

In safe hands: Empowering young people with disabilities who receive assistance with intimate personal care

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Abstract: This article explores the potential for social workers to engage in empowering relationships with young people whose disabilities necessitate that they receive help with certain physical functions, some of which would be termed both personal and intimate. We look firstly at different perspectives within social work on empowerment and what social workers can do to support service users gain more control over their lives. Drawing on the findings of a study by Muldoon (2012), we explore the application of these empowerment concepts into the working relationships that social workers develop with young people who require daily assistance with intimate personal care, and through this exploration we draw attention to the importance of understanding empowerment as a micro-level as well as the more often discussed macro-level action in social work.

Keywords: intimate personal care; disability; empowerment; social work

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Introduction

This article explores the potential for social workers to engage in empowering relationships with young people whose disabilities necessitate that they receive help with certain physical functions, some of which would be termed both personal and intimate. Assisted intimate personal care (IPC) takes place when there is a need for help with body functions which for most people are not the scene for interpersonal negotiation.

While IPC is a necessary reality for many young people with disabilities, it is also an arena where young people can be either empowered or disempowered very quickly. Social workers and other professionals who are members of multidisciplinary teams working with young people who receive assistance with IPC require awareness of the many issues that surround it if they are to fully engage with the young person's reality and be able to support them to feel and be empowered in their lives. The reality is that IPC is often an overlooked or unacknowledged aspect of the daily lives of this group of young people, including by those professionals who are not directly involved in providing this form of assistance. However, for the young people who receive it, assisted IPC is a constant element of their daily routine and a factor which can add or detract from the quality of their lived experience.

This article aims to encourage social workers who work with young people with disabilities to develop their awareness of this issue and to think, through an empowerment lens, about what their role might be in helping young people with this aspect of their lives. To achieve this, social workers must locate their work within an empowerment framework and this article highlights theoretical perspectives which can inform such a framework. Social workers also need to appreciate the realities of the daily negotiation of IPC as it is experienced by young people with disabilities and in this article we draw on a study by Muldoon (2012) which explicitly set out to address the dearth of empirical knowledge on young people's experiences of IPC. Relevant findings from the Muldoon study are presented here as they provide an insight into the everyday experiences of young people who receive this form of assistance. Muldoon's study found that while young people were in general satisfied with the IPC they received, they often felt disempowered and unsure about how to deal with aspects of IPC they found problematic and it is this particular finding from the study which we will explore in terms of the potential for social work support.

Empowerment perspectives in social work

There are many social work writers who offer varying perspectives on empowerment in social work practice, often locating the discussion of this topic in a macro-level context where social workers collaborate with service users to strengthen their

influence on policy or political decisions which impact on their quality of lives. In this article, we are more focused on micro-level empowerment, working from the idea that in day-to-day, person-to-person interactions the use of power is mediated either in a constructive or destructive manner. In this light, we aim to highlight concepts such as self-efficacy and autonomy, which are more process rather than outcome focused. At the same time, we acknowledge that empowerment at the micro level can impact on feelings of greater efficacy at the macro level and vice versa and see these as part of a continuum rather than two distinct issues. But for the focus of this article, which looks at empowerment (or the lack of it) as it plays out in some of the most private and personal spheres, we are particularly interested to consider how empowerment operates at the micro level of the individual.

Pierson and Thomas (2002) define empowerment as 'any process whereby those lacking, comparatively, in power become or are helped to become more powerful'. They position power as a central feature of professional-service user relationships and one which strongly influences the nature of that relationship in terms of its ability to encompass and support inclusivity and equality. Empowerment, they say, is 'liberational in intent [and it] means that service users can become more powerful' (p. 189).

Shera and Wells (1999) strip this conceptualisation of empowerment down to its core message. Empowerment they say is about 'who has the autonomy to decide, and whether as privilege or by right' (p. 17). Therefore, empowerment is not issue-centric; empowerment is not simply about the topic or the outcome of an interaction or what decision is made, rather in the Shera and Wells' perspective, it is about *how* interactions are enacted or *how* decisions are made. Further still, it is about control, authority and the *realpolitik* of interpersonal negotiation. Who is really in charge of a process, an interaction, a decision? These are central and vitally important questions for young people with disabilities in general, but particularly important for the cohort of young people who require assistance with IPC because the interactions and the decisions that are made each day concern and shape their embodied experiences as well as the quality of some of their key social interactions.

Miley and Dubois (1999), drawing from Miley, O'Melia and Dubois (1998), outline an empowerment framework for practice which attends to three essential elements of empowerment which they describe as 'dialogue, discovery and development' (p. 6).

While this framework applies to macro level empowerment strategies, it is also a valuable depiction of the stages of empowerment work which are necessary at the micro level. The three stages in their model incorporate an intrinsic assumption that empowerment is a process which involves meaningful conversations between service users and social workers, joint exploration of solutions, and collaboration together to positively influence more inclusive and suitable responses from systems (be that family, agency, or wider networks) to individual service user needs.

In relation to the power in empowerment, Beresford (1999) reminds us of the

need to adopt a critical awareness of power and what he describes as the 'competing concerns and agendas of people involved in social care as service providers and service users' (p. 259). Recognising the different positions, locations, outlooks and priorities of the worker vis-à-vis the service user is, therefore, a primary necessity if one is to fully support an empowerment approach because the potential for conflicting viewpoints and priorities can seriously impede the potential for service users to be in control of their lives, especially those whose disabilities require them to avail of on-going personal support. For Beresford (1999) empowerment is about liberation and it must, therefore, position the service user as the central figure in social transactions. In this light, unlike perspectives which equate a person's disability or dependency with a limited ability on their part to know what is in their best interests, Beresford's conceptualisation of empowerment locates expertism with the service user and places the onus more firmly on the worker to engage with the reality (views, experiences, feelings, hopes, desires) of the service user in a respectful, meaningful and ultimately supportive way. This requires a rewriting of the professional script and it essentially throws out the rule book of worker-user interactions in favour of inclusive, liberatory and user-focused service delivery.

Walsh (2010, p.202) reminds us that empowerment 'has an important contextual element'. It will be influenced, she says, by the 'context of the helping encounter' and the context for young people receiving IPC is that it is not a context they can choose, it is not a voluntary act to take part or not, as for most it is an essential daily task.

There is a grim reminder here for us all that while some worker-service user interactions may be empowering, and some may be empowerment-neutral, others may be disempowering. Even one-to-one, daily, mundane interactions will rarely be free of an underlying power agenda, often driven primarily by agency or system priorities. If service users are not in control of the interactions surrounding assisted IPC it is easy to consider how feelings of oppression, disillusionment, despair and eventually apathy may quickly set in to replace the potential for freedom to think, speak and disagree. Thompson (2010) writes that 'patterns of communication are also very significant in terms of the potential for empowerment' (p. 86). In the context of IPC, this is crucial to understanding the mechanisms of empowerment. The ability to raise an objection, to set the pace, to decide a pause, to ask for something to be done differently, more respectfully, less often, more often, and so on, are all part of the picture that emerges of empowerment or disempowerment in the enactment of assisted IPC. In few other contexts is oppression more easily experienced and empowerment more difficult to achieve.

Thompson (2010) also distinguishes different forms of power including:

- 'power to' ... do something, achieve something, direct something,
- 'power over' ... others or over situations. Where authority lies is central to the concept of 'power over'.
- 'power with' – this refers to collective power and the exercise of influence,

- ‘power from within’ – meaning internal feelings of strength and ability to cope (pp. 88-89).

These are useful reference points in working with young people with disabilities who experience IPC. We need to ask what do these young people have power to control during the process of receiving IPC? What power do they have to control what aspect of the process? Are they isolated in their experience or is there potential for collective strength among a cohort of young people? Do they individually feel in control of a process which invades the very core of what we term ‘personal space’?

Trevithick (2000, p.142) refers to Gutiérrez’ (1990) perspective which views empowerment as the journey away from apathy and despair towards personal control and she summarises the five actions identified by Gutiérrez which the social worker must enact to help the service user make this transition:

- ‘Accepting the client’s definition of the problem
- Identifying and building upon existing strengths
- Engaging in a power analysis of the client’s situation
- Teaching specific skills
- Mobilizing resources and advocating for clients’ (1990, p. 151-2).

The Gutiérrez model illuminates empowerment as an action-based method of social work and moves it beyond a simple aspirational conceptualisation of how we think we should think about the position of service users. Just as in Thompson’s categories of power, in the Gutiérrez model, each element requires the social worker to focus on the client experience rather than any professional, organisation or societal priorities. Furthermore, the social work role in this model is not a passive role – it involves actively resourcing the individual (or group) to be empowered, to think from an empowered as opposed to an oppressed position and of particular relevance to our discussion here, to feel (physically, psychologically, emotionally, spiritually) the presence of their inner strength and their ability to leverage power in social interactions with people involved in their care.

Why this is important for social work practice, and in particular, why it is important for the service user group we are discussing in this article, is captured very clearly by Trevithick (2000) when she says:

‘People who come to believe, through the process of internalized oppression, that they are worthless, ‘stupid’, ‘no good’ or that they ‘don’t count’ find it very difficult to stand up to others, to protect themselves or their loved ones from further oppression or to take risks without help. The way that help is offered is important: compassion, concern and the fact that we ‘care’ are important value perspectives we bring to our work’ (p. 143).

In summary, empowerment is a broad church of theory and actions which can substantially contribute to improved quality of life for service users and to the realisation of a more just and equal society where people with disabilities have control of their micro and macro level engagement with the wider society.

Intimate personal care

Intimate care is defined by Cambridge and Carnaby (2000) as:

‘The care tasks associated with bodily functions, body products and personal hygiene which demand direct or indirect contact with or exposure of the sexual parts of the body’ (p. 6).

Tasks which do not involve contact or exposure of sexual parts of the body are often referred to as ‘personal care’ (Cambridge and Carnaby, 2000). Therefore, IPC is a combination of both intimate and personal care and, in most instances, assisted IPC happens as part of a spectrum of care interactions.

Typically, IPC is a form of assistance which young people with disabilities receive from more than one or more adults and which presents them with a multiplicity of relationship issues that they must somehow try to negotiate. This interpersonal negotiation is in addition to the physical dimension of these interpersonal transactions which occur within what is generally regarded as a private and personal space. For young people who require assistance with IPC, this personal space becomes a shared, and sometimes a contested, space which must be negotiated on a daily basis.

When discussing IPC it is important also to note the two distinctive models of disability which surround this topic, namely, the social model of disability and the medical model of disability. The medical model is based on the assumption that a person is disabled by their impairment whereas the social model explores how ‘socially constructed barriers have disabled people with perceived impairments’ (Barnes and Mercer, 1997, p. 2). The importance of this distinction is in how we perceive the actions related to assisted IPC. In the medical model, assisted IPC is done *to* a person, usually called ‘the patient’, and it is regarded as something akin to a technical procedure, which must be done in a particular way and where the views and wishes of ‘the patient’ are secondary to the procedure. The social model, concerned as it is with the experience of the person with a disability, can more easily accommodate diversity and flexibility in how IPC is organised and provided. From this perspective, IPC is not something done to the service user; it is a conjoint activity that is carried out by someone in a caring role with the service user, and preferably with the service user in control as much as possible.

Clark (2009) notes that despite its significance in the lives of people with certain

disabilities, IPC is a topic which is generally hidden in the research, practice and policy literature. In particular, there is a research deficit on the experiences of people who require assistance with IPC and of those who provide that assistance.

Despite its importance to the quality of life experienced by young people with disabilities, Cambridge and Carnaby (2006) point out that care assistants who typically are involved in the provision of IPC are often not trained specifically in that task and are not encouraged to reflect or debrief on the experience of this form of service provision. Whilst service providers may have relevant practical skills they are less likely to have considered the 'bigger picture' impact of this form of care in terms of its influence on service users' feelings of self-efficacy or empowerment. Cambridge and Carnaby found that staff generally received training related to manual handling, first aid and hygiene but not specifically to IPC or the impact it has on the quality of life of the young people receiving it. Staff in a residential unit described how delivering intimate care was a very large part of their working day yet they were not well prepared for it and very little significance or recognition was attributed to it (Cambridge and Carnaby, 2006). Clark (2006) suggests that perhaps one reason why there is little training in this area is because it is considered 'dirty work' and is undervalued.

An exploratory study by Muldoon (2012) attempted to raise a wider research focus on this issue. Her study involved a set of interviews with five young people with a disability who experienced long-term and daily assisted IPC and five special needs assistants involved in their care. The purposive sample of young people aged 16 years or over was drawn from a population of young people attending an educational facility in the Republic of Ireland which caters for young people with moderate to severe physical disabilities. Purposive sampling has the advantage of recruiting participants who have an in-depth knowledge of the research topic (Ball, 1990) and given the challenges for researchers in accessing this difficult to reach population, purposive sampling helped identify participants who were willing and available to take part in this research project. In Ireland, the State recognises the need for assistance to be provided during the school day for children/young people with disabilities. Personal care, including intimate personal care, is an integral part of the care provided for a cohort of students with disabilities (DES, 2011). Muldoon's small-scale study aimed to amplify and record the views of young people who receive assistance with IPC in an educational context. While the study also collected data from the special needs assistants involved in delivering assistance with IPC, the findings reported here are mainly drawn from the data produced in the interviews with the young people.

The researcher encountered no difficulty in recruiting participants for the research interviews, a reflection perhaps of the lack of opportunity for young people to express their views on this issue. The interviews were conducted over a two month time period. The interview recordings were manually transcribed and thematically analysed (Cohen, Manion and Morrison, 2011).

The ethical dimension of this study necessitated careful consideration and the research design was strongly informed by guidelines from a range of relevant sources including the National Disability Authority (2009, 2002) and Whyte (2006).

Important themes emerged from Muldoon's study and three of these, namely, 'terminology', 'social interactions' and 'hearing and listening' are relevant to this discussion of empowerment in the context of IPC and are outlined in more detail below.

Terminology

Muldoon found differing views among the participants on the meaning of the terms 'intimate' and 'personal care'. A wide range of interpretations was offered by the young people who were interviewed when asked what they would describe as forms of assisted IPC. Their responses included:

Going to the nurses to be checked. (YP 1)

Feeding. (YP 4)

PE, they touch me in PE, ...hand over hand, when I am writing. (YP 5)

Essentially, the young people referred to a much wider range of activities than those encompassed by existing definitions of IPC. The young people classified many forms of help with their bodily functions which they regarded as either intimate or personal or both. For example, some included the assistance they needed to engage in activities such as Physical Education (PE) or hand over hand (where a person is unable to independently hold a writing implement and is assisted).

While their interpretations serve to broaden our understanding of the concept of IPC, the significance for the young participants of touch and invasion of personal space was a common theme across their interpretations of assisted IPC. The definition given by Cambridge and Carnaby (2000) does not include all of the types of bodily assistance which young people listed in this study such as the assistance received related to physical education or writing, as well as other issues such as suctioning or correcting posture during classroom or sporting activities. Of the ten participants interviewed in the Muldoon study (young people and special needs assistants) each one had their own interpretation of IPC and while there was a degree of overlap between different explanations for the term offered by participants, the variation across all the definitions reveals IPC as a concept much broader and more expansive than has been previously recognised in the literature.

Social Interactions

Research has shown that embarrassment can be a feeling related to both giving and receiving IPC. Conder and Mirfin-Veitch (2008) found that this embarrassment was overcome by a number of communication strategies which included talking about other topics during the provision of care, adding humour and having a fully engaged caregiver.

Muldoon's (2012) study explored the interactions surrounding the experience of giving and receiving IPC under three sub-themes, namely, 'communication, privacy and dignity' and 'humour'. While these are stand-alone concepts, they overlap and interweave across the experiences of young people who receive IPC. For example, humour and good communication are both very important in helping the young person and caregiver overcome any embarrassment which may arise in the context of IPC. The general quality of communication between the giver and receiver of assisted IPC emerged from the study as a pivotally important factor in determining the nature of the overall experience for the young people involved. In the main, young people indicated in the research interviews that in general they enjoyed positive communication and interaction with those involved in this type of caregiving.

For example, the young people seemed aware that the Special Needs Assistants like to be 'careful' and 'safe' (YP5) and ensure that the young person is comfortable:

They like to be able to say 'are you okay?' and that. (YP 5)

The Muldoon study also revealed that this general good experience of care could be hindered if the process was rushed (perhaps due to time pressures) or if privacy or dignity was compromised (such as in a swimming pool changing room where other people were also present).

don't like being rushed...I don't like it when they rush people. (YP 4)

O'Lynn and Krautscheid (2011) note that giving choices and including the recipient in decision-making during the process of assisted IPC increases their sense of dignity and privacy. Being able to address and tackle any communication or relationship problems that may arise between caregivers and receivers of IPC is important to the overall experience for the young person and their sense of control over the process. Clearly, there is a role for social workers to help young people with disabilities who may experience problems of communication with their IPC caregivers and to help them strategize and problem-solve any issues which cause them concern so as to regain their sense of control and wellbeing in the context of assisted IPC.

Hearing and Listening

The Muldoon study findings suggest that young people can be slow to voice their opinions on the nature of IPC they receive or the manner in which it is delivered. This echoes Cambridge's (2006) point that, 'intimate and personal care is visible but the invisible aspect is the feelings and responses of those providing and receiving intimate care' (p. 96). A strong theme that emerged in the context of 'hearing and listening' was choice and the extent to which the young people truly feel they can direct how IPC is provided to them. Throughout all the research interviews with the young people (even those who were very vocal about standing up for themselves), Muldoon identified a passivity or resignation in relation to how their care was delivered. A comment by one young person summed up the general tone of responses when they said,

I just let them at it. (YP 5)

Another participant indicated that independence is a treasured position and something which they felt was not available to them. Even in the IPC activities they wished for more autonomy but instead felt their caregivers were over-protective. They said,

Everyone fussing over me can be smothering. Fuss, fuss, fuss. (YP 2)

This young person went on to say how they no longer argue when the carers are doing things that they do not feel are necessary such as checking the pad or taking a urine sample. They expressed their feelings of disempowerment as follows:

I will just get really, really angry and won't be able to do anything about it, so I say nothing now. I let them do what they want to do and they are happy. (YP 2)

While the participants in Muldoon's study were generally positive about the relationships they had with IPC caregivers, an alternative picture emerges from a study by Pfefferle and Weinberg (2008) where an interviewee reported to them that recipients of intimate care had very little choice and control and were 'at the mercy of the whims and moods of staff' (p. 956). Therefore, choice and relationship-negotiation closely overlap in the processes of assisted IPC and when either or both are compromised, the young people may experience significant and quite powerful disempowerment. Social workers may be able to raise the voice of young people in such contexts. They may help with any concerns or anxieties arising within the multidisciplinary network, particularly among those directly involved in this form of caregiving, with the aim of ensuring that the experience of the young person is not overlooked or does not become one of enduring disempowerment. For young

people with disabilities who receive assistance with IPC, being able to articulate any concerns or wishes and to be heard are important cornerstones on which a climate of empowerment can rest. Locating respect by all involved for the dignity of the young person at the centre of the process is paramount and social work can provide a strong ally for the young person in situations where this is inadequate or lacking.

Discussion

Working to empower the marginalised, forgotten and discriminated sectors of society is a core aim of social work practice and one which transcends geographical and service sector boundaries. While often associated with macro-level challenges to oppression and injustice, empowerment is a concept and an approach which can inform all levels of social work intervention, including neighbourhood work, group work, family interventions and individual work. Many macro level issues exist for people with disabilities but this article is concerned to place a spotlight on the potential for disempowerment at the micro level of the individual with a disability, and in particular, for young disabled people who require assistance with IPC.

Social workers working with this cohort of young people with physical disabilities will be concerned to enhance their quality of life, their experience of services and to raise their voice within the decision-making contexts that affect their general well-being. While social workers are not usually directly involved in providing assisted IPC, they are located within multi-disciplinary services in which assisted IPC is provided, be it in a residential, educational or workplace contexts. In that role, they are ideally located to ensure that the issue of assisted IPC is recognised by the wider service team, and the young people themselves, as an arena in which young disabled people must negotiate a complex set of social, emotional and embodied experiences but also an arena in which it is essential that the young person feels a sense of control and is empowered to express their views. For example, the individual care plan, now an accepted feature of multidisciplinary service delivery, offers one potential opportunity to amplify the voice of the young person with regard to their views on assisted IPC, to empower them to make choices around their care or revise those plans on a regular basis (Carnaby and Mallett, 2006; Currie, Eales and Simpson, 1999).

Research studies on assisted IPC provide essential knowledge for social workers who work to advocate on behalf of young people with disabilities and who strive to ensure that young peoples' opinions on matters of importance to them are heard. In terms of empowerment work with young people with disabilities, recognising the many arenas in which assistance with bodily functions is required is fundamental to exploring feelings of disempowerment and oppression which the young people may be experiencing across a range of contexts and daily interactions. It is useful if

social workers can work from an evidence-informed base which requires access to a range of research outputs. It also requires a knowledge of empowerment theory. In this light the empowerment approach outlined by Gutiérrez is a helpful guide to social workers in how to firstly think about and then intervene to bring about greater involvement of young people with disabilities in key processes such as assisted IPC. Miley and Dubois' (1999) triad of dialogue, discovery and development offers a lens through which the social worker can view and engage with the issues that may be a source of disempowerment for young people who receive help with IPC and it is possible that in dealing with issues related to IPC through such an empowerment framework that in the future the young person may apply similar strategies into other areas of their lives

A key part of the Miley and Dubois (1999) framework requires communication and dialogue of the central issues. The lack of co-terminosity about what actually constitutes IPC and the absence of universally agreed definitions may confuse efforts to support service user empowerment in all relevant contexts. It is clear that the definitions of IPC emerging from studies such as Muldoon (2012) are expanding our understanding of what constitutes assisted IPC from a service user perspective as well as how it is experienced by those who receive it. It is important for social workers trying to work from an empowerment perspective with this group of young people that they do not unwittingly shut down discussion of certain forms of IPC because they do not recognise them as such. Furthermore, there is potentially a role for social workers in illuminating the many arenas in which young people with disabilities feel their personal space is not fully in their control and to help the wider network of service providers appreciate the importance of being sensitised to the experiences of young people in such contexts. This is empowerment at its most fundamental yet essential form; being able to identify the issue and any source of problem attached to it is essential preparation to finding and achieving solutions. Yet in the context of IPC, being able to articulate feelings about the experience of receiving IPC may be inherently difficult for some young people. There is great potential for social workers to take an active role in supporting the amplification of young people's views and experiences in relation to this issue.

And at the heart of this discussion lies the question of the location of power during the activity which is assisted IPC. It is extremely difficult, as the research demonstrates, for the young person receiving assisted IPC to express negative views on the way it is delivered, the relationships that are involved in it, the communication around it and any part of the process with which the young person is unhappy. The interconnectedness between assisted IPC and every other aspect of the young person's life is so entwined that without overt support and encouragement it is difficult for individual young people with a disability to voice their fears or negative experiences of assisted IPC. For those who receive it, usually, assisted IPC is a long-term feature of their lives and if left shrouded in silence the young people may be subjected to a lifetime of disempowerment but unsure how to voice their opinions

or bring about change.

In conclusion, empowerment can be a grand-scale activity through which the lives of many people can be changed, but it can also be highly valuable at the micro level of the single individual. Social workers, by virtue of their position within the wider network of disability services, can play a critical role in raising awareness of these issues within the service provider network. Crucially, in their support role with young people with disabilities, social workers have the potential, by adopting an empowerment approach, to raise awareness on the rights and needs of young people who receive assisted IPC and to enable them to achieve profoundly significant changes in their lives.

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