service-user involvement. In instances such as this, service-user involvement is "in the gift" (2005: 25) of those inviting participation from EBEs, meaning it has an inherent power imbalance, and is not collaborative. This inclusion can be revoked by those granting it, and it is not guaranteed. It has similarities with Beresford's conceptualisation of "co-opted" service-

user involvement (Beresford, 2002). These conceptualisations of service-user involvement are discussed in 'Chapter Three'.

Respondents noted that this form of inclusion is exploitative, and reifying of the injustices they had felt throughout their journey to becoming and being an individually professionalised EBE. Particularly to those who are new to the field:

> And not every Expert By Experience is minded well enough; I think there is an Expert By Experience exploitation. Because… when we are first given a platform – and I'm not going to say 'given a voice', because we all have fucking voices [emphatically]. Whether or not they are *heard* [their emphasis] is the problem. It is not being heard [that] is the problem. Not being *amplified* [their emphasis] is the problem. Not having a platform is the problem.
>
> So, when you start using your voice, when your voice is no longer suppressed, when you become familiar and comfortable with the words coming out of your own mouth, and going, 'This is my experience, and I'm owning it'… suddenly, somebody is listening. And I think that that happened to our [Ireland's] Experts By Experience: [names prominent mental health organisation], or the HSE, or the – whoever it is – ring you up and say 'Would you go on [names national TV show], and will you talk to so-and-so, and we'll buy you a sandwich after?', And they go, 'Oh my God, that'd be great. I'm going to be on the telly!', or 'I'm going to be on the radio!'. And they tell [about their own experiences], and they give – and they give too much [of themselves]

There was a sense amongst respondents that EBEs who have individually professionalised and are working in their given area should have security in their work, and be properly acknowledged as 'experts' and respected in the same manner as traditionally-recognised legitimate 'experts' with 'expert knowledge' (French & Raven, 1959). Otherwise, respondents found the calls for our expertise by these social and academic institutions to be somewhat insulting, as they acknowledge our worth and request our input, but in a way that suggests that asking for this input is inclusion enough. This once again reflects Pilgrim's concept of "the gift" of service-user inclusion which is given to us, rather than a right to inclusion inherent to us (Pilgrim, 2005).

To respondents, this indicated that these hegemonic institutions believe that EBEs should be grateful just to be included, and that the institutions view themselves as progressive for facilitating this limited, 'gifted' form of co-opted inclusion (Beresford, 2002; Pilgrim, 2005). This form of inclusion is tokenistic, as it reifies the injustices these very institutions have

wrought on minoritised people, and which they have facilitated through the normalisation and instruction of models of intervention, including the biomedical model, which have become hegemonic. These institutions, notably those practicing the biomedical model of mental illness in the current research, have proceeded to exercise power-knowledge and biopower over us which has othered, alienated, and harmed us; the experience of which they are now seeking our firsthand perspectives of through this 'gifted' inclusion. Respondents expressed that it is not enough. I count myself among the respondents in this belief.

It exploits the EBE's desire to help others, the sense of fulfilment that they receive in doing so, and their want to have their experience and expertise heard. It assumes that these institutions are egalitarian for including EBEs in *their* institutional discussions about what they *should do with them* (EBEs). This is done rather than asking the EBEs themselves what the people exercising power-knowledge in these *institutions* should do or could do for them, if anything at all, and letting *them* decide from their own base of both legitimate traditional expertise (French & Raven, 1959; Lukes, 2005; Weber, 1922). and experiential expertise (Dings & Tekin, 2023; Noorani, 2013). This echoes the work of Beresford (2002), Noorani (2013), and Pilgrim, (2005) amongst other key thinkers in this research area. Their work is discussed in 'Chapter Two' and 'Chapter Three'. One respondent eloquently captured the problem with this form of inclusion, and the exploitative nature it takes:

> [In our roles] As researchers and as academics, nobody ever tells us we're brave… But I think that sometimes, that can be part of the attraction, that somebody's going 'God, you're very brave to tell your story'… and 'They're very courageous', and 'Thank you so much for being so brave'. Because that's all you're getting out of it… you know, because 'Well, we can't pay you because you're not, you're not qualified!' Because [the assumption is] you'll do this, and you'll do this, for the joy of it. And for the helping of it. And people get sucked into that, you know? I mean, there are charities all over the country, that – that are run by well-meaning volunteers who support themselves [financially].

Another respondent echoed these sentiments alongside their own analysis of the broader socio-political context and nature of the 'Expert By Experience' from their perspective. In doing so, they also indirectly reflect upon the role of ideological and institutional hegemony (Gramsci, 1971), power-knowledge as historically contingent and flexible (Foucault, 1977, 1980: 81-87; May, 2006), and the worth of subjugated knowledges in challenging hegemony and processes of normalisation. They also echo the dichotomy of the individually professionalised mental

health EBE's status as it stands in Ireland, and the space that exists for an EBE stakeholder sphere that is neither purely "co-opted", nor purely "survivor" (Pilgrim, 2005: 19):

> There's travelling between [occupying the roles of] being a survivor and being a professional… There's good things happening as well. Kind of social movements; it has to be – society has to change, because, like, society interplays with psychiatry… if society changes its attitudes, then psychiatry will change its attitudes. But you still have this neoliberal – we live in a neoliberal kind of world.. crazy political system, which fringes [hinges] on madness back in the 1930s or 40s when it was first invented… You live in this now, where the rich destroy [mental health and health] services… They project this face like they really care, you know? And in a way, it's like, it's very, very duplicitous, you know?... you've conflict of interest here; you have politicians who are running the country, sitting on the boards of Big Pharma companies for lucrative salaries, yet you have a system that's governed, governed by them. But like, somewhere down the line I think drastic change has to come from the grassroots, from society, and that's the only way it's [change] ever gonna happen … Then there's the user-survivors who are very compliant and very like, 'Oh my doctor' this, and 'Oh, my pathology', that. And [they] are very kind of like, compliant? Very conservative? Like, I've had my head eaten off a couple of times by other users for suggesting that we get paid [for working as user-survivors] and stuff like that.

This respondent's observation demonstrates that there is a need for an EBE stakeholder sphere that occupies a space equal in legitimacy to the traditional expert stakeholder spheres that are currently and have historically exercised power-knowledge over EBEs and service-users in Irish mental health policy and practice. These traditional stakeholders are described in the 'Critical Analysis of Policies and Legislation', and 'Chapter Two'. An equal EBE stakeholder sphere would eschew the "co-opted"/"consumerist", and "survivor"/"democratic" binaries of service-user involvement in mental health policy and practice identified in the literature (Beresford, 2002; Noorani, 2013; Pilgrim, 2005). If realised, this stakeholder sphere could provide an actionable and unique dual expertise to the process of policy formulation, and the provision of services for those in distress. This EBE stakeholder sphere would equalise a great deal of the inequalities experienced by interview respondents and myself if meaningfully implemented and engaged with by policy actors and service-providers, with EBEs comprising part of this cohort if they have chosen to individually professionalise in a coherent discipline which aligns with these areas of engagement. The EBE stakeholders composing this proposed sphere would possess the combined experiential expertise that can only be attained through

lived experience of this policy and practice (Dings & Tekin, 2023; Noorani, 2013), and the individual professionalisation undertaken by the individual EBE to specialise and work as a 'legitimate' expert (French & Raven, 1959; Lukes, 2005; Weber, 1922), as described in respondents' experiences in this chapter.

CONCLUSION

This chapter thematically analyses the data collected through the six in-depth interviews conducted from a sample of five EBEs during the data collection phase of this research. Autoethnographical components are included in this analysis where applicable and appropriate. The chapter explores the uniquely personal, yet common journey to becoming an Expert By Experience that each respondent, as well as myself, undertook as a result of experiencing distress and seeking help. This journey consists of the key themes, or 'steps', of alienation, engaging with psychiatry and the biomedical model of mental illness, discovering alternatives to this model and its treatments, and finding community amongst peers. The final 'step' is that of individual professionalisation, through which the EBEs universally undertook further training, accreditation, and/or education in their own unique fields. This bolsters their experiential expertise (Dings & Tekin, 2023; Noorani, 2013) with a traditional 'expert authority' (French & Raven, 1959), imbuing them with more legitimate authority (Weber, 1922) in their roles, and allowing them to pursue careers founded on their dual traditional and experiential expertise. Respondent EBEs discuss their own understanding of and concerns surrounding the role of the 'Expert By Experience' based in their own experience of working as an EBE. From this, they identify the need for expertise by experience and the role of EBE to be treated with equal respect by those who exercise power-knowledge with legitimate authority, and whom many EBEs work with. Respondent EBEs note that any expertise said to be representing EBEs on a widescale level needs to be based on collective, cohesive expertise from individually professionalised EBEs. This demonstrates the need for the EBE stakeholder sphere in Irish mental health policy and practice this research calls for.

CHAPTER 7: CONCLUSION

INTRODUCTION

The purpose of this chapter is to bring together what has been presented in this study. The research process used to respond to the gap in knowledge this research identified surrounding Experts By Experience (EBEs) in Irish mental health policy and practice, significantly informed and shaped by the autoethnographical methodological approach, is summarised. Following on from this, the research's important contributions towards filling this gap in knowledge are discussed. The chapter concludes the study with a consideration of the implications this research's findings and methodology have for Irish mental health policy, knowledge generation and redress of power imbalances by minoritised groups universally, and the development and furthering of autoethnographical methodologies.

AUTOETHNOGRAPHICAL RESEARCH PROCESS AND SHAPE

This autoethnographical research, which was complemented with parallel in-depth EBE interviews, aimed to explore EBEs' lived experiences of and unique perspectives on Irish mental health policy and practice. In undertaking this exploration, the research posed two questions:

i) What are the views, experiences, and insights of Experts By Experience on Irish mental health policy and practice?
ii) What are the implications of Experts By Experiences' insights for the future development of mental health policy and practice?

This chapter draws together and presents the answers to both these research questions, their implications, and the contribution of this study to knowledge and future policy development.

The universal 'steps' EBEs including myself have taken on our journey to becoming Experts By Experience, which were identified in respondents' descriptions of their views, experiences, and insights on Irish mental health policy and practice, answer the first question, providing valuable insights. This study finds that EBEs have had negative and harmful experiences receiving treatments and interventions for their distress within the mental health services. These treatments and interventions have been characterised by service-providers' over-prescription of medications which EBEs have found unhelpful or harmful, a disregard for EBEs' will and preferences in their own treatment, significant power imbalances in the relationship between

EBEs and psychiatric practitioners, and a lack of any treatments or interventions aside from the aforementioned medications. These are definitive features of the biomedical model of mental illness, indicating that this model was still hegemonic in service provision during the timespan covered in the research study, and not the biopsychosocial model of mental health espoused in *A Vision for Change* (AVFC) (Government of Ireland, 2006), which was the active mental health policy at the time. This signifies a failure in realising the biopsychosocial ethos of AVFC in practice, with biomedical practices remaining hegemonic. The inclusion of EBEs in mental health policy formulation and implementation was found to be critical in this research to address this, until now, unfilled gap between the vision of mental health policy, and the realisation of its vision in practice.

EBEs' experiences and perspectives have been contextualised in the research by analysing Irish mental health legislation's evolving hegemonic ideologies through the lens of power-knowledge to critically analyse the real functions of mental health legislation's provisions, who these provisions grant legitimate power to, and who they abnormalise (Foucault, 1977, 1980; Gramsci, 1971; Weber, 1922). These evolving hegemonic ideologies have ranged from lunacy, criminality, biological mental illness, to mental and emotional distress in successive policies and laws over the years. They run the gamut of conceptualising the universal human experience of distress as 'mad', 'bad', or 'sad'. The current construction of mental and emotional distress remains heavily locked into a biomedical model, even when it is said to have moved towards a biopsychosocial paradigm. This research seeks to unlock this paradigm by daring to contemplate the validity of the distressed actors' definition of a situation, and its critical potential in generating a genuine move away from the biomedical model. The variety and spectrum of these different interpretations, explanations, and understandings of distress across time demonstrate clearly how our conceptualisations of this universal human experience are socially constructed products of their time, their society, and that society's broader hegemonic social beliefs and concerns, be they spiritual, moral, or medical. The research contributes to knowledge by demonstrating the partial, limited, and unfit understandings of distress posited in these interchanging, stubbornly durable constructs. This contribution comprises not only the evidence from autoethnography and in-depth EBE interviews, but the more fundamental endeavour to establish why the recognition of the unique form of knowledge inherent in the insights gained through experience is critical in the constructive disruption of the current consensus. This subjugated experiential knowledge is often reduced or even completely

unrecognised in the current patterns of discourse, policy, and professional practice by 'experts' trained in a specific field, with a specific outlook, and no lived experience.

Irish mental health policy and legislation, from the first legislative interventions in 'madness' with the Lunacy Acts (1811-1871), up to and including the 'mental health problems' of AVFC, Ireland's third official mental health strategy active from 2006-2020, are critically analysed in 'Chapter Three'. The dominant models of mental health employed in legislation to provide interventions based upon evolving ideologies, namely the biomedical model of mental illness (Laing, 2018 [1969]: 39) and the biopsychosocial model of mental health (Davidson et al., 2016), and how each model conceives of power and who should exercise it, are considered through the lens of the research's combined Gramscian hegemony (1971) and Foucauldian power-knowledge (1977, 1980) post-structuralist theoretical framework.

The research's investigation of how power has been exercised through the (re)production of hegemony in Irish mental health policy and practice, and who has exercised it, has clearly shown that service-users and EBEs have not been included in the development and implementation of mental health policy and practice. Through the power of the normalised, hegemonic biomedical model, and the stigma surrounding mental health (Rössler, 2016), service-user and EBE stakeholders have been excluded from decision-making processes and input into the policies which define them as actors in legal terms, and which outline the services that they and others experiencing distress can or cannot access. This exclusion has been shown in this research to be consciously undertaken, and is in keeping with the biomedical model's exercise of power-knowledge. Through diagnosis, it constructs those who do not belong or 'fit' into the hegemonic group, in this case those experiencing distress, as deviants and 'less than', and in need of normalising or fixing (Foucault, 2009). This has been demonstrated in the study's review of the literature surrounding the ideology and function of the biomedical model (Foucault, 1976, 1977; Gutting, 2019), its examination of Irish mental health legislation's provisions and its foundational ideologies, and its exploration of the lived experiences of EBEs.

The research contributes to knowledge by elucidating that, though a holistic biopsychosocial model of mental health, informed in part by the social model's corrective theoretical challenge to the hegemony of the biomedical model (Cameron, 2015; Oliver, 2004), was adopted as official government mental health policy for the first time in the history of the Irish state in 2006, the biomedical model remained hegemonic in practice. The insights of the EBEs presented in this research also contribute to knowledge, as they form the basis for this study's

key recommendation for the future development of mental health policy and practice. The second research question is answered with this recommendation.

RECOMMENDATIONS AND CONTRIBUTIONS TO KNOWLEDGE

Policy recommendations

The findings of this research, based on the accounts of the EBEs who participated, and my own experience described in the evocative autoethnography, 'Becoming', strongly support the establishment of an Expert By Experience stakeholder sphere in Irish mental health policy and practice as an appropriate and necessary corrective to the limited, harmful and hegemonic biomedical model evidenced in the data. This Irish mental health EBE stakeholder sphere is founded on and advanced based on the calls for service-user and EBE inclusion in mental health policy and practice found in the Irish literature (Brosnan, 2012, 2013; Department of Health and Children, 2008; McDaid, 2009; Social Care Regulatory Forum, 2009), and in the international literature (Beresford, 2007, 2010, 2012; Noorani, 2013; Tew et al., 2004). Contributing to knowledge, respondent EBEs, and my own, insights surrounding their and my individual journeys to becoming EBEs that share 'steps' taken by respondent EBEs and me described in this study provide an operational template for the research's proposed mental health EBE stakeholder sphere.

This mental health EBE sphere expands upon the role of the EBE proposed in the literature substantially through the addition of the research's findings, sited in the experiences of individuals occupying and living in the role of the EBE in "the concrete social world" (Pokinghorne, 1995: 19), beyond the theoretical. The template presented in this research for who should participate in the mental health EBE stakeholder sphere is drawn from the shared 'steps' that myself and respondent EBEs took on our journeys to becoming EBEs. These 'steps' are; alienation, engaging with psychiatry and the biomedical model of mental illness; discovering alternatives to this model and its treatments, and finding community amongst peers; and finally, individual professionalisation. Together, they outline the route we have independently taken to 'legitimise' (Weber, 1922) our subjugated EBE knowledges (Foucault, 1980: 82) and authority – both expert and experiential (Dings & Tekin, 2022; French & Raven, 1959; Noorani, 2013).

One of the research's important findings is the final 'step' on EBEs' journeys: the process of individual professionalisation undertaken by respondent EBEs. This process involves EBEs

attaining recognised qualifications and accreditations to advance their career in an area – or multiple areas – which typically relate to their unique experience of distress, and which builds upon their existing experiential knowledge (Dings & Tekin, 2023; Noorani, 2013). This process, which each respondent in the limited data sample of myself and five EBEs undertook, expands upon the role of the EBE described in the existing literature (Beresford, 2007, 2010, 2012; Noorani, 2013; Tew et al., 2004).

Individual professionalisation contributes a further layer to our understanding of the role EBEs truly occupy in mental health policy and practice, advancing this role beyond that of EBE inclusion in mental health policy and practice based purely on experiential knowledge. By undertaking individual professionalisation, respondent EBEs demonstrated that they are inherently aware of the power dynamics at play in the institutions and policy arenas in which they wish to progress their careers and improve outcomes. These EBEs recognise that they have been subjugated, and that they must legitimise their knowledge and match that of the actors exercising traditional, 'expert' power-knowledge (French & Raven, 1959; Weber, 1922) alone to overcome the barriers they may face in seeking to change those structures which they found harmful. Following individual professionalisation, the EBE possesses the equivalent legitimate qualification as those with this traditional, 'expert' knowledge (French & Raven, 1959; Lukes, 2005; Weber, 1922). The EBE possesses a discrete experiential knowledge which complements and enhances their traditional 'expert' knowledge. This grounded, dual knowledge is a distinctly privileged and unique knowledge, and a knowledge to be prized because it is knowledge uniquely combining direct experience and expertise. This finding contributes to the literature concerning EBEs by expanding the scope and role of the EBE beyond its current conceptualisations therein.

This dual EBE knowledge and the need for an EBE stakeholder sphere identified in this research disrupts the power-knowledge and paradigm of the biomedical model. Those exercising power-knowledge in hegemonic institutions understand the challenge this knowledge represents to their uninterrupted exercise of power. Traditionally hegemonic actors may perceive this dual EBE knowledge and recognition of an EBE stakeholder sphere to be a threat. Through their exercise of power-knowledge, they fend off rather than engage with this invaluable reservoir of knowledge. They fail to recognise the rational validity of EBEs and the shift in the paradigm that should come with that recognition. This position on EBE inclusion is untenable, as the internal validity of EBEs' dual experiential and expert knowledge and the need for their inclusion in policy formulation to address the failures and detrimental

interventions they experienced in the mental health services has been demonstrated in this research.

The research findings indicate that the recommended mental health EBE stakeholder sphere must operate with parity of respect and the equal exercise of power in decision-making amongst the medical and statutory stakeholder spheres this research has identified that, it is argued, have traditionally exercised power-knowledge (Foucault, 1977, 1980) over service-users. Without this equality – this true equality between stakeholders – the mental health EBE stakeholder sphere may fall into the dichotomy of "co-opted"/"consumerist" (Beresford, 2002; Pilgrim, 2005) service-users who are in receipt of 'the gift' (Pilgrim, 2005) of inclusion afforded by those exercising hegemonic power-knowledge, or "survivor/democratic" (Beresford, 2002; Pilgrim, 2005) service-users, who do not have the opportunity to meaningfully engage with and challenge the hegemonic institutions, as they will not engage with hegemonic actors due to this "co-opted" role.

The process of individual professionalisation that respondent EBEs undertook constitutes a means of moving past this dichotomy, as EBEs as service-users, are as legitimate in their knowledge and practice as those who have traditionally done the 'gifting'. They both hold an equivalent 'expert' knowledge and authority. EBE respondents stressed the need for EBE inclusion in decision-making processes to be conducted by EBEs who have furthered their experience, and who are not solely experts in their *own* experience. This reifies the research finding that EBEs had a knowledge and understanding of the legitimacy and authority offered through qualification and accreditation in 'expert' knowledge(s) (French & Raven, 1959). EBEs also felt that EBEs engaged in decision-making on behalf of other EBEs should have expanded their focus beyond their unique areas of interest that arise from their lived experience, to understanding the broader injustices and issues faced by other service-users. There is a need for such EBEs to be appropriately informed in their field, as such, to be best able to address these injustices and issues. Critically, it was found that to ensure the fullest representation of different EBE perspectives, insights, and concerns, EBE inclusion in mental health policy and practice must be collective and ongoing.

There was agreement between respondent EBEs that without individual EBE continuity in their role, there could be no accountability in the recommendations such a collective would make. In these responses, the participant EBEs have directly noted the need for a collective of varied, accredited, qualified EBEs to represent the service-user in policy and practice. The EBE

stakeholder sphere of individually professionalised Experts By Experience recommended by this research fits this criteria.

Emerging from this study's findings and analysis, an evidence based case has been firmly established for the development and inclusion of a formal role for Experts by Experience in all future government, HSE, and related statutory agencies' mental health policy development and review. A formal role descriptor should be developed and agreed in collaboration with existing EBEs in line with the criteria outlined above by respondent EBEs', and endorsed by relevant government departments and agencies. Formal terms and conditions should be developed recognising the specialist professional expertise that EBEs bring to policy development and review.

Methodological recommendations

This research has two distinct universal implications beyond the distinct recommendation made for Irish mental health policy and practice. The first of these implications concerns autoethnographical methodologies. An important contribution of this work relates to my use of autoethnography as a method and a methodology. Autoethnography is the primary lens through which this research has been viewed, conducted, and informed. The research's autoethnographical methodology has allowed the research to remain dynamic and flexible, letting it follow in the direction the data led the research and the researcher. The importance of this flexibility is noted throughout this research using analytic, reflective autoethnography (Anderson, 2006) where appropriate to reflect upon the research process and my role as the researcher within it. My decision as a researcher to depart from the original research topic is the most overt example of autoethnography's importance as a methodological approach, and its significance and centrality to the form the research took. This departure was facilitated by autoethnography's iterative nature (Berry, 2021a, 2021b). This departure was away from researching the implementation and provisions of AVFC from the perspectives of EBEs, *and* the perspectives of the two traditional medical and statutory policy stakeholder spheres identified in this research.

As I conducted in-depth interviews with EBEs, the themes which stood out as the most significant in the respondents' histories were concerned with something more fundamental than, but related to, an analysis of AVFC. Autoethnography provided me with the freedom as a researcher and a fellow EBE to focus on this story of becoming an EBE that had emerged at the heart of each EBE's interview, rather than choosing to focus on the initial research area

they had discussed. This, iteratively, informed the parallel research strand of autoethnography. I produced a piece of evocative autoethnography (Ellis & Bochner, 2016) discussing the formative experiences that informed my becoming an EBE to include my journey alongside those of the peers I spoke with through the in-depth EBE interview research strand. Regarding my combination of analytic and evocative autoethnography in this research, it is important to note that a combined approach has previously been debated in the field of autoethnographical methodologies. Witkin (2014) notes that autoethnography can be said to belong to one of two strands when reduced to its most fundamental components: evocative autoethnography, and analytic autoethnography. These have typically been considered to each represent the extreme at either end of the spectrum of autoethnography.

There has previously been disagreement over whether or not researchers can or should combine analytic and evocative autoethnography, with some perceiving the two as mutually exclusive opposites. More recently, thinkers in the field have considered the combination of both strands of autoethnography more favourably, finding that research which uses tools from across the spectrum of autoethnography is productive, and can yield deep insights and rich findings while benefitting the researcher (Hayler, 2013; Sparkes, 2020, 2021; Winkler, 2018). This research takes this methodological approach, and I have found it to be very positive experience, serving the research well and enriching it. The ability to reflect upon the research process and matters which arose that impacted both it and me as they took place using analytic autoethnography throughout the study, while also producing my standalone evocative autoethnography, has served to more fully accommodate the iterative nature of autoethnography. To me, it seemed an even more honest approach to doing autoethnography, as I was not only including my own story in the evocative autoethnography, which stands alone in time. I was also able to reflect on the journey of the research itself as it changed and evolved in real time and weave these observations on the methodology into the research. This research supports the combination of analytic and evocative autoethnography in future research, without the researcher having to limit themselves by choosing one. This research stands as a substantial successful application and interweaving of evocative and analytic autoethnography in one overall research study.

The themes which stood out in respondent EBEs' histories then led me to examine the concept of the 'Expert By Experience' and their potential and role as discussed in the literature to ground this new research focus in its academic discourse. The potential for EBE inclusion in mental health policy formulation as a stakeholder sphere was identified from this analysis of the literature (Amnesty International Ireland, 2009; Beresford, 2002, 2007, 2010, 2012;

Happell et al., 2019; Javed & Amering, 2016; Mac Gabhann et al., 2010; McDaid, 2009; Noorani, 2013; Tew et al., 2004). This potential mental health EBE stakeholder sphere then found its evidential grounding and elevation beyond the role posited in the literature upon thematic analysis of the interviews, which had inspired this shift in the focus of the research to begin with. This decision to change the research's focus led to the development of the recommended mental health EBE sphere, which has important implications for Irish mental health policy and practice. This process was all a result of the freedom autoethnography provided to me as a researcher.

My approach to doing autoethnography demonstrates the ability for the autoethnographical researcher to move with the current and heart of the research to produce an academically robust study. This approach includes following the emerging research to areas you had not anticipated. Autoethnography has also given me the chance to include my own story and experience, which has informed my decision to pursue and conduct this research at every step, alongside the stories and experiences of the EBEs who participated in in-depth interviews. As I have stated variously in the research, authenticity, honesty, and integrity are primary motivators for me in my life, and in my work: autoethnography frees the researcher to bring all of these qualities with them from their life into their work, without asking them to conceal their relationship with the research area they are investigating. This research's shift in focus, and the ability to iteratively detail the process of this shift and how I navigated it as a researcher using analytic autoethnography as a research method, can inform understandings of the different forms autoethnographical methodologies can take while retaining their academic rigour. I hope, also, that autoethnography has allowed me as a researcher and an EBE to produce a study that is not only robust, but engaging, in keeping with Gergen and Gergen's (2018: 5) observation that "An evocative ethnography is designed not to constrain the reader's attention but rather to invite a richer and more expansive appreciation of the possible. For the evocative ethnographer emotionally arousing discourse plays a central role."

Recommendations for future knowledge generation by minoritised EBE groups

The second global implication of this research relates to the development and furthering of knowledge generation and redress of power imbalances on the part of minoritised groups who hold discrete subjugated knowledges outside of the hegemonic power-knowledge that has been negatively exercised over them. The journey described in this research taken by respondent Irish mental health EBEs is not limited by any parameters to them and their discrete subjugated

knowledge alone. The process of individual professionalisation through which these individuals, including myself, have legitimised their experiential knowledge to challenge the hegemony of institutions and processes which have harmfully exercised power-knowledge over them is accessible to all groups who hold subjugated experiential knowledges and expertise by experience. This process provides an important avenue for EBEs from different minoritised groups to individually or collectively redress power imbalances by working to change the systems that have harmed them, while simultaneously developing and exercising their agency in an act of self-reclamation. The process is a source of knowledge generation and empowerment for those within minoritised groups, which challenges the established, normative knowledges, through developing new reservoirs of dual 'expert' and experiential knowledge. The identification and description in this research of a process to legitimise experiential knowledge and expertise by experience which can disrupt paradigms and the exercise of power-knowledge has implications for all minoritised groups with subjugated knowledges who wish to challenge and alter policy and practice that is detrimental to them. This is a universal application of this research.

Practice recommendations

This study establishes the case for the full inclusion of EBEs as valid experts who possess a unique dual expertise in the area of Irish mental health policy and practice through a solid evidence base. The study does this by exploring, giving voice to, analysing, and making the case for recognising and respecting the – until now – subjugated knowledge that EBEs in the field of mental health develop and possess through their unique experiences. This study establishes the place that exists for the distinctive, privileged dual knowledge that EBEs in mental health policy and practice possess, which is the only knowledge in this policy domain that is uniquely based on both experience and expertise. This study has demonstrated the necessity for parity of respect and consideration of EBEs' knowledge, authority, and expertise, and suggested that the paradigm move past the ineffective medical and statutory stakeholders' exercise of power-knowledge in mental health policy and practice. In doing so, this study has provided a missing link between the biopsychosocial vision set out in AVFC, and the continued wedding of mental health services to narrow forms of medical expertise in practice. The paradigm has been constructively disrupted by this study, and its parameters have been expanded. Practice, however, lags far behind. By affording EBEs their rightful place in matters

they are distinct experts in, both the paradigm can be further reformed and refined, and policy and practice response can be radically improved.

BIBLIOGRAPHY

Adams, T. E. and Herrmann, A. F. (2023) Good Autoethnography. *Journal of Autoethnography* [online]. 4(1)**,** 1-9. Available at: https://doi.org/10.1525/joae.2023.4.1.1 (Accessed 18/11/2023).

Allsopp, K. and Kinderman, P. (2021) The use of diagnoses in mental health service eligibility and exclusion criteria. *Journal of Mental Health* [online]. 30(1)**,** 97-103. Available at: https://doi.org/10.1080/09638237.2019.1677875 (Accessed 15/11/2023).

Altman, D. (2002) Writing the Self. *Anthropological Quarterly* [online]. 75(2)**,** 317-321. Available at: https://muse.jhu.edu/pub/35/article/2135/pdf (Accessed 15/11/2023).

American Psychiatric Association (1952) *Diagnostic and Statistical Manual of Mental Disorders – DSM-I*. Washington, DC: American Psychiatric Association.

American Psychiatric Association (1968) *Diagnostic and Statistical Manual of Mental Disorders – DSM-II*. Washington, DC: American Psychiatric Association.

American Psychiatric Association (1980) *Diagnostic and Statistical Manual of Mental Disorders – DSM-III*. Washington, DC: American Psychiatric Association.

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders – DSM-IV*. Washington, DC: American Psychiatric Association.

American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders – DSM-5*. Washington, DC: American Psychiatric Association.

American Psychiatric Association (2022) *Diagnostic and Statistical Manual of Mental Disorders – DSM-5-TR*. Washington, DC: American Psychiatric Association.

Amnesty International Ireland (2009) *Submission to the Independent Monitoring Group on A Vision for Change*. Dublin: Amnesty International Ireland.

Amnesty International Ireland (2010) *Hear My Voice: Challenging Mental Health Prejudice and Discrimination*. Dublin: Amesty International Ireland. Available at:

https://www.amnesty.ie/wp-content/uploads/2016/04/Hear-My-Voice.pdf (Accessed 16/11/2023).

Anderson, L. (2006) Analytic Autoethnography. *Journal of Contemporary Ethnography* [online]. 35(4)**,** 373-395. Available at: https://journals.sagepub.com/doi/abs/10.1177/0891241605280449 (Accessed 15/11/2023).

Ang, B., Horowitz, M. and Moncrieff, J. (2022) Is the chemical imbalance an 'urban legend'? An exploration of the status of the serotonin theory of depression in the scientific literature. *SSM - Mental Health* [online]. 2**,** 100098. Available at: https://www.sciencedirect.com/science/article/pii/S266656032200038X (Accessed 15/11/2023).

Aparicio, J. R. and Blaser, M. (2008) The 'Lettered City' and the Insurrection of Subjugated Knowledges in Latin America. *Anthropological Quarterly* [online]. 81(1)**,** 59-94. Available at: http://www.jstor.org/stable/30052740 (Accessed 18/11/2023).

Arts, B. J. M. and Verschuren, P. (1999) Assessing Political Influence in Complex Decision-Making: An Instrument Based on Triangulation. *International Political Science Review* [online]. 20(4)**,** 411 - 424. Available at: https://journals.sagepub.com/doi/10.1177/0192512199204006 (Accessed 18/11/2023).

Ashok, M., Ridha, J. and Amparo, G. (2015) Mental illness is like any other medical illness: a critical examination of the statement and its impact on patient care and society. *Journal of Psychiatry and Neuroscience* [online]. 40(3)**,** 147-150. Available at: https://www.jpn.ca/content/jpn/40/3/147.full.pdf (Accessed 18/11/2023).

Bacchi, C. L. (2009) *Analysing Policy: What's the Problem Represented to Be?* Australia: Pearson.

Bachrach, P. and Baratz, M. S. (1962) Two Faces of Power. *The American Political Science Review* [online]. 56(4)**,** 947-952. Available at: http://www.jstor.org/stable/1952796 (Accessed 15/11/2023).

Baker, J., Lynch, K., Cantillon, S. and Walsh, J. (2004) *Equality: From Theory to Action.* London: Palgrave Macmillan.

Barnes, C. (2019) Understanding The Social Model of Disability: Past, Present And Future. In: Watson, N., Roulstone, A. and Thomas, C., eds. (2019) *Routledge Handbook of Disability Studies*. 2nd ed. London: Routledge. 14-31.

Barrington, R. (1987) *Health, Medicine and Politics in Ireland 1900–1970.* Dublin: Institute of Public Administration.

Bartleet, B. L. and Ellis, C., eds. (2009) *Music Autoethnographies: Making Autoethnography Sing/Making Music Personal.* Australia: Australian Academic Press.

Beames, J. R., Kikas, K., O'Gradey-Lee, M., Gale, N., Werner-Seidler, A., Boydell, K. M. and Hudson, J. L. (2021) A New Normal: Integrating Lived Experience Into Scientific Data Syntheses. *Frontiers in Psychiatry* [online]. 12, 763005. Available at: https://www.frontiersin.org/articles/10.3389/fpsyt.2021.763005/full (Accessed 18/11/2023).

Beeker, T. (2022) Psychiatrization in mental health care: The emergency department. *Frontiers in Sociology* [online]. 7, 793836. Available at: https://www.frontiersin.org/articles/10.3389/fsoc.2022.793836 (Accessed 16/11/2023).

Beresford, P. (2002) User Involvement in Research and Evaluation: Liberation or Regulation? *Social Policy and Society* [online]. 1(2)**,** 95-105. Available at: https://www.cambridge.org/core/article/user-involvement-in-research-and-evaluation-liberation-or-regulation/E8B2D4E1989E63FA6508B49BD203F3F4 (Accessed 17/11/2023).

Beresford, P. (2007) User involvement, research and health inequalities: developing new directions. *Health Soc Care Community* [online] 15(4)**,** 306-12. Available at: https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2007.00688.x (Accessed 15/11/2023).

Beresford, P. (2010) Public partnerships, governance and user involvement: A service user perspective. *International Journal of Consumer Studies* [online]. 34**,** 495-502. Available at: https://onlinelibrary.wiley.com/doi/10.1111/j.1470-6431.2010.00905.x (Accessed 15/11/2023).

Beresford, P. (2012) From 'vulnerable' to vanguard: challenging the coalition: one of the main challenges to the government will come from the disabled people's and service user movements. *Soundings* [online]. 50. Available at: https://link.gale.com/apps/doc/A294371908/LitRC?u=googlescholar&sid=bookmark-LitRC&xid=a2f7b94a (Accessed 14/11/2023).

Beresford, P. and Wallcraft, J. (1997) Psychiatric System Survivors and Emancipatory research: Issues, overlaps and differences. In: Barnes, C. and Mercer, G., eds. (1997) *Doing Disability Research.* Leeds: The Disability Press. 66-87.

Beresford, P., Nettle, M. and Perring, R. (2010) *Towards a social model of madness and distress? Exploring what service users say* [online]. York: Joseph Rowntree Foundation. Available at: https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/mental-health-service-models-full.pdf (Accessed 16/11/2023).

Berry, K. (2021a) Autoethnography. In: Bamberg, M., Demuth, C. and Watzlawik, M., eds. (2021) *The Cambridge Handbook of Identity.* New York: Cambridge University Press. 324-344.

Berry, K. (2021b) Meditations on the Story I Cannot Write Reflexivity, Autoethnography, and the Possibilities of Maybe. In: Adams, T. E., Holman Jones, S. and Ellis, C., eds. (2021) *Handbook of Autoethnography.* New York: Routledge. 29-40.

Bertolote, J. (2008) The roots of the concept of mental health. *World Psychiatry* [online]. 7(2)**,** 113-6. Available at: https://onlinelibrary.wiley.com/doi/10.1002/j.2051-5545.2008.tb00172.x (Accessed 14/11/2023).

Biesta, G. J. J. and van Braak, M. (2020) Beyond the Medical Model: Thinking Differently about Medical Education and Medical Education Research. *Teaching and Learning in Medicine* [online]. 32(4)**,** 449-456. Available at: https://doi.org/10.1080/10401334.2020.1798240 (Accessed 14/11/2023).

Bleijenbergh, I., Korzilius, H. and Verschuren, P. (2011) Methodological criteria for the internal validity and utility of practice oriented research. *Quality and Quantity* [online]. 45**,** 145-156. Available at: https://link.springer.com/article/10.1007/s11135-010-9361-5 (Accessed 15/11/2023)

Bogart, K. R. and Dunn, D. S. (2019) Ableism special issue introduction. *Journal of Social Issues* [online]. 75(3)**,** 650-664. Available at: https://spssi.onlinelibrary.wiley.com/doi/10.1111/josi.12354 (Accessed 15/11/2023).

Boggs, C. (1976) *Gramsci's Marxism.* London: Pluto Press.

Borkman, T. (1976) Experiential knowledge: A new concept for the analysis of self-help groups. *Social Service Review* [online]. 50(3)**,** 445-456. Available at: https://www.journals.uchicago.edu/doi/abs/10.1086/643401 (Accessed 16/11/2023).

Boxall, K. and Beresford, P. (2013) Service user research in social work and disability studies in the United Kingdom. *Disability & Society* [online]. 28(5)**,** 587-600. Available at: https://doi.org/10.1080/09687599.2012.717876 (Accessed 15/11/2023).

Boysen, G. A. and Ebersole, A. (2014) Expansion of the Concept of Mental Disorder in the DSM-5. *The Journal of Mind and Behavior* [online]. 35(4)**,** 225-243. Available at: http://www.jstor.org/stable/43854371 (Accessed 15/11/2023).

Brazier, J. (2010) Is the EQ–5D fit for purpose in mental health? *The British Journal of Psychiatry* [online]. 197(5)**,** 348-349. Available at: http://10.1192/bjp.bp.110.082453 (Accessed 18/11/2023).

Bril-Barniv, S., Moran, G. S., Naaman, A., Roe, D. and Karnieli-Miller, O. (2017) A Qualitative Study Examining Experiences and Dilemmas in Concealment and Disclosure of People Living With Serious Mental Illness. *Qualitative Health Research* [online]. 27(4)**,** 573-583. Available at: https://journals.sagepub.com/doi/abs/10.1177/1049732316673581 (Accessed 15/11/2023).

Brosnan, L. (2012) Power and Participation: An Examination of the Dynamics of Mental Health Service-User Involvement in Ireland. *Studies in Social Justice* [online]. 6(1)**,** 45-66. Available at: https://journals.library.brocku.ca/index.php/SSJ/article/view/1068 (Accessed 17/11/2023).

Brosnan, L. (2013) Service-user Involvement in Irish Mental Health Services: A Sociological Analysis of Inherent Tensions for Service-users, Service-providers and Social Movement Actors. Unpublished PhD thesis, University of Limerick.

Bush, K. (1985) *Hounds of Love* [CD]. EMI, London

Cameron, C. (2015) Turning experience into theory: The affirmation model as a tool for critical Praxis. *Social Work and Social Sciences Review* [online]. 17(3)**,** 108-121. Available at: https://journals.whitingbirch.net/index.php/SWSSR/article/view/802 (Accessed 15/11/2023).

Campbell, F. K. (2005) Legislating disability: Negative Ontologies and Government of Identities. In: Tremain, S., ed. (2005) *Foucault & the Government of Disability.* United States: University of Michigan Press. 108-130.

Campbell, F. K. (2023) *Contours of Ableism: The Production of Disability and Abledness*. London: Palgrave Macmillan.

Cech, E. A. (2023) Engineering Ableism: The Exclusion and Devaluation of Engineering Students and Professionals with Physical Disabilities and Chronic and Mental Illness. *Journal of Engineering Education* [online]. 112(2)**,** 462-487. Available at: https://onlinelibrary.wiley.com/doi/10.1002/jee.20522 (Available 14/11/2023)

Codato, A. and Perissinotto, R. M. (2010) Marxism and elitism: two opposite social analysis models? *Revista Brasileira de Ciências Sociais* [online]. 5. Available at: http://socialsciences.scielo.org/scielo.php?script=sci_arttext&pid=S0102-69092010000100003&nrm=iso (Accessed 14/11/2023)

Conrad, P. W. (1992) Medicalization and Social Control. *Annual Review of Sociology* [online]. 18**,** 209-232. Available at: http://www.jstor.org/stable/2083452 (Accessed 14/11/2023).

Conrad, P. W. (2007) *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders.* Baltimore, US: Johns Hopkins University Press.

Corrigan, P. W. (1998) The impact of stigma on severe mental illness. *Cognitive and Behavioral Practice* [online]. 5(2)**,** 201-222. Available at: https://www.sciencedirect.com/science/article/abs/pii/S1077722998800060?via%3Dihub (Accessed 17/11/2023).

Corrigan, P. W. and Rao, D. (2012) On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change. *The Canadian Journal of Psychiatry* [online]. 57(8)**,** 464-469. Available at: https://journals.sagepub.com/doi/abs/10.1177/070674371205700804 (Accessed 17/11/2023).

Corrigan, P. W. and Watson, A. C. (2002) Understanding the impact of stigma on people with mental illness. *World Psychiatry* [online]. 1(1)**,** 16-20. Available at: https://pubmed.ncbi.nlm.nih.gov/16946807/ (Accessed 18/11/2023).

Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D. and Rüsch, N. (2012) Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatric Services (Washington, D.C.)* [online]. 63(10)**,** 963-973. Available at: https://doi.org/10.1176/appi.ps.201100529 (Accessed 17/11/2023).

Cowden, S. and Singh, G. (2007) The 'User': Friend, foe or fetish?: A critical exploration of user involvement in health and social care. *Critical Social Policy* [online]. 27(1)**,** 5-23. Available at: https://journals.sagepub.com/doi/abs/10.1177/0261018307072205 (Accessed 16/11/2023).

Craig, T. J., Goodman, A. B. and Haugland, G. (1982) Impact of DSM-III on clinical practice. *The American Journal of Psychiatry* [online]. 139(7)**,** 922-925. Available at: https://ajp.psychiatryonline.org/doi/abs/10.1176/ajp.139.7.922 (Accessed 15/11/2023).

Crehan, K. (2016) *Gramsci's Common Sense*: *Inequality and Its Narratives.* N.C, US: Duke University Press.

Dahl, R. A. (1957) The concept of power. *Behavioral Sciences* [online]. 2(3)**,** 201-215. Available at: https://onlinelibrary.wiley.com/doi/10.1002/bs.3830020303 (Accessed 14/11/2023).

Dahl, R. A. (1961) *Who Governs?: Democracy and Power in an American City.* New Haven: Yale University Press.

Dahl, R. A. (1967) The City in the Future of Democracy. *American Political Science Review* [online]. 61(4)**,** 953-970. Available at: https://www.cambridge.org/core/article/city-

in-the-future-of-democracy/247B40D5887B604CBADCC1EB295E7E18 (Accessed 16/11/2023).

Davidson, G., Campbell, J., Shannon and Mulholland, C. (2016) *Models of Mental Health.* London: Palgrave Macmillan.

Davidson, L. (2012) Use of Coercion in Recovery-Oriented Care: Staying Vigilant. *Psychiatric Services* [online]. 63(8)**,** 834-834. Available at: https://ps.psychiatryonline.org/doi/abs/10.1176/appi.ps.2012p834 (Accessed 15/11/2023).

Davidson, L., Bellamy, C., Guy, K. and Miller, R. (2012) Peer support among persons with severe mental illnesses: a review of evidence and experience. *World Psychiatry* [online]. 11(2)**,** 123-128. Available at: https://onlinelibrary.wiley.com/doi/10.1016/j.wpsyc.2012.05.009 (Accessed 15/11/2023).

Deacon, B. J. (2013) The biomedical model of mental disorder: a critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review* [online]. 33(7)**,** 846-61. Available at: https://www.sciencedirect.com/science/article/pii/S0272735813000482 (Accessed 17/11/2023)

Decker, H. S. (2013) *The Making of DSM-III®: A Diagnostic Manual's Conquest of American Psychiatry.* New York: Oxford University Press.

Deegan, P. E. (1993) Recovering Our Sense of Value After Being Labeled: Mentally Ill. *Journal of Psychosocial Nursing and Ment Health Services* [online]. 31(4)**,** 7-11. Available at: https://journals.healio.com/doi/10.3928/0279-3695-19930401-06 (Accessed 16/11/2023).

Del Rosal, E., González-Sanguino, C., Bestea, S., Boyd, J. and Muñoz, M. (2021) Correlates and consequences of internalized stigma assessed through the Internalized Stigma of Mental Illness Scale for people living with mental illness: A scoping review and meta-analysis from 2010. *Stigma and Health* [online]. 6(3)**,** 324-334. Available at: https://psycnet.apa.org/doiLanding?doi=10.1037%2Fsah0000267 (Accessed 17/11/2023).

Denzin, N. K. (1970) *The Research Act in Sociology.* Chicago: Aldine.

Denzin, N. K. (2012) Triangulation 2.0. *Journal of Mixed Methods Research* [online]. 6(2)**,** 80-88. Available at: https://journals.sagepub.com/doi/abs/10.1177/1558689812437186 (Accessed 15/11/2023)

Department of Health (1966) *Commission of Inquiry on Mental Illness: 1966 Report.* Dublin: The Stationary Office.

Department of Health and Children (2008) *National Strategy for Service User Involvement in the Irish Health Service 2008-2013.* Dublin: The Stationary Office.

Dings, R. and Tekin, Ş. (2023) A philosophical exploration of experience-based expertise in mental health care. *Philosophical Psychology* [online]. 36(7)**,** 1415-1434. Available at: https://doi.org/10.1080/09515089.2022.2132926 (Accessed 16/11/2023).

Dogra, N. and Cooper, S. (2017) Defining mental health and mental illness. In: Dogra, N., Lunn, B. and S, C., eds. (2017) *Psychiatry by Ten Teachers.* 2nd ed. CRC Press. 15-25.

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Abu Dabrh, A. M. and Murad, M. H. (2014) Patient engagement in research: a systematic review. *BMC Health Services Research* [online]. 14(1)**,** 89. Available at: https://doi.org/10.1186/1472-6963 (Accessed 16/11/2023).

Dukelow, F. and Considine, M. (2017) *Irish Social Policy: A Critical Introduction.* 2nd ed. Bristol: Bristol University Press.

Duxbury, S. W., Frizzell, L. C. and Lindsay, S. L. (2018) Mental illness, the media, and the moral politics of mass violence: The role of race in mass shootings coverage. *Journal of Research in Crime and Delinquency* [online]. 55(6)**,** 766-797. Available at: https://journals.sagepub.com/doi/10.1177/0022427818787225 (Accessed 16/11/2023).

Dyball, M. C., Poullaos, C. and Chua, W. F. (2007) Accounting and Empire: Professionalization-as-resistance: The Case of Philippines. *Critical Perspectives on Accounting* [online]. 18(4)**,** 415-449. Available at: https://www.sciencedirect.com/science/article/pii/S1045235406000207 (Accessed 18/11/2023).

Easteal, P., Bartels, L., Nelson, N. and Holland, K. (2015) How are women who kill portrayed in newspaper media? Connections with social values and the legal system. *Women's Studies International Forum* [online]. 51**,** 31-41. Available at: https://www.sciencedirect.com/science/article/pii/S0277539515000710 (Accessed 17/11/2023).

Elkins, D. N. (2009) The medical model in psychotherapy: Its limitations and failures. *Journal of Humanistic Psychology* [online]. 49(1)**,** 66-84. Available at: https://journals.sagepub.com/doi/10.1177/0022167807307901 (Accessed 18/11/2023).

Ellingson, L. L. and Ellis, C. (2008) Autoethnography As Constructionist Project. In: Holstein, J. A. and Gubrium, J. F. e., eds. (2008) *Handbook of Constructionist Research.* New York: Guilford Press. 445-465.

Ellis, C. (1999) Heartful Autoethnography. *Qualitative Health Research* [online]. 9(5)**,** 669 Available at: https://journals.sagepub.com/doi/abs/10.1177/104973299129122153 (Accessed 14/11/2023).

Ellis, C. and Bochner, A. (2016) *Evocative Autoethnography: Writing Lives and Telling Stories.* New York: Routledge.

Ellis, C., Adams, T. E. and Bochner, A. (2011) Autoethnography: An Overview. *Forum Qualitative Sozialforschung Forum: Qualitative Social Research* [online]. 12(1). Available at: https://www.qualitative-research.net/index.php/fqs/article/view/1589. (Accessed 14/11/2023).

Engel, G. L. (1977) The need for a new medical model: a challenge for biomedicine. *Science* [online]. Available at: https://www.science.org/doi/10.1126/science.847460 (Accessed 15/11/2023).

Erdelyi, M. H. (1985) *Psychoanalysis: Freud's Cognitive Psychology.* London: W.H. Freeman.

Evetts, J. (1999) Professionalisation and Professionalism: Issues for Interprofessional Care. *Journal of Interprofessional Care* [online]. 13(2)**,** 119-128. Available at: https://doi.org/10.3109/13561829909025544 (Accessed 18/11/2023).

Faedo, G. and Normand, C. (2013) *Implementation of 'A Vision for Change' for Mental Health Services: Report to Amnesty International Ireland* [online]. Dublin: Amnesty International Ireland. Available at: https://www.amnesty.ie/wp-content/uploads/2016/04/Implementation-of-A-Vision-for-Change-for-Mental-Health-Services.pdf. (Accessed 15/11/2023)

Farrell Delaney, O. (2021) *An Evocative Autoethnography of Living Alongside Myalgic Encephalomyelitis (ME).* Newcastle Upon Tyne: Cambridge Scholars Publishing.

Fielding, N. G. (2009) Going out on a Limb: Postmodernism and Multiple Method Research. *Current Sociology* [online]. 57(3)**,** 427-447. Available at: https://journals.sagepub.com/doi/abs/10.1177/0011392108101591 (Accessed 18/11/2023).

Finnane, M. (1981) *Insanity and the Insane in Post-Famine Ireland.* London: Croom Helm.

Finnane, M. (1985) Asylums, Families and the State. *History Workshop Journal* [online]. 20(1)**,** 134-148. Available at: https://doi.org/10.1093/hwj/20.1.134 (Accessed 16/11/2023).

Flick, U. (2007) *Designing Qualitative Research.* London: SAGE Publications Ltd.

Flick, U., Garms-Homolová, V., Herrmann, W. J., Kuck, J. and Röhnsch, G. (2012) "I Can't Prescribe Something Just Because Someone Asks for It . . .": Using Mixed Methods in the Framework of Triangulation. *Journal of Mixed Methods Research* [online]. 6(2)**,** 97-110. Available at: https://journals.sagepub.com/doi/abs/10.1177/1558689812437183. (Accessed 15/11/2023).

Foster, K., McAllister, M. and O'Brien, L. (2005) Coming to Autoethnography: A Mental Health Nurse's Experience. *International Journal of Qualitative Methods* [online]. 4(4)**,** 1-15. Available at: https://journals.sagepub.com/doi/abs/10.1177/160940690500400401. (Accessed 16/11/2023).

Foster, K., McAllister, M. and O'Brien, L. (2006) Extending the boundaries: Autoethnography as an emergent method in mental health nursing research. *International Journal of Mental Health Nursing* [online]. 15**,** 44-53. Available at: https://doi.org/10.1111/j.1447-0349.2006.00402.x (Accessed18/11/2023).

Foucault, M. (1963) *The Birth of the Clinic.* Paris: Presses Universitaires de France.

Foucault, M. (1965) *Madness and Civilization : A History of Insanity in the Age of Reason.* New York: Pantheon Books.

Foucault, M. (1976) *The History of Sexuality, Volume I: An Introduction.* New York: Pantheon Books.

Foucault, M. (1977) *Discipline and Punish: The Birth of the Prison. New York: Pantheon Book.* New York: Pantheon Books.

Foucault, M. (1980) *Power/knowledge: Selected Interviews and Other Writings, 1972-1977.* New York: Pantheon Books.

Foucault, M. (2007) *Security, Territory, Population: Lectures at the Collège De France, 1977 - 78.* Hampshire: Palgrave Macmillan.

Foucault, M. (2009) Alternatives to the Prison: Dissemination or Decline of Social Control? *Theory, Culture & Society* [online]. 26(6)**,** 12-24. Available at: https://journals.sagepub.com/doi/abs/10.1177/0263276409353775. (Accessed 14/11/2023).

Fournier, V. (1999) The Appeal to 'Professionalism' as a Disciplinary Mechanism. *The Sociological Review* [online]. 47(2)**,** 280-307. Available at: https://journals.sagepub.com/doi/abs/10.1111/1467-954X.00173 (Accessed 18/11/2023).

France, C. M., Lysaker, P. H. and Robinson, R. P. (2007) The "chemical imbalance" explanation for depression: Origins, lay endorsement, and clinical implications. *Professional Psychology: Research and Practice* [online]. 38(4)**,** 411-420. Available at: https://psycnet.apa.org/doiLanding?doi=10.1037%2F0735-7028.38.4.411 (Accessed: 17/11/2023).

Freeth, R. (2023) *Humanising Psychiatry and Mental Health Care: The Challenge of the Person-Centred Approach.* London: CRC Press.

French, J. R. P. and Raven, B. (1959) The Bases of Social Power. In: Cartwright, D., ed. (1959) *Studies in Social Power.* Ann Arbor: University of Michigan Press. 150-167.

Fuchs, T. (2010) Subjectivity and intersubjectivity in psychiatric diagnosis. *Psychopathology* [online]. 43(4)**,** 268-74. Available at: https://karger.com/psp/article-abstract/43/4/268/284781/Subjectivity-and-Intersubjectivity-in-Psychiatric?redirectedFrom=fulltext. (Accessed 16/11/2023).

Fusar-Poli, P., Hijazi, Z., Stahl, D. and Steyerberg, E. W. (2018) The Science of Prognosis in Psychiatry: A Review. *JAMA Psychiatry* [online]. 75(12)**,** 1289-1297. Available at: https://doi.org/10.1001/jamapsychiatry.2018.2530 (Accessed 15/11/2023).

Galderisi, S., Heinz, A., Kastrup, M., Beezhold, J. and Sartorius, N. (2015) Toward a new definition of mental health. *World Psychiatry* [online]. 14(2)**,** 231-233. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4471980/ (Accessed 18/11/2023).

Gaventa, J. (2006) Finding the Spaces for Change: A Power Analysis. *IDS Bulletin* [online]. 37(6). Available at: https://doi.org/10.1111/j.1759-5436.2006.tb00320.x. (Accessed 18/11/2023).

Geertz, C. (1973) Thick Description: Towards an Interpretive Theory of Culture. In: Geertz, C., ed. (1973) *The Interpretation of Cultures.* New York: Basic Books. 310-323.

Gergen, K. and Gergen, M. (2018) Doing Things with Words: Toward Evocative Ethnography. *Qualitative Research in Psychology* [online]. 15(2-3), 272-286. Available at: https://doi.org/10.1080/14780887.2018.1430004 (Accessed 18/11/2023).

Ghaemi, S. N. (2018) After the failure of DSM: clinical research on psychiatric diagnosis. *World Psychiatry* [online]. 17(3)**,** 301-302. Available at: https://doi.org/10.1002%2Fwps.20563 (Accessed 15/11/2023).

Giddens, A. (2006) *Sociology.* 5th ed. Cambridge: Polity Press.

Goffman, E. (1961) *Asylums: Essays on the Social Situations of Mental Patients and Other Inmates.* New York: Anchor Books.

Goldman, H. H. and Grob, G. N. (2006) Defining 'mental illness' in mental health policy. *Health Affairs (Millwood)* [online]. 25(3)**,** 737-749. Available at: https://www.healthaffairs.org/doi/10.1377/hlthaff.25.3.737 (Accessed 14/11/2023).

Goldstein, J. S. (2004) *International Relations.* Toronto: Pearsons Education.

Gornitzka, Å. and Larsen, I. M. (2004) Towards Professionalisation? Restructuring of Administrative Work Force in Universities. *Higher Education* [online]. 47(4)**,** 455-471. Available at: https://doi.org/10.1023/B:HIGH.0000020870.06667.fl (Accessed 18/11/2023).

Gough, J. and Neary, S. (2021) The Career Development Profession: Professionalisation, Professionalism, and Professional Identity. In: Robertson, P. J., Hooley, T. and McCash, P., eds. (2021) *Oxford Handbook of Career Development.* UK: Oxford University Press. 257-268.

Government of Ireland (2020) *Sharing the Vision - A Mental Health Policy for Everyone.* Dublin: The Stationary Office.

Government of Ireland, (2006) *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationary Office.

Government of Ireland, *Assisted Decision Making (Capacity) (Amendment) Act 2022.* Dublin: The Stationary Office.

Government of Ireland, *Assisted Decision Making (Capacity) Act 2015.* Dublin: The Stationary Office.

Government of Ireland, *Mental Health Act, 2001.* Dublin: The Stationary Office.

Government of Ireland, *The Mental Treatment Act, 1945.* Dublin: The Stationary Office.

Gramsci, A. (1957) *The Modern Prince & Other Writings.* New York: International Publishers.

Gramsci, A. (1971) *Selections from the Prison Notebooks.* New York: International Publishers.

Green, A., Dura, L., Harris, P., Heilig, L., Kirby, B., McClintick, J., Pfender, E. and Carrasco, R. (2020) Teaching and Researching with a Mental Health Diagnosis: Practices and Perspectives on Academic Ableism. *Rhetoric of Health & Medicine* [online]. 3(2). Available at: https://stars.library.ucf.edu/rhm/vol3/iss2/1/ (Accessed 15/11/2023).

Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B. and Chant, A. (2019) Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expect* [online]. 22(4)**,** 785-801. Available at: https://onlinelibrary.wiley.com/doi/10.1111/hex.12888 (Accessed 16/11/2023).

Guilbride, A. (2004) Infanticide: The Crime of Motherhood. In: Kennedy, P., ed. (2004) *Motherhood in Ireland, Creation and Context.* Cork: Mercier Press. 170–180.

Gutting, G. (2019) *Foucault: A Very Short Introduction.* 2nd ed. Oxford: Oxford University Press.

Häfner, H. (2002) Prevention and early intervention in schizophrenia: facts and visions. *Seishin Shinkeigaku Zasshi* [online]. 104(11)**,** 1033-1054. Available at: https://europepmc.org/article/med/12642908 (Accessed 15/11/2023).

Handerer, F., Kinderman, P. and Tai, S. (2022) Diagnostic labels: the problem is the signified not the signifier. *The Lancet Psychiatry* [online]. 9(7)**,** e31. Available at: https://doi.org/10.1016/S2215-0366(22)00111-0 (Accessed 16/11/2023).

Happell, B., Waks, S., Bocking, J., Horgan, A., Manning, F., Greaney, S., Goodwin, J., Scholz, B., van der Vaart, K. J., Allon, J., Hals, E., Granerud, A., Doody, R., MacGabhann, L., Russell, S., Griffin, M., Lahti, M., Ellilä, H., Pulli, J., Vatula, A., Platania-Phung, C., Bjornsson, E. and Biering, P. (2019) "I felt some prejudice in the back of my head": Nursing students' perspectives on learning about mental health from "Experts by Experience". *Journal of Psychiatric Mental Health Nursing* [online]. 26(7-8)**,** 233-243. Available at: https://onlinelibrary.wiley.com/doi/10.1111/jpm.12540 (Accessed 16/11/2023).

Hayler, M. (2013) When we Got to the Top of Elm Grove. In: Short, N. P., Turner, L. and Grant, A., eds. (2013) *Contemporary British Autoethnography.* Rotterdam: SensePublishers. 17-31.

Heckers, S. and Kendler, K. S. (2020) The evolution of Kraepelin's nosological principles. *World Psychiatry* [online]. 19(3)**,** 381-388. Available at: https://onlinelibrary.wiley.com/doi/abs/10.1002/wps.20774. (Accessed 16/11/2023).

Higgins, A. (2008) *A Recovery Approach Within the Irish Mental Health Services: A Framework for Development*. Ireland: Mental Health Commission. Available at: http://hdl.handle.net/10147/75113 (Accessed 18/11/2023).

Higgs, R. N. (2020) Reconceptualizing Psychosis: The Hearing Voices Movement and Social Approaches to Health. *Health Hum Rights* [online]. 22(1)**,** 133-144. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7348419/ (Accessed 17/11/2023).

Hobbes, T. (1651) *Leviathan, or, The matter, Forme, and Power of a Commonwealth Ecclesiasticall and Civil.* London: Andrew Crooke.

Hoff, P. (2015) The Kraepelinian tradition. *Dialogues in Clinical Neuroscience* [online].17(1)**,** 31-41. Available at: https://doi.org/10.31887/DCNS.2015.17.1/phoff. (Accessed 17/11/2023).

Hogan, A. J. (2019) Social and medical models of disability and mental health: evolution and renewal. *Canadian Medical Association Journal* [online]. 191(1)**,** e16-e18.Available at: https://www.cmaj.ca/content/cmaj/191/1/E16.full.pdf (Accessed 15/11/2023).

Horney, K. (1939) *New Ways in Psychoanalysis.* New York: W. W. Norton & Co.

Horwitz, A. V. (2021) *DSM: A History of Psychiatry's Bible.* Baltimore: Johns Hopkins University Press.

House of Commons (1817) *Report of the Select Committee to Consider the State of the Lunatic Poor in Ireland (1817)*. United Kingdom: The Parliamentary Archives.

Huckerby, J. (2003) Women Who Kill Their Children: Case Study and Conclusions Concerning the Differences in the Fall from Material Grace by Khoua Her and Andrea Yates. *Duke Journal of Gender Law and Policy* [online]. 10**,** 149-172. Available at: https://scholarship.law.duke.edu/djglp/vol10/iss1/4/ (Accessed 17/11/2023).

Huda, A. S. (2021) The medical model and its application in mental health. *International Review of Psychiatry* [online]. 33(5)**,** 463-470. Available at: https://doi.org/10.1080/09540261.2020.1845125 (Accessed 15/11/2023).

Independent Monitoring Group (2007) *First Annual Report on Implementation February 2006 to January 2007*. Ireland: Department of Health and Children.

Independent Monitoring Group (2008) *Second Annual Report on Implementation February 2007 to January 2008*. Ireland: Department of Health and Children.

Independent Monitoring Group (2009) *Third Annual Report on Implementation 2008*. Ireland: Department of Health and Children.

Independent Monitoring Group (2010) *Fourth Annual Report on Implementation 2009*. Ireland: Department of Health and Children.

Independent Monitoring Group (2011) *Fifth Annual Report on Implementation 2010*. Ireland: Department of Health and Children.

Independent Monitoring Group (2012) *Sixth Annual Report on Implementation 2011*. Ireland: Department of Health.

Javed, A. and Amering, M. (2016) Mental health and human rights: Working in partnership with persons with a lived experience and their families and friends. *Indian Journal of Psychiatry* [online]. 58(3)**,** 250-252. Available at: https://journals.lww.com/indianjpsychiatry/fulltext/2016/58030/mental_health_and_human_rights__working_in.3.aspx (Accessed 16/11/2023).

Jobes, D. A. and Chalker, S. A. (2019) One Size Does Not Fit All: A Comprehensive Clinical Approach to Reducing Suicidal Ideation, Attempts, and Deaths. *International Journal of Environmental Research and Public Health* [online]. 16(19)**,** 3606. Available at: https://www.mdpi.com/1660-4601/16/19/3606. (Accessed 14/11/2023).

Johnston, H. (2014) *All Vision but No Change? Determinants of Implementation: The Case of Ireland and Mental Health Policy*. Dublin: Institute of Public Administration.

Joll, J. (1976) *Europe Since 1870: An International History*. London: Penguin.

Jorm, A. F., Reavley, N. J. and Ross, A. M. (2012) Belief in the dangerousness of people with mental disorders: a review. *The Australian and New Zealand Journal of Psychiatry*

[online]. 46(11). Available at: https://journals.sagepub.com/doi/10.1177/0004867412442406 (Accessed 17/11/2023).

Kaminskiy, E., Zisman-Ilani, Y., Morant, N. and Ramon, S. (2021) Barriers and Enablers to Shared Decision Making in Psychiatric Medication Management: A Qualitative Investigation of Clinician and Service Users' Views. *Frontiers in Psychiatry* [online]. 12. Available at: https://www.frontiersin.org/articles/10.3389/fpsyt.2021.678005. (Accessed 15/11/2023).

Karlsson, H. (2012) Problems in the definitions of positive mental health. *World Psychiatry* [online]. 11(2), 106-107. Available at: https://onlinelibrary.wiley.com/doi/10.1016/j.wpsyc.2012.05.022 (Accessed 15/11/2023).

Kawa, S. and Giordano, J. (2012) A brief historicity of the Diagnostic and Statistical Manual of Mental Disorders: Issues and implications for the future of psychiatric canon and practice. *Philosophy, Ethics, and Humanities in Medicine* [online]. 7(2). Available at: https://peh-med.biomedcentral.com/articles/10.1186/1747-5341-7-2. (Accessed 16/11/2023).

Kelly, B. (2016) *Hearing Voices: The History of Psychiatry in Ireland.* Kildare: Irish Academic Press.

Kenneth S. Kendler, M.D. (2014) The Structure of Psychiatric Science. *American Journal of Psychiatry* [online]. 171(9), 931-938. Available at: https://ajp.psychiatryonline.org/doi/abs/10.1176/appi.ajp.2014.13111539. (Accessed 14/11/2023).

Keyes, S. E., Webber, S. H. and Beveridge, K. (2015) Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services. *Alter* [online]. 9(3), 236-248. Available at: https://www.sciencedirect.com/science/article/pii/S1875067215000516 (Accessed 16/11/2023).

Kimmel, M. S. and Mahler, M. (2003) Adolescent masculinity, homophobia, and violence: Random school shootings, 1982-2001. *American Behavioral Scientist*

[online]. 46(10)**,** 1439-1458. Available at: https://journals.sagepub.com/doi/10.1177/0002764203046010010 (Accessed 16/11/2023).

Kinderman, P. (2014) *A Prescription for Psychiatry: Why We Need a Whole New Approach to Mental Health and Wellbeing.* London: Palgrave Macmillan.

Kraepelin, E. (1899) *Psychiatrie: Ein Lehrbuch fur Studirende und Aerzte.* 6th edn. Leipzig: Johann Ambrosius Barth.

Lacasse, J. R. and Leo, J. (2015) Antidepressants and the chemical imbalance theory of depression: A reflection and update on the discourse. *the Behavior Therapist* [online]. 38(7)**,** 206-213. Available at: https://diginole.lib.fsu.edu/islandora/object/fsu:267045/datastream/PDF/view (Accessed 14/11/2023).

Laing, R. D. (1960) *The Divided Self: An Existential Study in Sanity and Madness.* London: Penguin Books.

Laing, R. D. (1969) *Self and Others.* London: Penguin Books.

Laing, R. D. (2018) *The Politics of the Family and Other Essays.* London: Routledge.

Laing, R. D. and Esterson, A. (1964) *Sanity, Madness and the Family.* London: Penguin Books.

Lavretsky, H. (2008) History of Schizophrenia as a Psychiatric Disorder. In: Mueser, K. T. and Jeste, D. V., eds (2008) *Clinical Handbook of Schizophrenia.* New York: The Guilford Press. 3-13.

Law Society of Ireland (2011) *Submission by the Law Society of Ireland to The Joint Committee on Justice, Defence and Equality: Proposed Mental Capacity Legislation.* Dublin: Law Society of Ireland.

Lemay-Hébert, N. and Visoka, G. (2023) *Normalization in World Politics.* Michigan: University of Michigan Press.

Leo, J. and Lacasse, J. R. (2008) The Media and the Chemical Imbalance Theory of Depression. *Society* [online]. 45(1)**,** 35-45. Available at: https://doi.org/10.1007/s12115-007-9047-3 (Accessed 15/11/2023).

Lewis, C. and Short, C. (1879) *A Latin Dictionary, by Charlton T. Lewis and Charles Short.* UK: Oxford.

Link, B. G., Yang, L. H., Phelan, J. C. and Collins, P. Y. (2004) Measuring Mental Illness Stigma. *Schizophrenia Bulletin: The Journal of Psychoses and Related Disorders* [online]. 30(3)**,** 511-541. Available at: https://doi.org/10.1093/oxfordjournals.schbul.a007098 (Accessed 17/11/2023).

Lukes, S. (1974) *Power: A Radical View.* London: Macmillan London.

Lukes, S. (2005) *Power: A Radical View.* 2nd ed. New York: Palgrave Macmillan.

Mac Gabhann, L., Lakeman, R., McGowan, P., Parkinson, M., Redmond, M., Sibitz, I., Stevenson, C. and Walsh, J. (2010) *Hear My Voice: the experience of discrimination of people with mental health problems in Ireland.* Dublin: Dublin City University. Available at: https://www.amnesty.ie/wp-content/uploads/2016/02/Hear_My_Voice_DCUReport.pdf (Accessed 16/11/2023).

Malcolm, E. (2003) 'Ireland's crowded madhouses': The Institutional Confinement of the Insane in Nineteenth and Twentieth-Century Ireland. In: Wright, D. and Porter, R., eds. (2003) *The Confinement of the Insane: International Perspectives, 1800–1965.* Cambridge: Cambridge University Press. 315-333.

Markey, P. (2013) *(Un)Comfortably Numb: Investigating the Lived Experience of Coercive Modern Irish Psychiatry.* Unpublished BA (Hons) Dissertation: Trinity College, Dublin.

Markey, P. (2017) *Were the Provisions of 'A Vision for Change' Meaningfully Implemented? An Autoethnographical Analysis.* Unpublished Master's Dissertation. Maynooth University.

Maser, J. D., Kaelber, C. and Weise, R. E. (1991) International use and attitudes toward DSM-III and DSM-III—R: Growing consensus in psychiatric classification. *Journal of*

Abnormal Psychology [online]. Available at: https://psycnet.apa.org/doiLanding?doi=10.1037%2F0021-843X.100.3.271 (Accessed 15/11/2023).

Mauger, A. (2018) *The Cost of Insanity in Nineteenth-Century Ireland: Public, Voluntary and Private Asylum Care.* London: Palgrave Macmillan.

May, T. (2006) *The Philosophy of Foucault.* New York: Routledge.

May, T. (2012) Poststructuralism. In: Chadwick, R., ed. (2012) *Encyclopedia of Applied Ethics.* 2nd ed. San Diego: Academic Press. 546-553.

McDaid, S. (2009) An equality of condition framework for user involvement in mental health policy and planning: evidence from participatory action research. *Journal of Disability & Society* [online]. 24(4)**,** 461-474.Available at: https://doi.org/10.1080/09687590902879064. (14/11/2023).

McDaid, S. (2010) Redefining Empowerment in Mental Health: An Analysis Using Hannah Arendt's Power Concept. *Journal of Power* [online]. 3(2)**,** 209-225. Available at: https://doi.org/10.1080/17540291.2010.493701 (Accessed 18/11/2023).

McDonnell, A. (2015) Transitioning: staff perspectives of service user involvement in mental health services. *The Irish Social Worker* [online]. October 2015, 14-18. Available at: http://hdl.handle.net/10147/580465 (Accessed 18/11/2023).

McGlashan, T., Walsh, B. and Woods, S. (2010) *The Psychosis-Risk Syndrome: Handbook for Diagnosis and Follow-Up.* Oxford University Press.

McLaughlin, H. (2008) What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next? *The British Journal of Social Work* [online]. 39(6)**,** 1101-1117. Available at: https://doi.org/10.1093/bjsw/bcm155 (Accessed 16/11/2023).

Mechanic, D. (1999) Mental Health and Mental Illness: Definitions and Perspectives. In: Horwitz, A. and Scheid, T. L., eds. (1999) *A Handbook for the Study of Mental Health: Social Contexts, Theories, And Systems.* New York: Cambridge University Press. 12-28.

Mental Health Commission (2005) *A Vision for A Recovery Model in Irish Mental Health Services*. Dublin: Mental Health Commission.

Mental Health Commission (2013) *Strategic Plan 2013–2015*. Ireland. Available at: https://www.mhcirl.ie/sites/default/files/2021-01/MHC-Strategic-Plan-2013-2015.pdf (Accessed 16/11/2023).

Mental Health Reform (2011) *Mental Health Reform Submission on Capacity Legislation*. Dublin: Mental Health Reform.

Mental Health Reform (2015) *A Vision for Change Nine Years On: A coalition analysis of progress* [online]. Dublin: Mental Health Reform. Available at: https://www.mentalhealthreform.ie/wp-content/uploads/2015/06/A-Vision-for-Change-web-final-2.pdf. (Accessed 17/11/2023).

Mental Health Reform (2017) *Mental Health Reform: submission on review of A Vision for Change* [online]. Dublin: Mental Health Reform. Available at: https://www.mentalhealthreform.ie/wp-content/uploads/2017/09/Submission-on-review-of-A-Vision-for-Change.pdf (Accessed 18/11/2023).

Mingus, W. and Zopf, B. (2010) White Means Never Having to Say You're Sorry: The Racial Project in Explaining Mass Shootings. *Social Thought & Research* [online]. 31**,** 57-77. Available at: http://www.jstor.org/stable/23333089 (Accessed 16/11/2023).

Moncrieff, J. (2008) The creation of the concept of an antidepressant: an historical analysis. *Social Science & Medicine* [online]. 66(11)**,** 2346-2355. Available at: https://www.sciencedirect.com/science/article/pii/S0277953608000129?via%3Dihub (Accessed 15/11/2023).

Moncrieff, J., Cooper, R. E., Stockmann, T., Amendola, S., Hengartner, M. P. and Horowitz, M. A. (2022) The serotonin theory of depression: a systematic umbrella review of the evidence. *Molecular Psychiatry* [online]. 28(8)**,** 3243-3256. Available at: https://doi.org/10.1038/s41380-022-01661-0 (Accessed 15/11/2023).

Morrison, C. and Dearden, A. (2013) Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service

design. *Health Policy* [online].112(3)**,** 179-186. Available at: https://www.sciencedirect.com/science/article/pii/S0168851013001334 (Accessed 16/11/2023).

Morse, J. M. (2004) Theoretical Saturation. In: Lewis-Beck, M. S., Bryman, A. and Futing Liao, T. eds., 2004. *The SAGE Encyclopedia of Social Science Research Methods.* Thousand Oaks: SAGE Publications, Inc. 1123-1123.

Murray, V., McKee, I., Miller, P. M., Young, D., Muir, W. J., Pelosi, A. J. and Blackwood, D. H. R. (2005) Dimensions and classes of psychosis in a population cohort: a four-class, four-dimension model of schizophrenia and affective psychoses. *Psychological Medicine* [online]. 35(4)**,** 499-510. Available at: https://www.cambridge.org/core/article/dimensions-and-classes-of-psychosis-in-a-population-cohort-a-fourclass-fourdimension-model-of-schizophrenia-and-affective-psychoses/797D4D20393EC23FC5C76A7AFE341300. (Accessed 16/11/2023).

Nail, T. (2016) Biopower and Control. In: Morar, N., Nail, T. and Smith, D. W., eds. (2016) *Between Deleuze and Foucault.* Edinburgh: Edinburgh University Press. 247-263.

Nario-Redmond, M. R. (2010) Cultural stereotypes of disabled and non-disabled men and women: consensus for global category representations and diagnostic domains. *British Journal of Social Psychology* [online]. 49(3)**,** 471-488. Available at: https://bpspsychub.onlinelibrary.wiley.com/doi/10.1348/014466609X468411 (Accessed 15/11/2023).

Nario-Redmond, M. R. (2019) *Ableism: The Causes and Consequences of Disability Prejudice.* New Jersey: John Wiley & Sons.

Nicholls, S., Giles, A. R. and Sethna, C. (2011) Perpetuating the 'lack of evidence' discourse in sport for development: Privileged voices, unheard stories and subjugated knowledge. *International Review for the Sociology of Sport* [online]. 46(3)**,** 249-264. Available at: https://journals.sagepub.com/doi/abs/10.1177/1012690210378273 (Accessed 18/11/2023).

Noorani, T. (2013) Service user involvement, authority and the 'expert-by-experience' in mental health. *Journal of Political Power* [online]. 6(1)**,** 49-68. Available at: https://doi.org/10.1080/2158379X.2013.774979. (Accessed 14/11/2023).

Nordgaard, J., Sass, L. A. and Parnas, J. (2013) The psychiatric interview: validity, structure, and subjectivity. *European Archives of Psychiatry and Clinical Neuroscience* [online]. 263(4)**,** 353-364. Available at: https://doi.org/10.1007/s00406-012-0366-z. (Accessed 15/11/2023).

Oliver, M. (1983) *Social Work with Disabled People.* Basingstoke: Macmillan.

Oliver, M. (2004) The Social Model in Action: If I had a hammer? In: Barnes, C. and Mercer, G. E., eds. (2004) *Implementing the Social Model of Disability: Theory and Research.* Leeds: Disability Press. 18-31.

Onken, S., Dumont, J., Ridgway, P., Dornan, D. and Ralph, R. (2002) *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators Phase One Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Recovery*. Virginia: National Association of State Mental Health Program Directors (NASMHPD). Available at: https://www.nasmhpd.org/sites/default/files/MHSIPReport%281%29.pdf (Accessed 16/11/2023).

O'Sullivan, E. and O'Donnell, I. (2007) Coercive confinement in the Republic of Ireland: The waning of a culture of control. *Punishment & Society* [online]. 9(1)**,** 27-48. Available at: https://journals.sagepub.com/doi/abs/10.1177/1462474507070549. (Accessed 14/11/2023).

Otte, S., Vasic, N., Nigel, S., Streb, J., Ross, T., Spitzer, C., Grabe, H. J. and Dudeck, M. (2017) Different yet similar? Prisoners versus psychiatric patients – A comparison of their mental health. *European Psychiatry* [online]. 44**,** 97-103. Available at: https://www.cambridge.org/core/article/different-yet-similar-prisoners-versus-psychiatric-patients-a-comparison-of-their-mental-health/9F989B32D327F58BA01FE201E9442FFA (Accessed 16/11/2023).

Paris, J. (2015) *Overdiagnosis in Psychiatry: How Modern Psychiatry Lost Its Way While Creating a Diagnosis for Almost All of Life's Misfortunes.* New York: Oxford University Press.

Paris, J. and Phillips, J. E. (2013) *Making the DSM-5: Concepts and Controversies.* New York: Springer Science + Business Media.

Park, J. S. and Ahn, H. Y. (2013) Direct-to-Consumer (DTC) Antidepressant Advertising and Consumer Misperceptions About the Chemical Imbalance Theory of Depression: The Moderating Role of Skepticism. *Health Marketing Quarterly* [online]. 30(4)**,** 362-378. Available at: https://doi.org/10.1080/07359683.2013.847337. (Accessed 13/11/2023).

Parker, J. D. (2009) Subjugated Knowledges and Dedisciplinarity in Cultural Studies Pedagogy. In: Claycomb, R. and Kristensen, R., eds. (2009) *Writing Against the Curriculum: Antidisciplinarity in the Writing and Cultural Studies Classroom.* New York: Lexington Books. 35-56.

Patton, D. (2013) Strategic direction or operational confusion: level of service user involvement in Irish acute admission unit care. *Journal of Psychiatric Mental Health Nursing* [online]. 20(5)**,** 387-395. Available at: https://doi.org/10.1111/j.1365-2850.2012.01927.x (Accessed 18/11/2023).

Perkins, R. and Goddard, K. (2004) Reality out of the Rhetoric: Increasing User Involvement in a Mental Health Trust. *Mental Health Review Journal* [online]. 9(1)**,** 21-24. Available at: https://doi.org/10.1108/13619322200400006 (Accessed 16/11/2023).

Pescosolido, B. A. (2013) The Public Stigma of Mental Illness: What Do We Think; What Do We Know; What Can We Prove? *Journal of Health and Social Behavior* [online]. 54(1)**,** 1-21. 10.1177/0022146512471197. Available at: https://journals.sagepub.com/doi/abs/10.1177/0022146512471197 (Accessed 17/11/2023).

Pescosolido, B. A., Manago, B. and Monahan, J. (2019) Evolving Public Views On The Likelihood Of Violence From People With Mental Illness: Stigma And Its Consequences. *Health Affairs (Milwood)* [online]. 38(10)**,** 1735-1743. Available at: https://www.healthaffairs.org/doi/10.1377/hlthaff.2019.00702 (Accessed 17/11/2023).

Pilgrim, D. (2005) Protest and Co-option – the Voice of Mental Health Service Users. In: Bell, A. and Lindley, P., eds. (2005) *Beyond the Water Towers: The Unfinished Revolution In Mental Health Services 1985–2005.* London: The Sainsbury Centre for Mental Health. 17-26.

Pilgrim, D. (2008) `Recovery' and current mental health policy. *Chronic Illness* [online]. 4(4)**,** 295-304. Available at: https://journals.sagepub.com/doi/abs/10.1177/1742395308097863 (Accessed 16/11/2023).

Pilgrim, D. (2017) *Key Concepts In Mental Health.* 4th ed. Los Angeles: SAGE.

Polkinghorne, D. E. (1995) Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education* [online]. 8(1)**,** 5-23. Available at: https://doi.org/10.1080/0951839950080103 (Accessed 18/11/2023).

Poulantzas, N. (1967) Marxist Political Theory in Great Britain. *New Left Review,* 1(43).

Poulantzas, N. (1968) The Problem of the Capitalist State. *New Left Review,* (58)**,** 67-78.

Poulantzas, N. (1978a) *Classes in Contemporary Capitalism.* London: Verso Books.

Poulantzas, N. (1978b) *Political Power and Social Classes.* London: Verso Books.

Powell, F. (1981) The Irish Poor Law controversy. *Social Policy & Administration* [online]. 15(3)**,** 286-303. Available at: https://doi.org/10.1111/j.1467-9515.1981.tb00683.x. (Accessed 16/11/2023).

Prior, P. M. (2005) Murder and Madness: Gender and the Insanity Defense in Nineteenth-Century Ireland. *New Hibernia Review/Iris Éireannach Nua* [online]. 9(4)**,** 19-36. Available at: http://www.jstor.org/stable/20558032 (Accessed 16/11/2023).

Prior, P. M. (2012) *Asylums, Mental Health Care and the Irish, 1800-2010.* Kildare: Irish Academic Press.

Rabinow, P. ed. (1984) *The Foucault Reader.* New York: Pantheon Books.

Ragins, B. R. (2008) Disclosure Disconnects: Antecedents and Consequences of Disclosing Invisible Stigmas across Life Domains. *The Academy of Management Review* [online]. 33(1)**,** 194-215. Available at: http://www.jstor.org/stable/20159383 (Accessed 16/11/2023).

Ragins, B. R. (2012) Relational Mentoring: A Positive Approach to Mentoring at Work. In: Spreitzer, G. M. and Cameron, K. S., eds. (2012) *The Oxford Handbook of Positive Organizational Scholarship.* Oxford Academic: Oxford University Press. 520-536.

Ragins, M. and Sunkel, C. (2023) The Recovery Model and Other Rehabilitative Approaches. In: Tasman, A., Riba, M. B., Alarcón, R. D., Alfonso, C. A., Kanba, S., Ndetei, D. M., Ng, C. H., Schulze, T. G. and Lecic-Tosevski, D., eds. (2023) *Tasman's Psychiatry.* Cham: Springer International Publishing. 1-47.

Raine, A. (2006) Schizotypal personality: neurodevelopmental and psychosocial trajectories. *Annual Review of Clinical Psychology* [online]. 2**,** 291-326. Available at: https://www.annualreviews.org/doi/10.1146/annurev.clinpsy.2.022305.095318 (Accessed 14/11/2023).

Reaume, G. (2006) Mad People's History. *Radical History Review* [online]. (94)**,** 170-182. Available at: https://doi.org/10.1215/01636545-2006-94-170 (Accessed 15/11/2023).

Reed, B., Cowin, L., O'Meara, P. and Wilson, I. (2019) Professionalism and Professionalisation in the Discipline of Paramedicine. *Australasian Journal of Paramedicine* [online].16**,** 1-10. Available at: https://journals.sagepub.com/doi/abs/10.33151/ajp.16.715 (Accessed 18/11/2023).

Ridgway, P. (2001) ReStorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal* [online]. 24(4)**,** 335-343. Available at: https://psycnet.apa.org/doiLanding?doi=10.1037%2Fh0095071 (Accessed 16/11/2023).

Ringland, K. E., Nicholas, H., Kornfield, R., Lattie, E. G., Mohr, D. C. and Reddy, M. (2019). *Understanding Mental Ill-health as Psychosocial Disability: Implications for Assistive Technology.* Unpublished paper presented at: Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility. Pittsburgh, 28-30 October 2019.

Riva, M. A., Tremolizzo, L., Spicci, M., Ferrarese, C., De Vito, G., Cesana, G. C. and Sironi, V. A. (2011) The Disease of the Moon: The Linguistic and Pathological Evolution of the English Term “Lunatic”. *Journal of the History of the Neurosciences* [online]. 20(1)**,** 65-73. Available at: https://doi.org/10.1080/0964704X.2010.481101 (Accessed 16/11/2023).

Rocca, E. and Anjum, R. L. (2020) Complexity, Reductionism and the Biomedical Model. In: Anjum, R. L., Copeland, S. and Rocca, E., eds. (2020) *Rethinking Causality, Complexity and Evidence for the Unique Patient: A CauseHealth Resource for Healthcare Professionals and the Clinical Encounter.* Cham: Springer International Publishing. 75-94.

Romme, M. and Escher, S. E. (2011) *Psychosis as a Personal Crisis: An Experience-Based Approach.* New York: Routledge.

Romsland, G. I., Milosavljevic, K. L. and Andreassen, T. A. (2019) Facilitating non-tokenistic user involvement in research. *Research Involvement and Engagement* [online]. 5(1)**.** Available at: https://doi.org/10.1186/s40900-019-0153-3 (Accessed 16/11/2023).

Rössler, W. (2016) The stigma of mental disorders: A millennia-long history of social exclusion and prejudices. *EMBO reports* [online]. 17(9)**,** 1250-1253. Available at: https://www.embopress.org/doi/abs/10.15252/embr.201643041 (Accessed 16/11/2023).

Rouse, J. (1994) Power/Knowledge. In: Gutting, G. ed. (1994) *The Cambridge Companion to Foucault.* Cambridge: Cambridge University Press. 92-114.

Rudnick, A. (2002) The molecular turn in psychiatry: A philosophical analysis. *Journal of Medicine and Philosophy* [online]. 27(3)**,** 287-296. Available at: https://doi.org/10.1076/jmep.27.3.287.2979 (Accessed 17/11/2023).

Saarni, S. I., Viertiö, S., Perälä, J., Koskinen, S., Lönnqvist, J. and Suvisaari, J. (2010) Quality of life of people with schizophrenia, bipolar disorder and other psychotic disorders. *The British Journal of Psychiatry* [online]. 197(5)**,** 386-394. Available at: https://doi.org/10.1192/bjp.bp.109.076489 (Accessed 13/11/2023).

Sarah, S. (2015) Homicide. In: Healy, D. ed. *The Routledge Handbook of Irish Criminology.* Abingdon: Routledge.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H. and Jinks, C. (2018) Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* [online]. 52(4)**,** 1893-1907. Available at: https://doi.org/10.1007/s11135-017-0574-8 (Accessed 16/11/2023).

Scheff, T. J. (1966) *Being Mentally III: A Sociological Theory.* Chicago: Aldine.

Schirmann, F. (2013) Badness, madness and the brain – the late 19th-century controversy on immoral persons and their malfunctioning brains. *History of the Human Sciences* [online]. 26(2)**,** 33-50. Available at: https://journals.sagepub.com/doi/abs/10.1177/0952695113482317 (Accessed 16/11/2023).

Schroder, H. S., Russman Block, S. and Moser, J. S. (2022) Chemical imbalance and etiological beliefs about depression among college students. *Journal of American College Health* [online]. 1-8. Available at: https://doi.org/10.1080/07448481.2022.2098037 (Accessed 15/11/2023).

Scull, A., MacKenzie, C. and Hervey, N. (1998) *Masters of Bedlam: The Transformation of the Mad-Doctoring Trade.* Princeton: Princeton University Press.

Secker, J., Membrey, H., Grove, B. and Seebohm, P. (2002) Recovering from Illness or Recovering your Life? Implications of Clinical Versus Social Models of Recovery from Mental Health Problems for Employment Support Services. *Disability & Society* [online]. 17(4)**,** 403-418. Available at: https://doi.org/10.1080/09687590220140340 (Accessed 16/11/2023).

Sedler, M. J. (2016) Medicalization in psychiatry: the medical model, descriptive diagnosis, and lost knowledge. *Medicine, Health Care and Philosophy* [online]. 19(2)**,** 247-252. Available at: https://doi.org/10.1007/s11019-015-9670-5 (Accessed 16/11/2023).

Seidman, A. and Seidman, R. B. (2011) Instrumentalism 2.0: Legislative Drafting for Democratic Social Change. *Legisprudence* [online]. 5(1)**,** 95-142. Available at: https://doi.org/10.5235/175214611796404831 (Accessed 16/11/2023).

Seidman, I. (2013) *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences.* 4th ed. New York: Teachers College Press.

Shakespeare, T. (2006) The Social Model Of Disability. In: Davis, L. J. ed. (2006) *The Disability Studies Reader*. London: Psychology Press. 2-197.

Shorter, E. (2022) The history of nosology and the rise of the Diagnostic and Statistical Manual of Mental Disorders. *Dialogues in Clinical Neuroscience* [online]. 17(1)**,** 59-67. Available at: https://doi.org/10.31887/DCNS.2015.17.1/eshorter (Accessed 16/11/2023).

Siegler, M., Osmond, H. and Mann, H. (1971) Laing's Models Of Madness. *Salmagundi* [online]. (16)**,** 84-104. Available at: http://www.jstor.org/stable/40546637 (Accessed 15/11/2023).

Smith, K. (2014) Mental health: A world of depression. *Nature* [online]. 515(7526)**,** 180-181. Available at: https://www.nature.com/articles/515180a#citeas (Accessed 14/11/2023).

Snow, M. E., Tweedie, K. and Pederson, A. (2018) Heard and valued: the development of a model to meaningfully engage marginalized populations in health services planning. *BMC Health Services Research* [online]. 18(1). Available at: https://doi.org/10.1186/s12913-018-2969-1 (Accessed 16/11/2023).

Sowislo, J. F., Gonet-Wirz, F., Borgwardt, S., Lang, U. E. and Huber, C. G. (2017) Perceived Dangerousness as Related to Psychiatric Symptoms and Psychiatric Service Use – a Vignette Based Representative Population Survey. *Scientific Reports* [online]. 7(1)**,** 45716. Available at: https://doi.org/10.1038/srep45716 (Accessed 17/11/2023).

Sparkes, A. C. (2020) Autoethnography: Accept, Revise, Reject? An Evaluative Self Reflects. *Qualitative Research in Sport, Exercise and Health* [online]. 12(2)**,** 289-302. Available at: https://doi.org/10.1080/2159676X.2020.1732453 (Accessed 18/11/2023).

Sparkes, A. C. (2021) When Judgment Calls: Making Sense of Criteria for Evaluating Different Forms of Autoethnography. In: Holman Jones, S., Adams, T. E. and Ellilä, H., eds. (2021) *Handbook of Autoethnography.* 2nd ed. New York: Routledge. 263-276.

Spicker, P. (2008) *Social Policy: Themes and Approaches.* 2nd ed. Bristol: Policy.

Stone-Johnson, C. (2014) Parallel Professionalism in an Era of Standardisation. *Teachers and Teaching: Theory and Practice* [online]. 20(1)**,** 74-91. Available at: https://doi.org/10.1080/13540602.2013.848514 (Accessed 18/11/2023).

Study Group on the Development of the Psychiatric Services (1984) *The psychiatric services - planning for the future: report of a study group on the development of the psychiatric services*. Dublin: The Stationary Office.

Sugiura, K., Mahomed, F., Saxena, S. and Patel, V. (2020) An end to coercion: rights and decision-making in mental health care. *Bulletin of the World Health Organisation* [online]. 98(1)**,** 52-58. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6933425/pdf/BLT.19.234906.pdf/ (Accessed 16/11/2023).

Surís, A., Holliday, R. and North, C. S. (2016) The Evolution of the Classification of Psychiatric Disorders. *Behavioral Sciences* [online]. 6(1). Available at: https://www.mdpi.com/2076-328X/6/1/5 (Accessed 14/11/2023)

Svensson, B. and Hansson, L. (1994) Patient satisfaction with inpatient psychiatric care: The influence of personality traits, diagnosis and perceived coercion. *Acta Psychiatrica Scandinavica* [online]. 90(5)**,** 379-384. Available at: https://onlinelibrary.wiley.com/doi/10.1111/j.1600-0447.1994.tb01610.x (Accessed 15/11/2023).

Swords, C. and Houston, S. (2020) Exploring the Concept of Recovery in Irish Mental Health Services: A Case Study of Perspectives within an Inter-Professional Team. *Irish Journal of Applied Social Studies* [online]. 20(1)**,** 31-46. Available at: https://doi.org/10.21427/9jw9-9j31. (Accessed 18/11/2023).

Swords, C. and Houston, S. (2021) Using Social Constructionism to Research the Recovery Movement in Mental Health in Ireland: A Critical Reflection on Meta-theory Shaping the Inquiry. *Irish Journal of Applied Social Studies* [online]. 21(1). Available at: https://doi.org/10.21427/9jw9-9j31. (Accessed 18/11/2023).

Swords, C. and Houston, S. (2023) Exploring the Evidence for the Paradigms of Recovery and Social Work Converging in Mental Health Service Delivery Worldwide: Reflections

from an Irish Case Study. *International Journal of Environmental Research and Public Health* [online]. 20(15)**,** 6460. Available at: https://www.mdpi.com/1660-4601/20/15/6460 (Accessed 18/11/2023).

Szasz, T. S. (1960) *The Myth of Mental Illness: Foundations Of a Theory of Personal Conduct*. US: Haper & Row.

Szasz, T. S. (1970) *Ideology and Insanity: Essays on The Psychiatric Dehumanization of Man.* Oxford: Doubleday.

Szasz, T. S. (1973) Mental Illness as a Metaphor. *Nature* [online]. 242(5396)**,** 305-307. Available at: https://doi.org/10.1038/242305a0 (Accessed 14/11/2023).

Szasz, T. S. (2007) *Coercion as Cure: A Critical History of Psychiatry.* New Jersey, US: Transaction Publishers.

Taylor, B. and Francis, K. (2013) *Qualitative Research in the Health Sciences: Methodologies, Methods and Processes.* London: Routledge.

Tew, J. (2002) *Social Theory, Power and Practice.* New York: Springer.

Tew, J. (2005) *Social Perspectives in Mental Health: Developing Social Models to Understand and Work with Mental Distress.* London: Jessica Kingsley Publishers.

Tew, J. (2006) Understanding Power and Powerlessness: Towards a Framework for Emancipatory Practice in Social Work. *Journal of Social Work* [online]. 6(1)**,** 33-51. Available at: https://journals.sagepub.com/doi/abs/10.1177/1468017306062222. (Accessed 14/11/2023).

Tew, J. (2008) Social Perspectives on Mental Distress. In: Stickley, T. and Bassett, T., eds., (2008) *Learning about Mental Health Practice*. New Jersey: John Wiley & Sons Ltd. 233-252.

Tew, J. (2011) *Social Approaches to Mental Distress.* London: Bloomsbury Publishing.

Tew, J., Gell, C. and Foster, S. (2004) *Learning from Experience: Involving service users and carers in mental health education and training*. Trent: National Institute for Mental Health in England.

Tew, J., Ramon, S., Slade, M., Bird, V., Melton, J. and Le Boutillier, C. (2012) Social Factors and Recovery from Mental Health Difficulties: A Review of the Evidence. *The British Journal of Social Work* [online]. 42(3)**,** 443-460. Available at: https://doi.org/10.1093/bjsw/bcr076 (Accessed 14/11/2023).

The Health & Social Care Regulatory Forum (2009) *Framework for Public & Service User Involvement in Health and Social Care Regulation in Ireland*. Available at: https://www.thepsi.ie/Libraries/News_-_Archive/Final_Framework_for_Public___Service_User_Involvement.sflb.ashx. (Accessed 14/11/2023).

Thoits, P. A. (1999) Sociological Approaches to Mental Illness. In: Horwitz, A.V. and Scheid, T. L. eds.(1999) *A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems.* New York: Cambridge University Press. 121-138.

Thompson, M. (2010) *Mad Or Bad?: Race, Class, Gender, and Mental Disorder in the Criminal Justice System.* Texas: LFB Scholarly Pub.

Thompson, N. (2018) *Mental Health and Well-Being: Alternatives to The Medical Model.* New York: Routledge.

Thurschwell, P. (2009) *Sigmund Freud.* 2nd ed. London: Routledge.

Timimi, S. (2014) No more psychiatric labels: Why formal psychiatric diagnostic systems should be abolished. *International Journal of Clinical and Health Psychology* [online]. 14(3)**,** 208-215. Available at: https://doi.org/10.1016/j.ijchp.2014.03.004. (Accessed 15/11/2023).

Townsend, M. (2015) *Psychiatric Mental Health Nursing: Concepts of Care in Evidence-Based Practice.* 8th ed. Philadelphia: F. A. Davis Company.

Tullis, J. (2013) Self and Others: Ethics in Autoethnographic Research. In: Holman Jones, S., Adams, T. E. and Ellis, C., eds. (2013) *Handbook of Autoethnography.* California: Left Coast Press. 244-261.

UK Parliament *Criminal Lunatics (Ireland) Act, 1838.* United Kingdom: The Parliamentary Archives.

UK Parliament *Irish Lunatic Asylums for the Poor Act 1817.* United Kingdom: The Parliamentary Archives.

UK Parliament *Lunacy (Ireland) Act, 1821.* United Kingdom: The Parliamentary Archives.

UK Parliament *Lunacy Regulation (Ireland) Act 1871.* United Kingdom: The Parliamentary Archives.

UK Parliament *Marriage of Lunatics Act, 1811.* United Kingdom: The Parliamentary Archives.

United Nations (2006) *Convention on the Rights of Persons with Disabilities*. In: *Treaty Series 2515.* Geneva: United Nations.

Van Dyke, D. J. and Hovis, R. (2014) Systemic Critique of the DSM-5: A Medical Model for Human Problems and Suffering. *Journal of Psychology and Christianity* [online]. 33(1)**,** 84-90. Available at: https://may.idm.oclc.org/login?url=https://www.proquest.com/scholarly-journals/systemic-critique-dsm-5-medical-model-human/docview/1533427870/se-2?accountid=12309 (Accessed 18/11/2023).

Velpry, L. and Eyraud, B. (2014) Confinement and Psychiatric Care: A Comparison Between High-Security Units for Prisoners and for Difficult Patients in France. *Culture, Medicine and Psychiatry* [online]. 38(4)**,** 550–577. Available at: https://link.springer.com/article/10.1007/s11013-014-9400-0 (Accessed 16/11/2023).

Vygotsky, L. S. (1968) *Thought and Language (Newly Revised, Translated, and Edited by Alex Kozulin).* Cambridge MA: MIT Press.

Walby, S. (1989) Theorising Patriarchy. *Sociology* [online]. 23(2)**,** 213-234. Available at: https://journals.sagepub.com/doi/abs/10.1177/0038038589023002004 (Accessed 14/11/2023).

Walby, S. and Towers, J. (2018) Untangling the concept of coercive control: Theorizing domestic violent crime. *Criminology & Criminal Justice* [online]. 18(1)**,** 7-28. Available at: https://journals.sagepub.com/doi/abs/10.1177/1748895817743541 (Accessed 15/11/2023).

Walsh, D. (2008) The Lunatic Asylums of Ireland 1825-1839. *Irish Journal of Psychological Medicine* [online]. 25(4)**,** 151-156. Available at: https://www.cambridge.org/core/article/lunatic-asylums-of-ireland-18251839/E859DF23D297F0779FD1B429ACB140B7 (Accessed 16/11/2023).

Watermeyer, B. (2012) *Towards a Contextual Psychology of Disablism.* London: Routledge.

Weare, S. (2017) Bad, Mad or Sad? Legal Language, Narratives, and Identity Constructions of Women Who Kill their Children in England and Wales. *International Journal for the Semiotics of Law - Revue internationale de Sémiotique juridique* [online]. 30(2)**,** 201-222. Available at: https://doi.org/10.1007/s11196-016-9480-y (Accessed 17/11/2023).

Weber, M. (1922) *Economy and Society.* Berkeley: University of California Press.

Weeks, W. (1988) De-Professionalisation or a New Approach to Professionalism? *Australian Social Work* [online]. 41(1)**,** 29-37. Available at: https://doi.org/10.1080/03124078808550030 (Accessed 18/11/2023).

Whitley, R. (2015) Global Mental Health: concepts, conflicts and controversies. *Epidemiology and Psychiatric Sciences* [online]. 24(4)**,** 285-291. Available at: https://www.cambridge.org/core/journals/epidemiology-and-psychiatric-sciences/article/global-mental-health-concepts-conflicts-and-controversies/251EAF01AF9298A82C4DB11C10D338A4 (Accessed 18/11/2023).

Wilczynski, A. (1991) Images of Women Who Kill Their Infants: The Mad and the Bad. *Women & Criminal Justice* [online]. 2(2)**,** 71-88. Available at: https://doi.org/10.1300/J012v02n02_05 (Accessed 17/11/2023).

Wilczynski, A. (1997) Mas Or Bad? Child-Killers, Gender and the Courts. *The British Journal of Criminology* [online]. 37(3)**,** 419-436. Available at: http://www.jstor.org/stable/23637950 (Accessed 17/11/2023).

Winkler, I. (2018) Identity Work and Emotions: A Review. *International Journal of Management Reviews* [online]. 20(1)**,** 120-133. Available at: http://10.1111/ijmr.12119 (Accessed 18/11/2018).

Witkin, S. L. ed. (2014) *Narrating Social Work Through Autoethnography.* New York: Columbia University Press.

World Health Organization (2022) *Mental Health* [Online]. Available at: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response (Accessed 13/11/2023).

Wright, D. (1997) Getting Out of the Asylum: Understanding the Confinement of the Insane in the Nineteenth Century. *Social History of Medicine* [online]. 10(1)**,** 137-155. Available at: https://doi.org/10.1093/shm/10.1.137 (Accessed 16/11/2023).

Wright, D., Day, S., Smith, J. and Flis, N. (2008) A Janus-Like Asylum: The City and the Institutional Confinement of the Mentally Ill in Victorian Ontario. *Urban History Review/Revue d'histoire urbaine* [online]. 36(2)**,** 43-52. Available at: http://www.jstor.org/stable/44136663 (Accessed 16/11/2023).

Young, R. E., Goldberg, J. O., Struthers, C. W., McCann, D. and Phills, C. E. (2019) The Subtle Side of Stigma: Understanding and Reducing Mental Illness Stigma from a Contemporary Prejudice Perspective. *Journal of Social Issues* [online]. 75(3)**,** 943-971. Available at: https://doi.org/10.1111/josi.12343. (Accessed 15/11/2023).

Zola, I. K. (1972) Medicine as an Institution of Social Control. *The Sociological Review* [online]. 20(4)**,** 487-504. Available at: https://journals.sagepub.com/doi/abs/10.1111/j.1467-954X.1972.tb00220.x. (Accessed 14/11/2023).

APPENDICES

APPENDIX A

Information and Consent Form and list of Mental Health Supports for interview participants.

INFORMATION AND CONSENT FORM FOR RESEARCH PARTICIPANTS
Information Sheet

Purpose of the Study. I am Paul Markey, a PhD student in the Department of Applied Social Studies, Maynooth University.

This study is concerned with individuals' experiences of the Irish mental health services from 2006-2019 to better understand and analyse the effectiveness of the Government's mental health strategy at the time, *A Vision for Change*.

What will the study involve? The study will involve participating in a single one-to-one interview of approximately one hour with myself regarding personal experience with the Irish mental health services during the years 2006-2019. The interviews are intended to be conducted face-to-face, in a location that is convenient for you. However, with the ongoing Covid-19 public health emergency and the associated evolving government guidelines to combat the virus, the interview may instead be conducted securely online using Microsoft Teams. Only the audio of online interviews will be recorded in line with Maynooth University guidelines, and it will be anonymised and stored securely at all times. Both the researcher and participant will agree to respect each other's confidentiality in the same manner as they would in a face-to-face interview, with only the sanctioned audio recording of the interview, anonymised and securely stored by the researcher, being permitted by both parties.

Who has approved this study? This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee. You may have a copy of this approval if you request it.

Why have you been asked to take part? You have been asked because you have specific and unique knowledge of and expertise concerning the Irish mental health services during the lifespan of *A Vision for Change* from your first-hand perspective.

Do you have to take part? No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to participate in a one-to-one interview with the researcher. It is entirely up to you to decide whether you would like to take part or not. If you decide to do so, you will be asked to sign a consent form and will be given a copy of both the consent form and the information sheet for your own records. If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up

until such time as the research is submitted as a thesis. A decision to withdraw at any time, or a decision not to take part, will not affect your relationships with Maynooth University.

What information will be collected? The information to be collected will relate to your experiences and engagement with the Irish mental health services between 2006-2019. The information will center on your perspectives on the efficacy of mental health policy and the mental health services from your interaction with them, based upon your area of expertise from an expert-by-experience, service-user, governmental, civil society, or medical background.

Will your participation in the study be kept confidential? Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time, and all potential identifiers in your information will be anonymised to protect your privacy. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on MU PC or servers and will be accessed only by Paul Markey, Dr Seamus Taylor, and Dr Joe Larragy.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

'It must be recognised 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.'

What will happen to the information which you give? All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the Principal Investigator (PI), Paul Markey). Manual data will be shredded confidentially, and electronic data will be reformatted or overwritten by the PI in Maynooth University.

What will happen to the results? The research will be written up and presented as a dissertation in fulfilment of the Maynooth University PhD Applied Social Studies doctoral programme. The research may be presented at conferences or published as a book, or in articles in academic journals. A copy of the research findings will be made available to you upon request. Articles or books may be written employing the original anonymised dataset.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part, though it is possible that talking about your experience may cause some distress.

What if there is a problem? At the end of our interview, I will discuss with you how you found the experience and how you are feeling. If you experience any distress following the interview, you may contact the appropriate support for you from a list of mental health services you are provided with overleaf, depending on the nature of your distress. You may contact my Supervisors, Dr Seamus Taylor at seamus.taylor@mu.ie, or Dr Joe Larragy at joe.larragy@mu.ie, if you feel the research has not been carried out as described above.

Any further queries? If you need any further information, you can contact me:
Paul Markey,
Department of Applied Social Studies,
Maynooth University,
paul.markey.2017@mumail.ie

If you agree to take part in the study, please complete and sign the consent form overleaf.

Thank you for taking the time to read this

Mental Health Supports

- **The Samaritans** are a 24/7 freephone service, available to anybody in Ireland experiencing emotional distress or suicidal ideation. They are contactable by telephoning 116 123 anytime of the day or night. Alternatively, you can visit https://www.samaritans.org/?nation=ireland.
- **GROW** is a mental health organisation helping people who have or are suffering from mental health problems through local group meetings. Members are helped to recover from all forms of mental breakdown, through the support members give each other. They are contactable by telephoning 01 840 8236. Alternatively, you can visit https://grow.ie/.
- **Aware** provide support and assistance to people affected by depression, bipolar and mood disorders. Aware has support groups around the country. Helpline and next-day email support service available. Aware have a freephone helpline that is open Monday-Sunday from 10am to 10pm - 1800 80 48 48. Alternatively, visit https://www.aware.ie/.
- **Turn2Me** offer free online counselling and online support groups for people over the age of 18. Visit turn2me.org.
- **Bodywhys** provides support to people affected by eating disorders and their family. They offer a helpline at 1890 200 444, and online support groups. Visit www.bodywhys.ie.
- **Crosscare** offer a wide variety of outreach services in different locations: homeless, migrants, Travellers, drugs and alcohol addiction, teen counselling, carer support, and also disability awareness programmes. Visit www.crosscare.ie.
- **Irish Friends of the Suicide Bereaved** provide counselling and support group for those bereaved by suicide. Telephone 021 431 6722.
- **Pieta House** offers specialised treatment to clients who self-harm, suffer from suicidal ideation or have made multiple suicide attempts. Clients receive an intensive programme of one-to-one counselling lasting about four to six weeks. Pieta House is a non-profit organisation and their service is free of charge. They now have branches at Ballyfermot, Finglas, Lucan, Limerick, Tallaght, Kerry, Tipperary and Galway. Telephone 1800 247 247 or visit www.pieta.ie.
- **Women's Aid** offer a 24hr National Freephone Helpline, providing confidential information, support and understanding to women in, who are being abused by current or former boyfriends, girlfriends, partners, or spouses. Telephone 1800 341 900.
- **The Rape Crisis Centre** National 24-Hour Helpline can be contacted at 1800 77 8888, at any time of day or night. They offer a free and confidential listening and support service for anyone who has been raped, sexually assaulted, sexually harassed, or sexually abused at any time in their lives. It is also possible to email to counselling@rcc.ie For those who are deaf or hard of hearing, we provide a text service, operating Mon-Fri from 8am to 6:30pm, at 086-8238443.
- **Traveller Counselling Service** is a counselling service designed to meet the needs of the Traveller community. It respects Traveller culture, identity, values, and norms and works from a perspective of culture centered counselling and psychotherapy. It is free and open to all members of the Travelling Community over the age of 18. Contact 086 308 1476.
- **The Gay Switchboard** is a helpline offering anonymous support for LGBT individuals, operating from 6:30am-9:00pm Mon-Fri, and 4pm-6pm Sat-Sun. Phone 01 8721055.

Consent Form

I……agree to participate in Paul Markey's research study titled *Policy Analysis of 'A Vision for Change' Mental Health Policy*.

Please tick each statement below:

The purpose and nature of the study has been explained to me verbally & in writing. I've been able to ask questions, which were answered satisfactorily. ☐

I am participating voluntarily. ☐

I give permission for my interview with Paul Markey to be audio-recorded. ☐

I understand that the interview with Paul Markey is intended to take place as a face-to-face interview, but this may not be feasible in view of the Covid-19 guidance at the time of the interview with Paul Markey ☐

In the event that Covid-19 restrictions in place at the time of the interview with Paul Markey make face-to-face interviews impossible, I give permission for my interview with Paul Markey to take place online using Microsoft Teams.
☐

I understand that I can withdraw from the study, without repercussions, at any time, whether that is before it starts or while I am participating. ☐

I understand that I can withdraw permission to use the data right up to the submission of the thesis [June 2023]. ☐

It has been explained to me how my data will be managed and that I may access it on request. ☐

I understand the limits of confidentiality as described in the information sheet. ☐

[*Select as appropriate*]
I agree to quotation/publication of extracts from my interview. ☐
I do not agree to quotation/publication of extracts from my interview. ☐

I agree for my data to be used for further research projects ☐
I do not agree for my data to be used for further research projects ☐

I agree for my data, once anonymised, to be retained for 10 years on the Maynooth University secure server, to be deleted May 2033. ☐

Signed……. Date…….

Participant Name in block capitals ……...

I the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Signed……. Date…….

Researcher Name in block capitals ……...
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@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Two copies to be made: 1 for participant, 1 for PI

APPENDIX B

Draft interview schedule intended for interviews with all stakeholders envisaged in original research design but limited to EBEs in practice.

DRAFT INTERVIEW SCHEDULE

This draft schedule outlines the research areas which will be covered in the questions that will be asked in the key-informant interviews. At this stage, the topics listed below in relation to these research areas are necessarily broad. The research areas outlined here will not apply to every interviewee. The topics discussed in interviews will depend on the participant in question, and their area of expertise: i.e., expert by experience, service-user, governmental, medical, civil society/NGO.

- Invitation to discuss initial engagement with the Irish mental health services (if service-user or expert by experience). Asking these participants to describe the trajectory of their experience with the services, how long they accessed public mental health services between 2006-2019, and to describe their overall experience and whether they found their engagement with the services positive or negative.
- Asking service-users and experts by experience if they availed of/had made available to them services and treatment options specifically provided for in *A Vision for Change*, such as occupational therapists, psychologists, talk therapy, etc. Asking these participants if they benefitted from/would have liked these treatment options in instances where they were not made available. Asking what they would have liked to have seen done differently during their engagement with the services.
- Asking self-described experts by experience to detail the process of critical self-reflection and critical reflection of the services/experiences they underwent which led to them developing their unique expertise, and what their expertise is and means to them.
- Following on from this, asking whether experts by experience, especially those who engage(d) in activism/lobbying, felt/feel heard/want(ed) to feel heard and involved with mental health policy formation and the monitoring of implementation. Inquiring about how they perceive the makeup of recognised policy drafters and decision-makers, and whether they feel that these decision-makers adequately represent the positions of service-users and experts by experience.
- Asking experts by experience whether they feel specific recommendations made in *A Vision for Change* were implemented or not based upon their experience of the services and their expertise.
- Discussing the *A Vision for Change* policy document and its provisions and recommendations with experts from the governmental, medical, civil society/NGO spheres, how they understand these provisions, and to what degree they feel they are adequate or inadequate. Inviting them to discuss any policy

provisions/recommendations they hold particularly significant positions on based upon their specific expertise or experience with the implementation of this policy.

- From these groups of recognised experts, inviting those who were involved in the decision-making and policy drafting stages of *A Vision for Change* to describe their experience of this process. Following on from this, asking these experts if there were provisions they would have preferred to have included in *A Vision for Change* that were not included, or if there were provisions included that they would have preferred to have been omitted from the policy, based upon their area of expertise, and the reasons behind these preferences.
- In a broader sense amongst all participants, their experiences of the Irish mental health services, and *A Vision for Change* between 2006 and 2019, will be discussed. This will involve discussions of the significant moments that are important to each key informant, whether positive, negative, or neither. Questions will be asked by myself based upon the provisions made in A Vision for Change to gauge whether participants' experiences indicate these provisions were or were not implemented during the lifespan of the policy. Those in positions of power regarding drafting the policy will be asked about the policy-making process, their expertise, and their input during this process, and whether they felt satisfied with the final policy document and its provisions or not. If there are areas of the policy that these experts were not satisfied with, they will be invited to elaborate on the reasons why this is, and what they would have changed about them based on their expertise.