EVERYDAY ETHNOGRAPHY
INTERPRETING AND *'DOING'* EMPOWERMENT AND PROTECTION CARE IMPERATIVES IN A SUPPORTED-LIVING ENVIRONMENT FOR INTELLECTUALLY DISABLED ADULTS. FINDINGS FROM EXPERIENCES AS A SUPPORT WORKER

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ABSTRACT

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This paper details findings from my own experiences as a support worker working in a UK-based supported-living home (previously residential care) for adults with intellectual (learning) disabilities. These findings, along with other previous research, which investigated access to health and social care for this population (Redley, Banks, Foody and Holland 2012), have formed the basis of my doctoral research—an ethnographic study of this environment—which, since submitting this paper, has now commenced. Importantly, the experiences to which I refer are drawn my own perceptions of the nature of the supported-living setting in which I worked. Although, it is not possible to remove my perceptions as a researcher from my experiences as a support worker, what is relayed in this paper is not formally connected with my previous work as a researcher.

In recent years, social care services have begun to alter the way that full-time support is provided to recipients of services. These changes are set within a larger context of reform that is premised upon empowerment, through independence and choice. Such principles require individual self-determination, and the introduction of this ethos in the lives of adults who are limited in intellectual functioning has been questioned. In undertaking employment as a support worker within an organisation providing support to adults with intellectual disability, my intention was to begin to gain direct insight into how, or whether, changes in the nature of services and models of care that are provided in an everyday supported-living home for people with intellectual disabilities are impacting upon daily care practices and relations between service providers and service recipients.

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Keywords: intellectual disability, supported-living, support worker, tenant, health and social care, empowerment, life quality, ethnography

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Introduction[1]

In recent decades, UK health and social care reforms have eradicated traditional care models, based on paternalism, in favour of a person-centred approach to support, also known as personalisation (Karlson and Nilholm 2007). These reforms have been shaped by a range of political and social movements including neoliberal and Third Way politics as well as rights discourses (Department of Health 2001, 2009, 2010; Messent Carlton and Long 1998, Messent Cooke and Long 2000; Oliver 1992) which, themselves reflect more general changes that have taken place in Western society relating to philosophical notions of liberty. Such notions have focussed on the right to citizenship and self-determination (Strasser 1991), and it is this belief that underpins the conditions of modern day democracy: ordinary persons are generally best qualified to 'govern themselves' (Dahl 1989). In this way, personal autonomy negates the legitimacy of paternalism by any kind of authority in so far as people are expected, to varying extents, to take responsibility for their own lives, their actions and choices.

The belief in the importance of self-determination has altered the social positioning of disabled people, and since the early 1990s activist groups have rallied for governments to improve the rights of disabled people in order that they are equally represented in society (Barton 1993). Out of these campaigns the social model of disability was developed, a stance that positions itself in opposition to the medical model, which is predicated upon defining disability as a person's inability to function (Brisenden 1986). The social model, instead, defines disability as a social construction in that it is societal perceptions and environmental structures that disable people, excluding them from adapting to the social demands of a particular society (Shakespeare 1993). In framing disability as a social construct, the social model argues that this construction can be dissolved as long as people are able to alter their opinions of 'disability' and perceive it not as something that inhibits the person, but instead as a barrier created by society that can be easily removed (Klotz 2004).

Initially, disability rights movements focused upon the rights of physically disabled men and women, but they soon became part of a wider movement for other disabled citizens, including people with intellectual disabilities (Karlson and Nilholm 2007; Department of Health 2001, 2009, 2010). Following this, an ethos in disability health and social care services has evolved which is oriented towards ensuring that individual choice for users is central to their empowerment, and an approach to care and support known as person-centred care has become the mainstay method of service delivery (Department of Health 2010). In accordance with this political reform, changes have been made to the way that community-based housing is provided to people in need of social care support, and what previously was referred to as residential housing is gradually being converted into supported-living, representing a change from local authority housing provision to the allocation of individual tenancies or licences (National Development Team for Inclusion 2010). Essentially, this means that users now become living tenants who pay rent to a private company. Whilst primarily providing tenants with security of tenure, it is also intended that including them in such processes will provide them with the opportunity to be financially independent, with direct access to the benefits system, thus allowing them to develop a better understanding of the responsibilities people hold in their daily

lives. There is, however, little empirical evidence which indicates whether inclusion in this particular kind of way is beneficial in terms of improving well-being and quality of life. This is reflective of more general debates that have begun to surface across various discourses, which relate to challenging a perceived correlation between choice, happiness and well-being (Stephens, Markus and Townsend 2007). In accordance with this, within intellectual disability research, there are growing debates about whether empowerment, in terms of self-determination, is necessarily appropriate for adults who, to varying degrees, lack decision-making capacity. Furthermore, incorporated into these debates are concerns about the difficulties that may exist for services to enact a duty of care whilst also enabling independence and choice for people considered to be vulnerable.

As outlined above, achieving quality of life through empowerment has been the concept upon which research, policy and regulation in the care and support for adults with intellectual disabilities are directed. Within the context of a care setting, interactions between staff and tenants are thought to be an important factor in determining whether these policy imperatives are actually improving tenants' quality of life (Felce 2000). However, few studies have empirically focused on the ways in which, or whether at all, these changes in policy might alter relational dynamics between support workers and tenants. Accordingly, the aim of gaining experience as a support worker was to informally explore this. In concurrence with this, the doctoral study, which proceeds from the experiences outlined in this paper, will formally explore this empirical research question by ethnographically assessing support worker and tenant dynamics within the context of a supported-living setting.

Although ethnographic research with people with intellectual disability is minimal, some anthropologists have conducted research into making the transition into the community for people with intellectual disabilities who have been living in long-term institutional care, some for the majority of their lives (see, for example, Hubert and Hollins 2007a, 2007b, 2010; Owen, Hubert and Hollins 2008). This research has sought to discern whether people's life quality improved once they had been removed from long-stay hospital settings. Furthermore, other ethnographic work has been conducted which has explored alternative ways of communicating with intellectually disabled people, particularly those who are non-verbal, in order to understand their experiences of the world from their own perspectives (see, for example, Goode 1980, 1984, 1990). Outside of intellectual disability research, but remaining within health and social care, the work of Annemarie Mol may provide a useful comparison as she addresses the relationship between 'individual choice' and 'good care' in the context of the treatment of people with diabetes in the Netherlands (2008). In her research, Mol states that positing patient choice as a central tenet of good health care does not improve services or people's health. Instead, it imputes certain changes into health care delivery, which are not concurrent with how we, as humans, deal with disease. Mol goes on to say that in fact the processes of care and caring are much better placed to handle the difficulties of coping with diseases.

Design and methodology

Theoretical and methodological considerations

The findings from my experiences as a support worker served to allow me to consider the most appropriate methodological approach that would sufficiently meet the demands of the research question to be explored in the doctoral study. In concurrence with this the development of a theoretical positioning followed, which will outline and shape the doctorate study design and analyses of findings. Such a stance is essential to the integrity of the research findings, as it directly reflects the epistemological claims emerging from the generated knowledge (Braun and Clarke 2006; Caelli Ray and Mill 2003; Denzin and Lincoln 2000; Holloway and Todres 2003). In drawing on both my practical experiences as a support worker and my academic training, it became evident that the doctoral research question and indeed its methodological approach are both premised upon understanding meanings imbued within people's experiences of each other and the world around. In light of this, a theoretical approach reflecting a social constructionist perspective was adopted (Boas 1938; Geertz 1979; Fischer 1993). This approach is also concurrent with the perspective derived from symbolic interactionism (Mead 1934; Blumer 1969), which also provides a focus on meaning derived from people's experiences with each other through their actions. Constructionism and symbolic interactionism are highly suited to methods that allow researchers to perform 'hands-on' research and, guided by this premise, an ethnographic approach was adopted, which itself is based on the understanding that meaning produced by actors exists exclusively within the context of the environment where it is produced (Geertz 1973). This approach fits squarely with the research question of exploring how policy initiatives of personalised care are played out in relationships between support workers and tenants.

Study design

Within a research context, in order to yield the most fruitful findings, the most appropriate tools must be selected in the process of data collection, and this is largely related to which tools can practically be utilised in particular research contexts. For my doctoral study I have already decided to use an ethnographic approach, which, by its nature, consists of a number of different complementary methods. Following my experiences as a support worker, I was able to gain some understanding into what types of ethnographic methods could be utilised successfully within the context of a supported-living setting, and, as such, it has been decided that the doctoral study's data collection tools will be field notes, observation and interview. These data collection techniques marry well with the theoretical assumptions of constructionism and symbolic interactionism in that they are predicated upon the belief that knowledge and understanding are generated through subjective experiences of actions in the world. Moreover, in utilising both observation and interview, I will be able to collate what people say with their actions, which then will allow me to challenge or confirm the ways that people described themselves and others.

The sample

Intellectual disability spans an extremely wide range and level of need (World Health Organization 1992); some people are able to live independently without support, whilst others require varying levels of support twenty-four hours a day for the continuation of their lives. As a result, when conducting research with people with intellectual disability, it is necessary to ensure that all participants encompass similar levels of disability and support needs. Adults with intellectual disability living in supported-living and other forms of group homes are, in large part, housed in particular places in relation to their support needs (Health and Social Care Act 2008). This was also the case as regards my experience of supported-living environments, and so, it will be expected that for the doctoral study I will be able to select a home where the tenants will possess a broadly similar range of support needs. The doctoral study focuses on a client group who are considered to be mildly to moderately intellectually disabled, because it is expected that they will be most suitable for providing information related to the research question. This can be justified in the following way: people with mild to moderate disabilities are expected to be more likely to be able to make informed decisions and be more independent than those with more severe disabilities. As such, processes of empowerment and protection and how, or whether, they impact upon support worker/tenant dynamics may be made more explicit in this context. In light of this, it is therefore suggested that working with this section of the population is a good starting point for research in this field.

The setting/gaining access

Whilst I was working as a support worker, the group of colleagues with whom I permanently worked were required to work between two supported-living homes. After a period of time, it became apparent that gaining very in-depth understanding of what happens within a care setting such as this is a very lengthy process. As such, it is suggested that no more than two sites, either in the same, or from different organisations will be selected for the doctoral ethnographic study. Importantly, this 'localised' approach fits squarely with the ethos of ethnography (Geertz 1973).

Whilst working as a support worker, I informed other support workers, managers, and the men and women living in the houses that I had previously researched and worked with people with intellectual disabilities. However, because my primary aim was to understand, from a first-hand perspective, the experiences of care-givers and care-receivers in this setting, I decided not to discuss my own background extensively, but instead to immerse myself as a participant observer: focusing on my role as a support worker whilst in the house, but also observing the actions and interactions of support workers and tenants, and reflecting on this behaviour in the context of policy imperatives and the chosen theoretical assumptions.

Further to the above, it is important to emphasis that whilst working for a care organisation, and independent of formal academic research, I was not required to seek ethical approval from a formal ethics committee, nor was I required to gain informed consent from the people with whom I was working. However, as regards the doctoral study, in which I am going to be formally conducting ethnographic research, ethical

approval and informed consent from all participants involved will be sought. In addition, due to the nature of this research approach, as well as the intimate nature of care work in general, whilst vital that I become part of the everyday lives of the people, it is also important that my role as a researcher is reinforced throughout. These considerations will be centred on ensuring that coercion and deception do not occur, and are issues that are intrinsically related to my role and identity as an ethnographic researcher (Hammersley and Atkinson 2007). To this end, a system of gaining consent known as sequential consent will be adopted (Seymour 2001). This is the process of continually 'reminding' research participants (both people with intellectual disability and staff members) of my role and the intention of my project, in order to ensure that they do not disclose information within what they believe to be part of a purely personal relationship, and also to ensure that researcher and participant are engaged in mutual decision-making throughout the research process.

Research methods, procedure and practical considerations

The following passages detail the research tools that I anticipate using as part of my ethnographic doctoral study. Whilst employed as a support worker, these methods were utilised in an informal 'everyday' sense, and, as already mentioned, being part of this type of environment prior to research has allowed me to assess the feasibility of these tools in the context of a care setting. Crucially, for the main study their use will be rigorously and systematically applied.

Observation

It was decided that participatory observation, rather than non-participatory, would be the most appropriate form of observation for this study. The justification for this was that by participating in the everyday activities of the people under study I will be able to develop a better understanding of their ethos and world-view. This process will hopefully provide me, as the ethnographer, with a role within the home and so consequently an insider's perspective (DeWalt, DeWalt and Wayland 1998), which is more effective than just becoming part of the 'wallpaper' of the home. As such, support workers and tenants may be more inclined to relate to and interact with me in ways not possible through observation alone.

Field-notes and diary entries

In order to enhance the rigour of documenting observations (Morse and Field 1995), activities in the home will be recorded with extensive field-notes and diary entries. It will be important, however, that my role remains as natural as possible and so I will carry writing equipment whilst at work and, when possible, make brief notes covertly, which will be followed up later with more extensive diary entries away from the home. Once written up, field-notes will be destroyed, and provisions will be made to securely hold all

diary entries on a password-protected hard drive, which will be deleted at a designated time in line with the Data Protection Act 1998.

Interviews

Interviewing provides the researcher with information about how participants construct their realities (Punch 2005). The type of information interviews elicit is directly related to the way that the researcher structures them and so this structure must be directly related to the research question (Fontana and Frey 1994). As stated above, it will be important that I remain part of the everyday fabric of the home and so in conjunction with this, interviews will be treated as discussions which are, as Patton (2002) notes, a natural extension of participant observation and rely on generating questions out of the natural flow of a conversation. Interviews will be recorded in the same way as covert field-notes and later written up as diary entries.

In reflecting upon my experience as a support worker, it is anticipated that the use of the above research techniques will have implications for the development of my conceptual ideas during the doctoral research. In order to elaborate, whilst working as a support worker, when the environment was very new, I recorded at least one diary entry after every shift, which I re-read before the next shift so as to refresh my memory of what had happened during the previous shift. As this process progressed, however, diary entries altered from descriptive recording towards the development of conceptual ideas. It is anticipated that this will be the case for the doctoral study, which will also be complemented by the changing structure of relational dynamics with the people with whom I am conducting research. In this sense, it is intended that as my own understandings develop, discussions with support workers, other staff and tenants will become more focussed towards these conceptual ideas. This approach also reflects the theoretical stances of constructionism and symbolic interactionism in that knowledge production is part of an on-going and interactive process.

The findings

The following passages are drawn from my experiences as a support worker. As already mentioned, although it is impossible for me to escape perceptions I have gained whilst formally conducting research in this field, importantly, no formal research project has been connected with what is presented here.

Soon after I began employment in the care organisation, I was informed that, as part of social care reforms that I have discussed above, the two houses where I was based would be changing from residential care to supported-living: the first houses in the organisation to make this move. This serendipitous change was highly beneficial for me, as it meant that I was given first-hand experience of a policy imperative that is an integral aspect of current social care reforms. The altered accommodation status consequently became a defining feature of my experience as a support worker and it is within the context of the move to supported-living that much of the experiences outlined in this paper are set. In order to explore this further, I will now discuss some examples that were recorded

during my employment and which I feel successfully highlight some of the issues at play concerning relations between support workers and individuals with intellectual disability in the houses where I was based.

The two houses where I was based are situated on the same street, with five tenants living in one house and four tenants in the other. In terms of my role as a support worker, broadly speaking, this involved assisting tenants in various aspects of their everyday lives, such as assisting each morning and evening to prepare for their day placements,[2] or assisting with personal care, household chores and emotional and psychological issues or concerns. In my own experience of working as a support worker, I found that much of my time was taken up with household chores such as cleaning, washing and cooking, which I either conducted independently, or alongside the men and women living in the houses.

Shortly after my employment commenced, in conjunction with changes in residential status, the houses in which I was based appointed a new manager. He was not, however, new to the organisation as he had previously been employed there as manager of another house and also, at one point, as a support worker. During one of my first conversations with the new manager, I brought up the topic of supported-living and asked him exactly what this was and what it meant for the tenants. The manager conceptualised the move to supported-living in terms of how the Government now expects its money to be spent:

> We must follow the Government's module of care, the module that they have decided. This is the expectation of our regulator, the Care Quality Commission (CQC). When they inspect the houses they will expect people to be living in them the way they want. This means that staff will no longer be doing everything for the tenants. Before, it was too easy [for staff] just to do everything, but, now, even if it takes longer, staff must get the tenants to take control of their lives.

The manager's statement reveals two interesting points. First, it appears that a significant priority of his was to toe the line with governmental and regulatory requirements and, in doing so, he emphasised how the structure of the care organisation and the nature of services they provide are beholden to the wider control of these institutions. Second, and in relation to the first point, his direct reference to 'taking control' relates to policy initiatives that are aspiring to achieve empowerment for this population. In particular, the concept of responsibility is an important element of this political rhetoric, of which the overriding aim is to improve life quality for people with intellectual disability by empowering them with *choice, rights, independence and inclusion* (Department of Health 2001). Of the support staff and managers in favour of supported living, all expressed a belief in the notion that the traditional paternalistic model of care is inappropriate and that tenants should take more responsibility for the management of their own lives. The way that these principles were conceptualised by the manager and other support workers, however, was in the context of tenants taking on the responsibility of their own legal tenancies. Following this, it was then perceived necessary, because the individuals were now paying tenants, that they must take on the responsibilities of paying tenants; that is, rather than support workers 'doing everything', the tenants should do their own household tasks. Although certain aspects of the manager's opinion of supported-living were not adopted by all support workers, he was still not alone in his opinion that empowerment, in the context of the care setting, was represented though a legal tenancy and looking after oneself in a domestic sense.

It appears that, within the context of the care setting, support workers and managers interpreted empowerment in very particular ways, which were specifically related to the responsibilities that living tenants should adopt. As outlined above, part of the perceived ethos of supported-living is that tenants are now expected to participate in all household chores, and support workers were instructed to encourage tenants to complete these chores independently. This, however, was not met with positivity from all tenants, and some did not want to participate in doing chores. One tenant in particular frequently expressed a dislike of doing housework. As a result of this reluctance, the tenant was often discussed among support workers and described as lazy. The lack of willingness of this tenant, and at times others, to routinely partake in household chores was perceived by support workers and managers as indicative of the ways that tenants have become complacent whilst living in residential care, as previously they had often tried to get support workers to do housework and other tasks of which they were actually capable. There was an expectation among many support workers and management that doing household chores directly correlates with living a normal and independent life. As a result, when the tenants did not acquiesce with this view, support workers and managers would perceive them in a negative light, articulating that they live unrealistic lives, which now must change following their move into supported-living accommodation. These beliefs would often be expressed by statements such as they need to 'wake up and live in the real world', or that they can no longer have an 'easy life'. Importantly, such statements were also often followed by statements pertaining to the need for tenants to live their lives 'like you or I' (non-disabled people).

The above examples clearly indicate that support workers' and managers' perceptions about what specific responsibilities tenants should be taking on in their daily lives were quite different from the tenants' own perceptions. As a result of these differences, tensions would regularly occur between support workers and tenants, and this appeared to be dealt with by quashing tenants' behaviour, and framing it as acts of selfishness. For example, when a tenant did not want to participate in cleaning, it would be pointed out that they were letting other housemates down, and not 'pulling their weight' as a tenant. As such, certain types of behaviour were therefore demarcated as morally incorrect. Further to the above, however, there were also times when, rather than attempting to alter tenants' behaviour by way of highlighting their moral obligations to the rest of the house, support workers and managers would take matters into their own hands and make decisions directly on behalf of tenants. These decisions would be made on the grounds that the health and well-being of tenants was in need of protection.

As outlined above, current political imperatives centred on enabling choice and independence are not presented as stand-alone principles in the delivery of social care and support. Combined with these principles is the 'duty of care' principle, which, in recent years, has been made explicit with the introduction of the Mental Capacity Act 2005 (MCA). The MCA provides a legal framework for acting and making decisions on behalf of adults who lack the capacity to make particular decisions for themselves. Within the everyday setting of a supported-living environment, the MCA is realised by support workers ensuring the everyday safety and protection of the individuals whom they support. As such, a support worker's role is to ensure the provision of a duty of care and also to enable tenants with choice and independence in their everyday lives. In practice, however,

merging two seemingly opposed values may not be a straightforward process. The tensions that are potentially created as a result of this can be nicely highlighted in observations I made as regards the case of one tenant who is allowed only a limited number of cigarettes, which are allocated daily by support workers. By restricting the tenant's cigarette supply, it is believed (by the care organisation) that his health and well-being are being improved as the tenant has various health problems, including Parkinson's disease, and is not very well off financially. Support workers and managers state that the tenant must be protected from the harm that would be caused to him by excessive tobacco use. It is in this kind of decision-making that the notion of providing both protection and empowerment begin to get sticky, as an argument could be put forward suggesting that this tenant's well-being would in fact improve if he was given free access to, and ownership over, his own cigarettes, a consumable item that appears to be a central factor in his life.

In these above examples, it appears that support workers' and managers' perceptions of what constitutes a right way to live were not concurrent with tenants' perceptions, and often it appeared that tenants found that many of the tasks that they were being asked to engage in were arbitrary in the context of their lives in that they held little significance for them, and certainly did not make them feel empowered. Support workers and managers, however, conceptualised the changes as a positive step towards empowerment for the tenants, and one change in the houses that represented this was the rule which stipulated that support workers were no longer allowed to answer or use the house telephone, unless it was initially answered by a tenant. The reasoning behind this change was premised on the fact that, following the move to supported-living, the telephones were no longer the property of the care organisation and, as tenants would now pay the telephone bills, staff were not authorised to use this service. Functionally, this rule created a number of problems for support workers, namely because household telephones were the primary means by which support workers in different houses communicated with each other and, consequently, the lack of telephone usage meant that they began to experience difficulty in receiving and transferring information; although management provided each house with a mobile phone, for the duration of my employment the majority of incoming calls were still being received via the house landline.

This is perhaps a good example of enacting empowerment policy via a very narrow and preconceived idea of what empowerment meant for the tenants. Under the assumption that becoming legal tenants is a meaningful experience, the care organisation has attempted to make their legal status more tangible by allocating them ownership over their house landline. Although the intention behind this initiative is justifiable, the way it was enacted appeared to do nothing to improve the everyday lives of the tenants and, consequently, in the context of the care home it became an arbitrary and meaningless process, and ultimately a source of tension between support workers and tenants.

Discussion

Through this paper, I have attempted to relay some of my personal experiences whilst working as a support worker in a supported-living home for adults with intellectual disability. The premise of partaking in this experience was to gain further understanding

of the ways that social-care policy reforms for adults with intellectual disability, relating to empowerment and protection, are interpreted and enacted within the daily practice of a supported-living setting, and it is argued that this could be achieved by exploring the relational dynamics between support workers and tenants. This rationale is founded upon theoretical assumptions of constructionism and symbolic interactionism, proposing that meaning is derived through experiences, which, in this context, are represented in the relationships between support workers and tenants. Within these relational dynamics, we therefore see subjective interpretations of political imperatives writ large.

A major feature of social-care reform for adults with intellectual disabilities has been the move from residential care to supported-living, which has transformed people's legal statuses from service users into legal tenants. This change is in accordance with the introduction of individualisation, in the form of person-centred care, into social care support for this population. These changes have been much debated in both academic and health and social-care discourse because of concerns pertaining to the issue of whether individuals receiving care and support from social services can be successfully empowered with independence and choice in their everyday lives when they are also considered, to varying extents, to be vulnerable and in need of protection.

During my employment as a support worker, I observed a number of difficulties relating to the interpretation and enactment of care imperatives of empowerment and protection by support workers and managers. One of the major problems with introducing these initiatives into daily practice was that support workers and managers conceived empowerment in very narrow terms, which were largely related to the shift in tenants' legal statuses. When observing interactions between support workers and tenants, however, it was evident that, even after the move from residential care to supported-living, tenants still perceived support workers as people to be reliant on for almost every aspect of their day-to-day living, particularly with regards household duties. Yet, under the principles of person-centred care, providing support in this way is considered to be overly paternalistic, and it is believed to be more appropriate for tenants to take on household responsibilities that would previously have fallen under the remit of support workers' roles. Very quickly tenants were expected not to rely on support workers in the ways that they previously had. This had implications for the ways that tenants and support workers were able to relate to one another in that their relational dynamics had been formally altered. It could be argued that the domestic duties, previously conducted by support staff were part of personal and intimate experiences of care between support workers and tenants, which were replaced with a type relationship based on market-style exchanges (Reinders 2008; Van der Laan 1998; Kirkpatrick, Ackroyd and Walker 2005). In the context of the care setting in which I worked, removing these elements of intimate meaningfulness was a catalyst for tension in that tenants were unable to fulfil the demands placed upon them, largely because they were unable to incorporate these requirements into their own value systems. Instead, the aspects of their lives that did represent meaningful and fulfilling experiences, such as experiences that fell outside the fixed definition of empowerment, were the very things that were being removed from their lives.

As a result of political reform relating to transforming people's legal housing status, the supported-living home appears to be situated in an ambiguous space. Policy dictates that paternalistic care is inappropriate and with the move to supported-living, people

receiving social care support are required to take responsibility for the daily running of their rented accommodation. In reality, however, support in this environment is not based on a professional agreement, but instead it is premised on the ability of support workers and tenants to form personal and social relationships with each other which are set within a caring dynamic. The support workers and tenants with whom I worked are trapped within a system that expects services to provide a better quality of life for users, yet paradoxically policy reforms are removing opportunities for particular kinds of meaningful relationships and experiences to be developed with tenants. At present, supported-living is only serving to confuse the situation and roles of individuals in this setting and renders relational dynamics between support workers and tenants unstable.

NOTES

[1] This study is a continuation of previous health-related research that I have conducted for The Cambridgeshire Learning Disability Partnership (LDP): first, an investigation of access to healthcare (Banks et al. 2010) and second, a weight loss intervention programme (Smith et al. 2011). These studies found that people with intellectual disabilities living in various community settings, are significantly reliant upon their immediate and extended social networks as regards their health and social care management. Following these findings, it was decided that knowledge in this area would improve from a more in-depth understanding of the everyday lives of people with intellectual disabilities living in the community and of the people who provide their support.

[2] Day centres, as non-residential institutions for people with learning disabilities, have been in existence in one form or another since 1913. The focus of what have been called at different times occupation centres, adult training centres, social education centres and day centres has shifted over the years. At various points they have concentrated on sheltered work, the need for training for independence, or developing social skills (Whelan and Speake 1977; National Development Group For The Mentally Handicapped 1977). During the 1980s and 1990s centres became increasingly specialised and education, leisure and employment functions were often separated. However, wide variations in what people actually do in centres persist, reflecting historical precedent more than deliberate design (Beyer, Kilsby and Lowe 1994).

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