

The School of Sociology and Social Policy

The University of Leeds

**An examination of the 'personalisation' of social care
services as a response to the needs of older disabled
people in the UK**

HUI YU KUO

**Submitted for the Degree of Masters of Arts in Disability
and Social Policy**

September 2012

Acknowledgements

I would like to sincerely thank everyone who has made this dissertation possible. Especially thanks to my supervisor Colin Barnes, you always give me helpful advice and support. Thanks to my lovely tutor Alison Sheldon, your support reduces my stress while writing the dissertation. I would like to thank my lovely classmate Takako Miya, I really appreciate you sharing with me the precious experiences and wonderful insights. The biggest thanks are for my family and friends in Taiwan, they are always being there for me.

Abstract

The 'personalisation' of social care services was launched in 2007. This new approach attempts to maximise the control and choice of service users. Service users can receive individual budgets and use it to purchase the social services that they need. However, the personalised services, to a certain extent, have proved problematic for older disabled people. This study aims to examine whether the personalised approach responds to the needs of older disabled people. This paper has explored the relationship between ageing and disability, and found that ageing has a close relationship with impairment in old age. It is obvious that older disabled people have been under-represented in both the disability and gerontology discourses for a long time. Overly emphasising the characteristics of adulthood has distanced older disabled people from the development of the British independent living movement and the discourses of successful ageing/active ageing.

To date, older disabled people have not completely benefitted from personalised social care services. The simplified assessment instrument cannot reflect the complex needs of older disabled people. Professionals hold a prejudice against older disabled people in terms of service

provision. In addition, several barriers hinder older disabled people from using the personalised services: insufficient information; the under-developed service market; the scarce support services, and the failed risk management. Despite the fact that the personalisation of social care services seeks to maintain the independence of all user groups, it still ignores older disabled people profoundly. The personalised approach is a double-edged sword. On the one hand, it protects the civil rights of every user by providing more choice. On the other hand, overly emphasising marketisation and individualisation in social care services will undermine the social rights of older disabled people. This new approach on the policy agenda should be examined with caution.

Abbreviations

ADLs	Activities of Daily Living
CIL	Centre for Independent / integrated/ inclusive Living
CRB	Criminal Records Bureau
DPI	The Disabled People's International
DPO	Disabled People's Organisation
DCIL	The Derbyshire Centre for Integrated Living
DRC	Disability Rights Commission
GLAD	The Great London Action of Disability's
HCIL	The Hampshire Centre for Independent Living
ICIDH	International Classification of Impairments Disabilities and Handicaps
ICF	International Classification of Functioning Disability and Health
ILF	Independent Living Fund
ODI	Office of Disability Issues
RAS	The Resource Allocation System
ULOs	User-led Organisations
UPIAS	The Union of the Physically Impaired Against Segregation
CRPD	Convention on the Right of Persons with Disability

Table of Contents

	Page
Acknowledgements	2
Abstract	3
Abbreviations	5
Chapter 1: Introduction	8
1.1 Background	8
1.2 Research Aims and Methodology	11
1.3 Organisation of the Project	13
Chapter 2: Changing Conceptions of Disability	14
2.1 Changing Conception of Disability	15
The Individual Medical Model	15
The Social Model of Disability	17
The Bio-psycho-social Model of Disability	20
2.2 The Independent Living Movement in the UK	21
The Origin of the Independent Living Movement	21
The Philosophy of Independent Living	22
The Direct Payment Schemes and Personal	

Assistance	25
2.3 Disability and Ageing	27
	Page
Chapter 3: Disability, Ageing and Older Disabled People	30
3.1 Impairment, Disability, and Ageing	30
Impairment and Ageing	30
Ageism and Older Disabled People	33
3.2 Independent Living and Older Disabled People	36
3.3 Autonomy and Older Disabled People	38
Chapter 4: Social Care Services and Personalisation	43
4.1 The Shifting Policy Agenda	43
The Traditional Professionally Led Service	43
User-led Services for Disabled People	44
Personalisation of Social Care Services	45
4.2 Personalised Social Care Services and Older Disabled People	47
Individual Budgets and Older Disabled People	47
Control and Choice Issues for Older Disabled People	50

Chapter 5: Conclusion	61
------------------------------	-----------

Reference	66
------------------	-----------

Chapter 1: Introduction

1.1 Background

The growing population who are 'ageing with disability' is a significant trend all over the world, but the rights of older disabled people are invisible and underrepresented (Zarb and Oliver 1993; Priestly 2003). The findings from the Health Survey for England suggest that 43 per cent of those aged over 65 report 'moderate' or 'serious' disability (Priestley and Rabiee 2002: 597). According to the *Local Authority Circular* report (DH 2008a), the numbers of people aged 50 and over with learning difficulties is projected to rise by 53 per cent between 2001 and 2021. In Japan, 67 per cent of all Japanese people with physical impairments are over 60 (Iwakuma 2001). Older disabled people have complex needs. For example, disabled people with a long-term disability feel that the effects of the ageing process itself are like the onset of a 'second disability' (Zarb and Oliver 1993). Iwakuma (2001) indicates that older disabled people may experience emotional changes associated with ageing. However, the majority of social policies highlight the challenges of policy for working-age adults, while older disabled people

are less well accounted for in the disability policy (Roulstone and Prideaux 2012: 123).

This topic particularly interests me because of my work experiences in Taiwan. I worked as a social worker in Taiwan, and found it difficult to deal with the ageing issue of disabled people. Firstly, it is not easy to recognise the needs of older disabled people, because their needs might arise from the interaction between ageing and disability. Secondly, there are limited resources for older disabled people. The social services in Taiwan are inflexible and fragmented, and cannot respond to the complex needs of older disabled people. Most social policy in Taiwan is age-based. Older disabled people, over 65 years old, will be supported by the elderly services rather than disability social services. As a result, older disabled people are more likely to be medicalised and institutionalised in elderly services (Lin 2009). The needs of older disabled people may be ignored because of the similarities between disability and old age. Priestly (2003) argues that there is a tendency to construct older people with impairment as 'disabled' only if their bodily functioning differs markedly from the generational norms. Hence, older disabled people are likely to be classified as older people rather than disabled people.

However, the needs of older disabled people are variable due to the interaction amongst disability, ageism, sexism and racism (Zarb and Oliver 1993). It is necessary to recognise the 'grey areas' between elderly services and disability services. Moreover, the services provision should become more flexible in order to respond to the needs of older disabled people (AIHW 2000). In 2007, the UK government launched a radical reform of public services: the 'personalisation' of social care services. This approach is set out in the *'Putting People First: a shared vision and commitment to the transformation of adult social care'* (DH 2007). This approach means that people are able to choose to live their lives as they wish. Social services should be improved to meet individual needs for independence, well-being, and dignity. This new approach attempts to respond to the social changes that have occurred in recent years. Firstly, people want more control over their lives, and need dignity when using services. In addition, the number of older people is obviously increasing in the structure of the UK population. In England alone, there were currently 570,000 people living with dementia in 2010 (NHS 2010). Finally, preventive services should be developed to achieve a more cost-effective health and social care system and provide better outcomes for individuals.

The personalised social care approach may response to the needs of older disabled people. This approach marks a strategic shift to early

intervention and prevention. Zarb and Oliver (1993) assert that services for older disabled people should be planned ahead for possible changes. Also, this approach highlights the significance of personal-centred services through the integration of different service providers. It attempts to maintain the autonomy and dignity of older disabled people. Every person who receives support from statutory services or is funded by them will be empowered to shape their own lives in all care settings (DH 2008b). This approach seeks to enable older disabled people to live in their communities independently, with access to flexible care services.

1.2 Research Aims and Methodology

Seemingly, the personalisation of the social care services is regarded as a panacea for catering for the needs of older disabled people. Nevertheless, the new approach should be examined cautiously. This approach emphasises the control and choice of services. In other words, it means that users have to take more responsibility for managing their individual budget and social services. It may be problematic for some older disabled people who find it difficult to manage the social services by themselves. Also, older disabled people may experience multiple impairment, which results in complex needs. For example, older disabled people who develop Alzheimer's disease may require additional support. Consequently, this personalised approach should be further

examined to see whether it effectively responds to the needs of older disabled people. The project aims to address three key questions:

- 1) What is the meaning of independence for older disabled people?
- 2) What are the implications of the personalised agenda for older disabled people?
- 3) Will the personalisation of the social care services reduce the problem of dependency for older disabled people?

To answer these questions, this project will employ a secondary analysis of the literatures dealing with the relationship between impairment, ageing and social policy with reference to the personalisation of social care services in the UK. The personalised approach is a new means of public policy, but it is not actually a new idea (Roulstone and Prideaux 2012). The personalisation is profoundly influenced by the philosophy of independent living. This study will focus on the period since the initiation of the British independent living movement in the late 1970's to the present policy agenda's 'personalisation' in the adult social care services.

The secondary analysis provides 'further analysis of an existing dataset which presents interpretations, conclusion, or knowledge additional to, or different from, those presented in the first report on the inquiry as a whole and its main results' (Hakim 1982: 1). Hyman (1972: 1) describes the secondary analysis of survey data as the 'extraction of

knowledge on topics other than those which were the focus of the original surveys'. Secondary research involves the accessing of information from both published and non-published sources, which include the relevant books, journal articles, official documents, and archival materials on the Internet (Shava 2008: 10). Choosing secondary analysis for this study was determined by two factors. Firstly, the secondary research approach analyses various data sources to create a time-series or area-based datasets in order to provide a better view of trends (Hakim 1982). This research method is appropriate for understanding the implications of personalisation for older disabled people, because it can represent the evolution of particular concepts and the shift in the policy agenda. Additionally, it would be difficult to locate interviewees, such as the policy makers, practitioners and service users, and conduct a field study in the limited time available for this project.

1.3 Organisation of the Project

Following this introductory chapter, Chapter 2 completes the examination of the perceptions and background of disability and the independent living movement, and raises question about how these ideas affect older disabled people. Chapter 3 deals with the link between attitudes to disability and ageing, and older disabled people. It raises questions about the changing agenda in social care services. Chapter 4 aims to look at the policy agenda change, which shifts from the

traditional professionally led services to user-led services and the personalised approach. It will conclude with questions about how these policy changes will affect older disabled people who may, due to the onset of impairment or increased frailty, need additional help and support. In the concluding chapter, it summarises the arguments from each of the above chapters, and provides policy insights.

Chapter 2: Changing Conceptions of Disability

Introduction

The Government published the *'Putting People First: a shared vision and commitment to transformation of adult social care'* in 2007. The paper outlined 'personalisation' as a new vision of adult social care services. One of the goals of personalisation is independent living. It does not mean living on your own or doing things alone, but rather it means 'having choice and control over the assistance or equipment needed to go about your daily life; having equal access to housing, transport and mobility, health, employment and education and training opportunities' (ODI 2008: 11). In order to understand this approach, it is necessary to recognise the conceptual evolution of disability and the progress of the independent living movement in the UK.

In this chapter, major models will be introduced to illustrate different interpretations of disability; namely, the individual medical model, the

social model of disability, and the bio-psycho-social model of disability. In turn, the development of the independent living movement in the UK will be addressed since it plays a crucial role in influencing the personalised social care services. The philosophy of independent living and the progress of the independent living movement will be explored. In later section, the chapter briefly touches on the questions of how these ideas affect older disabled people. The issue will be discussed in detail in chapter 3.

2.1 Changing Conception of Disability

The Individual Medical Model

In the late nineteenth century, the individual medical model of disability, located in medical knowledge, was widely accepted in Western industrialised society (Barnes and Mercer 2010). This model locates the 'problem' of disability within the individual. It also recognises the problem as stemming from the functional limitations or psychological losses that are assumed to arise from disability. The individual medical model is represented in the disability prevalence statistics in the UK. According to the Office for Disability Issues (ODI), there were over 10 million disabled people in the UK by 2009. The disability prevalence estimates is disaggregated by impairment (capacity affected), such as mobility, lifting, continence and so on (ODI 2011).

There are three main features of the individual medical approach. Firstly, disability is regarded as a problem at the individual level; additionally, it is equated with individual functional limitations; thirdly, medical knowledge and practice determine the treatment options (Barnes and Mercer 2003). Oliver (1990) states that bodily 'abnormality' is interpreted as a 'personal tragedy'. Medical judgment defines disabled people as 'less-than-whole', and they are unable to fulfil their social roles and obligations (Dartington, Miller et al. 1981: 126). Consequently, disabled people are likely to face social prejudice because of their physical or mentally difference. Goffman (1963) indicates that social stigma oppresses disabled people in everyday life. Disabled people deal with impairment by using 'passing' or 'covering' strategies to avoid embarrassment and social sanctions.

From the biomedical perspective, disability is closely linked to illness and regarded as something that needs to be cured. The medicalisation of disability not only over-emphasises the ill role of disabled people, but also rationalises the authority of medical professionals. Conrad and Schneider (1980) claim that the medicalisation of disability is confirmed by the orthodox medical profession, which involves the state authority in the delivery of health and illness services. Being seen as a the object of medical treatment evokes a negative image of disabled people, such as weakness, helplessness, dependency, repressiveness, abnormality of

appearance and depreciation of every mode of physical and mental functioning (Zola 1993: 168).

The individual medical model was represented at the international level. The World Health Organisation (WHO) launched The International Classification of Impairments Disabilities and Handicaps (ICIDH) in 1980. It seeks to find common ground for the results of disease to enable the better planning of services and the provision of treatment and rehabilitation (Hurst 2003: 573). The definition of disability in the ICIDH is as follows:

‘Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being’ (WHO 1980: 29).

Obviously, the perception of disability stems from the biologically functional limitations of individuals. Nowadays, this model is attacked by several authors. In the individual medical model, individuals are expected to cope with disability by adapting themselves to society; society is not expected to adapt to them (Borsay 1986). This approach also ignores the societal, economic, and cultural factor for interpreting disability (OECD 1987).

The Social Model of Disability

The social model of disability originated from the objective experiences of disabled people themselves in the 1970's. Hunt (1966: 146) argues that 'the problem of disability lies not only in the impairment of function, but also, in the area of our relationship with 'normal' people'. This unprecedented thinking was rapidly echoed by other disabled activists and disabled people's organisations (DPOs). The starting point of the social model was the publication of the Fundamental Principle of Disability by the Union of the Physically Impaired Against Segregation (UPIAS). The definition of impairment and disability in the UPIAS is as follows:

'Disability is the disadvantage or restriction of activity cause by a contemporary social organisation which take no or little account of disabled people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS 1976: 3-4).

In terms of its definition, disability, cut loose from impairment, is a result of social barriers rather than an individual problem. This socio-political perspective leads the disabled activists and the scholar Mike Oliver to talk of 'the social model of disability' (Thomas 2002: 39).

This model concerns the enabling of disabled people to participate in mainstream economics and social life (Barnes 1991). In the thinking behind the social model, disability is societally constructed rather than having the nature of impairment. The definitions of disability as relative rather than absolute have led some sociologists to conclude that disability can only be properly understood as a social construction (Oliver 1989: 6). Finkelstein (1980) indicates that capitalism heightens the mode of production and certainly influences the perceptions of disability. The emergence of capitalism has affected the social relations and acceptable social roles, and has directly affected disabled people in many instances (Oliver 1990).

Needless to say, the social model of disability has improved the lives of disabled people, but it is not without its critics. Crow (1996) claims that the social model fails to encompass the personal experiences of pain, which is often an aspect of impairment. Also, this model is unable to deal with the differences amongst disabled people, such as race, gender and age (Morris 1993a; Appleby 1994; Corbett 1994; Crow 1996). Although various debates about the social model are ongoing, it firmly plays a decisive role in the British disabled people's movement. This model forms the political identity of disabled people and pushes forward the development of disabled people's organisations. Furthermore, it views disability as social oppression and remains very

liberating for disabled individuals (Shakespeare and Watson 2002). Importantly, the thinking behind the social model of disability profoundly affects the progress of the independent living movement in the UK (Davis 1990) , and will be discussed in the later section.

The Bio-psycho-social Model of Disability

In recent years, the models of disability have moved toward the 'synthesis' approach (Hughes 2002). The bio-psycho-social model synthesises the polarised medical and social models, which presents a thesis-antithesis proposition. This model seeks to capture the interaction between the various dimensions of 'disability' comprehensively (Kuno 2008: 87). The WHO introduced the International Classification of Functioning Disability and Health (ICF) in 2002. The ICF represents the resolution of a long lasting theoretical debate between the individual medical model and the social model of disability (ÜSTÜN, Chatterji et al. 2003). Disability is defined as the outcome of a complex relationship between an individual's health condition and personal factors, and the external factors that represent the circumstances in which the individual lives (WHO 2001). The ICF identifies three level of human function: at the level of the body (health condition); the whole person (activities and participation); and the whole person in a social context (environment and personal factors) (WHO 2002a: 10).

Apparently, the ICF emphasises the interaction amongst the different levels, rather than the causal relationship between impairment and disability. However, it is criticised for retaining the individualistic, medical notion of disability and its causes (Hurst 2000). Barnes and Mercer (2010: 39) argue that the ICF provides a detailed taxonomy to structure the data collection, but lacks a coherent theory of social action as a new basis for understanding disability. After reviewing the three models of disability, this study will adopt the social model of disability as a viewpoint for addressing questions of impairment, and reference to older disabled people.

2.2 The Independent Living Movement in the UK

The Origin of the Independent Living Movement

The British independent living movement has its roots in disabled people's attempt to leave residential care in the 1970's (Morris 1993b). The most notable group of these disabled people was known as 'Project 81'. This group attempted to promote the cause of Independent living and helped disabled people to achieve their aim of moving out of the institution (Evans 2003). The British independent living movement is influenced by the ideology of independent living from the USA (Morris 1993b; Hurst 2003; Martinez 2003). The concept of independent living grew vigorously throughout the USA since the 1970's. It strove to

promote the right of disabled individuals to enjoy choice and control over their lives, and demanded that the state should take responsibility for ensuring those rights (Hurst 2003: 572). In 1962, four severely disabled students were provided with assistance to move into a modified home at the University of Illinois at Champaign-Urbana. In 1972, a similar programme culminated in the establishment of a Centre for Independent Living (CIL) in Berkeley, California (Finkelstein 1984: 3).

The CILs in the UK take inspiration from American CILs, aiming to provide advice and support for disabled individuals who wish to live independently (Morris 1993b: 20). Some British disability activists adopted the term 'integrated living' or 'inclusive living' to replace the term 'independent living'. This term, 'integrated/inclusive living', defines all humans, regardless of the degree and nature of their impairment, as interdependent, while a truly 'independent' lifestyle is inconceivable (Barnes 2004). The CILs are described as 'a system of services created by disabled people, which provide "peer counselling" serving people of all ages, whether blind, deaf or mobility impaired' (Davis 1988: 15). The Derbyshire Centre for Integrated Living (DCIL) and the Hampshire Centre for Independent Living (HCIL) were established in 1984, and started encouraging others around the country (Evans 2003).

The Philosophy of Independent Living

Independent living is an emancipatory philosophy and practice, which empowers disabled people and enables them to exert influence, choice and control over every aspect of their life (Frances 2003) . The Disability Rights Commission (DRC) defines independent living as follows:

‘All disabled people having the same choice, control and freedom as any citizen at home, at work and as members of the community. This does not necessarily mean disabled people “doing everything for themselves”, but it does mean that any practical assistance people need should be based on their own choices and aspirations’ (DRC 2007: 4)

There are four main assumptions related to independent living. Firstly, all human life is valued. Additionally, anyone is capable of exerting choice. Thirdly, disabled people, regardless of any form of impairment, have the right to assert control over their lives. Finally, disabled people have the right to participate fully in society (Morris 1993b). The conception of independent living is specifically represented in the ‘seven needs’ of DCIL: information, counselling, housing, technical aids, personal assistance, transport and access (Davis 1990). Furthermore, the philosophy of independent living is embodied in the United Nations Convention on the Right of Persons with Disability

(CRPD). Article 19 is entitled 'Living independently and being included in the community' (Jolly n.d). It is obvious that independent living has become the essential ethos in the disability right campaign.

Moreover, the conceptions of 'dependency' and 'independence' are reconstructed in the independent living movement. Generally, 'dependency' implies the inability to do things for oneself and consequently a reliance upon others to carry out some or all of the tasks of everyday life, whereas 'independency' means that the individual needs 'no assistance' whatever from anyone else and this fits nicely with the current ideological climate which stresses competitive individualism (Oliver 1989: 8). Consequently, people with impairment are usually regarded as passive, vulnerable, and needing to be looked after by others. However, the British independent living movement redefined the idea of 'independence' as follows:

'Independence means people have control over their lives, not that they perform every task by themselves. Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when how one requires it' (Barnes 1993: 13).

According to this definition of independence, disabled people who use personal assistants do not mean that they are dependent. For example, if a personal assistant has to push a wheelchair, help a disabled people to dress or reach for a book, then this should be seen as a enhancing the disabled person's ability to live independently (Bracking 1993: 13).

The Direct Payment Schemes and Personal Assistance

Funding is an essential factor for disabled people when they live in the community independently. There have been several important developments in the funding of independent living schemes. The first payment scheme in the UK was developed by a small group of disabled people, who operated 'Project 81' in Hampshire during the early 1980's. The group was enabled to move out of residential care by persuading their local authority to use some of the money spent on their residential care to pay for their personal assistants instead (Zarb and Nadash 1994: 19). At the same time, the Independent Living Fund (ILF) was launched following the passage of the 1986 Social Security Act (Evans 2003; Woodin 2006a). The ILF allows disabled people the opportunity to hire personal assistants, and offers far greater flexibility than the alternatives (Kent 1993; Kestenbaum 1993). However, the ILF will end in 2015 because the service expenditure is increasing (Jolly 2012).

Up to now, the direct payment scheme has played a crucial role in facilitating disabled people's independent lives. The British Council of

Disabled People (BCODP) Independent Living Committee started the Direct Payments campaign in the UK in 1989. It was initiated in order to change the legislation to make it easier for the local authorities to establish Direct Payment schemes (Evans 2003). Direct payments were technically legalised by the Community Care Direct Payment Act 1996. The local authorities were charged with ensuring that the money was used effectively, the costs monitored and that the provision made was within their budgets (Woodin 2006a). Notably, the direct payment scheme enables disabled people to live in the community independently (Barnes 1997). Disabled people utilise the direct payments to employ personal assistants and purchase the social care services that they need. Personal assistants enable disabled people to participate in social and personal relationships in the way that they wish, and in a way that was impossible for those who had to rely on services or informal carers (Morris 1993b: 120).

It is notable that independent living is not without critics. Firstly, quality of life was simply defined as living at home or doing domestic things. A service provider's understanding is often based on a resource led approach, which is more about hands-on activities, such as getting up, going to bed, but 'basic survival is not quality of life' (Evans 2003). In addition, independent living might be rhetoric enabling the government to take less responsibility for developing social services. Barnes (1997)

asserts that direct payments could be one of a range of service options, and it is neither intended to replace other services nor signal a cut in the spending on those services. Personal assistance is not a political device simply to reduce social care services with cash payment, nor a means of conveniently avoiding the wider social responsibility to remove other social barriers for disabled people (Davis 1993: 18).

2.3 Disability and Ageing

Obviously, a social model type analysis of disability is now enshrined in the national policy agenda and the greater user involvement in service provision (Barnes and Mercer 2006). Nevertheless, the ageing issue of disabled people is rarely addressed in the social model of disability. The needs of older disabled people are difficult to recognise, because the relationship between disability and ageing is a conflicting one. The social model of disability breaks the linkage between impairment and disability. The impairment is not denied, but it cannot be seen as a cause of disability (Oliver and Barnes 2012). On the contrary, disability is generally regarded as a result of 'bodily impairment' rather than social barriers in old age (Priestly 2003).

Likewise, older disabled people are said to be ignored by the British independent living movement. Some critics suggest that the philosophy and policies of the independent living movement favoured a relatively

small section of the disabled population: notably, young, intellectually able, middle class white males (Barnes 2004: 8). However, for older people who have high support needs (JRF 2010), their capacity for control and decision-making would be questioned. For example, the communication ability of people with learning disabilities would be exacerbated because of the onset of dementia (Kerr, Cunningham et al. 2006). Also, it is not easy for older disabled people to deal with the complicated process of employing a personal assistant, such as interviews, contracts, insurance and pay roll schemes (Ford and Shaw 1993). However, various solutions have been developed to ease those problems. The CILs provide peer support services, personal assistant training and so on; the Independent Living Trust or User Control Trust will be established to help people who are incapable of managing their own cash payments (NHS 2012). Those solutions will be discussed in more detail in the next chapter.

Summary

Obviously, the conception of disability has shifted from the individual medical model to the social model of disability. The thinking behind the social model further influences the development of the independent living movement in the UK. The independent living movement brings a new philosophy for disabled people: control, choice and equal participation. It redefines the perception of 'independence' and further

influences the service provision. Without a doubt, the thinking behind the social model of disability and the philosophy of the independent living movement have changed the social relations of disabled people. However, older disabled people remain under-presented in the discourses of the social model of disability and the independent living movement. It is necessary to explore how the social model of disability and independence living movement address the relevant issues of older disabled people. The relationship amongst impairment, disability and ageing will be discussed in further detail in the next chapter.

Chapter 3: Disability, Ageing and Older Disabled People

Introduction

This chapter will deal with the link amongst impairment, ageing and disability, and examine the affects for older disabled people. The relationship between impairment and ageing will be discussed in the first section. Also, the interaction between ageism and older disabled people will be explored. The second section will illustrate how the independent living movement addresses the needs of older disabled people. In the last section, the issue of control and choice in Independent living will be discussed with reference to older disabled people.

3.1 Impairment, Disability, and Ageing

Impairment and Ageing

There is a clear division between impairment and disability in the social model of disability. Impairment is presented as irrelevant and neutral (Crow 1996), while disability is viewed as a result of experiences of discrimination rather than individual functional limitation (Barnes and Mercer 2010). On the contrary, older people are generally viewed

through the 'medical model', and the stereotype of older people is relevant to dependence, care, frailty and pity (Blood and Bamford 2010). The perception of ageing nowadays is deeply influenced by the western culture. The interpretation of ageing is ambiguous in the western culture. In terms of the Biblical perspective, older people represent human wisdom:

'In the Old Testament, the elders are viewed as teachers: How becoming to the aged is wisdom ... the crown of old men is wide experience; their glory, the fear of the Lord (Sirach 25:5-6, cited in FAMIN 2011).

Reversely, old age was regarded as 'sad' in Ancient Greece, because this world admired physical beauty and marginalised the old (Thane 2000: 32). This assumption reinforces the inextricable connection between ageing and impairment. For example, older people are measured by the level of their dysfunction in term of the 'activities of daily living' (ADLs), so bodily function is assessed by means of a set of items related to self-reported limitations with varying degrees of severity of impairment (Christensen, Doblhammer et al. 2009). The prevalence rates of ADLs are much higher for the elderly than for the nonelderly (Wiener and Hanley 1990).

Impairment is taken for granted in old age. Priestly (2003: 152) indicates that the 'normalcy' of impaired bodies in older age means that older people with impairment are rarely regarded as 'disabled' in the same way as are younger adults or children. However, the normalcy of impairment will be problematic for older disabled people. Firstly, the impairment of older disabled people will be ignored or misunderstood. For older disabled people, the physical consequences might be caused by their long-term impairment rather than the ageing process (Zarb 1997). For example, people with Down's syndrome will experience 'premature ageing' and have a higher incidence of specific disorders than the rest of the general population (Janicki and Dalton, 1998). Walker and Walker (1998: 126) argue that the normalcy of impairment in old age influences the policy-making process:

'Radical theorists and campaigners have given legitimacy to the longstanding preference on the part of policy makers to draw a line between older and younger disabled people on the grounds that disability in old age is a 'natural' part of the ageing process'.

Secondly, older disabled people are likely to be medicalised in care services. The descriptions of 'older' strengthen the construction of ageing as a disorder, failure, abnormality, alteration, and damaged (Vincent, 2003: 237). Thompson (2005) claims that older people often

cope unnecessarily with disabling pain and immobility because they perceive these as 'symptoms' of old age rather than of a specific condition which has occurred as they have aged. However, ageing experiences could not be understood excessively from the biological perspective. Gangadharan, Devapriam et al. (2009) indicate that the ageing experiences of people with learning difficulties are affected by a number of contributory factors across the biological, psychological, and social continuum. Zarb (1997) claims that the concept of 'life events' provides a tool for identifying the experiences of older disabled people throughout their lives, including the experiences of impairment, and ageing with disability. Apparently, the experiences of older disabled people are complex and should be understood within a more holistic perspective. It is insufficient to view ageing as a demographic phenomenon in isolation from the social, economic, and political factors surrounding older people (Timonen 2008: 12).

Ageism and Older Disabled People

Nowadays, older people are subject to stereotyping and prejudice in society. Ageism is a set of social relations that discriminate against older people and sets them apart as being different by defining and understanding them in an oversimplified, generalised way (Minichiello, Brown et al. 2000). For example, the negative image of elderly people as redundant, dependent, decrepit and inferior abounds in our society

(Aeber and Ginn 1991; Comfort 1997). Ageism is embodied in the social policies and service provision. Barnes (1991: 3) states that 'institutional discrimination' is the policies and activities of public or private organisations, social groups and all other types of organisation in terms of the treatment and outcome result in inequality between disabled people and non-disabled people. Inevitably, older people are also discriminated against via 'institutional ageism' (Palmore 2005).

On the one hand, older people receive less support in terms of service provision. Social workers are reported to spend less time and have less contact with older oncology patients than younger patients, with the result that social workers may not be effectively assisting the older patients to cope with important health and social issues (Rohan, Berkman et al. 1994). On the other hand, social care services are debarred from the use of age in their eligibility criteria and policies or to restrict the available services. The inadequacy of the disability services, which are generally organised are either services for 'young disabled' or services for 'elderly people over 65' (Zarb 1997). However, utilising chronological age as a part of the definition to determine ageing is inappropriate, as the specific age chosen very much depends on societal and environmental factors (PCHW 2011). For example, the improvement in education and lifestyle, availability of adaptive technologies and

medical treatment are the factors that alleviate the degeneration of older people (Timonen 2008: 60).

Ageism provides a political-economic perspective for identifying a new social relation of older people. Seeking the positive characteristics of adulthood becomes a core principle in anti-ageism issues. In the 1960s, the USA suggested that the key to 'successful ageing' is to maintain the activity patterns and values typical of middle age, such as physical fitness, mobility, financial independence and the display of leisure consumption (Tulle-Winton 1999). Functional comparisons have been a trump card for anti-ageism, in the sense that the evidence has proven that older people are more capable and similar to non-old people than is generally believed (Jönson and Larsson 2009: 75). Furthermore, 'active ageing' is increasingly used in the current policy, which means the process of optimising opportunities for health, participation and security in order to enhance quality of life as people age (WHO, 2002b). The shifting conception of ageing profoundly reflects on extending the working lives of older people. Older people are more economically active than in the recent past and much of the increase in total employment over the last 10 years is attributable to increases in the participation of older workers (EMAR 2010: 2). Ageing and economic contribution no longer have an absolutely causal relationship. In the UK, the current

female pension age of 60 will gradually increase, by one month every two months, to 65 by 2020 (Clegg, Leaker et al. 2010: 25).

However, overly emphasising the characteristics of adulthood is not necessarily of benefit to all older people, particularly those with high support needs. Firstly, excessively focusing on the health and fitness of adulthood will distance older disabled people from older non-disabled people. Biomedical theories define successful ageing largely in terms of the optimisation of life expectancy while minimising physical and 'mental deterioration' and 'disability' (BMJ 2005). Even 'active ageing' has moved towards the rights-based approach, and still aims to recognise and prevent ill health and impairment rather than assuming that everyone can be equally active (Walker 2002: 131). Secondly, older disabled people may suffer from internalised oppression because they are unable to meet the standards of active ageing. Minichiello, Brown et al. (2000: 260) indicate that the term 'keeping watch' on older people means the process by which people observe and monitor older persons. An older person is observed to gather evidence to show whether or not they are still trying to participate in life, remain healthy, and engage in meaningful activity. As a result, old disabled people, who are failed to fulfil the role expectation of active ageing, may face more discrimination in society.

3.2 Independent Living and Older Disabled People

Several authors point out that independent living mainly benefits younger disabled people, rather than older disabled people and people with mental impairment (Morris 1992; Morris 1993b; Barnes 2004). Obviously, young disabled people initiated the independent living movement, both in the USA and the UK. The independent living movement in the USA was led by disabled students, who fought to live in an accessible community environment (Martinez 2003). Similarly, the British independent living movement was initiated by disabled adults who demanded much greater support to enable them to live in the community (Hunt 1966; Brattagard 1974; Barnes and Mercer 2003). This movement appeals to the modernist discourse of adulthood, such as independence, productivity, youth and progress, and devalues older and disabled people as non-adult dependents (Priestly 2003: 147-148).

However, older people are usually regarded as dependents and a social burden. For instance, the increasing 'dependency ratios' mean that there may be an increased burden on the productive part of the population to maintain the children and elderly of the economically dependent (Lin, Lin et al. 2010: 523-524). Those negative features of old age distance older people from the adult-led independent living movement. Hence, older disabled people are more likely to be overlooked by the independent living services. Woodin (2006b) argues

that the CILs have less sense for the overlap between the interests of the disabled user and older users. The limited funding of the CILs is a main obstacle to developing services for older user groups. In the report by the Hampshire Centre for Independent Living (HCIL), the major challenge to their growth is the absence of adequate funding for the 'organising' or management costs involved (HCIL 1990: 6).

3.3 Autonomy and Older Disabled People

In terms of the philosophy of independent living, everyone, whatever the nature, complexity or severity of their impairment, has the capacity to make choices and should be enabled to do so (Barnes 2004). For older disabled people, the capacity for decision-making is usually challenged. Firstly, the attitude of the professionals and service providers is problematic for older disabled people. Older people have decisions made for them, but they are assumed to be 'incapable' of having choice and control (NCB 2009: 77). Thompson (2005) indicates the 'infantilisation' (regarding as children) of older people, which means that older people are different from other adults and less worthy of respect. Adults are expected to have, and are usually accorded, more autonomy, although disabled and older people have often been infantilised (Hockey and James 1993). For example, people with dementia are more likely to be treated like children by professionals, and this attitude further affects the actions and decisions of their carers (Hughes, Hope et al. 2002).

Secondly, older disabled people face barriers to managing their direct payments and personal assistants. Barnes (1997) indicates that older people may worry about the administration of self-operated support systems, because most of them have had no previous experience as an employer. Some older people may not want to have the responsibility of organising their own personal assistants and may prefer a more structured support system (De Jong 1986). Furthermore, the gender difference may influence their willingness to employ a personal assistant. Zarb and Oliver (1993) claim that older disabled women find it particularly difficult to ask for help, because they are expected to provide support to others. Sometimes, disabled women feel humiliated about asking for personal and domestic services, such as a home help (Rae 1993: 48).

Several mechanisms have been developed to maintain the autonomy of older disabled people. A number of policies endeavour to safeguard the right of decision-making for disabled people in the UK and at the international level. In the UK, the Mental Capacity Act 2005 provides a legal framework for decision-making, and people have the capacity to nominate someone as a 'welfare attorney', who is able to make health or welfare decisions for them in the future (NCB 2009: 78). In the CRPD, Article 12 establishes a core principle of protecting the

equal legal capacity for decision-making of disabled people in all areas of life (Akinpelu, Flynn et al. n.d: 4). Besides, CILs are running peer support to enable disabled people to use direct payments and personal assistants (Woodin 2006b: 5). For example, CILs provide help with writing contracts for disabled people who decide to employ personal assistants (Ford and Shaw 1993). Moreover, the 'Independent Living Trust' aims to assist disabled people who find it difficult to manage their cash payments. Disabled people can choose trustees to run their money, such as family members, friends, or people who have worked with them and wish to help on a friendly basis (NCODP n.d: 4). For example, the local authority powers enable people with learning difficulties to access cash payments through 'independent living trusts'. It enables people to enjoy the benefits of direct payments whilst ensuring that they are fully safeguarded (JRF 1999).

Seemingly, those solutions attempt to maintain the independence of disabled people in the current service provision system. Nevertheless, the autonomy of older disabled people is still restricted to a certain extent. Older disabled people have less access to information. Older adults over the web are not taken into consideration by web developers while designing websites that is they don't make accessible websites for older adults (Ilyas 2012). Also, the financial ceiling profoundly restricts older disabled people from choosing services. The direct payments

allocated to older people are not always sufficient to cover the costs of their personal assistance or agency cover, and the older person has to contribute the extra cost (Clark, Gough et al. 2004: 26). Particularly older disabled people have to afford this 'extra cost' to maintain their quality of life. For instance, some assistive technology is difficult to adapt for older people because of the high cost (Beech and Roberts 2008). The financial hardship will be acute for older disabled people because of the inadequate benefit and pension provision and lack for recognition of the extra financial costs that they face (Zarb and Oliver 1993).

Summary

Ageing is closely associated with impairment in old age. Older disabled people are likely to be medicalised in elderly services. The ambiguous conception of ageing and disability makes it difficult to recognise the needs of older disabled people. It is necessary to understand the experiences of older disabled people together with the biological, cultural and societal factors. In addition, overly seeking the features of adulthood has excluded older disabled people from the discourses of successful ageing. Furthermore, older disabled people are ignored in the adult-led independent living movement. The autonomy of older disabled people remains restricted in terms of the service provision.

According to the discussion in this chapter, it shows that older disabled people are profoundly under-represented both in the field of gerontology and disability. The autonomy of older disabled people is restricted in existing independent living services. The needs of older disabled people should be seriously considered in the policy thinking. In 2007, the Government introduced a new policy agenda: the 'personalisation' of social care services. This approach aims to cater for the needs of every user by tailoring services personally. However, how can these personalised services respond to the diversified needs of older disabled people? And how can this new approach maximise the choice and control of older disabled people? Several of the questions that have been raised should be examined in more detail in the next chapter.

Chapter 4: Social Care Services and Personalisation

Introduction

The aim of Chapter 4 is to examine the shift in disability services. The traditional professionally led services, user-led services and personalised social care services will be discussed. It will conclude with questions about how these policy changes will affect older disabled people who may, due to the onset of impairment or increasing frailty, need additional help and support. The appropriateness of individual budgets for older disabled people will be examined first. The last section will discuss to what extent personalised services have maximised the control and choice of older disabled people.

4.1 The Shifting Policy Agenda

The Traditional Professionally Led Service

Historically, welfare provision in the UK is rooted in the traditional individual medical of disability. A disabled person is regarded as a victim, and dependent upon the 'care and attention' of others, in what has been summarised as a 'personal tragedy' approach to disability policy and services (Oliver 1983). In this approach, professionals particularly dominate the services, rather than disabled people. The medicalisation of disability is explained with reference to the accumulation of power by the medical profession (Barnes and Oliver, 1993: 16). For instance, the medical professionals determine the entitlement to social care and welfare services (Blaxter 1976; Brisenden 1989). Swain and French (2001) indicate doctors became involved in decisions and assessment procedures which had little to do with medicine, such as housing, education and employment. Accordingly, disabled people are powerless in the services provision, and their lives are controlled by the professionals. The traditional professionally led services have been attacked by disabled people's organisations (DPOs) since the 1980s (DLIB 2008). Disabled people began organising their own groups because many of them experienced oppression from charitable organisations (Campbell and Oliver 1996).

User-led Services for Disabled People

Two fundamental factors influenced the development of user-led services: the disabled people's movement since the 1970s and the New Right (Neo-liberal) agenda for political change in the 1980s (Barnes and Mercer 2006). Disabled people strongly call for control through all disabled people's movements, regardless of their political-economic or cultural differences (Charlton 1998: 3). Furthermore, the centres of Independent/Integrated/Inclusive Living (CILs) and User-led organisations (ULO) in the independent living movement have also pushed the user-led services forward. These grassroots organisations are run by disabled people, and aim to assist disabled people to take control over their lives and achieve full participation in society (Woodin 2006b: 5). Disabled people demand to be involved in the process of service planning and delivery themselves. For instance, three quarters of the committee representatives are disabled users of the Great London Action of Disability's (GLAD) services (Hasler 2003).

Besides, the traditional welfare paradigm made a radical shift towards the New Right approach in the late of the 1970s. The Thatcher government in 1979 represented a clear break with the past community care policies, particularly with regard to the private, for-profit and care services (Barnes and Walker 1996). This new call was to 'roll back' the role of the state, and introduce market forces and competition in the delivery of welfare services as a way of enhancing their efficiency and

effectiveness (Barnes and Mercer 2006: 23). Disabled people were no longer viewed as welfare recipients, but customers with control over their lives. In this approach, 'choice' is viewed as a core principle that should govern the organisations of social care (Clarke, 2006). Obviously, the user-led service could be seen as an inevitable result of the raising of disability rights awareness and the transformation of the New Right welfare paradigm.

Personalisation of Social Care Services

In 2007, the Government was ambitious to introduce a radical reform of the public services: the 'personalisation' of the social care services. Every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings (DH 2008b). It is obvious that personalisation is not a new idea, as it originates from the ethos of the disabled people's movement. Independent living, participation, control, choice and empowerment are key concepts of personalisation, and they have their origins in the independent living movement and the social model of disability (SCIE 2012). This approach is ambitious to build on best practice, and focuses on prevention, enablement, and high quality personally tailored services. People have choice, control and power over the support services they receive (DH 2007).

There are several characteristics linked with personalised services. Firstly, the practice has changed towards a personal-centred and relationship-focused assessment. Persons will be encouraged to identify their needs and make choices that support their lives (SCIE 2012). The users, family members and coordinators should be involved altogether (Glendinning, Challis et al. 2008; Slasberg 2010). Secondly, personalised services emphasise the co-productive approach. Services users not only receive services from providers, but also contribute their active input in the service provision process (DH 2010a). Finally, service performance management has shifted from the input approach to the outcome approach. The input approach focuses on measuring activity and processes and spending control, while it cannot capture the outcome for services users (Slasberg 2010; DH 2010a). Contrarily, the outcome approach believes that people are the best judge of what is happening in their lives, so ways to measure results need to be developed together with disabled people and older people, and their families (DH 2010b: 4).

4.2 Personalised Social Care Services and Older Disabled People

Individual Budgets and Older Disabled People

The individual budget play a key role in personalised social care services, it have been rolled out in England since 2008, with a target of providing every service user with one by 2013 (Samuel 2012). Individual

budgets ensure that people receive public funding and use the available resources to choose their own support services (DH 2007). Care service users are able to use personal budgets regardless of their age, gender, race or disability. However, older disabled people are profoundly marginalised from individual budgets. The Government's Individual Budget Pilot Programme indicates that older people do not find the individual budget system as easy to use as do some other groups (DH 2010a: 5). Recent figures for England show that 10 per cent of older people had an individual budget in 2006, compared with 23 per cent of adults with learning disabilities (Dunning 2011a).

Apparently, the implementation of individual budgets is still problematic for older disabled people. Firstly, the 'Resource Allocation System (RAS)', which gives an indication of how much money should be made available to the person in their individual budget, inappropriately reflects the needs of older disabled people. According to the discussion in Chapter 3, the needs of older disabled people are complex and changeable. For older disabled people, the sudden onset of disability or ill health, or the progressive decline experienced with dementia, sometimes accompanied with other life changes such as bereavement or moving home, require an individual approach and solutions (Zarb and Oliver 1993; DH 2010a). However, the RAS simplifies the user's needs with the quantitative method. It operates through applying weightings (points) to a number of questions about a person's social care needs,

and an allocation of funds is given per point. The RAS is too simplistic and would inhibit a creative response (Glendinning, Challis et al. 2008). This system is seriously damaging the front-line workers, who feel that important decisions about people's lives are made purely on the basis of mathematical formulae that are decided 'up there' (Duffy 2012). Also, it exposes the inequities between the different user groups in the current funding of care and support services, with significantly less being spent on older people (CSIP 2007: 9). Consequently, older disabled people may not obtain adequate resources due to the flawed assessment instrument.

Secondly, although personalised services highlight the person-centred approach, professionals still control the assessment process of the individual budgets. Slasberg (2010) argues that councils remain professional-centred in conception, even if they are changing the name of their process with terms such as self-assessment. Older disabled people are more likely to be regarded as vulnerable and powerless. The voices and active engagement of older people are still very quiet and very marginalised in the assessment process, particularly for older people with mental health difficulties (Bowers, Bailey et al. 2007). Besides, older disabled people are viewed as incapable of making a wise decision. Particularly for people with dementia, even if they have the capacity to make a decision, their decisions could be still seen as unwise by the professionals (Manthorpe and Samsi 2012).

Moreover, the prejudices of the professionals profoundly restrict older disabled people from using creative services. Dunning (2011a) claims that people are generally buying the same kinds of support through their personal budget as was the case for the traditionally commissioned packages of care. Nevertheless, older disabled people are not encouraged to use innovative services by professionals. A number of professionals believe that younger disabled people often have wider and more complex needs than older people, necessitating bigger care or direct payment packages (Clark, Gough et al. 2004). Pitt (2011) further argues that councils decide what they feel the person is eligible for and base this on the traditional services that the person would have received before personal budgets. Also, coordinators are less experienced and confident about developing more innovative and creative support plans with older people (Glendinning, Challis et al. 2008). As a result, older disabled people may have fewer opportunities to use the creative services.

Control and Choice Issues for Older Disabled People

The value of personalisation is that it makes it possible to build high quality, personally tailored services, and maximise the choice and control of users. In practice, several barriers restrict the control and

choice of older disabled people regarding personalised services. Firstly, the information available on the services is insufficient for older disabled people. According to the seven needs of disabled people (Davis 1990), sufficient information is a necessary condition if they are to live in the community. However, older disabled people have less access to information about personalised services. Dunning (2011b) argues that people with dementia are not reaping the benefit of individual budgets, because of the insufficient information and knowledge of the social care professionals. Also, older disabled people find it more difficult to understand the jargon related to personalised services. For instance, the experiences of self-assessment and support planning need to be passed on to older people who may fear or not understand the jargon of the processes (CRC 2008).

The appropriateness of information is particularly crucial for older disabled people, who have a sensory impairment, such as hearing loss and visual impairment (Janicki and Dalton 1988; Guralnik, Fried et al. 1996; Dalton, Cruickshanks et al. 2002). Older people may prefer to have things explained to them face to face, because they have less access to the Internet and online information (EHRC n.d). A number of volunteer organisations provide a range of services in a variety of personal and impersonal formats, including telephone helplines, websites, written materials and face-to-face support (Dunning 2005: 18).

However, those services cannot cater for the varied needs of older disabled people. For instance, there is more telephone-based information available through call centres such as NHS Direct, while those service providers ignore older people with sensory impairment, and who cannot afford to travel to libraries or advice centres (Gilroy 2005). Moreover, the improvement in the new technology does not necessarily make it easier for older disabled people to get information. Sheldon (2003) claims that disabled people will become isolated due to the development of Internet technology. The rapid pace of technological innovation renders the accumulated knowledge and skills of older people redundant, contributing to their devaluation (Aeber and Ginn 1991). For example, older disabled people face a range of barriers to using technological equipment, including the running costs, poor eyesight, decreasing manual dexterity and a lack of confidence in approaching new learning (Aldridge n.d).

Secondly, the under-developed service market has failed to respond to the complex needs of older disabled people. Spicker (2012) indicates many other cases in which quasi-market systems do not work, where imperfect information, locational costs, externalities and disadvantages conspire to limit choice and control. Personalisation attempts to integrate the whole system and find a way for people to work together (SCIE 2012). Nowadays, the lack of integration amongst the different service

providers hinders the development of personalised services. The major internal barriers to structural integration remain the professional domains and identities, and the differential power relationships between the newly integrated services and professionals (Glendinning 2002). Hence, older disabled people will be placed in a more disadvantaged situation due to these fragmented services. For instance, the issue of 'bed-locking' is used to refer to older people who cannot be discharged from hospital, if they do not require the appropriate services provided by health care services and social care services. This 'bed-locking' is a virtual result of the inefficient cooperation between the health services system and the social services system (Glasby and Littlechild 2004: 63).

In the *Open Public Service White Paper 2012*, the Government promises to increase the diversity of provision by opening up the commissioning to a range of traditional public sector agencies, independent trusts, employee mutuals, private enterprises, social enterprises or community groups (HMGovernment 2011). However, several barriers restrict the societal participation in the service market. At present, the local authorities have entered into block contracts with a small number of providers, which has had the effect of forcing others to leave the market or to increase their prices (EHRC n.d). The Government prefers to make contracts with larger, known providers (Barnes, Mercer et al. 2003). It is obvious that the CILs and ULOs often fail to gain the contracts because the larger companies and charities are

in a position to offer lower unit costs (Morris 2006). Therefore, those smaller organisations are either excluded from the service market due to their limited budget, or maintain the services in the status quo to secure contracts (CSCI 2005).

In the market, the price mechanism means that individual utilities are expressed in people's choices about consumption (Spicker 2012). Hence, these smaller, independent providers may raise the service price, which is frequently too high for many potential users (EHRC n.d). Particularly, older disabled people who live in rural areas may not get value for money and may end up with expensive, inferior services (CRC 2008). However, older disabled people may not be able to afford the costly social services due to their poor financial situation. According to the report *Monitoring poverty and social exclusion 2011*, many older people face serious economic hardship. In 2008 and 2009, three million people aged 55 and above lived in low-income households, giving a poverty rate of 18 per cent for the group as a whole (Aldridge, Parekh et al. 2011: 99). Seemingly, the quasi-market services allow users to identify their own needs and then purchase the services to meet them, and allow a close match between the demand and supply of services (Griffiths 2009). For some vulnerable users, their 'freedom' of choice is virtually undermined by the immature market mechanism.

Thirdly, the support services are inadequate for older disabled people with regard to personalised services. Older disabled people need a lot of time and support to help them, but they acquire insufficient resources from the existing support services. CILs and ULOs offer peer support for disabled people who are planning their own care and support packages, or offer experience-based advice and information (SCIE 2012). The peer support is extremely important for older disabled people, because they may contact the care services during a crisis and find it difficult to make a decision (Glendinning, Challis et al. 2008). However, older disabled people are overlooked in support services from CILs and ULOs. Woodin (2006b: 3) indicates that people with learning difficulties, older people, black and ethnic minority groups, mental health service users, and carers are under-represented in the support service of the CILs and ULOs. As well, the term 'peer' is questioned as to whether it reflects the experiences of older disabled people. Clark, Gough et al. (2004) indicate that this term refers to the common experiences of disability, rather than the experiences of older disabled people.

For a long time, CILs and ULOs faced a funding problem, which hindered them from developing support services. Although they seek to provide such services for all disabled people, the restrictions on funding and staff availability have meant that the predominant group of users is

people with physical impairments (Luckhurst 2005). For example, in Barnsley, older people are trained and working as volunteer peer support planners or brokers, but those services still attract little support from the local authorities (DH 2010c). Also, these organisations often struggle to compete with other traditional organisations. Many local authorities have been reluctant to engage with CILs and ULOs; contrarily, they prefer to cooperate with the organisations for disabled people and groups of carers (Barnes and Mercer 2006: 75).

A 'brokerage service' is an essential service for supporting older disabled people using individual budgets. For older people with high support needs and little family support, individual budgets will not work if free brokerage services are unavailable (Rabiee, Moran et al. 2009). Service brokers help people to make a plan, assist their negotiation for funding, and organise services between the service user and the whole system of social services (Dowson 1995: 2). However, older disabled people encounter several problems in the current brokerage services. For older people, they may prefer to employ family members or close relatives to help them (Clark, Gough et al. 2004), rather the professionals who are strangers. However, the training will be difficult for these 'nonprofessionals' who want to be services brokers, because being a service broker requires particular expertise and personal background (Moseley 2004). The NDTi's service broker training project

proved that 'nonprofessionals', including family members and people with no knowledge of social care, cannot achieve the baseline skill of being a service broker following this short-term training (Dowson 2011).

A brokerage service may effectively benefit older disabled people, but it is costly and time-consuming (NCVO 2009). Duffy (2011) argues that independent brokers are the most expensive support option and that investing in them will draw more money away from direct support and people's own budgets. Older disabled people feel stressed about consuming costly brokerage services since their individual budgets do not cover this (Slasberg 2010). For example, transport spending in rural areas could take up a disproportionate amount of an older person's individual budgets that should pay for other social care (CRC 2008: 20). Consequently, older disabled people themselves have to make an extra financial contribution to purchase brokerage services and other social care services.

Finally, the safeguarding issue of personalised services should be cautiously examined, particularly for older disabled people. Personalised services maximise the user's choice and control, and also mean that people have to take more risk by themselves. For example, personal budgets and direct payments might result in the abuse of people with dementia, and those with an impairment or declining capacity to make

decisions (Manthorpe and Samsi 2012). Risk assessment is essential for people who are eligible to receive individual budgets. Nevertheless, the voice of older disabled people is ignored in the risk assessment process. Ideally, service users should be encouraged to define their own risks and identify any safeguarding issues. Contrarily, practitioners may decide that whether older people can be offered cash payments base on the professional's risk perception and risk-avoidant practice (Arksey and Kemp 2008; Carr and Robbins 2009).

Direct payments and individual budgets bring a new opportunity for financial abuse (Madden 2006). Valios (2007) indicates that the risk of financial abuse is increasing for older people living alone, those in poor health and those who are divorced. In a survey conducted by the Alzheimer's Society, 76 per cent of people with dementia had experienced difficulties in managing their finances (Chandaria 2011). Older disabled people face some problems in managing their own finances, and necessarily depend on their family members or close relatives to deal with their money. For example, the way in which people manage their finances has changed rapidly in recent years, such as online transactions, cash machines and telephone banking. These new ways make it more difficult for older people to manage their money by themselves, and increase the financial abuse of them (Crosby, Clark et al. 2008). The Adult Safeguarding Coordinators (ASCs) indicate the risk

of 'befriending' people with dementia, generally in respect of people who encounter or target people who appear vulnerable in the community (Manthorpe and Samsi 2012).

Older disabled people also take a risk in employing personal assistants. Older disabled people prefer to employ their own personal assistants from the unregulated market rather than a home care agency, such as their family members or trusted friends (Slasberg 2010). In this situation, abuse is more difficult to recognise when disabled people receive assistance from family members and friends (Woodin 2006a). Older disabled people may be unwilling to report abuse due to a fear of losing family support (Chandaria 2011). Moreover, the monitoring mechanism of the service providers remains under-developed in the local authorities. The majority of councils check the Criminal Records Bureau (CRB) of personal assistants, but this is not obligatory (RIPFA 2012). Peer support groups contend that CRB checks are important in the case of families providing care, and should be made compulsory (Richards and Ogilvie 2010). Undoubtedly, personalised services to a certain extent have maximised the control and choice of some users. However, older disabled people may be placed in a risky services system without a sound safeguarding mechanism.

Summary

Obviously, the welfare paradigm has brought about a radical change from the professional-dominated approach towards the user-led perspective. Furthermore, personal-centred thinking is now embodied in the personalised social care services. Nevertheless, the shifting agenda remains problematic for older disabled people. On the one hand, individual budgets are inappropriate to respond to the needs of older disabled people. The simplified assessment instrument ignores the diversified needs of older disabled people. Also, practitioners have a prejudice against older disabled people in the assessment process.

On the other hand, the control and choice is still limited for older disabled people with regard to personalised services. Inappropriate information hinders older disabled people from accessing services. As well, the immature service market restricts the options of older disabled people. The inappropriate support services make it difficult for older disabled people to manage their individual budgets and social care services. Moreover, older disabled people face great risks through holding individual budgets. Balancing empowerment and safety remains a difficult challenge regarding the personalised social care services. According to the above discussion, it seems overly optimistic to view personalisation as a panacea for maintaining the autonomy of older disabled people with regard to social care services. This new approach still has several loopholes at the operational level. The effects of the

personalised approach for older disabled people will be briefly summarised and concluded, together with several policy insights, in the next chapter.

Chapter 5: Conclusion

In this project, the evolutionary conception of disability is demonstrated by three models; namely, the individual medical model, the social model of disability and the bio-psycho-social model of disability. The interpretation of disability has shifted from the biomedical perspective towards the political-economic approach. The social model of disability redefines the social relations of disabled people. Disability is regarded as an outcome of environmental barriers, rather than individual problems. Importantly, this model has had an immense impact on the independent living movement in the UK. This movement appeals for self-control and social inclusion; it emancipates disabled people from institutional residence into community life.

For quite some time, older disabled people were rarely addressed in the social model of disability. Older people are generally viewed through the 'medical model' and the related discourse is one of dependence, care, dignity, frailty and pity (Blood and Bamford 2010). Impairment is more likely to be normalised in old age. Consequently, the needs of older disabled people will be difficult to recognise, whether in the disability services or elderly services. In addition, older disabled people are invisible in the arguments about 'successful ageing' or 'active ageing' that over emphasise the features of adulthood. Likewise, older disabled people are marginalised in the adult-dominated independent living movement. Obviously, it is difficult to draw a clear line between the concepts of old age and disability. For older disabled people, their needs are complicated and changeable, and their experiences should be recognised comprehensively within the societal and cultural context.

Since the 1980s, the disabled people's movement has gradually influenced the policy-making and service provision. The traditional professionally led services are moving towards the user-led approach. The Government further introduced 'personalisation' in social care services in 2007. However, this approach raised some problems for older disabled people. The assessment instrument is too simple to reflect the complex needs of older disabled people; also, it may allocate

resources inadequately (Daly and Woolham n.d). Nowadays, older disabled people have limited options with regard to personalised services. Inappropriate information and the under-developed service market profoundly restrict the choice of older disabled people. Furthermore, older disabled people acquire fewer support services to manage their individual budgets and social services. CILs and ULOs face financial problems in developing support services for older disabled people; the brokerage services remain unsound. Also, the safeguarding mechanism does not operate well in personalised services. Older disabled people who hold individual budgets may be open to financial abuse. The flawed supervision mechanism of the service providers may place older disabled people in dangerous situations.

According to the above discussion, there are two main insights into the implementation of the personalised approach for older disabled people. Firstly, it is necessary to examine the current policy agenda for older disabled people under the social model of disability. Undoubtedly, older disabled people are still subject to institutional discrimination in the service provision system nowadays. Professionals assume that older disabled people are unable to make a wise decision. The individual medical approach dominates the social care services for older disabled people. However, the prejudices about older disabled people should be reconstructed by adopting the social model of disability. In brief, the

policy makers should take the social model of disability as a basis for examining the institutional failure when dealing with the issues affecting older disabled people.

Secondly, the personalised approach overly emphasises the consumerism and marketisation of welfare, and will prove problematic for older disabled people. Barnes and Mercer (2012: 166) indicate the worries about that the cash payments for disabled people may connect to individualisation and marketisation evidence of its incorporation into capitalistic social and welfare relations. Finkelstein (2004) further asserts that the marketisation of welfare services could be regarded as an expansion of capitalism:

‘...capitalism doesn’t stop here – competition means successful companies gobble up weaker groups , companies merge forming larger groups and those that fail, well, they go bankrupt and disappear. No surprise, that entrepreneurs are setting up companies to relieve stressed disabled people from managing their direct payments funding’ (Finkelstein 2004, cited in Oliver 2009: 151).

Apparently, marketisation and individualism are embodied in the current personalised services, and cause some problems for older disabled people: CILs and ULOs cannot compete against large charities

or enterprises; the price of services is mainly dominated by the market mechanism. Moreover, the safeguarding of the service users is under developed (see chapter 4), and older disabled people will be at greater risk in the services market. However, the policy makers should bear the spirit of the British independent living movement in mind. The independent living movement in the UK favours the democratic approach, rather than American individualism. The democratic approach highlights that people have a right to participate, to be heard, to exercise choice, to define problems, and to decide on appropriate action (Barnes and Mercer 2006: 72). However, in the personalised approach, individual budgets may offer a false prospectus to many people by promoting their market rights but actually diminishing their social rights (Daly and Woolham n.d).

It is reassuring to see that personalised social care services ensure that older disabled people have control over their lives. Nowadays, this new policy agenda still draws widespread criticism over whether personalised services help to maintain the autonomy of older disabled people, or contrarily place them in a hazardous situation. Otherwise, it may be a way for the Government to shirk its responsibility for developing the social care services. However, this research project remains some limitations. The secondary data may be unsuitable to present the research purposes. Also, it is not easy to analyse secondary

data precisely due to time bound. These controversial issues in the personalised social care services should be further explored on the policy agenda.

Reference

Aeber, S. and Ginn, J. 1991. *Gender and Later Life: A Sociological Analysis of Resources and Constraints*. London: Sage.

AIHW 2000. *Disability and Ageing: Australia population pattern and implications*. Canberra: Australian Institute of Health and Welfare.

Akinpelu, O. F., Flynn, E. et al. n.d. *Perspectives from the drafting of the UN Convention on the Rights of Persons with Disabilities*. Discussion Paper for Side Event at UN Open-ended Working Group on Ageing.

Aldridge, E. n.d. *PAT 15: Workshop: Age and ICTs*. [online]. [Accessed 9 August 2012]. Available from: <http://www.cabinet-office.gov.uk/seu/publications/pat/pat15.htm>.

Aldridge, H., A. Parekh, et al. 2011. *Monitoring Poverty and Social Exclusion*. York: Joseph Rowntree Foundation.

Appleby, Y. 1994. Out in the margins. *Disability & Society*, 9 (1), 19-32.

Arksey, H. and Kemp, P. 2008. *Dimensions of choice: a narrative review of cash-for-care schemes, Working Paper No. DHP 2250*. York: University of York.

Barnes, C. 1991. *Disabled People in Britain and Discrimination: A Case for Anti-discrimination Legislation*. London: Hurst and Co. .

Barnes, C., Ed. 1993. *Making Our Own Choice*. London: BCODP.

Barnes, C. 1997. *Older People's Perceptions of Direct Payments and Self Operated Support Systems*. London: The British Council of Disabled People's Research Unit.

Barnes, C. 2004. *Independent Living, Politics and Implications*. [Accessed 9 August 2012]. [online]. Available from: http://www.disability-archive.leeds.ac.uk/authors_list.asp?AuthorID=8&author_name=Barnes%2C+Colin.

Barnes, C. and Mercer, G. 2003. *Disability*. Cambridge: Polity Press.

Barnes, C. and Mercer, G. 2005. *The Social Model of Disability: Europe and the majority world*. Leeds: Disability Press.

Barnes, C. and Mercer, G. 2006. *Independent Future: creating user-led disability services in a disabling society*. Bristol: Policy.

Barnes, C. and Mercer, G. 2010. *Exploring Disability (Second Edition)*. Cambridge: Polity Press.

Barnes, C., and Mercer, G. et al. 2003. *Research Review on User Involvement in Promoting Change and Enhancing the Quality of Social 'Care' Services for Disabled People*. London: SCIE.

Barnes, M. and Walker, A. 1996. Consumerism versus Empowerment. *Policy and Politics*, 24 (4), 375-393

Beech, R. and Roberts, D. 2008. *Assistive technology and older people*. London: SCIE.

Blaxter, M. 1976. *The Meaning of Disability*. London: Heinemann.

Blood, I. and Bamford, S. 2010. *Equality and diversity and older people with high support needs*. York: Joseph Rowntree Foundation

BMJ (2005). *What is successful ageing and who should define it?* [Accessed 9 August 2012]. [online]. Available from: <http://www.bmj.com/content/331/7531/1548>

Borsay, A. 1986. Personal Trouble or Public Issue? Towards a model of policy for people with physical and mental disabilities. *Disability, Handicap & Society*, 1 (2), 179-195.

Bowers, H., Bailey, G., et al. 2007. *Personal Centred thinking with older people*. Cheshire: HAS Press.

Bracking, S. 1993. An Introduction of the Ideal of Independent / Intergrade Living. In C. Barnes. (eds), *Making Our Own Choice*. London: BCODP.

Brattagard, S. O. 1974. Social and Psychological aspects of the situation of the disabled. In D. M. Boswell and J. M. Wingrove. (eds). *The Handicapped Person in the Community*. London: Tavistock Publication and Open University Press, 7-9.

Brisenden, S. 1989. *A charter for personal care in Progress 16*. Edinburgh: Disablement Income Group.

Campbell, J. and Oliver, M. 1996. *Disability Politics; Understanding our Past Changing Our Future*. London: Palgrave.

Carr, S. and Robbins, D. 2009. *SCIE Research Briefing 20: The Implementation of Individual Budget Schemes in Adult Social Care*. London: Social Care Institute for Excellence.

Chandaria, K. 2011. *Short changed: Protecting people with dementia from financial abuse*. London: Alzheimer's Society

Charlton, J. I. 1998. *Nothing about us without us : disability oppression and empowerment*. Berkeley: Berkeley University of California Press.

Christensen, K., Doblhammer, G. et al. 2009. Ageing populations: the challenges ahead. *The Lancet*, 374 (9606), 1196 - 1208.

Clarke, J. 2006. Consumer, client or citizen? Politic , policy and practice in the refrom social care. *European Societies*, 8 (3), 423-442

Clark, H., Gough, H. et al. 2004. *'It pays dividends': Direct payment and older people*. Bristol: The Policy Press.

Clegg, R., Leaker, D. et al. 2010. Implications of the change in female state pension age for labour market statistics. *Economic & Labour Market Review*, 4 (1), 25-29.

- Comfort, A. 1997. *A Good Age*. London: Mitchell Beazley
- Conrad, P. and Schneider, W. J. 1980. *Deviance and Medicalization: From Badness to Sickness*. St Louis: Mosby.
- Corbett, J. 1994. A proud label: exploring the relationship between disability politics and gay pride. *Disability & Society*, 30 (11), 1257-1263.
- CRC 2008. *The personalization of adult social care in rural areas*. Gloucester: Commission for rural communities.
- Crosby, G., Clark, A. et al. 2008. *The Financial Abuse of Older People*. London: Help the Aged.
- Crow, L. 1996. Including all of our lives: renewing the social model of disability. In C. Barnes and G. Mercer. (eds), *Exploring the Divide: Illness and Disability*. Leeds: Disability Press, 55-73.
- CSCI 2005. *Social Care Performance 2004-5*. London: Commission for Social Care Inspection.
- CSIP 2007. *Older People's Services and Individual Budgets Care*. London: Care Service Improvement Partnership.
- Dalton, D. S., Cruickshanks, J. K. et al. 2002. The Impact of Hearing Loss on Quality of Life in Older Adults. *The Gerontologist*, 43 (5), 661-668.
- Daly, G. and Woolham, J. n.d. *Do personal budgets lead to personalisation and what can their promotion tell us about the nature of citizenship and public accountability in relation to social care? Reflections from a study of the impact of self-directed support and personal budgets*. Coventry: Coventry University.
- Dartington, T., Miller, E. et al. 1981. *A Life Together*. London: Tavistock.
- Davis, K. 1988. *Issue in Disability: Integrated Living in Social Problems and Social Welfare*. Milton Keynes: Open University Press.
- Davis, K. 1990. *A Social Barriers Model of Disability: Theory into Practice*. Derbyshire: Derbyshire Coalition of Disabled People.
- Davis, M. 1993. Personal Assistance: Notes on the Historic. In C. Barnes. (eds), *Making Our Own Choice*. London: BCODP, 15-18.

De Jong, G. 1986. *Evaluating housing and in-home service alternatives for persons ageing with a physical disability*. Annual Meeting of American Congress of Rehabilitation Medicine, Baltimore.

DH 2007. *Putting people first: A shared vision and commitment to the transformation of Adult Social Care*. London: Department of Health.

DH 2008a. *Local Authority Circular: Transforming adult social care*. London: Department of Health.

DH 2008b. *Personalisation*. [Accessed 9 August 2012]. [online]. Available from: <http://webarchive.nationalarchives.gov.uk/+/dh.gov.uk/en/socialcare/socialcarereform/personalisation/index.htm>.

DH 2010a. *Putting People First: Personal budgets for older people – making it happen*. London: Department of Health.

DH 2010b. *Changing lives together: using person-centred outcomes to measure results in social care*. London: Department of Health.

DH 2010c. *Putting People First: Support planning and brokerage with older people and people with mental health difficulties*. London: Department of Health.

DLIB 2008. *Thriving or Surviving: Challenges and Opportunities for Disabled People's Organisations in the 21st Century*. London: Disability Listen Include Build Alliance.

Dowson, S. 2011. *The role of the social care broker*. [Accessed 9 August 2012]. [online]. Available from: <http://www.communitycare.co.uk/Articles/19/10/2011/117377/the-role-of-the-social-care-broker.htm>.

DRC 2007. *Independent Living and the Commission for Equality and Human Rights*. [Accessed 9 August 2012]. [online]. Available from: http://www.leeds.ac.uk/disability-studies/archiveuk/DRC/IL_CEHR_Jan07.pdf.

Duffy, S. 2012. *Simplify the RAS*. [Accessed 9 August 2012]. [online]. Available from: <http://www.centreforwelfare reform.org/library/type/text/simplify-the-ras.html>.

Dunning, A. 2005. *Information, advice and advocacy for older people*

Defining and developing services. York: Joseph Rowntree Foundation.

Dunning, J. 2011a. *Hard-to-reach groups still face personal budgets barriers*. [Accessed 9 August 2012]. [online]. Available from: <http://www.communitycare.co.uk/Articles/05/08/2011/116913/hard-to-reach-groups-still-face-personal-budgets-barriers.htm>.

Dunning, J. 2011b. *Personal budgets system not set up for people with dementia*. [Accessed 9 August 2012]. [online]. Available from: <http://www.communitycare.co.uk/Articles/17/11/2011/117757/people-with-dementia-being-denied-direct-payments.htm>.

EHRC n.d. *Making the personalization of care and support work for all communities in the English regions*. London: Equality and Human Rights Commission.

EMAR 2010. *Review of the Default Retirement Age: Summary of Research Evidence*. [Accessed 9 August 2012]. [online]. Available from: <http://www.bis.gov.uk/assets/biscore/employment-matters/docs/r/10-1080-retirement-age-summary-research>.

Evans, J. 2003. *The Independent Living Movement in the UK*. [Accessed 9 August 2012]. [online]. Available from: www.independentliving.org/docs6/evans2003.html.

FAMIN 2011. *The elderly as viewed from the perspective Bible and Church's magisterium*. [Accessed 9 August 2012]. [online]. Available from: http://www.famvin.org/wiki/The_Elderly_as_viewed_from_the_perspective_of_the_Bible_and_the_Church's_magisterium.

Finkelstein, V. 1980. *Attitude and Disabled People: Issues for Discussion*. New York: World Rehabilitation Fund.

Finkelstein, V. 1984. *Schemes for Independent Living*. [Accessed 9 August 2012]. [online]. Available from: <http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/indepliv.pdf>.

Finkelstein, V. 2004. *'Phase 3: Conceptualising New Services*. Conference: Disability Studies: Putting Theory Into Practice . Lancaster: Lancaster University.

Ford, C. and R. Shaw 1993. Managing a Personal Assistant. In C.Barnes. (eds), *Making our own choice*. London: BCODP, 25-38

Frances, H. 2003. *Philosophy of Independent Living*. [Accessed 9 August 2012]. [online]. Available from: www.independentliving.org/docs6/evans2003.html.

Gangadharan, S. K., Devapriam, J. et al. 2009. People with learning disability, and ageing. *Psychiatry*, 8 (10), 382-386.

Gilroy, R. 2005. Meeting the Information Needs of Older People: A Challenge for Local Governance. *Local Government Studies*, 31 (1), 39-51.

Glasby, J. and Littlechild, R. 2004. *The health and social care divide : the experiences of older people*. Bristol: Policy.

Glendinning, C. 2002. Breaking down barriers: integrating health and care services for older people in England. *Healthy Policy*, 65, 139-151.

Glendinning, C., Challis, D., et al. 2008. *Evaluation of the Individual Budgets Pilot Programme Summary Report*. London: Department of Health.

Goffman, E. 1963. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs N.J: Prentice-Hall.

Griffiths, S. 2009. *Personalisation, choice and empowerment: a political and economic reality check*. London: Social Market Foundation.

Guralnik, J. M., Fried, L. P. et al. 1996. Disability as a public health outcome in the aging population. *Annu Rev Public Health*, 17, 25-46.

Hakim, C. 1982. *Secondary analysis in social research: a guide to data sources and methods with examples*. London: Allen & Unwin.

Hasler, F. 2003. *Personal Communciation*.

HCIL 1990. *Independent Living*. Hampshire: Hampshire Centre for Independent Living.

HMGoverment 2011. *Open Public Service 2012*. HMGoverment.

Hockey, J. and James, A. 1993. *Growing Up and Growing Old: ageing and dependency in the life course*. London: Sage.

Hughes, B. 2002. Disability and the Body. In C.Barnes, M.Oliver and L.Barton. (eds), *Disability Studies Today*. Cambridge: Polity, 58-76.

Hughes, J. C., Hope, T. et al. 2002. Dementia and ethics: the views of informal carers. *Journal of the Royal Society of Medicine* , 95, 242-246.

Hunt, P. 1966. *A Critical Condition. Stigma: The Experience of Disability.* London, Catholic Book Club.

Hurst, R. 2000. To revise or not to revise? *Disability & Society*, 15 (7), 1083-1087.

Hurst, R. 2003. The International Disability Rights Movement and the ICF. *Disability and Rehabilitation*, 25 (11-12), 572-576.

Hyman, H. H. 1972. *Secondary Analysis of Sample Survey.* New York: Wiley.

Ilyas, M. 2012. A Study of Web Accessibility Barriers for Older Adults, and Heuristics Evaluation of Email Websites Based on Web Accessibility Heuristics for Older Adults by AARP. *Journal of Emerging Trends in Computing and Information Sciences*, 13 (5), 806-813.

Iwakuma, M. 2001. Ageing with disability in Japan. In M. Priestly. (eds), *Disability and Life Course: Global Perspective.* Cambridge: Cambridge University Press, 219-230.

Janicki, M. and Dalton, A. 1988. *Dementia, Aging and Intellectual Disabilities: A Handbook.* New York: Brunner/Mazel Publications.

Jolly, D. 2012. *The Closure of the Independent Fund will cost Billions.* [Accessed 9 August 2012]. [online]. Available from: <http://www.digitalvoice.eu/?p=133>.

Jolly, D. n.d. *Personal Assistance and Independent Living: Article 19 of the UN Convention on the Rights of Persons with Disabilities.* [Accessed 9 August 2012]. [online]. Available from: <http://www.disability-archive.leeds.ac.uk>

Jönson, H. k. and Larsson, A. T. 2009. The exclusion of older people in disability activism and policies: A case of inadvertent ageism? *Journal of Aging Studies*, 23, 69-77.

JRF 1999. *Implementing direct payments for people with learning difficulties.* York: Joseph Rowntree Foundation.

JRF 2010. *Older people with high support needs: how can we empower them to enjoy a better life.* [Accessed 9 August 2012]. [online]. Available from: <http://www.jrf.org.uk/publications/better-life-high-support-needs>.

Kent, D. 1993. Financing Personal Assistance and the Independent Living Fund. In C. Barnes. (eds), *Making Our Own Choices*. London: BCODP.

Kerr, D., Cunningham, C. et al. 2006. *Responding to the pain experiences of people with a learning difficulty and dementia*. York: Joseph Rowntree Foundation.

Kestenbaum, A. 1993. *Making Community Care a Reality: The Independent Living Fund 1988-1993*. London: RADAR.

Kuno, K. 2008. *Concepts around Disability and Disabled People. Training them and us a guide to social equality for society*. DET. Malaysia: UTUSAN PUBLICATIONS & DISTRIBUTORS SDN BHD, 78-96.

Lin, J.D., Lin, L.P. et al. 2010. Aged and dependency ratios among autism, intellectual disability and other disabilities: 10-year trend analysis. *Research in Autism Spectrum Disorders*, 5 (1), 523–528.

Lin, W.I. 2009. *The risk of establishing the long-term care Insurance in Taiwan*. [Accessed 9 August 2012]. [online]. Available from: http://www.taiwansig.tw/index.php?option=com_content&task=view&id=1314&Itemid=123.

Luckhurst, L. 2005. *Wider Options: Report of a Research Project into Intensive Support Scheme for Direct Payment*. London: National Centre for Independent Living.

Madden, P. 2006. Direct payments: freedom from abuse? *The Journal of Adult Protection*, 8 (4), 32.

Manthorpe, J. and Samsi, K. 2012. 'Inherently Risky?': Personal Budgets for People with Dementia and the Risks of Financial Abuse: Findings from an Interview-Based Study with Adult Safeguarding Coordinators. *British Journal of Social Work*, 2012, 1-15.

Martinez, K. 2003. *Independent Living in the U.S. & Canada*. Internet publication . [Accessed 9 August 2012]. [online]. Available from: www.independentliving.org/docs6/martinez2003.html.

Minichiello, V., Brown, J. et al. 2000. Perceptions and consequences of ageism: views of older people. *Ageing and Society*, 20 (3), 253-278.

Morris, J. 1992. *Disabled Lives: Many Voice. One Message* BBC Continuing Education Department.

Morris, J. 1993a. *Gender and Disability*. In J. Swain and S. French et al. (eds), *Disabling Barriers-Enabling Environments*. London: Sage, 85-92.

Morris, J. 1993b. *Independent Lives: community care and disabled people*. Basingstoke: Macmillan.

Morris, J. 2006. *Centres for Independent Living / Local User-Led Organisations: a discussion paper*.

Moseley, C. 2004. *Support Brokerage Issues in Self-Directed Services*. National Association of State Directors of Developmental Disabilities Services Inc.

NCB 2009. *Dementia: ethical issues*. Nuffield Council on Bioethics.

NCODP n.d. *Independent Living Trust*. Norfolk Coalition of Disabled People.

NCVO 2009. *Personal budgets: Opportunities and challenges for the voluntary sector*. London: National Council for Voluntary Organisations.

NHS (2010). *Dementia*. [Accessed 9 August 2012]. [online]. Available from: <http://www.nhs.uk/conditions/Dementia/Pages/Introduction.aspx>

NHS (2012). *Direct Payment*. [Accessed 9 August 2012]. [online]. Available from: <http://www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/Directpayments.aspx>.

ODI 2008. *Independent living Executive Summary: A cross- government strategy about independent living for disabled people*. London: Office for Disability Issues

ODI 2011. *Disability prevalence estimates*. [Accessed 9 August 2012]. [online]. Available from: <http://odi.dwp.gov.uk/disability-statistics-and-research/index.php>.

OECD 1987. *Handicap and Adult Status: Policy Issues and Practical Dilemmas*.

Oliver, M. 1983. *Social Worker with Disabled people*. Basingstoke: Macmillan.

Oliver, M. 1989. Disability and Dependency: A Creation of Industrial Society. In L. Barton. (eds), *Disability and Dependency*. London: Falmer, 7-21.

Oliver, M. 1990. *The Politic of Disablement*. Basingstoke: Macmillan.

Oliver, M. 2009. *Understanding Disability: From Theory to Practice*, 2nd edn. Tavistock: Palgrave.

Oliver, M. and Barnes, C. 2012. *The new politics of disablement*. Basingstoke: Palgrave Macmillan.

Palmore, E. B. 2005. Typologies. In E. B. Palmore and D.K. Harris. (eds), *Encyklopedia of Ageism*. New York: Haworth Press, 332-334.

PCHW 2011. *Definition of Aging Concept Rejected by Active Aging Think Tank*. [Accessed 9 August 2012]. [online]. Available from: <http://www.philips-thecenter.org/>.

Pitt, V. 2011. *Users and carers fight restrictions on use of personal budgets*. [Accessed 9 August 2012]. [online]. Available from: <http://www.communitycare.co.uk/Articles/01/06/2011/116890/users-and-carers-fight-restrictions-on-use-of-personal-budgets.htm>.

Priestley, M. and Rabiee, P. 2002. Same Difference? Older People's Organisations and Disability Issues. *Disability & Society*, 17 (6), 597–611.

Priestly, M. 2003. *Disability: A Life Course Approach*. Oxford: Polity.

Rabiee, P., Moran, N. et al. 2009. Individual Budgets: Lessons from Early Users' Experiences. *British Journal of Social Work*, 2009 (39), 918-935.

Rae, A. 1993. Equal Opportunity, Independent Living and Personal Assistance. In C. Barnes. (eds), *Making Our Own Choice*. London: BCODP, 47-58.

Richards, P. and Ogilvie, K. 2010. *South West Region: A Safeguarding and Personalisation Framework Association of Directors of Adult Social Services*. London: SCIE

RIPFA 2012. *Do councils encourage CBR checks for PA?* [Accessed 9 August 2012]. [online]. Available from: <http://www.interactive.ripfa.org.uk/balancing-personalisation-with-safeguarding/topic/do-councils-encourage-crb-checks-for-personal-assistants/>.

Rohan, E. A., Berkman, B. et al. 1994. The geriatric oncology patient: ageism in social work practice. *Journal of Gerontological Social Work*, 23, 201-221.

Roulstone, A. and Prideaux, S. 2012. *Understanding Disability Policy*. Bristol: Policy Press.

Samuel, M. 2012. *Expert guide to direct payments, personal budgets and individual budgets*. [Accessed 9 August 2012]. [online]. Available from: <http://www.communitycare.co.uk/Articles/25/07/2012/102669/direct-payments-personal-budgets-and-individual-budgets.htm>.

SCIE 2012. *Personalisation: a rough guide Social care institution for excellent*. London: SCIE

Shakespeare, T. and Watson, N. 2002. The social model of disability: an outdated ideology. *Research in Social Science and Disability*, 2, 9-28.

Shava, K. 2008. *How and In What Ways Can Western Models of Disability Inform and Promote the Empowerment of Disabled People and Their Participation in Mainstream Zimbabwean Society*. Master Thesis, University of Leeds.

Sheldon, A. 2003. Changing Technology. In J. Swain, S. French, C. et al. (eds), *Disabling Barriers – Enabling Environments*. London: Sage, 155-168.

Slasberg, C. 2010. Can personalisation be a reality for older people? *Working with Older People*, 14 (3), 15-22.

Spicker, P. 2012. *Personalisation Falls Short*. *British Journal of Social Work*, 2012, 1-17.

Swain, J. and S. French 2001. The relationship between disabled people and health and welfare professionals. In G. L. Albrecht, K. D. Seelman and M. Bury. (eds), *Handbook of Disability Studies*. Thousand Oaks: Sage.

Thane, P. 2000. *Old age in English History: past experiences , present Issues*. Oxford: Oxford University Press.

Thomas, C. 2002. Disability Studies Today. In C. Barnes, M. Oliver and L. Barton. (eds), *Disability Theory: Key Ideas, Issues and Thinkers*. Cambridge: Polity Press, 38-57.

Thompson, S. 2005. *Age discrimination*. Lyme: Regis Russell House.

Timonen, V. 2008. *Ageing society*. Maidenhead: Open University Press.

Tulle-Winton, E. 1999. Growing old and resistance: towards a new cultural economy of old age ? *Ageing and Society*, 19, 281-299.

UPIAS 1976. *Fundamental Principles of Disability*. London: Union of the Physically Impairment against Segregation.

ÜSTÜN, T. B., Chatterji, S. et al. 2003. The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disability and Rehabilitation*, 25 (11-12), 565-571.

Valios, N. 2007. *Financial abuse of elderly people*. [Accessed 9 August 2012]. [online]. Available from: <http://www.communitycare.co.uk/Articles/29/08/2007/105618/financial-abuse-of-elderly-people.htm>.

Vincent, J. A. 2003. *Old age, sickness, death and importantly: a cultural gerontological critique of bio-medical models of old age and their fantasies of immortality*. Presented at the 4th International Symposium on Cultural Gerontology, Tampere, Finland: 'The Culture in gerontology: challenge, approaches, and method.

Walker, A. 2002. A strategy for active ageing. *International Social Security Review*, 55, 121-139.

Walker, A. and C. Walker (1998). Normalisation and 'Normal' Ageing: the social construction of dependency among older people with learning difficulties. *Disability & Society*, 13 (1), 125-142.

WHO 1980. *International Classification of Impairment, Disabilities and Handicaps*. Geneva: World Health Organisation.

WHO 2001. *International Classification of Functioning, Disabilities and Health*. Geneva: World Health Organisation.

WHO 2002a. *Toward a Common Language for Functioning, Disability and Health (ICF)*. Geneva: World Health Organisation.

WHO 2002b. *Active Ageing – A Policy Framework*. Geneva: World Health Organisation. [Accessed 9 August 2012]. [online]. Available from: http://whqlibdoc.who.int/hq/2002/WHO_NMH_NPH_02.8.pdf

Wiener, J. M. and Hanley, R. J. 1990. *Measuring the Activities of Daily Living: Comparisons Across National Surveys*. [Accessed 9 August 2012]. [online]. Available from: <http://aspe.hhs.gov/daltcp/reports/meacmpes.htm>

Woodin, S. 2006a. *Social Relationships and Disabled People: the impact of direct payments*. Ph.D thesis, School of Sociology and Social Policy. The University of Leeds.

Woodin, S. 2006b. *Mapping User-Led Organisations/ User-Led Services and Centres for Independent / Integrated/ Inclusive Living: A Literature Review Prepared for the Department of Health*. [Accessed 9 August 2012]. [online]. Available from: http://www.disability-archive.leeds.ac.uk/authors_list.asp?AuthorID=243&author_name=Woodin%2C+Sarah

Zarb, G. 1997. *Forgotten but Not Gone : the experience of Ageing with a Disability*. In S. Arber and M. Evandrou. (eds), *Ageing, independence, and the life course*. London: the British Society of Gerontology, 27-45.

Zarb, G. and P. Nadash. 1994. *Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services*. London: BCODP.

Zarb, G. and M. Oliver 1993. *Ageing with disability: What do they expect after all years*. London: University of Greenwich.

Zola, I. M. 1993. *Self Identity and the naming question: reflections on the language of disability*. *Social Science and Medicine*, 36, 167-173.

