Friend or Worker? Understanding Relationships Between People with Intellectual Disabilities and their Support Workers through Institutional Ethnography.

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Introduction

An international change in disability policy and practice, often referred to as ‘personalisation’, has influenced how paid support is being delivered to people with disabilities. Personalisation is aimed at placing people with disabilities at the centre of decision-making about their lives to promote self-determination and independence in terms of how and where they want to live (Beresford, 2008; Fawcett & Plath, 2014). One of the support models consistent with this thinking is the personal budget model. A personal budget usually consists of a certain amount of money that is allocated to a person with disability based on an assessment of their needs. One of the intentions of this model is to empower the service user by enabling choice about how their money is spent and how the support is delivered. One type of support that can be purchased to help the person achieve this kind of independence is support work.

A support worker may assist with personal care; help the person get changed and dressed, or stay overnight and sleep in the person’s home. This can lead to a blurring of professional tasks and home location, and may influence the way people relate to each other (Rogers, 2009). Some work has been done on how personal budget policies create different types of support work relationships (Christensen, 2012; Guldvik, 2014; Leece, 2010; Leece & Peace, 2010; Yamaki & Yamazaki, 2004). However, it remains largely unexplored how the current social policy context of support work affects the lived experience of both people in the relationship with each other. This research note introduces ongoing PhD research that aims to address this gap by answering two research questions:

- How are people with intellectual disabilities in receipt of a personal budget and their support workers experiencing their relationships with each other?
- How have the lived experiences of people with intellectual disabilities and their support workers
in their relationships with each other been influenced by personal budget policies organising support work?

This research note critically engages with conceptual literature on policies of personal budgets, support work, and support work relationships. On this basis it suggests a conceptual framework for this research project to explore the nature of relationships between people with intellectual disabilities and their support workers within the contemporary social policy context of support work. It proposes a methodological approach, Institutional Ethnography (IE) to study both research questions in two different countries, Germany and Australia, and discusses how this could be applied.

Background and conceptual framework

Personal budgets policies and support work

The policies of personalisation are rooted in ideas about the persons with disability’s independence, which is to be increased by giving them more choice and control in relation to their support (Christensen & Pilling, 2014). A reform that derived from the policies of personalisation was the introduction of personal budgets. A personal budget (also known as self-directed support or cash-for-care) can be a sum of money allocated to a person with disability with information about what resources and services he or she is entitled to use (Beresford, 2008; Glendinning et al., 2008). One of the intentions of personal budgets is to put the person who receives support in the role of a custumer who should have the option of choosing and controlling the purchase of his or her support services (Christensen, 2010; Ellis, 2007; Glendinning et al., 2008). Empowering the recipient of support in this process is designed to mean “in principle that the power relation between the service user and the care worker is turned upside down” (Guldvik, 2014, p. 147). However, not all people with disabilities feel empowered by utilising a personal budget. Many recipients with intellectual disabilities and their families feel discouraged by the complexity and bureaucracy associated with this fairly new service system and still prefer using a service option that allows less control over how support (and funding) is managed (Metzler et al., 2007).

People in receipt of a personal budget sometimes have the option of employing a support worker. A support worker is a direct support professional who provides assistance on a daily, weekly, or monthly basis in helping a person with disability to acquire independent living skills, such as housework, cooking, shopping, making decisions and using public transport (Fisher & Byrne, 2012). Being in control of this support is meant to promote freedom and self-respect of the person with disability, rather than making them feel dependent on support from family or workers (Shakespeare, 2014). While the conditions of support work can vary depending, for example, on the policies of the organisation that employs the support worker, they generally require support workers to work with people with disabilities in their homes and places of work, on the latter’s terms (Kelly, 2011). Some disability researchers challenge the personal budget model as it may create working conditions where it is difficult to prevent exploitation of support workers or abuse of the person with disability due to the greater difficulty of monitoring the relationship (Guldvik, 2014; Kelly, 2011; Shakespeare, 2014; Watson et al., 2004). In contrast, Ungerson (2003) argues that the provision of support in the domestic domain, such as the home of the person with disability, may create an opportunity for the development of a more affectionate relationship between support worker and
the person with disability. The environments of support work relationships will be considered in this study as I plan to conduct participant observations with support worker-person with intellectual disability dyads.

The nature of support work relationships

I intend to further explore the paid support work relationship in my PhD study. It is not a relationship between a person with intellectual disability and a familial caregiver who manages the personal budget on the former’s behalf for example. It is a relationship that comes into being through the personal budget arrangement. Often support workers are expected to set ‘professional boundaries’ that are sometimes suggested in the policies of the organisations that employ them (e.g. Antaki et al., 2007; Christensen, 2010, 2012; Kittay, 2009). For example, a support worker may not be expected to share their personal contact details with a person with intellectual disability according to specific policy guidelines or an ethical code of conduct of an organisation. This raises the question of whether such guidelines are still relevant to both people in a support work relationship based on personal budget arrangements and if it is appropriate to follow them.

Christensen conducted a comparative analysis of personal budget systems and support work relationships in the UK and Norway (e.g. 2009, 2010, 2012; Christensen & Gulsvik, 2014; Christensen et al., 2013; Christensen & Pilling 2014). She found three types of relationships between the support worker and the person with intellectual disability. She characterised the first as a ‘professional friendship’ which stressed the professional boundaries to the relationship set by employment contracts and formal regulations; the second as a ‘solidarity-based companionship’ which was characterised by an emotional bond between both people; and the third as a care master-servant model, where the master (person with disability) had the power to get things done the way he or she wanted. On this basis, Christensen identified two key themes of relationships in her dataset, power and emotionalism. The structure of power can provide information about the hierarchy of relationships, whereas emotionalism can be explored through the character of the interaction between support worker and person with intellectual disability and the ways they care about each other. These themes will be important to consider in this research study. I may include people with intellectual disabilities who have communication support needs and use non-verbal communication symbols in addition to spoken language. The character of interaction between both persons can be studied by observing their communicative behaviours within relationships and talking to them about it. Understanding and exploring how they exchange and reveal information about themselves in relation with each other will form part of the investigation of my PhD study.

Rogers (2007, 2009) and Kelly (2013) both use an auto-ethnographic approach and draw on their personal experience of being disability support workers. They try to understand their past experiences where personal and professional aspects of their relationships seemed to slide into one another. Rogers (2009) questions how a person with intellectual disability might feel when he or she has a live-in support worker and this might be the only person who is close to them. In her reflexive account (2009, p. 277) she reveals that she befriended Sam, a man with intellectual disabilities, who she feels misread their relationship when she was his live-in support worker: “After a year ago or so… our relationship changed forever. I was … in the kitchen
with Sam. The 6-foot man grabbed the waist-band of my trousers clear in his intention to undress me.” Rogers explains that she felt ‘shaken’ at first, left the place, and withdrew from the relationship. After a while, she tried to talk to Sam, but realised that the relationship had become more difficult, and felt like a ‘break-up’. With respect to my study, it is important to keep in mind that people can place their own meanings on the support work relationship. They can become sexually attracted to the other and this can influence the development of their relationship to a certain degree.

Kelly (2013) sheds light on the awkwardness of a particular situation by reflecting on her relationship with a male friend who has a physical disability, and whom she supports occasionally by helping him eat or use the washroom. She explains that her friend is aware of her vulnerability to exploitation and abuse, and is sensitive to the risk of crossing her boundaries. However, she also identifies a feeling of weirdness, embarrassment, and discomfort within herself when she recalls the following situation, where she tried to help her friend use the washroom: “Inside the cramped public bathroom stall my social discomfort was palpable as I grasped for appropriate body language and conversation within this space” (Kelly 2013, p. 791). Her situation raises questions about whether she felt uncomfortable because she was a female support worker helping a male person with disability in a public toilet or whether it was the awareness of their personal friendship while engaging with the man as if he was her client. In this study I seek to understand how men and women relate to each other in support work relationships and will also include reflexive elements in my thesis. This will form part of the ethnographic methodology I will use in this study.

Methodological approach

In this PhD study I will use Institutional Ethnography (IE), a methodology developed by the Canadian sociologist Dorothy Smith in the 1980s (e.g. Smith, 1987, 1990, 2005). IE examines local phenomena with the aim of understanding how these are shaped by larger power relations (Slade, 2010). The local phenomena within my study will be the lived experiences of support workers and people with intellectual disabilities in relation to each other. I aim to understand how these local phenomena are shaped by larger power relations, including the ways support is organised through policies of personal budgets. The ‘institution’ analysed in IE is not one organisation (such as government, corporation, the media, and academic discourses), but rather the work of several seemingly disconnected organisations that form the ‘ruling relations’ (Slade, 2010; Smith, 2005). IE assumes that relations do not dominate, but rather influence the local experiences of those who live the experience.

Critical reflexivity is an important part of ethnographic research and can assist in understanding and examining one’s own reactions to situations. It can also help me manage my own subjectivity within the research process (Etherington, 2004, 2007). I have been writing reflections into an online journal since the beginning of this study. The reflections focused on my personal experiences and perceptions about the social world, values and beliefs concerning relationships in general, and my past experiences of being a disability support worker and being in support work relationships. By sharpening the awareness of my own experiences, I might find it easier to ‘leave them behind’ and place the focus on the experiences of both people in the relationship. This process might help me to ‘surrender’ myself to
the spaces in which support workers and persons with intellectual disabilities encounter one another.

Although personal budgets have been introduced in many countries, the ways they have been implemented varies in each. In order to examine the significance of such varied arrangements, this research study will focus on the contemporary context of support work in Germany and Australia and its influence on the lived experience of support workers and people with intellectual disabilities. By understanding this context in both countries, this study aims to contribute to new understandings of how it is linked and related to the felt experience of both people within the support work relationship.

Discussion

Previous studies have focused on either the nature of support relationships (e.g. Kelly, 2011; Rogers, 2009; Shakespeare, 2014) or the policies that create new types of relationships (e.g. Christensen, 2012; Ungerson, 2003). The former have focused on the experience and feelings of people in these relationships, but didn’t specifically aim to understand how these experiences might be influenced by specific policies. The latter explored the connection between personal budget policies and the conditions it creates for support work relationships, but were limited in that they did not explore the felt relational experiences of both, the support worker and the person with disability. In this study, I will be looking more closely at the ways in which support work within the contemporary personal budget contexts can influence the felt experiences of both people in the relationship. Understanding how these policies shape support work can help in generating a new understanding of how people relate to each other in support work relationships. In particular, this PhD study will generate new in-depth knowledge about the German and Australian support work context and the location of the relational experiences of support work relationships within that context.

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Footnotes

Support work is the common terminology used in Australia to describe the personal, direct, and regular support delivered to people with disabilities by a paid worker. In other countries it is often referred to as Personal Assistance (PA). As the majority of this research will be conducted in Australia, I am using the term ‘support work’ in this research note.

References


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