Exploring independent living in the lives of disabled people

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ABSTRACT

To adopt a critical semi-structured interview approach to investigating disabled people’s meaning of independence. To explore conceptual ideas and frameworks around the phenomena of independent living in regards to the narratives being spoken.

This work follows on from Davis (1990) & Southampton Centre for Independent Living (2003) emergence of the seven needs and extension into 12 basic needs that must be possessed in order for a disabled individual to successfully live independently.

The interview approach critically engaged with both of, the social model of disability and a critical disability theory stance allowing voices to be heard.

The research used a semi-structured interview approach to investigating disabled people’s meaning of independence. Participants were selected from a purposeful sample of personal friends and volunteers via disability organisations, aged 18-30, all male and were specifically chosen to reflect on their own insights and experiences within the phenomena of independence and could therefore be described as an expert sample, N = 6.

A thematic analysis identified three broad themes: Choice and control over a variety of support, Exclusion can result in emotions and behaviours which manifests as abusive or rebellious and Integration leads to independent living equality and aspirations.

KEY WORDS: DISABILITY, INDEPENDENT LIVING, SOCIAL MODEL OF DISABILITY, SEMI-STRUCTURED INTERVIEW, THEMATIC ANALYSIS
Introduction

The independent living movement has been fighting a big struggle over the last 30 years pertaining to disability rights in the realms of employment, education, and access to leisure and many other influential areas. This research is interested in exploration of how disabled individuals have been denied access to person centred community forms of health and social care prohibiting independent living. Independence has been defined by Adolf Ratzka (2004) as, ‘a philosophy and a movement of people who work for self-determination, equal opportunities and self respect’. Ratzka (2004) adds that ‘Independent living is essentially a challenge to the place of disabled people in society’. The goal of independent living is thus motivated by three fundamental ideas: disabled people should have access to the same human and civil rights as nondisabled people; society's reaction to impairment, and the failure to meet needs relating to impairment, have undermined disabled people's human and civil rights; this is not inevitable; impairment does not have to determine life chances, our biology is not our destiny (Morris, 2004, p.428). In 1948 traditionally, there were two categories of support available; the first distinction was care for those in need and the second distinction supplying welfare benefits to those in poverty. The distinction between the two categories is that care is carried out locally and benefits are disseminated on a national basis. The care social policy in 1948 made it clear that it was prohibited for a local authority to offer cash instead of care, which in turn, prohibits the disabled individual from exerting their own control in their personal care. A political shift had begun in the ways we theorise disability from a medical perspective to a social paradigm. Oliver (1990) stated that there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component. There are two fundamental points that need to be made about the individual model of disability. Firstly, it locates the 'problem' of disability within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability. These two points are underpinned by what might be called 'the personal tragedy theory of disability' which suggests that disability is some terrible chance event which occurs at random to unfortunate individuals.

The need for independent living schemes have been highlighted perfectly by John Evans (2002): 'Disabled People in the UK, like many other disabled people in other countries were very disenchanted by the services being provided for them at this time. Disabled people felt the services were paternalistic, institutional, second class, too medically orientated and out of touch with their real needs. As a result of this they looked elsewhere for solutions to overcome their restricted predicament and living conditions.' With growing numbers of disabled individuals in the UK gathering momentum through the common negative feelings of
isolation and lack of control, disabled activists groups such as The Disabled People's Movement and the British Council of Disabled People (BCODP), grew in power and political voice which put the Government under increasing pressure from the growing voices of the disabled demographic to be heard and change political policies accordingly.

In terms of the development of independent living in the UK there were two other significant early developments, which led to an increase in the numbers of disabled people running their own form of independent living schemes that are worth highlighting. These were the introduction of the Independent Living Fund and the formation of the British Council of Disabled People (BCODP) Independent Living Committee (Evans, 2002, p.11). The Independent Living Fund was one of the first personal care schemes that adopted a social model of disability focus. According to Oliver (1990) ‘disability is a social construct. People with impairments are oppressed/disabled by society. Primary barriers are discrimination, social isolation, economic dependence, high unemployment, inaccessible housing, and institutionalization’. The social model’s alternative perspective to personal care in the community led to the creation of direct payments scheme. Direct payments was based around all of the inadequacies of the individual model whereby the disability or impairment want to sell purpose for social isolation and other disability related issues ultimately placing the blame disabled within individual. According to Priestley & Jolly (2006):

Having a direct payment means that disabled people can choose whether they want to receive services or whether they want to receive money to organise their own support services.

Direct payments offered a person centred approach, which empowers disabled individuals within the community to choice and control in every aspect of their lives. However, in recent years, direct payments hasn’t been implemented as well as the government anticipated due to the complex nature of recruitment, training and management of the individual’s personal care support systems without any local authority assistance in terms of establishing the care package, most disabled people revert back to a virtual budget through their council as a result of lack of knowledge and advocacy services available.

The social of disability can be defined by Barnes and Mercer (1997: 1-2): The significance of disability theory and practice lies in its radical challenge to the medical or individual model of disability. The latter is based on the assumption that the individual is ‘disabled’ by their impairment, whereas the social model of disability reverses the causal chain to explore how social constructed barriers have disabled people with a perceived impairment. The social model's standpoint is that all disabled adults' and children’s right to belong to and be valued in their local community. Using this model, you start by looking at the strengths of the person with the impairment and at the physical and social barriers that obstruct them, whether at school, college, home or work. The 'social model' defines 'impairment' and 'disability' as very different things.
Impairment is the loss or limitation of physical, mental or sensory function on a long-term or permanent basis. Disablement is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’ Disabled People’s International (1982). The social model forms the basis of the research because I feel that it is the best approach that can provide a voice to individuals with disabilities. Being physically disabled myself I feel that the emancipatory nature of the social model enables ‘real issues’ to be highlight directly from the people that it concerns.

There has been much research into the theoretical criteria of what is needed in order to achieve successful independent living, is there a universal formula that could be discovered and adopted to remedy the current issues of independent living in the community? According to Davis (1990) independent living is associated with the words ‘choice’ and ‘control’, and concerns both the environment in which someone lives and the assistance needed in order to go about daily life. The disability movement identified first 7 (Davis, 1990) and then 12 ‘basic needs' which are central to achieving independent living. These are:

- Full Access to our environment.
- A fully accessible Transport system.
- Technical Aids – Equipment
- Accessible/adapted Housing
- Personal Assistance
- Inclusive Education and Training
- An adequate Income
- Equal opportunities for Employment
- Appropriate and accessible Information
- Advocacy (towards self-advocacy)
- Counselling
- Appropriate and Accessible Heath Care Provision

(Southampton Centre for Independent Living, 2003)

These are areas in which disabled people have requirements, over and above those of non-disabled people, which must be met if they are to experience equal access to human and civil rights. However, the philosophy of independent living also emphasises that the way in which these additional requirements are met is crucial to whether this level playing field is achieved: ‘the disabled person must have choice and control over how needs are met.’ (Morris, 2004, p.429.) However there are still struggles to provide disabled individuals within the community
with full independent living schemes that are successful because local authorities and the government are overlooking the important implications of initiating, recruiting, accounting and managing of an individual budget or a direct payment. The complications just mentioned are the main confounding factors that prohibit the majority of disabled individuals from succeeding in independent living. This research aims to investigate and test whether Davis’s 7 needs and Southampton’s 12 needs theory to independence is really as vital as the research suggests in the likelihood of a disabled individual living independently successfully.

Method

Design

The research used a semi-structured interview approach to investigating disabled peoples’ meaning of independence. The interviews were very informal, face-to-face discussions, which often lead to topics that weren’t directly related to the research aims. The semi-structured interviews were organised to be at a convenient time and place to the participant. The most convenient place for all of the participants involved was their homes. The semi-structured interviews were shaped by a set of pre-determined questions derived from Davis (1990) & Southampton Centre for Independent Living (2003) emergence of the seven needs and extension into 12 basic needs of independence. The sequencing of the questions occasionally differed from each participant and there are additional questions that are context specific to a particular participant. There were no questions left out from the semi-structured interview. This research collected narratives from physically disabled adults with disabilities such as Duchenne Muscular Dystrophy and Spinal Muscular Atrophy Intermediate (Type II) via audio recording. All participants had experiences of independent living and are a recipient of health and social care. A theoretical thematic analysis was utilised to identify emerging themes within the data. Welsby & Horsfall (2011) utilised thematic analysis of their data that successfully showed that the intellectually disabled women experienced practices of social and emotional exclusion, and inclusion, in their everyday lives.

Participants

Participants were selected from a purposeful sample of personal friends and volunteers via disability organisations, aged 18-30, all male and were specifically chosen to reflect on their own insights and experiences within the phenomena of independence and could therefore be described as an expert sample, N = 6. All participants are known to the researcher and due to the nature of emancipatory research interview, power imbalances are removed from the study investigation since the participants represent the core elements of the exploration. Therefore the participants in the study act as a co-researcher to collect data. Barnes
(1992) was critical of the exclusion that disabled people have experienced in the research process as subjects, not participants in research, and the powerless position this put disabled people in. The research concurs with Barnes’s ethos of the notion that distributing power to the participants will in turn produce truly emancipatory outcomes. This was achieved by the participants being completely in control within the research interview process delving into rich experiences pertaining to independent living which at times may go off on tangents, however this semi-structured approach allows more holistic narratives to emerge providing context specific authentic conclusions.

**Materials & Procedure**

Audio recorder, computer with word processing software and printer for ethics and information pack documentation. The semi-structured interviews were recorded via audiotapes and subsequently transcribed for the purposes of thematic analysis. The shortest interview was 22 minunities and the longest interview was 75 minutes. The interviews had no time limitations applied to the semi-structured interview. The interviews ended when both parties had nothing to say.

The participants were given the following labels to remain anonymous Mr.LM, Mr.TB, Mr.TM, Mr.RJ, Mr.PF and Mr.SR. Initially the semi-structured interviews were centred on 21 broad questions, which aimed to give the participants a chance to talk about experiences and understandings of disability.

Example questions:

1. Would you define your environment as wheelchair accessible?
2. What technical equipment influence and aid your life?
3. What are your experiences of personal assistance?
4. What are your experiences of health care provisions?
5. What are your experiences of education?
6. What are your experiences and thoughts of employment?

**Theory**

The data was analysed by drawing on Neo-Marxist ideologies with the considerations of the contemporary social, cultural and economic factors that impinge independent living inequalities. The research corresponds greatly with the social model of disability praxis (Oliver and Zarb, 1989; Barton, 2001). This research values and adopts a participatory approach which calls for strategies involving the research participants. This is emphasized by Oliver (1992) when he argued that research has essentially failed disabled people on at least three counts. First, it has failed to accurately capture and reflect the experience of disability from the perspective of disabled people themselves. Second, it has failed to provide information that has been useful to the policy-making process and has contributed little to improving the material conditions under which disabled people live. Third, it has failed to acknowledge the struggles of disabled people themselves and to recognize that disability
is not simply a medical or welfare issue, but a political one as well. Thus suggesting we should challenge the traditional roles of researcher and researched.

Critically engaging with notions of thematic analysis, this qualitative technique allows the data to push the research into findings rather than researcher pushing data into findings. This idea has also influenced research on disabled people, often carried out by non-disabled people, which have contributed to deficient understandings. Linton (1998a: 531) argues that:

The overwhelming majority of scholarship on disability either utilises or implies the third person plural: ‘they’ do this, ‘they’ are like that, ‘they’ need such and such. This contributes to the objectification of disabled people and contributes to their experience of alienation.

Thematic analysis will be utilised in order to discover commonalities between the participant’s transcripts in the form of themes. Bond and Hurst (2010) utilised thematic analysis to successfully understand the identified issues for nine people with mild learning disabilities who were currently managing to live independently. Thematic analysis will allow data immersion to occur according to Braun & Clarke (2006) and if this process is successfully accomplished then the availability of rich narratives can immerse themselves and subsequently be organised into themes and codes derived from extracts of interview transcripts.

The researcher and participants all had a rapport through membership of personal friendship and the identity of disability, which enabled the research to be participant led and therefore has the potential to be emancipatory as described by Barnes:

...emancipatory research is about the demystification of the structures and processes which create disability, and the establishment of a workable dialogue between the research community and disabled people. To do this, researchers must put their knowledge and skills at the disposal of disabled people. (Barnes, 1992, p.122)

Furthermore, the research question underpinning this study was generated through literature. The use of open-ended questions generated discussions on broad topic areas, which enabled the analysis to focus on the participant’s meanings and perspectives rather than attempting to impose an interpretative framework. This enabled the content of the discussion to be determined by the participants and Burman (1994) suggests this type of research can be empowering by offering the potential to ‘document perspectives not usually represented or even envisaged by researchers’ (p.51).
Ethics

The interview questions were not delivered in a probing manner due to being disabled myself. I was able to de-stigmatise many of the sensitive issues by sharing personal experiences and empathising subsequently leading to congruence. The participants will understand the research aims to explore their interpretations and experiences of disability and independent living. Therefore there will be no deception. The participants were fully briefed before the semi-structured interview began as to their rights. The participants all gave informed consent before the interview began and knew that they were able to stop during the interview at any time requested and all data from the participant will be deleted if withdrawal occurs. The participants are all over 18 and are able to eligible consent to the research.

Results

Data Analysis

This thematic analysis followed the six basic steps described by Attride-Stirling (2001), this approach was chosen because it can be applied flexibly to fit the research question and data.

Attride-Stirling describes ‘devise a coding framework’ (p. 391). Themes were identified in terms of relativity and connectivity pertinent to the research question. The analysis identified latent themes that go beyond the explicit level of the data. Identifying underlying assumptions and ideologies within the data required interpretative work and latent thematic analysis is compatible with a neo-Marxist framework, whereby experiences and meanings are arguably addresses the socio-structural barriers consequential of societal discourses. The thematic map was created and reviewed and three main themes were identified during an ongoing analysis.

Three broad themes were identified on analysis of the data:

1. If Choice and Control is evident in relation to a variety of support, subsequently the individual is empowered. If choice and control was absent consequently the individual is marginalised.

2. Exclusion can result in emotions and behaviours which manifests as abusive or rebellious. Exclusion consequently results in inequality.

3. Integration leads to independent living equality and aspirations

Choice and Control

The thematic map has found that having choice and control over a variety of support greatly contributes to the likelihood of successful disability
independent living. In addition if choice of control is handed to the individual then this in turn will lead to empowerment. Empowerment is represented through the basic theme of imagery and perception. Empowered imagery and perception seems to enable disabled individuals to access basic themes such as equality in education, appropriate information, environment, employment, transport and aspirations. If choice and control are not present subsequently marginalised imagery and perception becomes apparent. Marginalised imagery and perception seems to prohibit disabled individuals to access basic needs such as in education, appropriate information, environment, employment and transport resulting with inequality. In regard to the theme of employment, reviews of the position of disabled people in the labour market continue to demonstrate that disabled people still have a long way to go before they achieve parity with non-disabled people (Martin et al., 1989; Buchardt 2000) and some have questioned the centrality of paid work for the full integration of disabled people and called for a reconfiguration of the meaning of work for disabled people (Abberley, 1997; Barnes & Mercer, 2005).

Researcher: In terms of personal care, how long have you been recipients of personal care?

MR.RJ: I've organised my own care since I went to university. I went on a direct payments plan, which basically means I can hire my own carers.

Researcher: Your experiences changed much since ‘99 to now of care?

MR.TM: Employing my own people you have a bit more control of who you have and quality and that kind of thing.

Researcher: In terms of your everyday life what technical aids or equipment, would you say, impacted on you constantly in a social way?

MR.SR: Oh my electric chair definitely allows me to have the option just to go to any place but some point near by

MR.SR: In the other chair is just so long

MR.SR: Also, my chair it raises up so that's a pretty good that really helps if you're in a pub or something. It can really help

Researcher : Funding your wheelchair has it always been difficult ?

MR.SR: For my electric wheelchair, I've had to try loads of charities and filling in loads of forms

Researcher: What technical aids influence your life and how?

MR.RJ: Mainly there is my electric wheelchair erm it's it's different from most chairs. Cos it can do a lot more erm firstly it can tilt me back and foward and erm when i need wee or repositioning in the chair, I wouldn't be
able to do that if I didn't have the ability to standing back. Can go rise up or lowered me down. I find that useful, especially when I'm in social environments, and I wanna be at everyone's eye level. Erm I also have my mobility van.

Technical aid is an interesting theme because the data suggests that finance support is required for special electric wheelchairs that can reposition themselves in order for the user to assist with toileting and many other health needs in a social environment, therefore without the technical aid accessing the social environment would be virtually impossible. In addition the technical aids or so impacts socially by allowing the user to rise up to a standing height which creates feelings of integration. Previous research in this area has shown that people with different impairments have differing requirements for technical aid service provision and can impact positively in the grand scheme of independent living (Harris et al. 2005). Many technologies that are currently on the market hold the potential to enhance the lives and independence of disabled people (Dewsbury et al. 2002)

Integration

Integration relates to empowerment and equality. Empowerment relates to the idea that the individual feels fully integrated into equal opportunities within education, employment environment and accessible information. Equality relates towards access to self actualising ambitions and goals that aspirations bring. In regards to education the term SEN is defined as children who have special educational needs and they have a learning difficulty which calls for special educational provision to be made for them (Department for Education and Skills, 2001b). Learning Support Assistant (LSA) can be defined as a person employed by the school to provide support in the classroom or undertake specific work with a child or group of children who have learning difficulties.

Mr. TB: Yeah I went through the mainstream system so my primary school I had care assistant at school one kind of LSA that then at er secondary school I was again mainstream with a proper SEN Department there but I was supported by a few LSAs and kind of followed around

Mr. TB: And then secondary school the centre point were brilliant I think I was really lucky with my school it was actually not the school I I chose to go to and this is perhaps like something to throw in as though I actually chose another school and they said that they wouldn't make their school accessible for me.

The above education experiences suggest that due to the equal integrative embracement that both schools possessed seems to have overall empowerment of Mr. TB for future aspirations of university education and independent living. However research suggests disability had not previously been identified in terms of equality and 'rights' within higher education. This was evident in a study by Leicester and Lovell (1995) into equal opportunity practices within higher educational institutions (HEIs). The authors claimed that evidence indicated that disability was not
understood in terms of oppression, as with other groups experiencing inequality. Therefore, whilst gender, ethnicity and social class were more likely to be recognised in terms of inequality and oppression, disability was not.

Researcher: Right, first of all, would you define your environment as wheelchair accessible?

Mr.TM: Err I would say, yeah largely it is, but not 100% ex

Researcher: And like how do you get about, do you use your transport system to do all them social activities?

Mr.TM: Yeh I mean I mainly, erm in London I mainly use taxis, erm I occasionally use buses. Erm, yeh those are my two main, and I use trains as well

Researcher: In terms of employment, what are your experiences and thoughts of employment?

Mr.TM: Erm I think it’s really important, erm I’m quite, you know, I’ve had a work ethic from a very young age, so erm, you know. My first job I got when I was 15.

The research suggests that Mr.TM would be integrated because he has equality within employment, from a very young age. Having an accessible environment and transport system has largely contributed to the employment success that Mr.TM has achieved. This is support by Werneck (1997, pp. 51–53), who says:

The integration system is organised on the basis of the concept of mainstream. The process of integration that happens through the notion of mainstreaming is designed by the cascade system. In it, all the students have the right to enter the mainstream and move around in it. They may either go up or down along the cascade according to their special educational needs. Inclusion questions the cascade concept.

**Exclusion**

Exclusion is related to the notions of marginalisation and inequality. Peter Leonard (1984, p.180) defines social marginality as ‘being outside the mainstream of productive activity and/or social reproductive activity’. Inequality relates to oppression subsequently limits access/opportunity to employment or education.

Researcher: Would you do define your environment as wheelchair accessible?

Mr.PF: Erm at home no I wouldn't define it as fully wheelchair accessible. I live in Maidenhead, so I live in a local town
Researcher: In terms of getting around and you know getting out and about doing your social activities. How would you get there do you use your local transport system for example?

Mr.PF: Erm, no, I actually, I actually use my own motorbility car it’s like I don’t need local transport, because I found that to be sort of hassle all of that with trains and stuff, but certain, well, I can sort of do maybe.

Researcher: What are your experiences of employment?

Mr.PF: Oh erm well I only been kind of employed once that’s with this Age Concern, erm they were very helpful I’ve I’ve kind of I’m kind of bit annoyed with my help Ways into Work and er because they didn’t get back to me sooner for example at the moment she said she’ll contact me she hasn’t even contacted me so there was a bit a communication issue I think I’ll contact her but I don’t know it just seems a bit why should I contact her when it’s her job erm.

Mr.PF’s case demonstrates marginalisation and inequality in relation to accessible employment regardless of the fact he a university graduate on face value would seem highly employable. He has been employed but only as a volunteer and now has become stuck in unemployment for a period of time. The local environment and transport system only seem to provide unequal access to opportunities and therefore the Mr.PF is marginalised.

Mr.LM: I been left by some agencies because I was being called a dictator I was being called Hitler I was being called a racist, feminist, sexist I was abusive to my carers physically abusive the carers erm

Researcher: Physically abusive to the carers?

Mr.LM: Apparently when I used to have apparently when I used to go out and drink sixteen pints of stella, sixteen pints

Mr.LM: Well yeah i was apparently erm erm umm abusive to to this umm to this umm this person the carer the felt that she couldn't handle me.

Mr.LM: Yeah because year seven on my first day I wasn’t allowed to go in because of the health and safety regulations one of the ramps was broken which put the school unaccessible for disabled persons and the only thing is with secondary school is what I found frustrating was I couldn't go out with my mates much I had to go into a room full of disabled persons

Researcher: And it's nice everyone had that sort of community feel where everyone sort of like you know what I mean no one was sort of nasty to each other

Mr.LM: I know but I was nasty to the ice machine

Researcher: Yeah but that not human haha it's a machine

Mr.LM: It's a machine
Mr.LM: There’s gotta be more understanding and more appearance of disability on popular media posts we see. You know you don’t see enough, you don’t see a James Bond wheelchair actor.

Researcher: So you’re saying that the media’s not, not sort of giving any disabled people any

Mr.LM Positive credibility.

The transcription above indicates that abuse and rebellion are associated with the notion of exclusion because Mr.LM seems to display frustration with the media and society’s representation of the phenomena of disability as being oppressive and not accurately represented. A core concept developed in the symbolic interactionist literature is the concept of ‘self’. Several theorists argue that the self is a product of the individual’s relationship with others, and is developed through the process of social interaction (Mead, cited in Anthias & Kelly, 1995, pp. 365–367). According to Mead it is the reaction of others that allows an individual to develop a symbolic construction of the self. The individual’s self image is developed through interaction and internalisation. The term used by Cooley (1902) to describe this process is the ‘looking glass self’, suggesting that we are influenced by others as we receive messages and communications about ourselves from others, and these influence our self construct (Brown, 1979, p. 116). The self construct, in this exchange, is based on the interpretation placed on incoming communications. In most instances people with disabilities see themselves as being fundamentally no different to others. However, this raises conflict, or ‘noise’, when the social meaning of disability as a symbol dominates, and people with disabilities are socially seen as being different, based on the premise that disability relates to dependency, deficiency and inability (Oliver, 1996; Morris, 1991). Gething takes this further, suggesting that people with cerebral palsy are often deprived of being touched or approached due to their appearance (Gething, 1997, p. 84).

Abuse can be manifested in a variety of ways an example from the above extract is when the disabled individual was being verbally abusive towards the personal assistant and the personal assistant being described as physically abusive towards the disabled individual.

Discussion

Main findings

Disabled individuals who have choice and control over all aspects of support consequently become empowered identities.
Research findings suggest that empowerment has a link with integration into employment, access to appropriate information, education, transport and environment resulting in equality in achieving aspirations.

Disabled individuals who don’t have choice and control over all aspects of support consequently become marginalised identities.

The thematic analysis established that marginalisation is linked with low credibility of disability represented in the media and society. This negative representation of suggest marginalised imagery and perceptions.

Exclusion has been found to be an outlet for a combination of marginalisation and inequality. Abuse and rebellion appear to be directly linked with exclusion as a result of inequality and marginalisation towards access to appropriate information, education, transport, health, care and social life.

This research found that Davis’s 7 needs and Southampton’s 12 needs theory to independence is a proven useful theory for what’s needed for successful independent living for disabled individuals.

**Findings interpreted in relation to research**

Ratzka’s (2004) definition of independence corresponds with the thematic analysis findings relating to promotion of positive imagery and perception of identity. Individuals with impairments who are typically excluded from employment and education seem to encounter inequalities and marginalisation which relates to research from Oliver (1990) which instigated that ‘disability is a social construct. People with impairments are oppressed/disabled by society. Primary barriers are discrimination, social isolation, economic dependence, high unemployment, inaccessible housing, and institutionalization’. The importance of the global theme established from this research, choice and control, suggested that current support services are often inadequately prescribed. Swain *et al.* (2003) demonstrated that disabled people increasingly view independence in terms of self-determination and control, rejecting the narrow, professional definition as oppressive and contra to their rights. Bracking (1993) described independent living as a rights issue when he stated that ‘independent living for disabled people as a right has evolved from within the disability rights movement— and not from within able-bodied society’. Swain *et al.* (2003) lent credence to the idea of independent living as a rights issue: ‘independent living has been achieved in the face of considerable opposition by professionals.’ Disability research acknowledges that independent living over the years has been a fundamental battle for rights. It is evident with the findings from this study that this movement is still experiencing difficulties today. There is a participant in this study that has experienced a dramatic cut in support services provided from the local authority which therefore according to the above research from Swan and Bracking is deemed a breach of human right.

According to Priestley (1999), independent living and the funding for it ‘is being played out within a needs-based system of distributive welfare rather than within a rights-based citizenship framework’. This needs-led framework is dependent upon means tests, charging for care and fixed budgets (Oliver,
MacFarlane (1999) argued that having all one’s impairment needs met and paid for in full to enable independent living must be free of means tests, charging and budgetary restraints, and conferred as a human right when she suggested that ‘as society believes that basic health care should be a fundamental right because you cannot live without it. In the same way disabled people cannot live without basic personal care i.e. is not in keeping with basic human rights’. This supports the idea of the notion of financial support being the core contributor to integration and empowerment because having a person centred care package fully funded and all needs met subsequently leads to the equal human rights.

The major findings of the research indicated that participants who describe themselves as integrated and empowered possessed high levels of control and choice over their lives. The research draws a parallel with Houston (2004) where he found that those disabled individuals who were most likely to see themselves as empowered were those physically impaired people with severe impairments, i.e. service users, e.g. 24-hour provision and had all their needs met.

Relating to the themes of media and society research has suggested that all too often individuals with disabilities are absent from the mainstream media or are inaccurately portrayed. Presence of disability is often within a documentary about a particular disability itself. There is so little representation of people with disabilities living normal lives that they have quite accurately been referred to as the ‘invisible minority’ (Nelson 1999). The first time an individual with a visible disability appeared in film was 1898 (Safran 1998) when a person with a physical impairment was presented in a 50 second segment of a film. Thereafter, many of the early movies depicted people with disabilities in slapstick comedy or as villains in a drama. Still today when individuals with disabilities are portrayed in the media, they may be presented as a cause for inspiration or an object of pity (Barnes & Mercer, 2003). According to Shapiro (1993, p.30), ‘These images are internalized by disabled and nondisabled people alike and build social stereotypes, create artificial limitations, and contribute to the discrimination and minority status hated by most disabled people’.

The ownership of choice and control in regards to support is the catalyst in determining whether the disabled individual ultimately experiences integration and empowerment or marginalisation and exclusion. Rock (1988) discovered in his research that independence implied choice and that independence was meaningless without some level of choice being exercised.

**Critical evaluation of the study**

Due to time constraints and limited sample opportunity all of the participants were male. In addition in order to explore the concept of independent living in the lives of disabled people and provide more authenticity to the data suggestions of a larger sample would be recommended. To provide a more holistic view of the overall phenomena of independent living with regards to individuals with impairments is to
interview a much wider spectrum of disabilities. Furthermore the age of the participants in this research were 18 to 30 years old there is a possibility to extend understanding expanding the age bracket by perhaps 30 or 40 years. Another suggestion would be to interview the social worker and carers of the disabled individual in order to make direct comparisons of overlapping experiences.

Reflexivity

The participants in the research were all fully aware of my personal political emotional and academic investments into the topic of disability and independent living. In addition a proportion of the participants are personal friends of mine which allowed authentic experiences to come to the surface because they felt comfortable and congruence. The very fact that there is history provides a platform for deeper issues pertaining to independent living to become the main area of focus. The remaining proportion of the participants were obtained from disability organisations such as the muscular dystrophy group. Again there were many mutual common grounds with regards to the phenomenon of independent living and disability.

Research was conducted with awareness that there may be different accounts in the representations and functioning of the same topic. The research was completely based upon the experiences of the participants and not myself. My personal experiences contributed to understanding of an ambiguous question or to bring out confidence for a socially sensitive or taboo subject. During the interview process I made a conscious effort to ensure my understanding of an answer is correct by reiterating the answer back to them to check. This is so that intermissional assumptions and interpretations are avoided and authenticity is maintained.

An understanding that the experiences explained may not be completely truthful or representative of what actually happened and therefore other psychological research methods could contribute to a more authentic research conclusion into exploring independent living in the lives of disabled people.

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