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Coláiste na hOllscoile Corcaigh

Direct Payment: the lived experiences of eight individuals in Ireland

Aoife O Brien

CARL Research Project



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Date completed:	05/10/15

What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a service provided by research institutes for the Civil Society Organisations (CSOs) in their region which can be grass roots groups, single issue temporary groups, but also well structured organisations. Research for the CSOs is carried out free of financial cost as much as possible.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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Why is this report on the web?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public. We are committed to the public and free dissemination of research results.

How do I reference this report?

Author (year) Project Title, [online], School of Applied Social Studies, Community-Academic Research Links/University College Cork, Available from: http://www.ucc.ie/en/scishop/completed/ [Accessed on: date].

How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?

The UCC CARL website has further information on the background and operation of the Community-Academic Research Links at University College Cork, Ireland. http://carl.ucc.ie

CARL is part of an international network of Science Shops. You can read more about this vibrant community and its activities on this website: http://www.scienceshops.org

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Executive Summary

This following piece of research identifies the life experiences of eight individuals in receipt of Direct Payment in Ireland. Direct Payment is funding for persons "who need assistance with a range of daily living activities to buy their own support" (Carmichael et al, 2002 p.798). Initially the literature on the subject of Direct Payment was examined and the themes that emerged from this were, the movement from a medical model to a social model of disability, citizenship, personalisation and individualised funding supports. Policy in relation to people with disabilities, from the 1937 Constitution onwards, was reviewed and the incremental changes were outlined. It was noted that there are still 4000 individuals in institutional care despite proposal to move towards independent living.

This research was done under the auspices of Community Academic Research Links (CARL) which is an initiative in UCC which assists Civil Society Organisations (CSO) with research they wish to undertake. Full cooperation was received from Áiseanna Tacaíochta (ÁT-network) which is the first and main organisation to facilitate Direct Payments to people with disabilities in Ireland. The ÁT-network nominated the topic for research with the agreement of CARL, the thesis supervisor and the researcher.

Having interviewed the eight recipients of Direct Payment the advantages of this system became evident. The final recommendations included a move towards a Direct Payment system with appropriate information and training and adequate safe guards against exploitation.

Chapter 1: Introduction

1.1 Introduction

In last few years there has been an increasing move in policy to create personalisation within disability services with an aim to put people with disabilities in control of their care. This research seeks to explore the developing policies within the disability sector. It will also introduce Áiseanna Tacaíochta (ÁT-network) for whom the research has been carried out. The rationale for working within the Community Academic Research Links (CARL) programme in University College Cork (UCC) will be identified. The research aims and objectives will also be discussed in this chapter and will conclude with a summary of the subsequent chapters.

1.2 Research Rationale

This research has been conducted as a component of the MSocSc Social Policy in association with (CARL). CARL is an initiative in UCC which assists Civil Society Organisations (CSO) with research they wish to undertake. Applications from students are invited to undertake the research and are allocated based on the application criteria. After consideration of topic outlines, the researcher together with the ÁT-network, the college supervisor and CARL representatives agree on the research outline.

The main objective that was initially outlined on the CARL website by the ÁT-network is as follows. "Should legislation be adopted in Ireland to allow individuals with a disability total control of their allocated funding from the state to manage their Personal Assistant service? Using the example of

individuals' experiences it is hoped that it can be discovered how with the correct support we, people with a PA service, can receive a direct payment to manage their own service" (http://www.ucc.ie/en/media/research/carl/Available_Projects_2013_2014.pdf).

As the concept of receiving individualised supports for persons with a disability is relatively new in Ireland, it was agreed in the first meeting with all parties mentioned above that the ÁT-network would provide a list of individuals for the interviews. Each of the participants that took part in the interviews had experiences of being in the process of receiving or in receipt of Direct Payments with the support from the ÁT-network.

1.3 Áiseanna Tacaíochta

"Áiseanna Tacaíochta (ÁT) is the first and main organisation to facilitate Direct Payments to people with disabilities in Ireland". They represent a diverse group of individuals with life experiences of living with disabilities. The people they represent have a common goal and desire to direct their own lives. The model that the ÁT-network works off is that of Direct Payments (which is a payment that individuals receive to purchase their own support). This model aims to "redefine the lived experience of disability" for their members – whom they call Leaders – and "represents the next step forward for the disability movement in Ireland". "Together with our supporters, people with disabilities and wider communities, we are breaking the historical culture of dependency on service providers, and driving a shift towards a personalised and empowering model of support that gives power back to the person" (http://www.theatnetwork.com/about-us/). They operate as a Company Limited by Guarantee and are running as a non-profit organisation, granted with charitable tax exemption.

1.4 Research Aim

One of the main provisions that supports people to integrate into society is the access to one's own finance, which provides greater power of choice. A key type of payment that gives a person the power of choice is Direct Payment which is a payment that "enables disabled adults who need assistance with a range of daily living activities to buy their own support" (Carmichael et al, 2002 p.798). This piece of research aims to investigate the social realities and the lived experiences of eight individuals with a disability who are in receipt of or in the process of receiving Direct Payment in Ireland.

1.5 Research Objectives

The objectives of this piece of research are as follows:

- How do people with disabilities experience individualised funding supports, and with what outcomes?

- What are the barriers which face people with disabilities accessing their own financial supports?

- What factors would support the development of individualised funding for people with disabilities?



_Áiseanna

Tacaíochta http://www.theatnetwork.com/

1.6 Thesis Outline

Chapter 1

Introduction This chapter introduces the research project and explains the aims of the research. It gives a detailed background of Áiseanna Tacaíochta and outlines the rationale behind the research. It identifies the research objectives in carrying out this study.

Chapter 2

Literature Review This chapter focuses on the literature on understandings of disability, on the notion of active citizenship, personalisation and individualised supports for persons with disabilities. It will examine the historical values in Ireland and how they have changed in the context of people with disabilities. It will aim to give the reader the information needed to show the importance of the research at hand and give them more awareness of the subject being researched.

Chapter 3

Policy Review This chapter will focus on the impact of social policies in relation to individualised budgets for people with disabilities living in Ireland. It will examine current policy issues and policies that are in place to support the integration of people with disabilities. The chapter will highlight the inconsistencies and difficulties current policies may create and it will examine policies in other countries in relation to individual funding for persons with disabilities.

Chapter 4

Methodology This chapter will outline the methodology of the study. There will also be an explanation of the choice of perspective and the methods used in the research. Ethical issues and challenges that were experienced during the research process will be explained here.

Chapters 5 & 6

Findings & Discussions The findings of the research will be outlined in these two chapters. This will be an exploration of the issues faced by persons with disabilities in obtaining Direct Payments which were conveyed to the researcher during the interview process. This section will be structured in terms of themes, some emerging through examination of the literature and some introduced during the interview process. This section will be structured in terms of themes, emerging predominantly from the interviews with recipients of Direct Payments and will focus on the experiences of the individuals that were interviewed.

Chapter 7

Conclusion This chapter will set out the conclusions from the interviews and tie together empirical material and key themes from the literature and policy chapters. The key learning points of the researcher will be explained and final thoughts will also be explored. Recommendations will be made on the basis of findings and theoretical background research.

Chapter 2: Literature Review

2.1 Introduction

This chapter will discuss the literature on individualised funding supports for people with disabilities in Ireland. Quin et al (2003p.3) have identified that "in spite of service development in various fields, the position of people with disabilities in Ireland has remained marginalised in many respects". Historically in Ireland there has been more of a focus on the institutionalisation of persons with disabilities. There has also been more of an emphasis on the disability that the person has rather than on the social and economic factors which serve to debilitate people with disabilities within society. It was only since the 1950s that community based services started to emerge; however it was not until the 1980s that policy and practice have been "moving steadily towards community inclusion for people with disabilities" (HSE, 2011p.10).

The main aim of this research is to explore one mechanism/support which holds out the potential for disabled people's participation in society through direct financial support. One of the main provisions that supports people to integrate into society is the access to one's own finance which provides greater power of choice. A key type of payment that gives a person the power of choice is Direct Payment which is a payment that "enables disabled adults who need assistance with a range of daily living activities to buy their own support" (Carmichael et al, 2002 p.798). Ireland has not yet incorporated Direct Payment into a policy or legal framework; therefore, people do not yet have a fundamental right to individual funding which would "enable them to employ a personal assistant or buy support" (Power, 2010 p.25).

Direct Payment is a topical debate for policy makers in Ireland, with the United Kingdom having included direct payment schemes into legislation via the Community Care Act 1996 and other countries such as Sweden, Norway and Canada also having individualised budgets (ibid). This research will identify key debates in relation to Direct Payment schemes being developed in the Republic of Ireland.

A fundamental change in Irish society in relation to disability is the slow shift from a medical model to a social model of disability which is where the development of personalisation has emerged. The history of this shift and the prevalence of the social model to date will be identified in this chapter. The emergence of the social model has led to the development of a disability rights agenda which sees people with disabilities as 'equal citizens' with the right to actively participate in society in the same way as able-bodied people.

The final topic that was identified is the concept of personalisation, which simply means the enablement of an individual with finding the right solutions for them to participate in the delivery of a service. "From being a recipient of services, citizens can become actively involved in selecting and shaping the services they receive" (Service Development Group, 2009 npn). This theme will be explored throughout this chapter.

2.2 The shift from a medical model to a social model of disability

There has been a significant change in the relationship between disability and society in Ireland and internationally (McDonnell, 2007). Traditionally the medical model has been dominant in Ireland in relation to disability. However, there has been a gradual shift in certain areas of policy where we can see the development of social model principles but less so in other areas of policy. The main focus in the medical model is on a person's functional limitations (impairments) as being the principal cause of any

disadvantages experienced. It is therefore seen that these disadvantages can be rectified by providing treatment to cure or alleviate a person's impairments (Crow, 1996).

An interesting definition that Crow (1996) highlighted, which shows the strength of the medical model, was from the World Health Organisation (WHO). It defined disability as "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (p.2).

Another medicalised definition was for 'handicap' as being a "disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents fulfilment of a role that is normal, depending on age, sex, social or cultural factors for that individual" (United Nations Division for Economic and Social Information, 1983, p.3 cited in Crow, 1996 p.2). In both definitions there is no mention of the environmental or social discriminations that are experienced by individuals which in many ways can be more debilitating than the impairment itself. There has however, been an incremental shift away from this medical model to a social model.

The social model resulted from the critique of the medical model of disability. This model of disability should not be considered as a "monolithic entity, but rather as a cluster of approaches to the understanding of the notion of disablement" (Lang, 2001p. 2). There has been a shift from the focus on the impairment being the cause of the disability to a more external view. The social model is "collective not individual, explicitly constructed to reverse individual understandings of disability and address the full range of disabling barriers" (Dodd, 2013p.264).

It is suggested that the "disabling social, environmental and attitudinal barriers" that restrict an individual are more influential and debilitating than the impairment itself (Crow, 1996 p.3). This is not to say that an impairment which causes functional limitation(s) on the body is not debilitating. However, the social model focuses more on the loss or limitation of opportunities due to direct or indirect discrimination as the main forms of disability. Oliver (1995) argues that "disablement has nothing to do with the body and that impairment is in fact nothing less than a description of the physical body" (cited in Hughes, 1997 p.330).

The social model identifies the need for social change such as removing social barriers and negative perceptions as being key to the removal of disadvantages that may be faced by individuals with disabilities (Crow, 1996). This model gives precedence to the importance of "politics, empowerment, citizenship and choice" (Lang, 2001 p.4).

A common notion in the social model is that disability and disablement are "socio-political constructions" (Lang, 2001 p.2). It therefore concentrates more on the "inhospitable physical environment and the negative social attitudes" that may cause oppression, discrimination and exclusion for some individuals (ibid). However, Shakespeare (2006) suggests that there may be too much emphasis on the social model being the 'right way' and the 'medical model' being the wrong way. He states that it is unrealistic to totally ignore the impact an impairment has on the lives of many individuals with a disability. Shakespeare also notes that it is far too simplistic to merely distinguish disability as either a physical or social issue. Rather, what is of invaluable importance is for people with disabilities themselves to identify what impacts most in their lives (cited in Bollard, 2009). There is no one size fits all solution, which is why it is imperative that there are a diverse range of supports and services available to all individuals with a disability.

2.3 Citizenship

A fundamental part of the social model is the concept of citizenship which gives people a sense of belonging. Citizenship is defined by disability scholars as a "process of proactive engagement" in society in which 'differentials of power' are acknowledged and addressed (Beckett, 2005 cited in Bartlett, 2013 p.1). Although there has been significant progress in the development of services for people with disabilities in Ireland, they are still a relatively marginalised group in society.

Quin et al (2003) identify the importance of citizenship for any marginalised group in society. They also highlight Marshall's (1952) description of citizenship as having three essential elements, 'civil, political and social rights' (ibid p.2). Sims and Gulyurtlu (2014) discuss how, although persons with disabilities may have the same entitlements as other citizens in society they may not always have the same opportunities, such as employment or housing. They also highlighted Stone's (1984) argument that people with disabilities were often treated as second class citizens (ibid).

Abberley (2002) states that the concept of the enhancement of citizenship is often used to highlight the social exclusion that is experienced by some individuals with disabilities from mainstream society. Quin et al (2003) note that potential to obtain full citizenship for persons with a disability is undermined by such factors as unemployment. It was highlighted that educational disadvantage in the area of disability is an early determinant that can affect the ability of disabled people to achieve "economic participation in society" (Quin et al, 2003 p.4). Failure to provide adequate education has a knock-on effect in relation to entering into the labour market and obtaining meaningful work.

Conroy (2003) outlines that the lack of educational and training opportunities that are available for people with a disability were identified in a study conducted in 1996. This study showed that "67 per cent of

people of working age without a disability participated in the labour market in comparison to only 32.9 per cent of those with a disability" (cited in Quin et al, 2003 p.4). Another concerning statistic that Conroy (2003) highlighted from a report by Eurostat (2001) was that up to 62 per cent of persons with a moderate disability did not proceed to second level education. It was also noted that 95 per cent of those with a disability living in Irish households have an income; however, "it is not an earned income; that is it does not come from employment" (cited in Quin et al, 2003 p.48). The main origins of the income are from social welfare payments or family money. This would suggest that there are not sufficient policies put in place to ensure meaningful participation in society for persons with a disability.

2.4 Personalisation

Personalisation is a relatively new concept that seeks to promote equal citizenship for persons with disabilities. Over the last number of years there has been an increasing development in personalisation based on the provision of Direct Payment or individual budgets, which have been fundamental in adult health and social care policy in the United Kingdom (UK) (Ferguson, 2012).

Personalisation is sometimes used synonymously with individualised funding mechanisms such as "Individual/Personal Budgets (a budget held by the state but allocated by the user), or Direct Payment (a direct cash payment to the individual), but it involves a framing of these mechanisms within a narrative that is not logically necessitated by their existence" (Dodd, 2013p.261). This has brought about a more flexible model which has included more choice and control for its service users (Sims et al 2013). **"**Internationally there is growing evidence of how personalised supports allied with greater opportunities for community inclusion can improve the quality of people's lives" (McConkey et al., 2009, cited in

McConkey et al, 2013 p.9). The term personalisation relates to the individualised and personalised supports tailored to meet the specific needs of an individual (ibid).

Under the notion of personalisation there is a focus on community based support with an emphasis on inclusion and participation. The individual obtaining the support is involved in the planning process of care or support that is being provided and is given the opportunity to identify their strengths and abilities rather than solely focusing on their needs and disabilities (McConkey et al, 2013). Personalised or individualised supports have been described in the following way (Genio, 2012):

- "planned and delivered on the basis of a consideration of the wider needs and potential contributions of the person, moving away from a focus on deficits;
- a response to one person rather than group-based; · chosen by the person with disabilities or mental health difficulty (or their advocate as appropriate);
- delivered in the community fostering inclusion and participation rather than in segregated, stigmatising settings;
- inclusive of family and community supports and mainstream services; · reliant on paid professionals only when necessary" (cited in Mc Conkey et al, 2013 p.9).

There have been many studies undertaken by groups such as In Control (who are a national charity organisation based in the U.K that promote self-directed support). These studies have identified that personalisation, when implemented effectively, can have a positive impact on individuals with both physical and intellectual disabilities. It is of paramount importance that the autonomy and independence of persons with intellectual disability are supported by social workers or other professionals that may be

working with them, to ensure that they achieve their personal goals. "Without the right support to manage budgets and autonomy, people with learning disabilities could be left vulnerable" (Sims, 2013 p.13).

An important aspect of personalisation is that it not only gives control and choice to the individual about what service they receive, but it also pushes services to be tailored to the needs of the individual rather than having a one size fits all approach (Dunning, 2008). The need for personalisation in the health, social care and other public sectors areas is a key element in the area of independent living, inclusion and well-being. However, it is important to note that it is not a means to an end and that there are other factors that cannot be over looked. The removal of disabling barriers is a vital part of greater inclusion as well as the establishment of greater rights for people with disabilities (Routledge, et al 2014).

The whole concept of personalisation tends to be viewed as the way forward for many disability activist groups. However, it has been argued that this model has a neoliberal and economic agenda (Ferguson, 2012). Could there be too much of an emphasis on individualism? The concept of independence, choice and control for all individuals is and should be a human right and this should be promoted. However, a flipside to individualism is as Scournfield (2007) identified, the shift of responsibilities from the State to the individual (cited in Ferguson, 2012). Scournfield (2007) also argues that the underpinning ideology that is present in personalisation is one that is 'market-consumer' led or has a neoliberal discourse.

The market-based model has been criticised as not being suitable in the area of the welfare sector (Taylor-Gooby, 1994; Pfeffer & Coote, 1996 cited in Askheim, 2010). It restricts the numbers of supplies to certain areas that have greater potential for gaining profit. Therefore the notion that individuals gain a greater sense of choice of a diverse range of services is more often than not an illusionary idea (Barnes, 1997, cited in Askheim, 2010).

There has been a lot of criticism in relation to the ability of service users to make well-informed decisions. It has been argued that the relevant information may not be accessible to service users or in some cases individuals may not have the ability or the competence to make certain decisions. It has been highlighted that a worrying concern is there is the potential that the most vulnerable among the users may fall through the cracks due to the lack of information and understanding (Sundran, 1994; Caruso, 1999 cited in Askheim, 2010).

There is an emphasis on empowerment for the users and for this to be successful there needs to be a "balance against the responsibility the welfare state has for all its inhabitants and for protecting them against misfortunes and risks, of which users might not realise the consequences due to for example, cognitive limitations, lack of life experiences or mental imbalance" (Askheim, 2010 p. 24). It has been argued that through the personalisation model it is the government that is reaping in the financial benefits. Drake (1999) asserts that the new community care market allows governments to take financial advantage, while reducing per capita funding for Personal Social Services (PSS). This has resulted in community care being heavily reliant on "unpaid 'carers', such as friends and family members (the majority of whom are female)" (Carmichael et al, 2002 p.798).

An important critique of personalisation is that there is a disproportionate emphasis on how the individual's autonomy can be improved through personalised supports, with a lack of focus on the structural oppression and collective forms to make substantial structural change (Dodd, 2013). Personalisation does however, provide greater opportunities for individuals with a disability in becoming active citizens and employees which presents a challenge to the position of disabled people in society (ibid). Dodd (2013) notes that although this model is creating greater inclusion for disabled people it does not address the 'root cause of disability' in relation to society nor does it highlight other barriers in

areas other than supports. By contrast, the social model is collective not individual, explicitly constructed to reverse individual understandings of disability and address the full range of disabling barriers.

2.5 Individualised Funding for persons with a disability

An issue that is relevant to the allocation of funding in Ireland is the lack of clarity regarding the levels of funding with respect to the quality of care. It is evident that there are large allocations of funding being assigned to service providers, some of whom are providing institutionalised care with poor levels of community-based alternatives (Power, 2010). A worrying finding by O'Keane et al (2005) was that there was "no clear relationship between financial allocation and the provision of clinical services" (cited in Power, 2010 p.23). This would suggest that proper arrangements need to be put in place to ensure that the allocation of resources is sufficient to the personal circumstances and the needs of the individuals it is meant to support (ibid).

In order to tackle the problem of insufficient regulation of funding the Value for Money Policy Review (VFM Review) was established in 2012. This review was undertaken Expert Reference Group on disability policy to identify the efficiency and effectiveness of disability services in Ireland which are either partly or fully funded by the state. Although this review is a welcome one, one cannot help but wonder is the focus on ensuring greater citizenship for people with disabilities or solely about saving money?

One key point that was highlighted in the Value for Money Review was the move to a system of individualised budgeting for persons with a disability. Such payments would include Direct Payment which is cash paid to individuals with a disability to "enable them to employ, either directly or indirectly,

individuals to assist them with their everyday tasks" (Egan, 2008 p.2). A Direct Payment gives an individual with a disability a greater sense of choice and provides them with the opportunity to purchase personal assistance to facilitate an individual to live independently (Power, 2011). The introduction of such payments would mean that the service recipient would become the consumer/employer of his/her supports. This would change the power dynamics between the service providers and the users and it would enable a shift from "provider-led services to an independent life in the community" (Power, 2011 p.9).

Direct Payment (DPs) have the potential to radically influence the 'community care' market economy and the way personal support services are purchased and delivered in the future (Carmichael et al.,2001). As the power of the consumer evolves it puts more pressure on the service providers to compete for its users which should, one would think, improve the services that are being provided. An important aspect however, is that "care will need to be taken to support the consumer in their choices and to ensure that predictable deficiencies in market-led provision are anticipated and adequately handled before they happen" (Power, 2011 p.3).

Direct Payment operates in a number of European countries such as the United Kingdom (U.K), Sweden, Austria, Finland, Belgium and Germany (Egan, 2008). In the U.K Direct Payment was introduced for adults in the social care system under the 1996 Community Care (Direct Payment) Act. Studies have identified that Direct Payment has had beneficial effects on the people who receive such payments, which include a greater sense of choice and control over their services and supports. It allows individuals to organise their services for a time that suits them as well as giving them the choice of accessing personal assistance with persons they choose and with whom they feel comfortable to. They have, however,

shown that there is a need for support schemes to be available to offer facilitation with the use of Direct Payment (Power, 2011).

A study conducted in 2007 has shown that there was up to 80% take-up of the direct payment schemes in the UK when sufficient supports and provisions were put in place (Davey, et al 2007). Many local authorities demand detailed spending plans and accounts for public funds which is why it is vital that the right supports are available to individuals with managing budgets. Individuals in receipt of Direct Payment may also need assistance in hiring support workers. The right supports available help people to govern their "own supports and use their individual funding to the best advantage" (Power, 2011 p.10). Although there are many undeniable positive aspects to individualised supports, one must also be aware of the negative implications that may arise if sufficient procedures and protocols are not put in place to ensure the successful introduction of such systems in Ireland.

A report published by the Personal Social Services Research Unit (PSSRU, 2007) found that in the UK there was a number of shortfalls regarding direct payment arrangements. It was noted that there were significant disparities between local councils with regards to the level of hourly payment rates as well as the number of individuals eligible for Direct Payment. The level of payments has significant influence on how and whether individuals obtain a fair level of care in the market for 'social care' (Moore, 2012). This is a worrying finding as it would suggest that the same service is not provided for everyone and it depends on the region in which one is living; therefore there is not a sufficient standardisation of the Direct Payment UK packages available for people (ibid).

There is also a concern that without the right supports in place the funds that are available to an individual may not be used in the best interest of the recipient. An example of this is where a person may be living

in the family home and the income that they receive through Direct Payment ends up in the family budget; therefore it is not being used in the way it was intended (Moore, 2012).

In Ireland we have not yet opted for the Direct Payment model. Rather, our system provides a practice of allocating blocks of core funding directly to service providers. In 2010 however, the then Minister of State for Equality, Disability & Mental Health, John Maloney T.D; stated that he would "draw up plans to introduce a system of Direct Payment to enable people with disabilities here (Ireland) to purchase their own support services" (Moore,2012 p.3).

One of the key provisions in the United Nations Convention on the Rights of Persons with Disabilities is to support individuals with disabilities with their financial affairs. Although Ireland has not yet ratified this Convention it is moving to a more choice and control driven service system rather than solely a support and care system. In a more recent speech the now Minister for Equality, Disability and Mental Health, Kathleen Lynch, states that what is envisaged for Ireland is that public services where possible would be delivered by State providers. She also noted that that there will be a move to more individual based needs assessment for individuals to purchase relevant supports and services needed.

This is proposed to be done through a Direct Payment system or a broker system "which is where the persons still has choice and control but the broker administers the budget and contracts for supports and services on their behalf" (Lynch, 2011). New Labour policy in the UK was not opposed to market development in the social care sector; whether that will continue under the current leadership is not yet evident. An important part of the policy is that local authorities are transformed from being "providers of services to being concerned with the purchase of services" (Askheim, 2010 p.249).

Another important contribution to the debate around personalisation in Ireland is the Report entitled Time to Move on from Congregated Setting which is a strategy devised to promote community inclusion and was initiated by the "Primary, Community and Community Care Directorate in 2007". The main objectives of this report were to "develop a national plan and associated change programme for moving people from congregated settings to the community in line with Government policy" (Report of the Working Group on Congregated Settings, 2011 p.3). There has been a declining number of congregated settings in Ireland due to public policy. However, the admissions of persons entering into congregated has exceeded those people leaving in the period 1999-2008 (ibid, p.10).

2.6 Conclusion

It is evident that Ireland has come a long way from the institutional care that was prevalent for so many years. However, the method of allocating funding to individuals seems to be open to question with undue emphasis on funding for institutional care vis-à-vis individual payments for services. The fact that there is lack of clarification on how funding is being used is a worrying concern (O'Keane et al 2005).

Although it is evident that there has been a shift from institutionalisation to community based care it is clear that there is still a lot to be done as these congregated settings are still accommodating up to 4000 residents across Ireland. In order to ensure the implementation of the Strategy the Health Service Executive (HSE) set up the Working Group on Congregated Settings. The group developed a national plan for transferring people into the community. International comparisons, such as the UK which has developed a personalisation model of health and social care, would be useful to help in developing a similar model for Ireland. Although the personalisation model is one that will create greater independence

for individuals with disabilities the critics of this model must not be underestimated if Ireland is to adopt this system.

Chapter 3: Policy Review

3.1 Introduction

As identified in the previous chapter Irish disability policy has slowly shifted from the traditional institutionalisation and segregation of persons with disabilities to a focus on integration (Quin & Redmond, 2003). The main purpose of this chapter is setting the emergence/trialling of Direct Payment in Ireland in the context of broader shifts in policy. In order to get a greater understanding of the important changes that have emerged in Irish society in relation to people with disabilities this chapter will initially look at the history behind the policies that have been put in place to date.

The chapter will then highlight the development of independent living through various social policies in Ireland. It will identify how developments such as Direct Payments and individual funding are an essential part of independent living. There have been many policy developments to date in Ireland that are aimed at promoting greater inclusion of persons with disabilities, such as the National Disability Strategy, the Disability Act 2005, Time to Move from Congregated Settings 2011 and the Value for Money Policy Review 2012 (VFM Review). This chapter will examine how these policies and strategies have been implemented and what role people with disabilities have had in the establishment of these policy strategies.

3.2 Historical Context of disability policy in Ireland

Since the establishment of the Irish Constitution in 1937 the Irish government had been seen to take a hands off approach in the areas of health, social care and education, which were mainly dominated by Catholic Religious Orders (Linehan, et al, 2014). Prior to the 1980s public policy in relation to disability was primarily seen 'as a matter for the Department of Health and its agencies' (Doyle, 3003 p.10). In Ireland there was a "social climate where intellectual disability was often stigmatised, religious orders were entrusted with providing services that could be relied upon to be confidential" (Linehan, et al, 2014 p.2). Although disability services were financed by the government through capital and land grants, the government possessed little control of the running and order to which these services were provided (ibid).

In the 1950s concerns were highlighted about the coordination and organisation of services and accommodation made available to people with disabilities. It was then that the establishment of non-religious voluntary groups such as the 'parents and friends association' was developed by individuals that did not wish to avail of the institutional care made available (Linehan, et al, 2014). Such groups expanded rapidly in the 1960s which brought with it more public awareness of disability matters such as poor treatment in institutions. With the increase of disability services and rising expenditure on residential accommodation the government produced a White Paper 'The Problem of the Mentally Handicapped' (Department of Health 1960). The main recommendations of this paper were to double the amount of residential places to deal with the growing demand of residential care for people with intellectual disabilities (Linehan, et al, 2014).

It was in the 1980s that government published papers published in the area of disability such as the Green Paper 'Towards a Full Life' 1984. These started to show a growing trend towards community based care for persons with milder levels of intellectual disabilities. A policy document entitled 'Needs and Abilities'

in 1990 for people with intellectual disabilities highlighted the need for new residential provision. It identified the need to move away from large numbers of persons with high dependency living in one large area, to be replaced with a small residential units of 3 to 4 houses. It also outlined the need for greater supports for families in order for them to maintain their family member in a home situation (Hogan, 2006). In 1996, "the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, "Towards an Independent Future" also signalled a move away from large institutions, towards small living units and mainstream housing provision" (ibid p.11).

Since the publication of 'Needs and Abilities' in 1990, there have been a number of policies developed which aim to 'transform disability services from a traditional, and congregated model of care, towards a model whereby people with disabilities are supported to live a life of their choosing within their own local communities' (Linehan, et al, 2014 p.10). This proposed a new model of disability service provision which is underpinned by values of 'person-centeredness, inclusion, community integration, participation, independence and choice' (ibid p.10).

This was the beginning of a move from a medical model to a social model of disability. Policies were beginning to focus more on developing society to become more inclusive rather than focusing on individual's disabilities. An important report that highlighted a significant change in how disability was viewed, was the 1996 Strategy for Equality. This report was the first of its kind in that it included persons living with a disability in Ireland to validate its findings. The report was influenced by "international recognition that disability is a social rather than a medical issue" (Government Commission, 1993 p.4).

Another important development in Irish policy was the establishment of the Disability Act 2005 which is a significant piece of legislation that became law on the 8th of July, 2005. The aim of the Act is to enhance

and improve the everyday lives of persons with a disability. The Act forms part of the framework of the Government's National Disability Strategy which supports social inclusion**.** The main focus of the Disability Act is about the right to an assessment of needs. A significant development through the Disability Act that enhanced the daily lives of many people with a disability was the implementation of a requirement that Dublin Bus and 'most public services and facilities are fully accessible to people with disabilities' (Moore, 1994 p.3). This important change in policy was due to the ongoing protests by disabled people themselves and their advocates (ibid).

Although the passing of this Act was a significant step in improving the rights of people with disabilities it took a long campaign for the introduction of such legislation. The Disability Act also fell short of the comprehensive rights-based legislation that people with disabilities and their advocates had campaigned for. A key concern that was highlighted by people with disabilities and their representative organisations was the "omission from the Act of the right to seek judicial remedies where any of the provisions of the Act are not carried out" (Inclusion Ireland, 2013 p.9). These concerns were shared by the Irish Human Rights Commission and the United Nations Committee on Economic, Social and Cultural Rights.

3.3 Moves to independence

Prior to the enactment of the Disability Act there had been significant steps to improving the lives of people with disabilities. In the early 1990s there was a pilot scheme called INCARE which was set up by a small group of individuals with significant physical and sensory disabilities. They received funding by the EU and FÁS and they campaigned for the establishment of a Personal Assistant (PA) service in Ireland. The introduction of PAs was to support individuals that had once been resident in an institution or parental home and wanted to live independently. An essential part of the pilot scheme was to ensure that relevant

training was provided for the PAs as well as peer support for the individuals receiving PAs (DFI, 2014 sec. 2.2).

The Centre for Independent Living (CIL) in Dublin was established under this pilot scheme which has influenced policy development for independent living in Ireland. When the funding for the pilot scheme had finished and the CIL were struggling financially, a group of disabled people protested outside the Dáil demanding public commitment to the initiative. The protest lasted for up to 36 hours until the government agreed to act (ibid).

The government seemed to show signs of continued support for the personal assistance programme with the expansion of personal care hours in the National Disability Strategy (NDS), although it is referred to as 'home support'. The NDS is a whole-of-Government approach to advancing the social inclusion of people with disabilities" (NDSI, 2013 p.3). It is important that economic challenges do not affect the implementation of the Disability Strategy. The Implementation Plan was devised to ensure that measures would be taken so that the National Disability Strategy would advance over the period 2013 to 2015.

An important aspect of the Implementation Plan is that it is undertaken within an ever changing external environment. These include such changes as the "public sector reform, the Croke Park Agreement, reforms within the HSE and new policy directions following key reviews" (NDSI, 2013 p.3). Such reviews include, for example, "the Value for Money and Policy Review of Disability Services, the Housing Strategy for people with disabilities and implementation of the report on closing disability institutions, Time to move on from Congregated Settings" (ibid).

3.4 Time to Move on from Congregated Settings 2011

An important strategy that was devised to promote the move to greater independence and community inclusion for people with disabilities was Time to Move on from Congregated Setting 2011. The term congregated setting relates to persons that are living in accommodation of 10 or more people. Over 4,000 people with disabilities in Ireland live in the congregated settings with many of these areas being isolated from the rest of the community and from families; with many individuals experiencing "institutional living conditions where they lack basic privacy and dignity" (Report of the Working Group on Congregated Settings, 2011p.10).

The main objectives of this report were to "develop a national plan and associated change programme for moving people from congregated settings to the community in line with Government policy" (Report of the Working Group on Congregated Settings, 2011 p.3).

The aim is to move people from the congregated setting to housing that is situated in ordinary neighbourhoods in the community. There is also the need to provide individualised support (supported needs) which help the individual to live independently. All housing arrangements for people moving from congregated settings should be in ordinary neighbourhoods (dispersed housing) in the community, with individualised supports (supported living) designed to meet their individual needs and wishes (ibid).

In the last twenty years there has been a declining number of congregated settings in Ireland due to public policy. However, the admissions of persons entering into congregated settings have exceeded those of the number of people leaving in the period 1999-2008 (Report of the Working Group on Congregated Settings, 2011p.10). Although it is evident that there has been a shift from institutionalisation to community based

care, it is clear that there is still a lot to be done as these congregated settings are still accommodating up to 4000 residents across Ireland.

Despite the government's perceived support to promote the move of residents in institutionalised care to community based care, O' Brien (2014) notes that sufficient funding has not been allocated to make this feasible. Inclusion Ireland, an umbrella organisation for people with intellectual disabilities and their families have argued that there has been "no real Government commitment to move people from these inappropriate and demeaning institutions" (cited in O' Brien, 2014 npn). Research studies examined by the Working Group showed that community-based services are superior to institutions as places for people with disabilities to spend their lives (HSE, 2011p.11). Therefore, it should be paramount on the government's agenda to provide adequate funding to ensure that suitable accommodation and support are made available to people with disabilities.

In the Time to Move from Congregated Settings Report "there is clear evidence that providing respite is a key element in supporting families to remain in their communities and avoid admissions to residential settings"(White, 2014 npn). White (2014) has noted that despite the evidence of respite care being an essential part of successful community care the present Government has slashed the grant for this provision by over a quarter. This highlights the disconnect between the Government and the real lives of people with disabilities and their families.

3.5 Individualised Funding for Persons with a Disability

In Ireland the main source of income support for persons with disabilities is provided through grant funding by the Health Service Executive (HSE). In order to ensure that funding of services and supports that are

made available to persons with disabilities were being allocated effectively the Department of Health established a Value for Money Policy Review in 2012 (VFM Review). The aim of this review was to identify the efficiency and effectiveness of disability services in Ireland which are either partly or fully funded by the state. The Review was established under the Governments programme of Value for Money Reviews for 2009-2011.

One of the key purposes of this review was to assess whether the services provided for people with disabilities were meeting their needs. It endeavours to ensure that the substantial funding that is provided to this sector is used in an efficient and effective way so that persons with disabilities receive the best sources of support that benefit their lives (ibid).

The fundamental purpose of the VFM Review is to change the approach of the "governance, funding and focus of the Disability Services Programme" (Department of Health, 2012 p.xvii). One of the significant issues highlighted for change is the move from a group based service delivery to a person-centred approach. The services that are provided for individuals need to be underpinned by a "more effective method of assessing need, allocating resources and monitoring resource use" (ibid). It recommends that organisations aim to seek the most beneficial outcomes for the service users at the most economically viable cost. The core principle of the VFM Review is to make organisations providing services for people with disabilities, which receive money from the state, accountable for the funding allocated to them (ibid).

In a bid to ensure that existing disability policy was meeting the expectations and objectives of people with a disability, an Expert Reference Group on Disability Policy was established, which was part of the overall VFM Reviews (Department of Health, 2012 p.xvii). A review conducted by this group confirmed that people with disabilities and their families "are looking, more than anything else, for more choice in the

services they receive and more control over how they access them" (ibid). This report is a fundamental step to ensuring that people with disabilities have more choice and control to one's own life.

The review also acknowledges the importance of the delivery of "efficient and effective health services and supports", which are fit for purpose and, most importantly, that are relevant to the needs of the individuals with a disability (Department of Health, 2012 p.xvii). It identified the importance of ensuring that persons with a disability are supported and facilitated to live their lives as integrated into society as possible, and as fully included citizens of the State (ibid).

Lynch (2012) discusses the importance of the Value for Money Review in relation to a move to a more person centred support system made available to persons with disabilities. It was also highlighted that this report has laid the ground work for a system of individualised budgets, which would support the process of independent living, although sufficient analysis of the most effective way of proceeding with this system would need to be carried out (Lynch, 2012).

The core principles of independent living stem from values of "choice, options, control, and empowerment" (Cunningham, et al, 2009 npa). In order for independent living to be possible for persons with a disability it is essential that both the community and the state provide equal choice in the areas of "housing, transport, education and employment" (CIL Strategic Plan, 2009 cited in Cunningham, et al, 2009 npa). One of the key ways of promoting greater choice is having control of one's own finance which can come in the form of individualised budgets.

An individualised budget is money that is provided to an individual to help them meet their needs and goals. One form of individualised funding for people with disabilities is Direct Payment, which is funding that is

paid to individuals to enable them to employ, either directly or indirectly, individuals and services to assist them with everyday tasks to facilitate their living independently (Cunningham, et al, 2009 npa).

In Ireland at present there is no right to or legislation in the area of Direct Payment which may indicate the lack of commitment by the government to promote greater independence for people with disabilities. There are several pilot programmes around the country that are promoting individualised budgets and Direct Payments which are involved in advising the Minister for Disability, Equality and Mental Health in developing policies in Ireland on the area of Direct Payments (Cunningham, et al, 2009 npa).

One of the pilot schemes that promote individualised budgets in Ireland is Áiseanna Tacaíochta (ÁT). This was a pilot scheme set up in 2010 by four individuals with lived experiences of disability. One of the leading drives for this scheme is 'breaking the historical culture of dependency on service providers, and driving a shift towards a personalised and empowering model of support that gives power back to the person' (http://www.theatnetwork.com/about-us/).

The ÁT-network is 'the "first and main organisation to facilitate Direct Payment to people with disabilities in Ireland. They represent diverse groups of people with different disabilities and different experiences, united by a common desire to direct their own lives". ÁT stands as the "intermediary between the person with a disability and the HSE to set up a Direct Payment to the person. This means that they are responsible for dealing with the HSE and negotiating personal budgets on the person's behalf." (http://www.theatnetwork.com/about-us/what-we-do/).

For this process to be successful there needs to be a shift in how society perceives disability and there needs to be a focus on developing more inclusive policies that are implemented successfully. Watson and Nolan

(2011) have highlighted that there has been a shift from the medical model of disability to a 'biopsychosocial' model of disability which understands disability "in terms of how the individual interacts with their physical and social environment" (vii) which would suggest that the society is beginning to change.

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It has been suggested that individualised funding Individualised Funding/ Direct Payment is the way forward to ensure greater control and choice for people with disabilities. One needs only look at the Direct Payment system in the United Kingdom. The 2005 Cabinet Office Strategy Unit report 'Improving Life Chances of Disabled People' described Direct Payment "the most successful public policy in the area of social care" (Cunningham, et al, 2009 npa).

Another important step that Ireland needs to take is the ratification of the United Nations Convention on the Rights of Persons with Disability (CRPD) which aims to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UN, 2006). Ireland was one of the first countries to sign the CRPD in March 2007. The CRPD reaffirms the right of every person with a disability to "self-determination, autonomy, equality and dignity" (Inclusion Ireland, 2013 p.21).

The CRPD also sets out guidelines that government and public bodies are to adhere to in order to ensure that the human rights of people with disabilities are protected. "It is the task of national authorities; national human rights institutions and civil society organisations to ensure that the rights of people with disability as enunciated in the CRPD are promoted and protected" (Irish Human Rights Commission, 2010 cited in Inclusion Ireland, 2013).

When Ireland signed the CRPD it signalled that there would be a compliance with the provisions set out in the United Nations report. However, Ireland has yet to "ratify the CRPD and is therefore not legally obliged to comply with its provisions at this time" (Inclusion Ireland, 2013 p.22). Seifu (2014) notes that it is long overdue for Ireland to ratify the CRPD. He highlights the point that John Douglas, President of the Irish Congress of Trade Unions, among others has called for the ratification of the CRPD by Ireland. It has been reported that the "Taoiseach committed to ratify the UN Convention on the Rights of People with Disabilities (CRPD) this year" (Flaherty, 2015 npn). One hopes that the commitment will be honoured.

3.6 Conclusion

This chapter has sought to set out the various polices which have been devised by government to support people with disabilities to live independently. These are often the result of pressure from bodies concerned about the rights of people with disabilities. A significant obstacle that has been faced in Ireland with regards to our disability culture is that disability has been primarily defined over the past few decades using a medical model. Although there has been a considerable shift from the medical or expert model to more of a civil rights and community model it is evident that a lot of changes still need to be made.

The movement from congregated settings to community based living is an essential ingredient of this progression. The fact that there are still up to 4000 people with disabilities living in congregated settings indicates that there is quite a distance to go. The stories of abuse in some of the large institutions and also the damaging effects of institutionalisation are further reasons for an accelerated move towards community based living. Disability policy creates "structures by which our services and supports are designed and implemented" (HSE, 2013 p.63). Therefore the policies are in place; all is needed is to put them fully into effect.

There is evidence to support the promotion of greater independence and choice as being beneficial for people with disabilities. Therefore it is essential that the government ensures that sufficient provisions are put in place to ensure that independent living is a reality for the majority of people with disabilities. Independent budgeting is a vital part to ensuring greater independence and control with particular emphasis on Direct Payment as it gives individuals more choice of the services that they may require. In Ireland there needs to be significant policy and legislation put in place with regards to individualised budgeting for people with disabilities to ensure greater equality and rights.

Chapter 4: Methodology

4.1 Introduction:

This chapter will outline the methodological approach employed in carrying out the research and will explain the principal research methods used to undertake the research. The research was carried out with the ongoing participation of an organisation called Áiseanna Tacaíochta (ÁT-network). The organisation is based in Dublin and is run by a "diverse group of people with different disabilities, united by a common desire to direct our own lives" (http://www.theatnetwork.com/about-us/). The ÁT-network supports the individuals in the company who are called leaders to have full control of their funding. In order to obtain their financial support the leaders in this organisation have to set up as an individual company so that their funding can be channelled directly to them. "These are usually a Company Limited by Guarantee, although some leaders operate as Sole Traders" (http://www.theatnetwork.com/about-us/what-we-do/). The ÁT-networks role is to facilitate the individuals with this process.

The research was also carried out in collaboration with Community-Academic Research Links (CARL) in University College Cork (UCC). CARL is an "initiative in UCC which provides independent research support to Civil Society Organisations, e.g. community and voluntary groups" (http://www.ucc.ie/en/scishop/).

This chapter will describe the chosen methods and explain why they were used for this particular research. There will also be an explanation of the method of sampling that was undertaken, with the number of participants that took part in the research also explained. Consideration will also be given to the ethical issues and challenges that arose during the research process.

4.2 The principles of participatory research

According to Blaikie (2000 p.160) "a theoretical perspective provides a particular language, conceptual framework, or collection of 'theoretical' concepts and related propositions, within which society and social life can be described and explained". The approach that was chosen to guide the process was participatory research. Participatory action research is characterised by the strong commitment to a research topic by the organisation or communities in the research process (Whyte, 1991 cited in Sarantakos, 1998 p.8).

It has been argued that disabled people and radical disability theorists have rejected the notion of individualistic and personal tragedy models that are used by interpretive research paradigms (Stone et al, 1996). Disability activists have had more difficulty with positivist approaches because of the assumptions embedded in this approach about the relationship between the researched and the researcher. Instead, disability is seen through a social lens; the new epistemology of disablement is understood through social relationships. The disability is created by a "disabling environment and disabling attitudes", (UPIAS, 1976 cited in Stone et al, 1996 p.701) which are "socially constructed and culturally, produced", (Oliver, 1990 cited in Stone et al, 1996 p.701) and which in turn cause a "form of social oppression" (Abberley, 1987 cited in Stone et al, 1996 p.701).

Participatory research aims to break down the barriers that may be faced by the researcher and the 'researched', and strives to create a positive experience of the research process for all parties involved (Ormston et al 2014). In more recent years there has been a shift to a more 'user led' approach from the

more conventional user involvement which is where the persons being researched were involved in some aspects of the research but were not involved in the direction of the research(ibid).

A similar methodological approach to participatory research is emancipatory research in the context of disability which focuses on the "environmental, cultural and social barriers that exclude people with an accredited impairment from mainstream society" (Barnes, 2008 p. 8). Oliver (1990) highlights an important aspect of emancipatory research as being the emphasis on the significance of the knowledge and experiences of disabled people to guide the research (cited in Barnes, 2008). Lynch (1999) describes the importance of emancipatory research as an approach that is "analytically, politically, and ethically essential if research with marginalised and socially excluded groups is to have a transformative impact" (p.41).

4.3 Methodological approach: qualitative research

To gain a more personal insight into the experiences faced by people with disabilities I used a qualitative methodological approach. "Qualitative research is based on the theoretical and methodological principles of interpretive science" (Sarantakos, 1998:313). Qualitative data collection, via semi-structured interviews, was the principal method used in this research study. This method of data collection refers to 'descriptive characteristics rather than numerical measurements' (O'Leary, 2007:214).

Qualitative methods are 'especially interested in how ordinary people observe and describe their lives' (Silverman, 1993:170). An important aspect of this research was to obtain an insight into the lived

experiences of persons with disabilities with regards to direct payment in Ireland. The aim was to get a greater understanding of the importance of having control and receiving one's own financial support and how it can impact on the everyday lives of persons with disabilities.

4.4 Using a Case Study Approach

This study involves a case study of members of one particular organisation in Dublin called Áiseanna Tacaíochta (ÁT-network). A case study allows the gathering of information of persons' experiences and attitudes on a particular subject (Yin, 2009). The case study design was relevant to generate knowledge from a small but socially significant group of persons with a disability in receipt of direct payments in Ireland (Creswell, 2007).

The key characteristic of this case study design is a social unit, which would be the ÁT-Network (Payne & Payne, 2004). Kumer (2005) suggests 'through intensive analysis, generalizations may be made that will be applicable to other cases of the same type' (p113). Using a case study approach was hugely beneficial in identifying key issues which relates back to the secondary research that was carried out.

4.5 Methods of research

The qualitative data obtained through individual interviews enabled 'the researcher to change words or order and adjust the interview so that it meets the goal of the study' (Sarantkos 1998:255). As the participants in the interview process varied in age, sex and ability it was important that the questions in the interview would suit all individuals. The individual interviews were digitally recorded and transcribed verbatim with the permission of the interviewees. Measures were put in place to anonymise the data and treat it confidentially. For the purposes of privacy.

4.5.1 Semi structured interviews

I used a semi-formal interview process which helped to guide the conversation of the interview (can be seen in Appendix 5). It also allowed openness for new themes to emerge during the interviews and it gave the individuals the opportunity to take control of the topic being discussed. The questions devised for the interview process were done so with the main objectives of the research in mind. The questions aimed to get an insight of the process that was involved in obtaining Direct Payment as well as the experiences of that people had prior to and after receiving DP.

Qualitative data methods provide in-depth accounts of the participants' interpretations of the research questions by inductive procedures (Payne and Payne, 2004). Qualitative methods are 'especially interested in how ordinary people observe and describe their lives' (Silverman 1993:170). I conducted qualitative data collection in the participants' home via Skype or telephone and I also interviewed three participants face to face in the ÁT network in Dublin. This type of research process aims to 'make sense of or interpret phenomena in terms of the meaning people bring to them' (Denzin & Lincoln, 1994:2).

4.6 Developing purposeful sampling

A meeting was held with the researcher, ÁT-network, the supervisor of CARL, and the researcher's supervisor. A decision was made that individual interviews would be conducted with persons that were in receipt of Direct Payment within the support network of the ÁT-network. It was agreed that eight individuals would be interviewed, six of whom had a physical/sensory disability and two of whom had an intellectual disability. I interviewed a total of eight individuals one of whom had an intellectual disability.

In order to gather suitable participants for the interview process, purposive sampling was undertaken. This is where the researcher can "purposely choose subjects who, in their opinion, are thought to be relevant to the research topic" (Sarantakos, 1998 p.152). Purposeful sampling was the most relevant type of sampling for this research as the research is based specifically on individuals with a disability that are in receipt of direct payments in Ireland.

Purposeful sampling ensured that participants were suitable to make a contribution to the research topic. The participants for the interviews were chosen by the ÁT- network each of whom was a member and in receipt of direct payments. This type of sampling allows the research to be undertaken with people who have first-hand experiences of the process involved with obtaining direct payment in Ireland. It is similar to the process of qualitative data collection, using specific participants, because 'they are not typical: they know more about the topic, [living with a disability] than other people' (Payne & Payne 2004:210).

4.7 Table of participants

Gender	Physical disability	Intellectual disability	Rural area/town	Urban area/suburbs	Age 10-19	Age 20-29	Age 30-39	Age 40-49	Age 50 +
Male	6	1	2	5	1	1		3	2
Female	1		1						1

4.8 The research process

The topic of this research was devised in collaboration with the Át-network, CARL and myself (see Appendix 1). A meeting was set up to discuss what the aim of the research would be and what could be achieved in the available time frame. The research was undertaken through a participatory action which aims to break down the negative power imbalance barriers that can be present between the researcher and the researched (Ritchie et al, 2014). It is important that participatory research would take place from the outset and that the people being researched have an important role in "shaping or creating the research topic, questions and design" which was evident in this research (Ritchie et al, 2014 p. 68).

The research began when I contacted CARL in UCC on the 13th of November 2014 and discussed my interest in researching the topic in the area of individualised funding for persons with a disability. The coordinator of CARL contacted the ÁT-network and then arranged an interview with me to discuss what would be expected from the research process. I then began the secondary research which is information gathered from already published material (Sarantakos, 1998). This allowed me to gain a greater understanding of the various types of individualised funding and supports available for persons with a disability in Ireland.

A meeting was set up between one of the founders of the ÁT-network, the coordinator of CARL, my research supervisor and myself to discuss the research topic. During the meeting with the ÁT-network the main aims and outcomes that they hoped would be achieved through this research were outlined. With the information gathered at the meeting and my own research in the area of personalisation and individualised funding I devised a list of research questions. These were forwarded to the ÁT-network

and with the feedback the research objectives were reconstructed. The same process was also done with the questions for the interviews.

It was agreed that I would keep in regular contact with the ÁT-network throughout the research process to ensure that there was a consensus between both myself and the ÁT-network with the direction of the research. In the meeting it was also agreed that I would interview eight individuals from the ÁT-network, six of whom had physical disabilities and two of whom had an intellectual disability.

The purpose of the interviews was to get an understanding of the individuals' experiences in trying to obtain their personal Direct Payment and if they were happy with the outcome. I interviewed eight individuals in total, seven of whom had a physical disability. There was also one individual that had an intellectual disability. Due the age of one of the participants a parent took part in the interview on behalf of her child. There was a limitation in gaining a personal insight of the experiences of that individual in relation to obtaining Direct Payment. However, getting a parent's perspective on the benefits of DP for their child was very relevant to the research.

Due to the fact that the ÁT-network was based in Dublin many of the members were living in the Dublin area so many of the interviews were carried out using Skype (video calls) and through the telephone. One of the members requested to fill out a questionnaire so I sent the interview questions (see Appendix 5) and received the replies through e-mail. I did however, travel up to Dublin on one occasion to conduct face to face interviews which I did with three of the members.

Prior to proceeding with the interviews I sent each of the members an email explaining what the research was about with a consent form attached (see Appendix 4). As I was not able to meet all of the members face to face to sign a consent form I had asked them to send me an email stating that they did consent to the interview. It was also highlighted that the information that they were giving during the interview process was to be used in the final research project.

4.9 Research Ethics

Gomm (2004: 298) defines research ethics as "rules of morally good conduct for researchers" such as doing no harm, maintaining privacy, ensuring informed consent. There are different sets of values upheld within different groups of researchers. Qualitative research needs to ensure that what is being claimed in the research is supported by authentic sources and is not solely influenced by the researcher's views or values (ibid). However, one must realise that the researcher's position/viewpoints do influence how the research is undertaken.

In relation to the interview process issues such as anonymity were addressed sensitively and respondents were informed that any information they provided would be treated confidentially. Bell (2010) notes that 'confidentiality' may not necessarily mean the same thing from one person to the next, so it is imperative that it is clearly explained from the outset how this will be attained. In order to ensure confidentiality the identities of the participants will not be disclosed and this was stated to the participants before the interviews commenced. It was however, explained that the research may be used by the ÁT-network, but that the information given in the interviews would be used solely for research purposes.

I wanted to provide a safe and trusting atmosphere during the interviews. Therefore, I felt it was important not to make the interviews too formal, in order to encourage the participants to engage freely with the interview process.

4.10 Challenges

One of the key challenges that I faced in carrying out the research was the geographical distance that the participants lived from where I was based. I did manage to get to Dublin on one occasion where I got the opportunity to conduct three face to face interviews in the ÁT-network building. During the last interview the memory on my recording device became full, so I had to do a lot of writing during the interview, of which I was conscious, although the interview went well.

The participants were selected solely by the ÁT-network. However, I feel that it may have been beneficial to find participants that were in receipt of direct payments without the support of the ÁT-network or who were not in receipt of direct payments. It would also have been beneficial to the research if I had been able to interview persons involved in granting the funding to individuals but I did not have sufficient time.

Initially I was meant to interview two individuals with an intellectual disability; however, only one participant was available. The interview was carried out with a parent, rather than the individual themselves. Whilst the information I gathered was very beneficial, I feel that it would have been useful if I had been able to interview an individual with an intellectual disability. Another issue with the client profile was that only one female in receipt of Direct Payments took part in the interview. I feel it would have strengthened the findings if there was a more diverse range of individuals.

4.11 Conclusion

This piece of research was done through a participatory methodology with the involvement of the participants being paramount to the research process. The ÁT-network was involved with the formation of the objectives for the research which ensured that the research questions for the interviews were relevant to what needed to be researched.

This research carried out was done using qualitative research which focuses on the lived experiences of the persons that are being researched. Interviews were carried out in order to get a greater understanding of the experiences that individuals have had in obtaining Direct Payment. This chapter sets out the steps involved in this research and outlines the ethical issues and challenges that arose.

Chapter 5: Findings and Discussions

5.1 Introduction

This is the first of two chapters that set out the findings and analysis of the research study on persons with disabilities in receipt of or in the process of receiving Direct Payment in Ireland. They will be structured in a way that will highlight the themes that emerged and recurred during the interviews. The next chapter will focus more on the life changes that have been experienced since obtaining DP. The main themes that will be explored in this chapter are the respondents' experiences of financial support prior to receiving Direct Payment. The chapter will also identify some of the challenges that the respondents may have experienced such as getting information about, and the process of, obtaining Direct Payments. Another theme that emerged was the experience of having to manage and employ Personal Assistants. This chapter aims to highlight the significance of the support that the ÁT-network has provided to individuals that are in receipt of or in the process of obtaining Direct Payments. In order to retain the anonymity of the participants in the interview process I will identify them by using pseudonyms such as P1, P2 and so on.

5.2 Participant Profile

As outlined in the methodology chapter, eight individuals took part in the interviews, each of whom was contacted by the ÁT-network prior to their information being passed on to the researcher. The age profile of the participants ranged from 12 years to 64 years. The mother of the 12-year-old took part in the interview on behalf of her child. There were diverse types of disabilities among the participants such as physical, sensory and intellectual. The majority of the participants live in the suburbs of Dublin city; one

lives in the suburbs of Galway, another in a town in Limerick, another in a town in Clare and finally one individual was living in a rural area 6 miles outside a small town. The longest time that participants have been in receipt of Direct Payment has been up to four years with one participant being in the middle of the process of receiving his payment. The average time that respondents have been in receipt of their payment ranges from one-and a-half years to two-and-a-half years.

5.3 Experiences of financial support prior to receiving Direct Payment

One of the key elements that was noted throughout the interviews was the drive to obtain Direct Payment due to the lack of control, choice and input that individuals had in relation to their supports. Participant 3 (P3) noted that very early on in the care package that was provided to him, he and his family knew that it was not working for them. The funding for his care was given to an organisation that then provided care for him "whatever way they deemed best practice". He was not involved in the organising of care provided and stated that there "was not a lot of communication between us and the company" providing the care.

The support that P8 received prior to Direct Payment was Personal Assistants (PA) under an organisation which allowed him to choose his own PA. He noted that he was happy enough with the choice of PAs available to him until for whatever reason the organisation decided to change their policies. This meant that he was only able to choose PAs from a panel that the organisation set up. He noted that even though he was not happy with this "I could have lived with that…….except for my speech……It is hard for most people to get used to my speech but it is all the more difficult for people whose first language is not English". He explained that the organisation "gives you four weeks to see if the PA is suitable; then a fixed term contract is given". It was at this time that he felt "enough is enough" and he decided to go

down the route of Direct Payment. For him, the benefit of DP is "the possibility of employing all part-time PAs" which he feels will give him more security. If a person cannot come for whatever reason then having a number of PAs working part-time gives him more choice to call on someone else "who is accustomed to my speech".

Prior to receiving Direct Payment P4 explains that initially he was on a Supported Package with an organisation which gave him little or no control over who came to his home to support him or when that person would call. He then moved to a Self-Directed Package under the umbrella of the same organisation which allowed him to hire PAs that matched his needs. As he noted"…..the quality of my service improved dramatically". This gives an indication that organisations are trying to provide more avenues of support in a bid to give service users more choice and control which is one of the remits of the Value for Money Policy Review in 2012 (VFM Review). Recently however, the organisation insisted on only hiring PAs with a FETAC Level 5 Certificate which, he suggested, made the choice of PAs "extremely limited". He does not believe that the service he requires would benefit from PAs having a certificate, which he found frustrating. Although it could be argued that it is important that service providers are certified to provide care, it is however limiting the control that the individual has in choosing whom they want to provide their support.

P4 explains that as a result of this new measure the Self-Directed Package has "become diluted and the independent ethos has been chipped away at, to the point of almost non-existence". Therefore he notes that "Direct Payment Service is ideal for my service plan". A really thought-provoking point that P4 expressed was the importance of being able to choose the PAs that are most suited to one's own personal situation. He stated that Direct Payment allows him to "hire those who do not have a devotion to the disability sector, thereby breaking down the barriers between disabled and able-bodied people". This is

an important point that reflects back to the concept of 'them' and 'us'. I believe that this relates to moving away from the traditional caring role that has been generally used within support services for people with disabilities. It means moving to a system that creates equality between the person being supported and the persons who is there to support. Crow's (1996) suggestion that the "disabling social, environmental and attitudinal barriers" that restrict an individual are more influential and debilitating than the impairment itself (p.3). P7 discussed her experience of a PA that came from a nursing background. She thought that she was a very nice person; however, she felt that she was treated "like a child and I am very much not that". This can be a recurring issue that people face both in institutions and in home care.

It was highlighted by P7 that, since she lived in a rural area the HSE were having problems finding personal assistants to provide her care. The HSE had agreed that if she "found somebody they would pay ….. a Direct Payment". The issue with this was that there was no insurance or back up, which she conveyed to the HSE to no avail. When she heard about the ÁT-network she describes it as "pure luck". The ÁT-network acts as a broker for her and within two weeks of getting in contact with them they had her insurance set up. It was not an issue for the HSE that this was being done through the ÁT-network; instead she stated that "it was a solution for them".

During the interviews one of the most significant aspects of receiving Direct Payment identified was the power of being able to choose by whom and what times their care support was provided. Prior to receiving Direct Payment, P7 stated that there was a lot of change of staff; "with new people coming into the house, I felt that I had a spy in the house". This was not due to the staff that came into her home but due to how concerns raised to management were dealt with and she felt that reports were "translated very differently" by management. P4 also noted that she "didn't feel secure at any time until I started with the ÁT-network", because then she had control of who and when staff were to come into her house.

P6 discussed how prior to receiving Direct Payment the support that was initially offered by the HSE for her family was home help which involved someone coming into her home to help with the cleaning. She went to the HSE to explain that this was not the help she needed and requested to change companies as the supports that she required for her family were speech and language therapy and teacher support. This request was initially denied. However P6 noted that on returning to the HSE the "disability manager went on maternity leave……and this other guy said "'yeah no problem' we could change" company. This support went on for about three years when she decided to look into the possibility of individualised funding. She noted that she would not have gone down the route of individualised funding if they were "getting regular occupational therapists and speech and language therapists".

5.4 Awareness of and access to direct payments

5.4.1 Information available on Direct Payments

It was highlighted throughout the interviews that information on Direct Payment in Ireland is not made readily available by the HSE, with the onus of gathering information being left mainly to the individual. P7 discussed the difficulty in trying to find out the relevant information in relation to the care that she should be expected to receive. It was noted by P6 that she "would not have gone down the route of individualised funding if the HSE had been working".

The majority of recipients that took part in the interview process had to seek the information on individualised funding themselves with no/little support from the HSE. It was argued by P2 that "the HSE could have been better …they are not good for giving advice". He also felt that the HSE "don't want it known (Direct Payment) because more and more would look for it". It was a recurring theme that individuals felt that they were lucky to have heard of the ÁT-network, and there was a general

consensus that the ÁT-network provided a good sense of support in the process of gaining Direct Payment.

P3 notes that with the initial step to obtaining Direct Payment "we were quite apprehensive at first". However the ÁT-network insists that you have a network of support with at least seven individuals". In essence he was "building a foundation of a company" which required a "fair bit of organising at the beginning". P3 also highlighted that a person "would have to be fairly motivated to take this on in the first place" and that one "can't have enough information".

5.4.2 Access to Direct Payment

Moore (2012) identifies that the level of payments that a person receives has a significant influence on how and whether individuals obtain a fair level of care in the market for 'social care'. This was evident when P7 made it very clear that the hours allocated to her by the HSE have made her "excluded from social inclusion" and she has felt "isolated for the last four years…. reliant on my carers".

The majority of the participants were using their Direct Payment for the hiring of personal assistants. However, in one case it was used for professional therapies such as speech and language to support the development of the individual in receipt of the payment. Since receiving this support however, P6 feels that the "HSE are still trying to dictate". The HSE "don't want the funding to be used on therapies even though I know that it is what is best" for her situation. This relates back to Barnes' (1997) observation on the idea that the market based model in relation to community care does not guarantee more choice on a diverse range of services. In fact he notes that this is more often than not an illusionary idea (cited in Askheim, 2010).

5.5 Challenges experienced in obtaining Direct Payment

5.5.1 Setting up as a company

One of the key challenges that was highlighted during the interviews was the daunting prospect of having to set up as a company in order to receive one's Direct Payment. For many however, the process was made easier through peer support. The ÁT-network insists that before proceeding with the Direct Payment model one must have a support network of seven individuals. The ÁT-network supports the individuals with this procedure and recommends that individuals get persons in their own community to be in the circle of support.

Participant 8 noted that he included people in his circle that have had previous experience in setting up a company. However it is up to each individual whom they have in the circle. Once the circle is set up the ÁT-network contact the HSE to arrange the Direct Payment. The ÁT-network provides support for the administration work. However, a few of the participants have opted to do the administrative work themselves to save money. Once payment has been set up the individuals have to give monthly reports to prove how the money was spent and then quarterly returns have to be sent to the registration office. P7 highlights that one of the key difficulties that she experienced was with the Revenue forms but notes "there is someone there to help (ÁT-network)". P4 explains that "there is a lot of paperwork to keep on top of; the rewards are more than worth it". Although the idea of setting up a business may have been daunting at first each of the participants has had positive experiences.

5.5.2 Availability of Personal Assistants

In chapter 2 Power (2011) highlights the point that one of the key supports that enable people to integrate into society is the access to one's own finance which provides greater power of choice. This concept was reiterated among the majority of participants on a number of occasions during the interview process,

although it was noted that the concept of choice is hindered by the lack of personal assistants available, particularly in rural areas. It was highlighted by P3 that one PA "had to drive one-and-a-half hours" to work for just a few hours which does not tend to be sustainable.

However not all participants were unhappy with the choice of PAs in their area. P4 noted that he would generally hire local students as "it is easy for them to come into me (especially during bad weather)……..It also means that they usually stay with me for a few years". Contrary to this example P7 feels that once PAs get Fetac Level 5 courses "they leave agency work and go do twelve hour shifts where they can earn more money with less travel". The availability of PAs seems to depend very much on geographical influences.

5.5.3 Hiring of Personal Assistants

It was highlighted by a few of the participants that a significant barrier that they experienced was the difficulty of recruiting PAs, which P2 noted as being "very difficult at first …….. got easier through experience". During this process he felt that there was "a lot of personal growth" but at the same time you are very much "on your own". P3 felt that the process of "hiring people was very daunting"; however, the ÁT-network and "other people in my support network advised what way to go about hiring staff". Prior to receiving Direct Payment P3 stated that up to "twenty-eight people came working in our house over a three year period". Although the hiring of staff may be daunting, P3 believes that "it removes the feelings that you are being looked after….. you are in charge……. you have a job to do".

5.5.4 Issues of accountability

Power (2011) makes an important observation in relation to Direct Payments, which notes that with this system, the service recipient becomes the consumer/employer of his/her supports. The power dynamics between the service providers and the users shift from "provider-led services to an independent life in the community" (p.9). The shift of the balance of power relations between the service user and the provider was certainly evident during the interview process. P7 explains that since having Direct Payment it has meant that "the girls' loyalties are to me, I am the employer …….we sort things out between ourselves so there's flexibility", which had not been the case while the care was being provided by the HSE. This raises concerns however, about employment practice and being as a good employer which is putting more accountability on the individual in receipt of Direct Payment.

P3 explains that since receiving individualised funding he has begun to do the administration work which allows "more money to be put into my support package". One drawback that P3 identifies however, in relation to DP, is that you are "limited with what you can use finance for" and in his situation it is solely used for PA support.

It was noted by P1 that "as we go forward into the future, I don't think everyone needs to have a company" in order to receive Direct Payments. He gave the example of the UK where "nobody needs to have a company" to receive their payment. Davey (2007) identifies that there was up to 80% take-up of the direct payment schemes in the UK when the sufficient supports and provisions were put in place. It was also acknowledged by P1 that the ÁT-network is there because it "is a way around the problem……in an ideal world you would not have ÁT at all". He feels that a lot of people "would rather if the HSE would just pay people directly" and at present the money is going from the "HSE- ÁT – ÁT – Company" therefore the ÁT- network is acting as a broker.

To conclude it was identified by participants that the HSE are not ready as of yet to go down the route of Direct Payment. P5 notes "the HSE are not geared to go individual yet". He also explains that the ÁT-network has a role "to give comfort and education to the funders" which relates to the HSE's reluctance to moving to individualised funding. The ÁT-network aims to demonstrate that "actually they can get better value and the individual will get greater flexibility". It does seem like a win, win situation; however it is essential that the right supports are put in place prior to policies being adopted for Direct Payment.

5.6 Conclusion

This chapter discussed the different types of support that individuals were receiving prior to obtaining Direct Payment. It was also evident that one of the key reasons that individuals went to seek individual funding was due to the lack of control and choice of one's support. An important finding that was evident through the interview process was the significance of being able to choose with whom and at what times a person receives their support. One would think that it should go without saying that if a person were to come into the home to support an individual with daily activities then it should be up to the person receiving the support to decide when this happens. However, this was not evident during the interviews with many saying that they had little or no involvement in the organising of their support plan prior to receiving Direct Payment.

There was a recurring notion that one of the key barriers that deters persons from going down the route of individualised funding is the lack of information available. It was also mentioned that if one were to go through the process of receiving Direct Payment in Ireland through the ÁT-network one would have to be very determined and dedicated. It was highlighted that although there was a lot of support provided

in the process of setting up a company it was still quite a daunting experience. Individuals felt very much on their own with a lot of extra responsibilities being left to them. A number of the individuals found the process of interviewing and hiring PAs challenging at first; that became easier with practice.

The main objective of the ÁT-network is to facilitate Direct Payment for persons with disabilities in Ireland. It was noted during the interviews by one of the founders of the ÁT-network that the organisation exists due to the simple fact that there was a need for something to be put in place to work around the problem that exists within the disability sector. It was also highlighted that in an ideal world there would be no need for such an organisation to exist and people would be able to access their individual financial support without having to set up as a company. This does not stand out as an outrageous notion; on the contrary it seems like a very basic and fundamental right.

Chapter 6: Findings of experiences after receiving Direct Payment

6.1 Introduction

This chapter is the second part of the findings and analysis section and aims to examine life experiences after receiving Direct Payment. One of the main objectives of this research was to gain greater understanding of how people with disabilities experience individualised funding supports. This was done so through the input of individuals who are in receipt of or in the process of obtaining Direct Payments. It also aims to identify the significance of the ÁT network in relation to the process of receiving Direct Payment. This chapter focuses on the significance Direct Payment has had on the lives of the individuals that took part in the interview process.

One theme that has emerged during the interviews was the concept of greater control and choice in relation to one's own support. This links back to Chapter Two which identifies the concept of personalisation which focuses on community based support with an emphasis on inclusion and participation. Another theme that emerged was the idea that Direct Payment has provided greater value for money for the respondents. This will be examined further in this chapter. Finally an important theme that was also evident was how Direct Payment has influenced how individuals can participate in society and gain a greater sense of citizenship.

6.2 The concept of personalisation

6.2.1 Gaining greater Independence

As identified in Chapter Two the notion of personalisation focuses on community based support with an emphasis on inclusion and participation. McConkey et al (2013) discuss the concept of personalisation as an individual being actively involved in the planning process of the support that is being provided. This gives an individual the opportunity to identify their strengths and abilities rather than solely focusing on their needs and disabilities. This notion was evident throughout the interview process. P3 stated that receiving DP has given him far more independence in his life. He also notes that "what I have been able to achieve in the last nine months has been unthinkable to where I was two years ago…… so it has definitely given me a lot more control". It has given him the opportunity "to go out into the community more and has encouraged me to be more independent".

P2 notes that having greater control over the hours that your PA comes to you has helped him "to participate in society". An important part of being independent is being able to experience both good and bad parts of being in control of ones choices. P4 made an interesting point about one of the key benefits of Direct Payment, which he expressed in the following way: "freedom to make our own choices, and to fail. Let us fail if need be. By failing, we can learn from our failures. If we do fail, do not blame it solely on our disability. We are only human after all". This is an important point that may be forgotten in many areas of the disability sector.

6.2.2 Greater value for money

Prior to receiving Direct Payment the funding for P3's support was given to an organisation, but once they received the money for his support a percentage of the funding was used for administration purposes. An important aspect of Direct Payments is getting the best value for money for the support that is required. It was highlighted by P6 that prior to receiving Direct Payment "the HSE were paying a company…….. we were losing one-third of it (finance)" by the time they received the supports required. Now she feels that "we are able to get more bang for our buck" which has increased the hours of therapy that her son receives.

Participant 7 explains that she has far more choice in relation to PAs since receiving Direct Payment but she is still experiencing inequality due to the lack of hours allocated to her under the HSE. She feels that the hours she is given "are totally subjective" which resulted in her having to "supplement my package in order to have someone to cook for me". She has repeatedly asked for support to go shopping but can only get one hour a week which is not a lot if you include travel time. "I can speak out about it but I am sure that there are many who can't".

P4 is also doing his own administration work which gives him extra money to use for extra PA hours. "I get to choose when I have my PAs work…….. I get to select my PAs pay rate; I like to pay my PAs as much as possible on Sundays and Bank Holidays. This way, they do not mind working on these days".

At present individuals have to prove every month that the money they receive was used for purpose. P1 pointed out that "it is in my interest to make sure that my money is being used well…….. If I spend

foolishly I can't get out of bed in the morning ….. it's not in people's interest to let money go missing". He states that one day he hopes that Ireland will have a system similar to the United Kingdom.

6.2.3 Greater control of supports

As identified in Chapter Two "Internationally there is growing evidence of how personalised supports allied with greater opportunities for community inclusion can improve the quality of people's lives" (McConkey et al., 2009, cited in McConkey et al, 2013 p.9). This was evident when P4 explained that since receiving Direct Payment he "can plan PA hours with a lot more ease…… In the summer, I can use more of my PA hours to go out. I can attend events with the ease of knowing that I don't need to cut my valuable PA hours on another day". Personalisation relates to the individualised and personalised supports tailored to meet the specific needs of an individual which is clearly beneficial to the lives of the participants.

P3 highlights that Direct Payment allow him to "direct and dictate what kind of way my hours of support are managed…….you are in charge, you have a job to do". P5 explains that since obtaining DP "I'm no longer somebody who is just being cared for" he is now the employer of his support. It was noted by P6 that DP has given them the opportunity and "ability to seek out and find the best people to work with us". However as P3 stated "it is up to you to make it (DP) work to the fullest.

6.3 Active Citizenship

Active citizenship was defined in Chapter by disability scholars as a "process of proactive engagement" in society in which 'differentials of power' are acknowledged and addressed (Beckett, 2005 cited in Bartlett, 2013 p.1). Although there has been significant progress in the development of services for

people with disabilities in Ireland, they are still a relatively marginalised group in society. As regards to the findings the important of ensuring active citizenship relates to the opportunities that the participants have in relation to their participation in society. This section will focus particularly on education and employment.

6.3.1 Education and Employment

As highlighted in Chapter Two Quin (2003) noted that educational disadvantage in the area of disability is an early determinant that can affect the ability of disabled people to achieve "economic participation in society" (p.4). Failure to provide adequate education has a knock-on effect in relation to entering into the labour market and obtaining meaningful work.

This concept relates to comments made by P6, who noted that "when you move to special education you no longer get supports in the community". She explained that prior to receiving Direct Payment for her son he was receiving "6 hours speech and language in school per school year" while now "we are getting 46 hours per year (1hour per week)". She notes that she can "see the benefits of the extra therapy that he wouldn't have got…… I feel I can take my foot off the brakes". P6 highlights that although she knows that the extra therapies are what is best for her son at this time and she can see the difference it has made to him she feels that "the HSE don't want the funding to be used on therapy". Although she is getting the funding now the HSE were apprehensive at first, maybe due to the lack of knowledge of Direct Payment or the lack of procedures put in place to allow for Direct Payment.

As mentioned in Chapter Two Quin et al (2003) note that the potential to obtain full citizenship for persons with a disability is undermined by factors such as unemployment. A number of the participants that took part in the interviews are not in paid employment However, there was a recurring notion that

being involved with the recruitment of one's PAs was a very fulfilling and purposeful role. It allowed individuals more control and choice over whom they received support from. P3 felt that since receiving Direct Payment it has brought far more independence and control back into his life. "I went from being an unemployed disabled person at home to taking on the running of a company hiring five staff".

An important aspect of active citizenship is for one to have control of where one lives. As outlined in the third chapter Sims and Gulyurtlu (2014) discuss how, although persons with disabilities may have the same entitlements as other citizens in society they may not always have the same opportunities, such as employment or housing. This is evident in relation to congregated settings where the individuals do not get to choose where or with whom they live. Since the Time to Move from Congregated Settings Review in 2012 there has been an incremental shift to more independent living. P1 made a very interesting point in relation to the transition stage from congregated settings to independent living. He noted that although "there seems to be resources, however the people will be lacking life skills ……. they are set up to fail".

P1 also explains that the individuals have not had the proper opportunities to experience the value of money. He provided an example of a young child given a small amount of money to buy something in the shop; here, they get to learn what they can buy with the amount of money they have. This skill is not learnt overnight, but rather is a continuous learning experience that people who have been in long term residential care often miss out on. Therefore, he explains that it is not enough to transition individuals into independent living without the essential life skills; so the sufficient supports need to be provided, otherwise these individuals "are set up to fail".

6.4 Challenges of obtaining Direct Payment under the Current System.

There was a recurring theme that the overall the process of obtaining Direct Payment was a positive experience that creates greater choice and control for all individuals in receipt of the payment. However, there were some disadvantage to the current system that were highlighted which could deter an increasing take up of this individualised support. As mentioned in the previous chapter the availability of PAs can be limited particularly in rural areas. This could be a deterrent for some individuals to go down the route of DP as the onus of getting a PA is solely on the individual.

6.5 Conclusion

This chapter outlines the impact that receiving individualised funding has had on the lives of participants in this research. There was a recurring theme that having access to one's own funding brings with it greater choice and control in many aspects of their daily lives. It was identified that since receiving Direct Payment individuals experience far more independence in their lives. An important point that was made in relation to independence was the chance to experience mistakes and to take chances which many able bodied people take for granted. This is a concept that may not usually be an issue of concern in relation to policy making; however it is an important aspect for individuals to experience 'normal' lives.

A significant advantage of receiving Direct Payment which was identified in this research was greater value for money for the recipients. Individuals expressed that they were able to receive a lot more hours of support which is invaluable to the quality of their daily lives. One of the most important parts of receiving DP was the ability to have the control to choose with whom and when an individual received their support. The process of obtaining DP has generally been a positive experience for the participants

with the main drawback being in relation to having to set up as a company. However, it has been expressed that there has been good peer support that has made the process easier.

Chapter 7: Conclusion

7.1 Introduction

This is the final chapter which will summarise the thesis and will outline the findings of the research. It sets out the keys themes that were examined in the literature and policy chapters. It will also identify a link between the findings to the relevant literature. It will conclude with recommendations.

7.2 Key Findings and Discussion

For this section I will relate back to the initial objectives outlined in the introduction chapter. The overall aim was to get an understanding of the individual experiences of people with disabilities in receipt of or in the process of obtaining Direct Payment. The research objectives aim to examine how people with disabilities experience individualised funding supports and how it affects their lives. The barriers which face people with disabilities accessing their own financial supports were also highlighted in the findings. Finally the research aimed to get a greater understanding of factors that support the development of individualised funding supports for people with disabilities.

An important aspect of the development of greater inclusion for people with disabilities within Irish policy is the gradual move from a medical model to a social model of disability. This means that there is less emphasis on the impairment that an individual has and more focus on making society inclusive. An example of where this is evident is in the Disability Act 2005 where provision is made to ensure that public places and amenities, such as buses and public buildings, are accessible to all.

Irish society has become far more inclusive of people with disabilities in the last twenty years. However, there is still a lot more that can be done to ensure that all individuals have equal rights and choices. The

independent living movement draws on the social model of disability and focuses on the autonomy and dignity of the individual. There needs to be a general understanding that independent living does not mean one must live fully independently. One can still be dependent on others yet have the capability of choosing what is best for them as an individual.

Another important aspect of greater independence for people with disabilities that has been discussed in this research is the concept of personalisation. This relates to the individualised and personalised support packages tailored to meet the needs of individuals with disabilities (McConkey et al, 2013). The result of this means that there is more focus on the specific needs, goals, likes and dislikes of every individual with a move away from a 'one size fits all' approach. An important aspect of personalisation is a model of Direct Payment. This allows individuals to have far more control in their lives and it allows them to personalise their own support package and also provides great independence.

The importance of having control over one's support was certainty evident during the interview process. Direct Payment has given the participants greater choice as well as greater value for money. Through the Direct Payment model individuals experienced far more flexibility with their hours of support and they could use the hours more affectively to meet their personal means. An important aspect of the process in obtaining DP which was identified during the interviews was peer support. The ÁT-network insists that individuals have a circle of support of seven persons prior to applying for DP which is an important aspect for individuals to ensure that they do not need to go through the process of setting up as a company alone.

The basis of this research has highlighted the key benefits of Direct Payment for individuals with disabilities. It is evident from the findings that there is significant need for policy to be changed to

emphasise a move towards Direct Payment. There was strong evidence that indicates that Direct Payment increased the individual's independence, choices, and control in their daily lives. Having control of one's support needs seems to be an essential part of a person's well-being.

7.3 Recommendations

1 The most important and clear recommendation that has been identified through the research is that adequate policy needs to be put in place to give individuals the choice and opportunity to take control of their support. This can be done through Direct Payment which gives individuals the opportunity to choose with whom they receive their support. However, it is crucial to ensure that adequate safeguards are put in place to ensure that individuals are not exploited. At present the number receiving this payment is quite low; however the research identifies that persons in receipt of this payment have had positive experiences.

2. Relevant information needs to be provided for individuals to make informed decisions to ensure that Direct Payment is suitable for their situation. Also what is imperative is that the information is easily accessible and easy to read so that individuals get a clear understanding of what Direct Payment entails.

3. If policies were put in place for a Direct Payment system it would be vital to provide adequate training for individuals on how to manage their financial affairs independently in any case where that may be necessary.

4. For the successful implementation of a Direct Payment system it is imperative that large scale organisations such as COPE Foundation and the Brothers of Charity who support people with disabilities

adopt such an approach. Organisations need to provide relevant facilities for clients within these foundations to avail of Direct Payment. In this way the clients both the freedom to make their own choices while still having the support of the Organisation. This would be a further step towards moving away from congregated settings. First of all there needs to be awareness followed by adequate supports to ensure that individuals are not set up to fail. Direct Payment may not be for everybody; however, it should be a choice that is accessible to all.

5. Prior to implementing such policies for Direct Payment there needs to be sufficient procedures and plans put in place to ensure its success. These would include adequate supports, training and easy access to relevant information. Ireland can learn from other countries such as the UK, from both their successes and failures.

6. The ÁT-network model is certainly a welcome one for persons with disabilities, which brings great independence to the lives of individuals that have obtained Direct Payment under this model. However, the key downside to receiving Direct Payment through this model is having to set up as a company. Therefore a strong recommendation is to ensure that individuals do not need to set up a company to be in control of their Direct Payment, as is seen in the UK.

7.4 Conclusion

This chapter has highlighted the most important findings and discussions that have been identified through the research process. It has also aimed to outline some main recommendations that emerged through the findings. One of the key recommendations that was discussed is the importance of introducing a policy that would ensure that people with disabilities will have the right to receive Direct

Payment. However, like many other policy changes in Ireland it may take some years for this to be implemented.

Much has been achieved over the last twenty-years in the disability sector. One hopes a further step in recognising the independence and rights of people with disabilities will occur by making provision for Direct Payment which should happen in the not too distant future.

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Appendices

Appendix 1: Research Agreement

Appendix 2: Topic Guide

Appendix 3: Information Sheet for Participants

Appendix 4: Consent Form

Appendix 5: Semi-Structured Interview Guide



Direct Payment: The Lived experiences of eight individuals in Ireland

Research Agreement

Name of student(s):	Aoife O'Brien
Name of community partner:	The AT-network (Áiseanna Tacaíochta)
Date:	14 January 2015

An agreement between **The AT-network** and **Aoife O'Brien (MSoc Science Social Policy)** at University College Cork, Cork.

This agreement relates to arrangements agreed between the student and the group for the execution of a research project entitled: Direct Payments: the lived experiences of 8 individuals in Ireland

1. It has been agreed that **Aoife O'Brien** will carry out research on behalf of and in participation with **The AT-network** as follows:

    - *A qualitative research documenting the experiences of 8 people who are receiving direct payment to manage their own services (2 of whom would have ID)*
    - *Martin to recruit participants*
    - *In depth interviews either face-to-face or over telephone/Skype*
    - *Ethical discussion to take place between Martin, Aoife and Claire to be mindful of the participants' confidentiality*
    - *Disseminations of research to take place in various forms post submission: for example at the AT-network's annual conference in December 2015 and at the NDA.*

2. The time of the academic supervisor of the student undertaking the research will normally be provided without charge as part of the student's degree course at the University.

3. The University will provide accommodation, the use of equipment, the services of technical and other supplies to the extent that is normally provided for internally based student projects. Where the provision required for the timely and efficient execution of the project exceeds the normal allowance for student projects or exceeds the host department's budget, the may be asked to pay for such provision or to join with the University in securing provision from a third party source. No costs will be incurred without prior agreement. (These additional provisions will be listed in an appendix at the end of the Agreement if deemed necessary).

4. The name of the student(s) will be listed below. The names of the students, the academic supervisor, or the University may only be used after obtaining prior approval. Permission to refer to the University will not be unreasonably withheld.

5. The copyright, or any other intellectual property rights, created by the project will rest with the University. Free and full use by the Community Partner for the purpose declared when the project was initiated is agreed in advance. Use for any further purpose(s) will be for negotiation and approval on a case-to-case basis. Permission will not be unreasonably withheld.

6. Use of the project report in other than its complete form will be checked with the University in reasonable and sufficient time before the intended date of such use to allow discussion as to the accuracy or suitability of the modified form.

7. Students will normally carry out the project. Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Community Partner, or users, to ensure that any outcome from the project meets safety and other requirements. The Community Partner agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed

to a very high standard and to the satisfaction of the Community Partner. Upon completion of the project the student (as well as completing the requirements of his or her University course) and CARL will be responsible for providing the Community Partner with a completed copy of their project report. The student and CARL shall provide the Community Partner with the completed project report within a reasonable amount of time, not more than two months after submission of the dissertation to the University.

8. Typically, upon completion of the project, students meet with the Community Partner within one month of the submission of the dissertation to the University to discuss the study findings, to explore actions / implementation plan arising from the study and to discuss future public presentations of the study by the student and/or the Community Partner.

9. All parties agree that upon completion of the project, that the research report will be placed, with the approval of the course tutor providing it reaches the requisite academic and presentation standards, on the UCC CARL website: http://carl.ucc.ie.

Student dissertation submission date:	October 2015

Completion date of research report to Group: *(normally after examinations board has formalised grade, which is usually 2 months after submission of dissertation)*	December 2015

Date report to go on CARL website: *(normally after examinations board has formalised grade, which is usually 2-3 months after submission of dissertation)*	December 2015

Signed on behalf of The AT-network

Signature:	
Print Name:	Martin Naughton
Title/Role in Group:	Director
Date:	14 January 2015

Signed by student(s)

Signature:	
Print Name:	Aoife O'Brien
University Course and Year:	MSoc Sc Policy
Date:	14 January 2015

Signed by CARL Coordinator / Academic Supervisor

Signature:	
Print Name:	Anna Kingston/Claire Edwards
University Course and Year:	
Date:	14 January 2015

Topic guide for UCC Research project on Direct Payments

Historically in Ireland there has been a focus on the institutionalisation of persons with disabilities. There has also been more of an emphasis on the disability that the person has rather than on the social and economic factors which serve to debilitate people with disabilities within society. It was only since the 1950s that community based services began to emerge; however it was not until the 1980s that policy and practice have been "moving steadily towards community inclusion for people with disabilities" (Report of the Working Group on Congregated Settings, 2011p.10).

The main aim of this research is to explore one mechanism/support which holds out the potential for disabled people's participation in society through direct financial support or direct payments. One of the main provisions that supports people to integrate into society is the access to one's own finance which provides greater power of choice. A key type of payment that gives a person the power of choice is direct payment which is a payment that "enables disabled adults who need assistance with a range of daily living activities to buy their own support" (Carmichael et al, 2002 p.798)

Objectives

How do people with disabilities experience individualised funding supports, and with what outcomes?

What are the barriers which face people with disabilities accessing their own financial supports?

What factors would support the development of individualised funding supports for people with disabilities?



UCC
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland

My name is Aoife O Brien and I am currently studying a Master's Degree in Social Policy in UCC. Part of the criteria of this Masters is to carry out a research study. The concept of this thesis has been commissioned by Áiseanna Tacaíochta (ÁT-network) through the Community-Academic Research Links (CARL) in UCC. CARL provides independent research support to Civil Society Organisations, e.g. community and voluntary groups, in the region. This research project is concerned with gaining an understanding of the different life experiences of persons with a disability who have received direct payments in Ireland via the ÁT Network.

The study will involve individual interviews and only I will have access to the information that is provided. I will be using a tape recorder to record the interview sessions.

In order to preserve anonymity, no names will be disclosed in the writing up of the study and all data received from the study will be stored securely. You will each receive a consent form which needs to be signed before the interview can take place.

The data will be kept confidential for the duration of the study. The results will be presented in the thesis. They will be seen by my supervisor, CARL, the ÁT-network and the external examiner. The thesis may be read by future students on the course.

Participation in the study will be voluntary and participants can withdraw from the interview at any stage.

Consent Form

I _____ agree to participate in Aoife O Brien's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Aoife O Brien to be tape-recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that all data will be treated confidentially throughout the study.

Signed_____ Date_____

Questions for Interviews

Background

1. Could you start by telling me a little about yourself?

Awareness of and access to direct payments

1. How did you first hear about the possibility of individualised financial support?
2. What did direct payments mean to you at the time?
3. Where did you go about obtaining information about direct payments?
4. What supports were you receiving prior to accessing this funding?
5. vCan you tell me about the process that was involved in obtaining this individualised funding support?
6. What changes, if any, did you have to make to enable you to receive individualised funding support?
7. Were there any particular obstacles, if any, that you experienced during the process of gaining your financial support?

Effects of receiving direct payments

8. How do you think that receiving direct payments has affected your life, and the things that you wish to do?
9. How did you find the process of recruiting personal assistants?
10. Have you received support for this?

11. Is direct payments used mainly/solely for personal assistants or are there other supports and services that can be obtained through this payment?
12. How significant is your relationship with the other members of the AT Network in terms of receiving direct payments?
13. To what extent do you feel that receiving individual financial supports gives you greater control and choice in your life?
14. What do you feel are the greatest advantages of gaining direct payment?
15. Can you give any examples of disadvantages of receiving direct payments?

Supports and barriers to receiving direct payments

16. Do you feel that the Government or the Heath Service Executive (HSE) are supportive of direct payment?
17.
18. Do you think that direct payments is suitable for all individuals with a disability?
19. From your experience of accessing direct payments do you feel that there were any specific areas are supports that could have been available that would have helped the process?
20. Do you feel that there is enough choice in relation to services and supports available for persons to live independently?
21. In your opinion do you feel that there could be a better system put in place to gain access to individualised funding?
22. What do you feel has been the most beneficial part in receiving direct payments?

23. Do you feel that this personal support has influenced how you as an individual can participate in society allowing you to become more of an active citizen?

24. Do you feel that there is sufficient support for people in receipt of direct payments in relation to accessing services and personal supports?