



REPORT

INDEPENDENT LIVING:
AN EVALUATION OF THE
ÁISEANNA TACAÍOCHTA
MODEL OF DIRECT PAYMENTS

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Glossary of Terms

Áiseanna Tacaíochta

Áiseanna Tacaíochta (ÁT) is the Irish name for the organisation that facilitates Direct Payments for persons with disabilities. It translates to English as “Supported Facilities”.

Circle of Support

A Circle of Support is a group of people, who act as a community around the Leader, that help the Leader to accomplish their personal goals in life and assist them with running their company. Each member of a Circle of Support brings their own skill and plays a different part in the company, covering everything from accounting and Human Resources to Health and Safety, so that the Leader is fully supported in everything that they do.

Community Healthcare Organisation (CHO)

CHOs are community healthcare services outside of acute hospitals, such as primary care, social care, mental health, and other health and well-being services. These services are delivered through the Health Service Executive (HSE) and its funded agencies to people in local communities, as close as possible to their homes. Nine CHO areas have been established across the country.

Direct Payment

A Direct Payment is a cash payment made directly to an eligible person with a disability to enable them to purchase their own care or support needs.

Health Service Executive (HSE)

The HSE is responsible for the delivery of health and personal social services in Ireland.

Independent Living

Independent Living refers to the philosophy that persons with disabilities should be able to make decisions that affect their own lives. It also refers to a civil rights movement that advocates for equal participation in community life, and a service system made up of centres for independent living. Instead of emphasising a person’s disability, independent living stresses an individual’s right to certain types of help and assistance in order to be able to live independently.

Individualised Funding

Individualised funding is an umbrella term for various funding mechanisms that aim to provide personalised and individualised support services to persons with disabilities.

Leader

A member of Áiseanna Tacaíochta that is managing their own support services with the help of ÁT.

National Service Plan (NSP)

The HSE publishes a National Service Plan on an annual basis. It sets out the type and volume of health and personal social service to be provided by the HSE each year and within the budget available.

Section 38 and Section 39 Organisations

Where the HSE are unable to provide services to persons with disabilities at regional level, primary responsibility is transferred from the HSE to locally-based voluntary, non-statutory organisations called Section 38 or section 39 organisations. Section 38 grants apply to organisations providing services on behalf of the HSE. Section 39 grants apply to a wide range of non-statutory organisations that provide a service similar, or ancillary to, a service that the HSE may provide and across a variety of sectors.

1. Executive Summary

Introduction

Commissioned by ÁT and carried out by the Centre for Disability Law and Policy at NUI Galway, this report presents an evaluation of the experience, the costs and the benefits, both in monetary and social terms, of the Direct Payments model of individualised funding that is facilitated and supported by Áiseanna Tacaíochta (ÁT) and how this model, where the individual directs their own services, compares to the traditional dedicated service provision model.

Method

The qualitative results are derived from one-to-one semi-structured interviews with twenty-three Leaders. Seventeen of the Leaders interviewed, mostly with physical and sensory disabilities, manage their own support services with the help of ÁT and six of the Leaders interviewed are unable to direct their own services, due to age or disability type, therefore family-led membership is facilitated by ÁT. These Leaders were interviewed with family or members of their Circle of Support present. A Circle of Support is a group of people, who act as a community around the Leader, that help the Leader to accomplish their personal goals in life.

Policy Context

A move towards individualised supports for people with disabilities in Ireland is gathering momentum. The Government's commitment to a new model of disability service provision underpinned by values of person-centeredness, inclusion, community organisation, participation, independence and choice that provides flexible support services for persons with disabilities to lead full and independent lives and to participate in work and society was set out in policy frameworks such as the Towards 2016, Ten Year Framework Social Partnership Agreement 2006-2015 and the 2012 Value for Money and Policy Review of Disability Services in Ireland. Furthermore, in 2016 a Task Force on Personalised Budgets was set up by the Government with the aim to make recommendations on a personalised budgets model which will give people with disabilities more control in accessing health-funded personal social service. Minister of State for Disability, Finian McGrath T.D. stated that one of the key aims of the Government is to provide services and supports for people with disabilities which will empower them to live independent lives, provide them with greater independence in accessing the services they choose, and enhance their ability to tailor the supports required to meet their needs and plan their lives. Though Ireland has made a commitment to the advancement of service provision for persons with disabilities and the disability sector has advanced somewhat, individualised funding has not become a reality, except for the limited numbers using the Direct Payments model facilitated by ÁT.

1.1 Overview of Findings

Outcomes for Individuals

Overall, this report finds that the outcomes for persons with disabilities directing their own services with the support of ÁT reaffirm the findings of international literature that point to considerable benefits for users of direct payments, arising from greater flexibility, choice, independence, continuity of support, customizing of care packages and so forth. The Direct Payments model of service provision facilitated by ÁT places Leaders at the centre of the decision-making process, recognises their strengths and preferences and gives them the confidence, support and means to shape the way in which their care is provided by transferring choice and control over funding decisions to them and allowing them to identify their unique individual needs. This evaluation indicates high levels of satisfaction with the Direct Payments model and level of support received. Several Leaders noted an initial reticence and cautiousness with moving to the Direct Payments model however all of the Leaders expressed their satisfaction with the level of flexibility and subsequent choice that comes with the Direct Payments model. Particularly striking were the ways in which the positive effects of the Direct Payments model touched aspects of the lives of the Leaders well beyond the direct influence of their Personal Assistance or care package. Specifically, directing their own services and enables Leaders to exercise control over their assistance and has instilled in them a sense of confidence and empowerment as well as helping them to achieve social integration, personal life goals and economic independence and participation.

Cost-Effectiveness and Cost-Savings

The Direct Payments model of individualised funding facilitated by ÁT offers value for money through cost savings and cost efficiencies. Cost efficiencies to the value of €69,966 were made in 2016 from eighteen Leaders being

able to stretch their budgets further in terms of hours of Personal Assistance and a saving of €66,162.10 was made by eighteen Leaders receiving their Personal Assistance through the ÁT model of Direct Payments when compared to a Section 39 organisation. While the cost saving element of Direct Payments is to be commended, the potential introduction of the Direct Payments model should not be seen only as a cost saving measure, as this may ultimately deny persons with disabilities a real choice.

1.2 Key Recommendations

This report highlights the key benefits of the Direct Payments model for individuals with disabilities. The research indicates that there is a significant need for a policy change in Ireland and an emphasis on a change to the current model of service provision in Ireland. There is strong evidence that reveals that the Direct Payments model of service provision gives those directing their own services a greater sense of control and empowerment. Having control of one's support needs is an essential part of well-being and active citizenship. An important aspect of the Direct Payments model that was identified during the interviews was the support that ÁT provides to Leaders. As an organisation, ÁT was found to provide a high level of guidance, advice and knowledge to Leaders which ensures that they do not have to go through the process of setting up and managing a company alone.

Given the advantages of the Direct Payments model of Individualised Funding facilitated by ÁT and the growing emphasis, both from a public and policy point of view, for change in policy and legislation relating to the current system of service provision, this report finds that it is vitally important that the ÁT Direct Payments model continues to be funded by HSE, at the very least until such time as a clear national strategy and framework is agreed in the area of Direct Payments. It is equally important that persons with disabilities in receipt of services through the traditional service provision model be provided with the relevant advice, information and guidance to establish if the Direct Payments model of service provision is suited to their needs and is compatible with their aspirations for independent living. Every person with a disability in Ireland should be afforded the opportunity to direct their own services and those wishing to transition to the ÁT model of direct payments should be supported to take this step.

As there is no standard assessment tool by which person with disabilities are assessed in terms of their care needs, a single assessment tool is required to evaluate individuals' resource allocations based on the individual's goals, the impact of their disability, their family circumstances, their living arrangements and so on. The absence of a standardized assessment tool means that there is little clarity in the way that resources are allocated to persons with disabilities in different parts of Ireland and this brings a sense of inequality to the system. The lack of a standardised assessment tool also means that the changing needs of persons with disabilities are not correctly being monitored and subsequently reviews and revaluations of needs are not being carried on a regular basis.

This report finds that persons with disabilities in receipt of disability services perceive that their movement from one Community Healthcare Organisation (CHO) to another is restricted as there are significant bureaucratic hurdles to be overcome for them to receive disability services in a different CHO. A need exists to transform the disability service provision model to permit persons with disabilities to more easily move their service provision from one CHO to another should they need to for personal, employment or educational reasons.

At present, Leaders can use their budgets to purchase Personal Assistance. However, the budget should be extended to the purchase of equipment, aids, and other goods and services that relate to the healthcare needs of the individual following an assessment. This would give further choice and control to the individual, decrease the time that it takes for persons with disabilities to receive certain goods and services, create demand in the private market and drive a more efficient system of service provision.

However, for personal budgets to work effectively, the process of implementing personal budgets must be clear and easy to access and that training for all parties is essential in order to access and utilise personal budgets effectively. supplying resources, providing templates on setting up and running a company, organising training for Leaders, Circles of Support and PAs and by providing access to the Peer Support Network.

2. Introduction

In April 2016, there were 643,131 persons with a disability living in Ireland accounting for 13.5% of the population, an increase of 47,796 persons or 0.5% since 2011 (Census, 2011, 2016). Many of these persons with disabilities require some form of support to enable them to live full and independent lives in the community. This support can include personal assistance and domestic assistance as well as other forms of practical help such as assistance with participation in social and leisure activities. In many cases, the needs of an individual can be addressed using a combination of these different kinds of assistance. In Ireland, these supports are usually supplied by direct service providers, by relatives or friends or by individual workers employed by persons with disabilities themselves using individualised funding that is facilitated by an organisation. From the perspective of a person with a disability receiving individualised funding or using the traditional dedicated service provision model, the key considerations are the quality of the support available, how effectively it meets their own needs and, most importantly, the extent to which it enables them to lead full and independent lives.

The focus of this report is to evaluate the experience, the costs and the benefits, both in monetary and social terms, of the Direct Payments model of individualised funding that is facilitated and supported by Áiseanna Tacaíochta (ÁT) and how this model, where the individual directs their own services, compares to the traditional dedicated service provision model. One of the main aims of the research has been to examine if direct payments, where individuals direct their own services, creates a better quality of life than that of the traditional model of service provision at no extra cost as suggested by previous research in other countries and as advocated by the disability movement itself (Zarb and Nadash, 1994). Finally, the report presents and critically evaluates the cost effectiveness of the Direct Payments model and compares it to the cost effectiveness of the dedicated service provision model.

3. About the Research

Following the award of a grant from the Department of Health 2015 National Lottery Fund and the Disability Federation of Ireland (DFI), Áiseanna Tacaíochta (ÁT) commissioned the Centre for Disability Law and Policy (CDLP), located within the Institute for Lifecourse and Society at the National University of Ireland, Galway to carry out this evaluation of the Direct Payments model of Individualised Funding facilitated by ÁT. While the research has been carried out completely independently, the development of its aims and objectives have been a collaborative process between the primary researcher and the Evaluation of the ÁT model of Direct Payments Steering Committee. The Steering Committee was made up of researchers from the CDLP, the Disability Federation of Ireland and ÁT as well a number of persons with disabilities and self-advocates from across Ireland. The Steering Committee consulted regularly throughout the research and provided feedback to the primary researcher.

The research involved a review of policy documents while the core work consisted of one-to-one semi-structured interviews with twenty-three of the Leaders managing their own support services with the help of ÁT, from all parts of Ireland and with various types of disabilities including physical, neurological and intellectual disabilities. For leaders who are unable to direct their own services, due to age or disability type, family-led membership is facilitated by ÁT, and these Leaders were interviewed with family or members of their Circle of Support present. A Circle of Support is a group of people, who act as a community around the Leader, that help the Leader to accomplish their personal goals in life. The interviews focused on each person's experience of Direct Payments and how it compared to the traditional service provision model with which they had used prior to the Direct Payments Model. Almost all of the interviews were conducted in the homes of the Leaders by a single researcher and were audio recorded where the Leader was comfortable with being recorded. Ethical approval was received from the Research Ethics Committee at NUI Galway (Reference: 16/FEB/10) and the researcher was Garda vetted before the interviews commenced.

This evaluation has been conducted in the context of the current economic, social, cultural, and disability policy climate where many of the services being provided to persons with disabilities are not considered adequate. In the last decade, there has been a growing emphasis in Ireland and across the world that policy and legislation needs to

move towards a more personalised way of meeting the needs of persons with disabilities. Advocates of independent living argue that if persons with disabilities require personal support or other services to ensure their citizenship and social inclusion, these supports must be funded and provided in such a way that the individual, as far as possible, remains in control. Such advocates argue that persons with disabilities should have a right to individualised funding so they can plan, purchase and gain control over their own support arrangements (Zarb and Evans, 1998, Glasby and Littlechild, 2002, Stainton and Boyce, 2015).

In the Towards 2016, Ten Year Framework Social Partnership Agreement 2006-2015, the central policy objective for persons with disabilities is that they should be supported to lead full and independent lives, to participate in work and society (Department of the Taoiseach, 2006). Furthermore, the 2012 Value for Money and Policy Review of Disability Services in Ireland outlined that persons with disabilities are looking for flexible services that meet their individual needs and systems that vest more control with the service user and, where appropriate, their families (Department of Health, 2012). Though the disability sector has advanced somewhat since the Value for Money report, individualised funding has not become a reality, except for the limited numbers involved in pilot projects such as ÁT, and disability support services are considered largely inadequate.

4. Literature Review

A growing body of policy describes how persons with disabilities should be autonomous and self-determined members of their community and of society in general. It is no surprise then, that in recent years individualised funding mechanisms, reflecting trends towards a person-centred decision making process, have become a focal point for the worldwide disability movement (Dowling et al., 2006). Individualised budgets, such as the Direct Payments model facilitated by ÁT, place persons with the disabilities at the centre of the decision-making process, recognising their strengths, preferences and aspirations and empowering them to shape the way in which their social care is provided by transferring choice and control over funding decisions to them and allowing them to identify their needs, and to make choices about how and when they are supported (Carr, 2010). This might or might not involve the transfer of actual funds to the individual (Department of Health, 2012).

As a result, many countries are following suit and recommending and developing individualised funding strategies. A range of personalised budget models have been implemented in Canada, Australia, New Zealand, the USA, the Netherlands, Germany, Sweden, England and Scotland with many more countries developing and evaluating a range of programmes and models appropriate to their cultural, political and legislative context. Individualised funding mechanisms vary in the way they are funded, some are large scale national programmes financed from central taxation, and others, such as Germany and Holland from long term insurance. Schemes also differ in the payments offered, the way they operate and the numbers using them. The sections that follow outline the outcomes of various studies of individualised funding schemes from different countries across the globe.

4.1 Choice, Control and Well-Being

There have been several reports and evaluations of the Direct Payments scheme for people with disabilities in the UK. A review of the impact of Direct Payments on the choice and control of persons with disabilities in Scotland, carried out by Witcher et al. (2000), found that Direct Payments can dramatically increase the choice and control recipients exercise over their own lives. Following a two year evaluation of Direct Payment scheme in Wales, Stainton and Boyce (2004) found that users of Direct Payments reported improved self-esteem and increased control over their lives as a result of the greater flexibility and freedom of choice that Direct Payments afforded them. Furthermore, a 2008 evaluation of thirteen local authorities across England who were involved in an individual budgets pilot programme found encouraging indications of the impact of individual budgets on people's lives (Glendinning et al., 2008). It was noted that those who received individualised budgets were significantly more likely to report feeling in control of their lives, the support they accessed and how it was delivered compared to those not in receipt of individualised budgets. A study by Rabiee et al. (2009) on the experiences and outcomes of Individual Budget users in England, two to three months after being offered an Individual Budget in a pilot scheme reveals that individualised budgets have the potential to be innovative and life-enhancing.

In Ireland, an analysis by Fleming (2016) of how personalised budgets work found that the pilot based individualised funding initiatives in Ireland had many positive impacts on the lives of the individuals with a disability and their support network. The report noted that individuals in receipt of individualised funding described themselves as more successful, confident, adaptive, skilled, empowered, independent, in control and with a greater sense of purpose.

A report by the Social Policy Research Centre (SPRC), University of New South Wales, examined the effectiveness of approaches to individual funding of disability support in Australia by comparing peoples experiences before and while using individual funding (Fisher et al., 2010). It was found that people using individual funding experienced personal well-being, and physical and mental health at levels similar to both the Australian population norm and the Victorian norm of people with intellectual disabilities. The persons interviewed attributed these positive results to the better control they have over the way they organise their disability support. Persons with disabilities and their families also commented on how changing to individual funding had improved the wellbeing of family members because they could share the responsibilities. In the Australian context, individual funding has not resulted in an increase in the total specialist disability support cost to government (Fisher et al., 2010).

The self-directed Cash and Counselling programme available to persons with disabilities in the United States offers a monthly allowance to persons with disabilities out of which they can purchase care and care related goods and services. The model also offers services such as counselling and bookkeeping to individuals to make the programme more accessible and user friendly though a study has revealed that funds are mainly used to hire workers. This model was not designed to be a money saving initiative, but instead, to give individuals much greater control and flexibility over their care without costing the health service any more per month than that care would have cost under the traditional agency based model. In their US study, Dale and Brown (2006) note that those availing of Cash and Counselling reported being more satisfied with how they were spending their lives than those receiving care through the more traditional methods. They also report that the additional costs involved in the provision of personal budgets could be offset by the associated prevention of the need for some nursing home places.

4.2 Cost Savings

Cost savings or cost efficiencies have been shown to be an ancillary benefit of individualised funding. The largest and most influential study of cost effectiveness argues that Direct Payments are more cost effective than conventional service provision (Nadash and Zarb, 1994). This study found that support arrangements financed by direct payments were, on average, between 30% and 40% cheaper than equivalent service based support. Services arranged via Direct Payments are almost invariably cheaper than more traditional forms of service delivery offering equivalent hours of support. User-controlled money, it is argued, goes further. Powerful personal incentives exist for recipients to use their money wisely, efficiently and prudently because their survival and independence depend upon it (Zarb and Evans, 1998). In addition, because the user often acts as an employer and budget holder, he/she soaks up much of the administrative and management costs. This may mean that recipients can get greater levels of social care at no greater cost. Furthermore, small-scale studies in the UK by Jones et al. (2011) and Stainton et al.'s (2009), indicate that personal budget schemes were cheaper than services delivered by the local authority, and relatively cost neutral when compared with independent sector provision. However, both research teams warn of the need to adequately budget for start-up costs.

A further cost saving of personal budgets has been identified from research in the Netherlands. According to Kremer (2007), the estimated expenditure on personal budgets in the Netherlands in 2007 was considerably less than the budgets for nursing homes or residential care services, and equivalent to home care services. Kremer (2007) also notes that in addition to autonomy and empowerment, the Personal Budget model of individualised funding available in the Netherlands increases competition between providers, increases efficiency and improves the quality of care.

4.3 Uptake of Individualised Funding

In England, Scotland, Wales and Northern Ireland, individualised funding in the form of Direct Payments for social care became possible with the Community Care (Direct Payments) Act (1996) that came into effect in 1997. The Act gave discretionary powers to Local Authorities and health and social service trusts, to make direct cash payments in lieu of services available to persons with disabilities, older people and parents of children with disabilities

(Department of Health, 1996, Spandler and Vick, 2005). In April 2003, it became mandatory rather than a discretionary responsibility for local authorities to offer cash payments to service users and Direct payments were made available to people assessed as needing care services and willing and able to use cash payments to purchase their support. However, take-up of Direct Payments was low (Commission for Social Care Inspection, 2005; Priestley et al., 2006) and there was considerable variation in the take-up of Direct Payments between different groups of service users (Leason & Sale, 2004; Spandler & Vick, 2004, 2005) and within and between different parts of the UK (Priestley et al., 2006). Spandler (2004) and Leece (2004) note that in the UK while Direct Payments are offered to all persons in need of care service, they are taken up disproportionately by well-educated, more affluent and middle-class people who feel able to take advantage of the opportunities offered and therefore creating a two-tiered system of social support. Furthermore, Leece and Leece (2006) show a strong concentration of Direct Payments take up among younger age groups, suggesting that there may be a need for more supports for older people and greater awareness of the benefits of using Direct Payments.

4.4 Relationships and Family

In the UK Stainton and Boyce (2004) found that family carers expressed satisfaction with Direct Payments schemes, citing greater freedoms as a result of increased flexibility. Furthermore, they found that users of Direct Payments reported deeper and more lasting relationships with other people, and new interpersonal, vocational and lifestyle opportunities, as a result of the greater flexibility and freedom of choice that Direct Payments afforded them. Furthermore Glendinning et al., (2008) found that those who accepted the offer of individualised budgets described living fuller lives, feeling that they were 'less of a burden' on their families and had greater control and independence.

4.5 Administrative Burden

Stainton and Boyce's (2004) study of the Direct Payments scheme in the UK outlined that while some potential users expressed concern over the possible administrative burden of the Direct Payments scheme, users found that, with the support from a user driven Independent Living Scheme (support and advice network), the administrative burden was manageable.

4.6 Sweden – The Gold Standard

Sweden has traditionally been seen as the 'gold standard' on Direct Payments since the introduction of 'The Personal Assistant Act' in 1994 (Egan, 2008). Sweden remains the only European country which confers a right in law to a Personal Assistant without regard to cost. The Assistant Act includes personal assistant cover for all assessed needs including personal assistance, assistance at work, household work and assistance associated with parenting. Other significant features of the Act are the absence of means testing and a payment for the administrative costs associated with Direct Payments. Needs assessed are expressed in the numbers of hours required to meet that need. A tax-free payment enables assistance users to purchase their personal assistance from any service provider or to employ personal assistants directly. There are no upper limits on the number of hours to which an individual is entitled. Twenty-four seven personal assistance is a feature of the system. For those who qualify under the Personal Assistant Act there is one centralised source of funding – The National Social Insurance Fund.

Each assistance user has his or her personal assistance needs assessed by the local government or the National Social Insurance Fund. The need is expressed in the number of hours of service required per week. The local government or the Insurance Fund pay each qualifying person a monthly amount that consists of the number of hours that he or she has been assessed for multiplied by the flat rate that the government determines each year as the remuneration for one hour of personal assistance services. The amount is to cover wages, wages for unsocial hours, employer's social insurance costs, insurances for the employee, the user's and assistants' training costs (if deemed necessary by the user), the cost of accompanying assistants in the form of travel costs or entrance fees, administrative fees, meals, etc. The money is paid into the individual banking account or to their service provider's account, depending on the assistance user's preference. The funds can be used for personal assistance only and have to be accounted for by showing proof of the number of hours used. This proof is provided by sending each month the 'time sheets' of all one's assistants signed by them. An interesting feature of the Act is that persons with disabilities who are assessed as needing less than 20 hours of personal assistance per week do not qualify for personal assistance under the Personal Assistance Act. In Sweden, less than 20 PA hours per week is not considered 'independent living' under the Act and

persons with disabilities whose needs are assessed at less than 20 hours per week have their needs met from a home help service provided by their local municipality.

In 2013, 19,500 persons with disabilities in Sweden received a personal assistance budget and 98% of those recipients pointed to personal assistance as the most important factor in their quality of life. By 2014, 230 local authorities and over 800 private entities offered personal assistance services on a competitive basis (Council of Europe, 2015).

4.7 Conclusion

Overall, the literature suggests that there are considerable benefits for users of direct payments, arising from greater flexibility, choice, independence, continuity of support, customizing of care packages and so forth (Dawson, 2000, Leece, 2000, Carmichael and Brown, 2002, Stainton and Boyce, 2015). Leece and Leece (2006) noted that direct payments are likely to become a major method of providing support to not only persons with disabilities, but to older people. However, a number of studies have suggested that direct payments may be offered to and taken up disproportionately by well educated, more affluent, middle-class people, who feel able to take advantage of the opportunities offered by arranging their own support as opposed to accepting the traditional model of service provision (Leece, 2004, Spandler, 2004, Leece and Leece, 2006). This suggests that a system of individualised funding could potentially create a two-tiered system of social support if users find the paperwork and bureaucracy in the scheme burdensome and the correct supports are not put in place. In line with this, Fleming (2016) pointed out that for personal budgets to work effectively, the process of implementing personal budgets must be clear and easy to access and that training for all parties is essential in order to access and utilise personal budgets effectively.

5. The Policy Context: Disability Services in Ireland

5.1 The Disability Sector

The disability sector in Ireland has advanced since the publication of the Value for Money and Policy Review of Disability Services in Ireland in 2012. The Value for Money report has been used as a benchmark for achieving disability sector improvements and a number of policies have been developed aiming 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 communities (Department of Health, 2012). This proposed new model of disability service provision is underpinned by values of person-centeredness, inclusion, community organisation, participation, independence and choice (NDA, 2010).

The Value for Money report recommended the restructuring of disability services in Ireland through personalised supports and more effective systems of resource management. The report noted that disability services' infrastructure in Ireland has developed in an ad hoc way over many years and systems of allocation of resources and accountability have evolved differently in the former Health Board Regions. The report also highlights concerns regarding the numbers of agencies providing disability services, the likelihood of inefficiencies in the system, the potential for geographical or sectorial inequalities in resource allocation and service provision as well as the level of administrative costs, management structures, advertising and infrastructure (Department of Health, 2012). In general, research has found that the traditional model of service provision does not provide flexible services that are tailored to the needs of the individual, nor does the traditional model allow the service user to control the services they receive. It is worth noting, however, that some agencies, particularly those serving people with physical disabilities, have developed from a community base with the aim of promoting and protecting client choice, control and independence. Some of these agencies already operate a client-focused model of service and they provide examples of good practice, which can be used to inform decision-making in the wider disability sector (Department of Health and Children, 2010).

5.2 Delivery of Services for Persons with Disabilities in Ireland

Under the direction of the Department of Health, the Health Service Executive (HSE) has primary responsibility for the delivery of specialist disability services to all eligible persons with disabilities in Ireland. Community Healthcare Services are the broad range of services that are provided outside of the acute hospital system and include disability services such as the provision of personal care packages that meet the essential care and social needs of persons with disabilities. These services are delivered through the HSE and its funded service providers to persons with disabilities across nine different Community Healthcare Organisations (CHOs) across the country. In each CHO a Chief Officer leads a local management team which focuses on all of the specialist services in their area. The annual National Service Plan (NSP) sets out the type and volume of health and personal social service to be provided by the HSE each year and within the budget available. In its 2017 NSP, the HSE stated that it expects 2,357 adults with physical and/or sensory disabilities to receive 1.4 million Personal Assistance service hours in 2017 (HSE, 2017). These Personal Assistance hours are distributed across the nine CHOs. A case manager is assigned to each person who has been referred to the HSE as needing a care package and a needs assessment is carried out. Care is divided into essential care and social needs and essential needs get priority over social care needs. It is important to note that there is no standardised needs assessment tool by which persons with disabilities are assessed in terms of their care needs however in its 2017 NSP, the HSE noted that a priority action in 2017 is to select and commence implementation of a standardised assessment tool for disability services. A standardised needs assessment tool would also mean that the changing needs of persons with disabilities would be addressed as an assessment tool could be used to review the needs of each individual on a more regular basis. In relation to Personal Budgets and individualised funding the 2016 NSP states that one of its goals for 2016 is to "support the phased transition to person-centred models of services and supports" while the 2017 NSP lists the support of the Taskforce on Personalised Budgets as one of its priorities (HSE, 2016 & 2017).

Where the HSE are unable to provide services to persons with disabilities at regional level, primary responsibility is transferred from the HSE to locally-based voluntary, non-statutory organisations. These Section 38 or section 39 organisations are funded by the HSE under the Health Act 2004. Section 38 grants apply to organisations providing services on behalf of the HSE², mainly 40 and 50 bodies in the acute hospital and disability sectors. Section 39 grants apply to a wide range of non-statutory organisations that provide a service similar, or ancillary to, a service that the HSE may provide and across a variety of sectors. There are approximately 95 disability related Section 39 organisations funded by the HSE, many of which provide Personal Assistance for persons with disabilities (McInerney & Finn, 2015). The HSE has in place Service Level Agreements that set out the level of service to be provided by the grant to the individual organisation and requirements in relation to the standards of care, with all Section 39 funded organisations. These are reviewed and agreed annually by the HSE and the Agency to reflect any changes in levels of service, funding etc. The HSE has also established a Governance Framework to cover funding relationships with all Non-Statutory Bodies and it is the policy of the HSE that all funding agreements with Section 39 agencies are formalised by complying with the Governance Framework.

The Irish Wheelchair Association (IWA), Cheshire, Rehab, Bluebird Care and Enable Ireland are examples of section 39 agencies that provide Personal Assistance. This means that Under section 39 of the Health Act 2004 these organisations signed up to service level agreements and receive funding to provide certain services. In 2016 one Section 39 organisation received €40.7 million from the HSE to deliver a wide range of services. The largest service delivered by these Sections 39 organisation is the Assisted Living Service and in 2016 this Section 39 organisation spent €27.1 million euro in delivering 1.17 million hours of personal assistance to 1,863 people.³ In 2016 the HSE funded approximately 1.5 million hours of personal assistance, including personal assistance provided by Section 39 service providers. This means that the one Section 39 organisation delivered approximately 78% of all of the Personal Assistance hours in Ireland in 2016 at a cost of approximately €23 per hour.

6. Independent Living, Individualised Funding and Direct Payments

Individualised funding is an umbrella term that refers to types of funding models that offer individuals more control over the choice of services they receive. Individualised funding ranges from a method of determining resource allocation to agencies based on assessed client need and actual costs, to a 'money follows the client' model, a brokerage system or a personal budget model administered by the individual service user. Individualised budgeting places the person at the centre of the decision making process, recognising their strengths, preferences, aspirations and empowering them to shape public services, social care and support by transferring choice and control over funding decisions to the service user and allowing them to identify their needs, and to make choices about how and when they are supported (Carr, 2010). This might or might not involve the transfer of actual funds to the individual (Department of Health, 2012).

The evolution of payments schemes that facilitate persons with disabilities to direct their own personal assistance and care is closely tied to the development of the Independent Living movement. Central to the concept of Independent Living are the principles of choice and control over the way in which their care is delivered. The practical application of the principles of Independent Living can be traced back to 1972 when the first Centre for Independent Living (CIL) was established in California. These centres were founded to be run and controlled by persons with disabilities themselves, with the intention that expertise around Independent Living issues could be developed using approaches such as peer support and advocacy. Since then, persons with disabilities from around the world have developed an increasing variety of assistance and care options which enable them to live independently in the

1 <http://www.irishstatutebook.ie/eli/2004/act/42/enacted/en/html>, Accessed August 9th 2017

2 <http://www.irishstatutebook.ie/2004/en/act/pub/0042/sec0038.html>, Accessed 14th February 2011.

3 Irish Wheelchair Association (2017). *Annual Financial Statements for the Year Ended 31 December 2016*. Available at http://www.iwa.ie/downloads/information/publications/annual-reports/1499_WEB_IWA_2016_Financial_Accounts.pdf, Accessed August 11th 2017.

community (Crewe and Kenneth Zola, 1983, Shearer, 1983, Barnes, 1992, Morris, 1993). With the aim of ensuring that all people with disabilities can achieve Independent Living and participate fully in society, a core group of individuals with disabilities set up the first Centre for Independent Living (CIL) in Dublin in 1992. The idea of personal assistants working under the direction of persons with disabilities has also been a central feature of this Independent Living movement which saw a second Centre for Independent Living set up in Galway in 1994 and in excess of 27 other Centres opened across Ireland since its inception.

The past number of years have seen a global shift from a welfare system, which has treated persons with disabilities as dependent, passive recipients of 'care', towards a growing recognition of the need for a new approach that enables persons with disabilities to assume an active role in the society in which they live. Individualised funding is central to this new approach that puts the individual at the centre of their care, offering more choice and control over how the individual meets the needs of their personal circumstances and offers the potential for the individual to develop their lives in a way that is self-directed rather than prescribed.

A move towards individualised supports for people with disabilities in Ireland is gathering momentum. The Value for Money and Policy Review evaluation of the efficiency and effectiveness of disability services in Ireland recommended that the Health Service Executive (HSE) should drive migration towards a person-centred model of services and supports through the Service Level Arrangement (SLA) process. A report on the transition to personal budgets by Carter Anand et al. (2012) for the National Disability Authority noted that the introduction of individualised budgets is thought, by some, to have the potential to increase opportunities for the misuse of funding or budget allocation difficulties. However, it is thought that the benefits of cost effectiveness and efficiency of individualised funding far outweighs the negatives (Zarb and Nadash, 1994, Zarb and Evans, 1998).

Furthermore, in 2016 a Task Force on Personalised Budgets was set up by the Government with the aim to make recommendations on a personalised budgets model which will give people with disabilities more control in accessing health-funded personal social services, giving them greater independence and choice in accessing services which best meet their individual needs. Minister of State for Disability, Finian McGrath T.D. noted that "one of the key aims of the Government is to provide services and supports for people with disabilities which will empower them to live independent lives, provide them with greater independence in accessing the services they choose, and enhance their ability to tailor the supports required to meet their needs and plan their lives" (Department of Health, 2016). This would be a fundamental change in the way that services and supports for people with disabilities are currently provided.

7. Áiseanna Tacaíochta: Direct Payments Model

Direct Payments have long been a goal of disabled persons organisations both in Ireland and internationally (Carmichael & Brown, 2002; Lord & Hutchinson, 2005) and became a reality in Ireland with the establishment of Áiseanna Tacaíochta in 2010. Initiated by four people with lived experience of disability who recognised the problems and inadequacies of traditional models of service provision, ÁT is the first and main organisation to facilitate Direct Payments to people with disabilities in Ireland. A Direct Payment is a cash payment made directly to an eligible person with a disability to enable them to purchase their care or support needs. ÁT supports both self-directed and family-led services by acting as an intermediary between its members, called Leaders, and the Health Service Executive (HSE) and by supporting Leaders to support themselves. At present ÁT represents over thirty new and existing Leaders from a diverse group of people with different disabilities and different experiences, united by a common desire to direct their own lives.

ÁTs model of Direct Payments aims to give people with disabilities control over their own budgets and services. They act as the intermediary between the person with a disability and the Health Service Executive (HSE) and negotiate a personal budget on behalf of the individual which is outlined in a Service Level Agreement. The personal budget is transferred from the HSE to ÁT. With the support of ÁT, each Leader establishes a company, usually a Company Limited by Guarantee, through which their funds are channelled directly to them. The Leader then receives a Direct Payment from the HSE through ÁT, it goes into their company account and the Leader uses their budget to choose and manage their own services, mainly the recruitment and hiring of Personal Assistants to provide the required support. This means that each Leader becomes the employer or contractor, assumes responsibility for insurance, tax deductions etc. and can decide when and how they use their services, ensuring that supports fit in with the way that they live their life. ÁT support the Leaders to submit financial reports to the HSE on the use of their budgets through a monthly and quarterly reporting system. As well as submitting financial reports, all Leader companies are individually audited, as is ÁT as an organisation. This provides a double lock, ensuring the financial accountability and transparency in the use of public funds. ÁT also support Leaders to ensure their company is compliant with requirements such as governance, Personal Assistant (PA) contracts, Garda vetting, and more.

One of the important features of the ÁT model of Direct Payments is the Circle of Support. With the help of ÁT, each Leader establishes a personal Circle of Support to assist them with running their company. Circles of Support comprise of people from the Leaders local communities and the aim is that each person in the Circle brings their own skill and plays a different part in the company, for example accounting, Human Resources and Health and Safety, so that the Leader is fully supported in everything that they do. ÁT has a Peer Support Network that encourages Leaders who are directing their own services to connect with new and potential members to help support advising and mentoring them, training and upskilling them, and sharing their experiences so that success builds upon success. This demonstrates ÁTs position as a user-led network promotes solidarity among people with disabilities and supports people to live as active and participating members of society in a practical way. The staff at ÁT support Leaders though supplying resources, providing templates on setting up and running a company, organising training for Leaders, Circles of Support and Pas and by providing access to the Peer Support Network.

8. Results of Qualitative Analysis/ Outcomes for Individuals

This section presents the findings about outcomes for Leaders who are directing their own services. The Leader interviews yielded a large amount of information on the benefits and disadvantages of Direct Payments but overall, comments and reviews of the Direct Payments model facilitated by ÁT indicated high levels of satisfaction with the model and level of support received. Many Leaders noted an initial reticence and cautiousness with moving to the Direct Payments model however all of the Leaders expressed their satisfaction with the level of flexibility and subsequent choice that comes with the Direct Payments model. Particularly striking were the ways in which the positive effects of the Direct Payments model touched aspects of the lives of the Leaders well beyond the direct influence of their Personal Assistance or care package. Specifically, directing their own services and enabling them to exercise control over their assistance has given confidence and a sense of empowerment to the Leaders. A key issue with the evaluations of the Direct Payments model is the size of the budget given to each Leader and the purpose to which it is used. The semi-structured interviews revealed that many of the Leaders do not have a comprehensive understanding of how the amount of funding they are allocated is calculated. Leaders with intellectual disabilities who have family led support were most likely to be unsure of what they can spend their budgets on.

The qualitative results that follow are derived from one-to-one semi-structured interviews with twenty-three Leaders. Seventeen of the Leaders interviewed, mostly with physical and sensory disabilities, manage their own support services with the help of ÁT. Six of the Leaders interviewed are unable to direct their own services, due to age or disability type, therefore family-led membership is facilitated by ÁT, and these Leaders were interviewed with family or members of their Circle of Support present. Of these Leaders, seven were female and sixteen were male. The breakdown of the twenty-three Leaders by Community Healthcare Organisation (CHO) is as follows:

Table 8.1: Breakdown of Interviewees by CHO

COMMUNITY HEALTHCARE ORGANISATION	LEADERS MANAGING OWN SUPPORT	LEADERS WITH FAMILY-LED SUPPORT
CHO 1	1	1
CHO 2	4	2
CHO 3	2	0
CHO 4	1	0
CHO 5	1	0
CHO 6	1	0
CHO 8	2	0
CHO 9	5	3
<i>Total</i>	17	6

It should be noted that five Leaders, who direct their own services have joined ÁT subsequent to this data being collected therefore ÁT are now (February 2018) supporting thirty-one Leaders to direct their own services. The individual experiences of the Leaders of Direct Payments can be summarised under the following headings:

8.1 Moving to the ÁT model of Direct Payments

Most Leaders came into contact with or became aware of ÁT through conversations with other Leaders, through referral from the HSE or from seeing representatives of ÁT speak at various conferences organised by Inclusion Ireland and Clan Beo for example. The examples below typify the way many Leaders discovered the ÁT model of Direct Payments and why they chose to leave their traditional service provider and move to the ÁT model of Direct Payments;

“when I was having all the trouble (with the service provider) I spoke to another Leader and I decided to give it a go.”

Another Leader outlined the issues they were having with their old service provider in terms of getting their PA to travel abroad with them and enable them to perform their duties of employment in the correct way;

“having PAs travelling with me was a problem so XXX told me about ÁT and I decided to give it a go.”

One Leader felt that they were not getting enough support from their service provider to help them to source Personal Assistants;

“before I moved I was having difficulty getting staff and I felt they weren’t giving me support getting staff ... I thought I wasn’t getting support and that’s why I moved to ÁT.”

Many of the Leaders transferred to the ÁT model of Direct Payments because of dissatisfaction or problems with their support or a change in the circumstances to their support needs. Leaders identified a range of shortcomings with their previous service providers. For example, Leaders expressed frustration at the times at which their Personal Assistance was provided, which was often incompatible with their own lifestyles and commitments;

“I left the (service provider) because they were taking more and more control away from me, I could not advertise for my own PA and I had to pick from their list.”

and another revealed;

“they said to me that I have to go to bed at 9 o’ clock ... I felt I had no choice, I had to leave”

and

“I was put to bed at 8 o’ clock every evening, with a sleeping tablet at 8 o’ clock.”

Several Leaders expressed frustration with the inflexibility within the provision of support with their previous service provider; “the other service provider used to let me have say 3 hours on a Sunday but now I can have 6 hours if I want or one hour if I want”. Another Leader indicated the lack of control when choosing a Personal Assistant and the associated problems that this caused them;

“I ended up with a PA, a good man, Italian, but he couldn’t pick up on my speech it was then I decided to quit.”

Additionally, Leaders indicated that there are heavy constraints imposed by rigid working practices within traditional service providers which were insensitive to their needs and wishes and this was largely what prompted them to move to the Direct payments model;

“The joy of going to ÁT and getting a Personal Assistant is that they can support you in anything you need to carry out. Before, they could only carry out what the company would allow them to do. I could have a child that would need a coat buttoned up or a shoe lace tied and that wouldn’t be allowed happen because the company wouldn’t allow it... .. It used to drive me mad to think that you wouldn’t be able to assist my child with something that is natural as a father that I need to be able to do myself.”

Another example of rigid working practices is that of a Leader whose Personal Assistant was nearing the national retirement age and therefore their employment was due to be discontinued. Both the Leader and the Personal Assistant stressed the very close and personal relationship that they had built up and their commitment to continuing with the current arrangement to the service provider. The service provider was reluctant to continue with the contract of employment and this prompted the Leader to transition to the Direct Payments model. This Leader now has control of who their Personal Assistant is and they have a mutual understanding of if and when this contract of employment will cease.

The interviews revealed that the staff of ÁT play a central role in helping persons with disabilities to decide whether to proceed with the ÁT model of Direct Payments. Many of the Leaders described the information and advice that they received from the staff of ÁT and the other Leaders as comprehensive, supportive and indicated that they felt no pressure to make a decision on transitioning to Direct Payments. The professionalism of the staff of ÁT clearly

influenced individual decisions to take up Direct Payments with one Leader pointing out that “leaving was very stressful, it would have been very easy to back out but ÁT stepped in”.

8.2 Independence, Well-being and Social Relationships

Leaders talked in an extremely positive light about the Direct Payments model;

“happy to stay with this and recommend it to other people”

and

“Direct Payments is hugely important, I wouldn’t be able to live my life without them.”

They discussed how empowered they have felt since setting up their own company and how their confidence has been boosted. There were many examples across the data where Leaders referred to ‘independence’ and ‘confidence’. Leaders expressed how they are “better able to arrange my life the way I want to arrange it” since transitioning to the Direct Payments model.

The benefit of the Direct Payments model is the flexible spending within the package, including the ability to respond to changing preferences and needs. Inadequate funding to meet these needs restricts the potential for the person to fulfil their rights as pointed out by one Leader;

“I need support 24 hours a day to live independently, to live.”

Leaders revealed that they are “way more independent”, “more confident” and the Direct Payments model allows them to “be more social”. Another Leader discussed how

“with ÁT, you’re not passive anymore. Not waiting for someone to come and go. ÁT are more engaging (than the traditional service provider), they won’t sit by and see waste”

and

“I feel more independent because I’ve got the money ... I wouldn’t go back the other way.”

Furthermore Leaders discussed how the Direct Payments model simply allows them to “get out”. One Leader talked about having the flexibility to be able to go to a family wedding and go on a holiday “the simple pleasure that everyone enjoys”. Another discussed their love of gardening and how with the help of their Personal Assistant, they have a garden that they get complimented on;

“Direct Payments means the world to me because it’s so much a part of my life. I love doing a bit of gardening with my PA, I get great credit, they tell me I must be a great plant lover.”

Leaders discussed the independence and control that comes with directing one’s own services as changing their outlook on life “my aspirations had changed in terms of living a fuller life, having greater control and independence”. Another revealed;

“What I’ve been able to do is increase my hours from 120 – 125 hours a week, if anything I’ve increased my hours. I can go on holidays now, I can purchase support in a different country – it’s something that wasn’t applicable before.”

Leaders reported high levels of satisfaction with their social relationships and with time spent with family and friends following the transition to the Direct Payments model. Generally Leaders indicated that the type of support they received under the Direct Payments model helped them to build better and stronger social relationships and networks in their communities;

“I am very well known in the community, involved in the local football community.”

Several Leaders revealed that the model facilitates the forming of close relationships with Personal Assistants, at both a professional and personal level and that being an employer “builds a different kind of relationship I can surround myself with people who hold my life in high regard” and;

“it is such a great advantage when I was able to have my own company and my own PAs, to dictate and to control all kinds of situations I am a better father for it because I am able to make decisions with the PA myself.”

The choice and control afforded to Leaders by directing their own payments gives Leaders the opportunity to build better quality support networks. Generally, Leaders felt they were in control of their daily lives, the support they accessed and how it was delivered and that this subsequently had a positive effect on their wellbeing and their social relationships;

“I could not see myself any longer in the care of the service of some other provider, I’ve been heavily affected by the fact that I’ve been let down on many different occasions that would have affected me mentally, physically, emotionally, from being provided care from a different service provider.”

Another point that was raised during the interviews was that the traditional service provision model of Personal Assistance has restrictions around the provision of Personal Assistance when an individual is hospitalised. This is addressed in the Direct Payments model as this model affords the Leader to use their Personal Assistant while they are in hospital. This is an important factor as *“a person’s need for a Personal Assistant does not cease just because they are ill and in hospital, sometimes that is when you need your Personal Assistant even more.”*

8.3 Choice and Control Over Care

The qualitative research illustrates that the concept of control over support arrangements is in fact made up of a number of different elements; control over how assistance is provided, when it is provided and by whom. In addition, all of these elements have wider benefits in terms of enhancing personal freedom, relationships with others and general quality of life. It was indicated numerous times by Leaders that traditional service providers fail to reflect some of the needs and preferences of the users of services in terms of the timing and methods of delivery of care and the individuals delivering the care. Without exception, Leaders reported a significant change in their level of care and support through the Direct Payments model. This was usually because of the increased flexibility and choice that the Direct Payments model affords them. For example, being able to choose their own Personal Assistant which was usually not possible under the traditional service provision model;

“a Personal Assistant is no longer forced on me, I have control over the person I employ”

and

“with them (the service provider) I was so much more restricted on who I could hire.”

At least two of the Leaders indicated that being given the liberty to choose their own Personal Assistant, with the help of their support network, meant that “strangers” or “random individuals” were no longer coming into their homes where they and their family live;

“It’s a lot better, the fact that you know them.”

There were also numerous examples of increased flexibility over the hours that Personal Assistants work. Leaders are now able to work closely with their Personal Assistants and arrange for their Personal Assistants to work at times that suit their individual needs. For example, if a Leader wants to go to a concert or travel to another city at the weekend, they can arrange to use their allocated hours of Personal Assistance at the weekend instead of during the week;

“I was with XXX prior to AT but it was not flexible. Now I can bank hours, I can go to the zoo and I can bank hours to have longer hours with a PA”

and another Leader noted;

“When I was with the previous services they said I only had so many hours basic and so many hours anti-social and so many hours for Sunday but now I can work out when I want them.”

Leaders indicated that the flexibility afforded to them by the Direct Payments model not only suited their needs but contributed to a better working relationship with their Personal Assistants and there was increased flexibility on both sides;

“they can swop around ... or come in early if they need to. We work it out together.”

Another leader indicated “I can do things on different days” and “I was able to travel to Australia, I could hire a PA to travel with me”. One Leader indicated that the flexibility afforded to them through the Direct Payments model of individualised funding has permitted them to return to University to further their education, something that they believe wouldn't have been possible due to the rigidity of the hours of Personal Assistance delivered through their previous service provider. This contrasted significantly with the traditional service provision model where the hours of Personal Assistance that individuals received were very restrictive;

“There was no flexibility with them, we had to give seven day's notice of a change of timetable Now we have a choice, we can go anywhere”

and

“when you were with the other system you'd be worried you wouldn't be using all your hours and if someone got sick and I couldn't get anyone to cover ... now I can hire agency staff if I'm stuck.”

In the traditional service provision model, an individual is usually allocated a set number of Personal Assistance hours each week and the times that those hours of Personal Assistants are delivered are dictated by the service provider and not by the individual. This means that individuals getting their service through the traditional service provision model are severely restricted in the activities that they could do.

“It has allowed me to take control once more of the direction that my life goes .. no longer am I restricted by someone else's timeline of where I should get support and how I should get support, instead I implement my support, I'm able to implement rosters, I'm able to negotiate contracts, I'm able to hire PAs on short and long-term hours and there's more of an ability to hire localised staff than staff travelling hours and long distances to come and support me for a limited amount of time.”

Leaders noted that transitioning to the Direct Payments model has been “a ray of light”, has “given me a new lease of life” a “sense of independence” and “has allowed me breathing room”. One Leader noted that they finally feel like they are “being treated like a real person”. Another pointed out that they “have been able to join a choir and can arrange for my Personal Assistant to take me there twice a week”, a “luxury” that they could not do through their Personal Assistance service provided by a traditional service provider due to the lack of flexibility in hours provided. Another pointed out;

“What I've been able to do is increase my hours per week, if anything I've increased my hours and I can go on holidays now, I can purchase support in a different country - it's something that wasn't applicable before.”

The flexibility and control over care that comes with the Direct Payments model is not confined specifically to Personal Assistance. As noted previously, for Leaders who are unable to direct their own services, due to age or disability type, family-led membership is facilitated by ÁT. The family members of these Leaders discussed the increased level of care and the flexibility that these Leaders have because of the Direct Payments model. One family member indicated that;

“we are all much happier being in charge of funding. ÁT is much better. My needs change as time goes by and this model allows flexibility so those needs can be met”

The Direct Payments model has permitted one Leader to apply a behaviour analysis programme designed specifically for them and to meet their individual needs. This is meeting the needs of the individual and their family members feel

that the Leader has made significant progress since this tailor-made programme has been in place.

8.4 Relationship with Personal Assistants

Leaders referred to the stronger and more personal relationships that they have with their Personal Assistants as a result of the Direct Payments model. Leaders spoke about the importance of familiarity and empathy in the relationship between them and their Personal assistant and how being able to choose their own Personal Assistant was extremely important to them. The ability to choose and hire a Personal Assistant that meets the needs of the Leaders has led to a positive change in the relationship between most Leaders and their Personal Assistants;

“I wasn’t the employer but when I moved to ÁT my PAs saw me as their employer and their boss and they saw that even before I saw it ... I started to realise that the buck starts with me and my company, I can no longer pass it to the employer, I am the employer. I saw that initially as a bit scary but having done it over the last few years, I’m not a bad employer.”

Having choice over one’s Personal Assistant has also had a significant positive impact on the lives of the Leaders and their family members. One Leader revealed that they prefer to hire a Personal Assistant who is studying so that they can discuss their studies with them and that “I’ve really benefited from it, I wouldn’t have had it with my service provider.” Another Leader discussed how before they moved to ÁT, they had care assistants and not Personal Assistants and this was difficult for them and their family;

“I wouldn’t have had a personal assistant until I came to ÁT, I would have had carers, health care assistants ... they had different titles. They’d be called one thing one week and a service would change and they would be called another thing another week. It was very difficult they could only provide a certain level of support.”

A number of Leaders referred to what they felt was a “lack of respect” from Personal Assistants that were provided to them by their previous service provider but that being the direct employer of their Personal Assistant means that “I get more respect from my PAs”, “we joke about me being the boss now” and “I have a better rapport with my Personal Assistants.” Leaders felt that their previous service provider was “overly cautious about moving on PAs when it wasn’t working out” and they alluded to a fear and a reluctance of bringing any issues with Personal Assistants to the attention of their previous service provider in case there was a change to their service provision as a result;

“If I wasn’t getting on with my PA I’d be worried that I’d be putting the service provider into a scenario where they would have to deal with this person and how is it going to impact on my service.”

However, Leaders feel that with the support of ÁT and their circle of support that they have been and are able to solve any issues that arise with their Personal Assistants as they are in control and they are the direct employer;

“with the previous service provider, I had a problem with a Personal Assistant and I felt that they didn’t give me enough support through it. Now I know that if I have a problem I can just go look for help, I’m in charge. When you are with a service provider you’re adhering to their rules and there are so many rules. If I had a serious problem now I’d get help.”

It was clear from the interviews that many of the Leaders have the best interests of their Personal Assistants at heart with some remarking how they “treat their Personal Assistant like they are family” and that being an employer allows a more stable relationship to be formed. Leaders also felt that being an employer of a Personal Assistant also benefits the Personal Assistant as the flexibility within the model works to the benefit of the Personal Assistant also;

“We are a team much more of a team than we ever were before. We all take care of this small business, it’s much more like a small corner shop, I love it. We share the same dream.”

Leaders commented that they were willing to pay above the going rate to retain quality support workers and Personal Assistants that they have built up lasting relationships and friendships with. Furthermore, many of the Leaders were starting to think about the future of their Personal Assistants and their long-term prospects with one commenting;

“I’m beginning to think of this and their security into the future ... we’re negotiating pension contributions into the future. I’m keen to see them do external training, beyond being a PA. I’m helping them to start thinking about the future

and further opportunities outside of being a PA.”

Leaders, as employers, have a range of responsibilities and obligations to ensuring that all of their employees, or Personal Assistants, receive certain employment rights and supports, as governed by Irish employment legislation. ÁT is instrumental in making sure that Leaders are knowledgeable about employment legislation and adhere to the rights and obligations under employment law.

8.5 Administration and Burden

The administration that come with setting up one's own company was discussed in detail by each of the Leaders. Leaders talked about the advantages and of the “burden” and “responsibility” that comes with the administration of setting up and running a company successfully. For example, one Leader noted that;

“I do prefer the flexibility that I have now but there is a lot of responsibility that comes with it”

and another pointed out that

“the first month I paid wages to other people's accounts I was so nervous I was shaking at the computer ... it's calmed down a lot since then”

and

“I was nervous of setting up my own company but it was a good challenge and I have good support.”

For Leaders who were successfully directing their own services for a number of years, there were two evident feelings relating to the administration, self-confidence and empowerment. A number of those directing their own service through their own companies feel that there is an increased self-confidence that comes with managing one's own company following an initial period of uneasiness;

“it's been great, there is a lot of work to it ... it's not an easy option, a lot of paper work and computer work and I do it all myself but you've got to be committed to it ... I've gotten more confident, I worry less about it”

and

“when I started doing the ÁT paperwork I got my confidence back, that if I really wanted to, I could get a job”

and

“it's given me more responsibility and makes me feel better.”

Several Leaders felt empowered once they had gotten to grips with completing their own timesheets and payroll;

“I find the paper work empowering, I enjoy it and I like to keep on top of it”

and

“hiring and firing, implementing policies, procedures and making sure that the staff are safe and I am safe is overwhelming but really if you put the ground work in at the beginning, if you have a solid policy procedure and a good circle of support and ÁT are there to nurture and support the company if and when you need it, it's empowering.”

Some studies have identified that users can find the paperwork and bureaucracy in some Direct Payments schemes burdensome and for people with fewer support needs, this may cause them to reject the use of Direct Payments on the grounds that they are “not worth the trouble”. This was reinforced by several Leaders who felt that “it may be exclusionary for people with less skills” and “it's not for everybody - it wouldn't suit everybody, not everyone has the ability”. Another indicated that;

“Direct Payments wouldn’t suit everybody. The paperwork. I think 90% of people would be able to do it but a small portion of people wouldn’t.”

The responsibility and energy required to effectively implement Direct Payments in one’s life may be time consuming and overwhelming for some with most Leaders reporting that financial reporting took them approximately four to five hours per month. Two of the Leaders questioned the need for the reporting and the setting up of a company;

“why do we need all this paperwork in the first place, the UK don’t need all this paperwork”

and

“you should not have to set up a company to live your life as you see fit.”

However, ÁT, as the facilitator of Direct Payments, play a significant role in ensuring that the Leaders are comfortable with the regulations and with the administrative burden associated with owning a company. Leaders identified the important role of ÁT stating that “it is not easy to do” but “ÁT are great for support, support is very important for rules and regulations” and that “any time I’ve had a question, it’s answered straight away.” Leaders benefitted from the knowledge that ÁT are available to advise and felt that “it’s good that they add little things at a time and not all at once.”

8.6 Community and Economic Participation

Suitable and adequate support types, such as Personal Assistance, can help persons with disabilities to achieve social integration, personal life goals and economic independence and participation. As highlighted by Quin and Redmond (2003), educational disadvantage in the area of disability is an early determinant that can affect the ability of persons with disabilities to achieve economic participation in society. Failure to supply adequate and flexible supports that enable persons with disabilities to access education can affect that person’s access to the labour market and obtaining meaningful work. It was evident that the choice and control afforded to a number of Leaders by the Direct Payments model has permitted them to return to education, to take up gainful employment and for some to have the confidence and belief in themselves that if they can run their own company that they can return to the workforce.

One Leader identified that the flexibility and control that they now have over their Personal Assistance has contributed to them returning to the education system;

“By taking this on, it has freed up so much more time and availability for myself to go out and do social things and education ... with the providers I had before, staff could only come in at a certain time and go home at a certain time. I don’t think I would have been able to go back to University on a full-time basis if I wasn’t getting Direct Payments.”

Furthermore, a Leader whose job requires significant international travel outlined that before they moved to the Direct Payments model, the “service providers weren’t very flexible to me” and that using their monthly allocation of hours of Personal Assistance for two weeks while travelling internationally for work was involving a significant amount of bureaucracy. They indicated that they now have the flexibility to use their allocation of Personal Assistance hours to best suit their employment needs.

Another Leader outlined how “since taking up Direct Payments, I’ve taken up employment. I’ve used the flexibility of the budget to get Personal Assistants when I need them.” Moreover, and as outlined in Section 7.5, Leaders noted that the experience and confidence instilled in them through the running of their own company has prompted them to seek employment.

Direct Payments not only has an effect on the person with a disability, it also has significant effect on their family and support network. This research has found that giving Leaders choice and control over their Personal Assistance has permitted their family members and supporters to return to the workforce. Leaders indicated that having flexibility in terms of their hours of Personal Assistance has ensured that their spouses and family members have been able to return to work, something that wasn’t possible with their previous service provider. This in turn contributes the employment rate in Ireland and the local economy.

Furthermore, it was alluded to by several Leaders that the Direct Payments model of service provision allows them to employ people in their locality with a number noting that previously, their Personal Assistants had to travel long distances to work with them.

“I have a more enthusiastic, a more localised and more efficient workforce than what I would have had before and with that then comes independence, authority and dependence on me as a manager and owner of a company. I’ve benefited greatly and so has my local community by the fact that I’ve been able to put money back into that area. It works on so many different levels. I feel that my life has increased dramatically in self-worth and ability in that I’m able to control a lot more of what I hadn’t been able to do before.”

This demonstrates that the Direct Payments model of service provision not only contributes to the economy by providing employment for Personal Assistants but it also makes a contribution in terms of encouraging and permitting persons with disabilities to return to the workforce and taking the responsibility of caring away from family members and allowing them to return to the labour market while contributing to the growth of employment in the local economy.

8.7 The Future of Direct Payments

Leaders discussed their aspirations for their Companies and how they believe the Direct Payments model of individualised funding can grow and evolve. Several Leaders expressed an interest in expanding the Direct Payments model to the purchase of aids, appliances and services such as wheelchairs, hoists, occupational therapy and physical therapy;

“I would like choice over my wheelchair, would prefer to get money for physio and organise it myself... I might not have to wait a year to get physical therapy then.”

Leaders feel that “taking out the middle man” would mean giving them greater choice over more of their lives and would potentially increase the pace at which they receive aids and equipment as well as services such as a physical therapist. One Leader recounted having to wait one year to see a physical therapist and indicated that as their condition had worsened during that year without therapy, they required more physical therapy than they would have if they had been seen earlier. Several Leaders noted that the list of aids, appliances and services which could be purchased using an individualised fund could be limited and in the interest of transparency, receipts for all purchases should be provided for any reporting period. From an economic point of view, this would create more demand in the private market for certain goods and services, increase the quality of the goods and services provided and therefore decrease the prices of certain goods and service. This research finds that users of Direct Payments feel that there would still be a role for the services of traditional services providers if Direct Payments was available to everyone but that persons with disabilities would buy services directly from service providers instead of being provided with them.

Freedom and movement of budgets within the Direct Payments model was something that Leaders would like to see integrated into the model. Currently, if a Leader moves from one CHO to another CHO, they must reapply for an individualised budget in that CHO. This brings restrictions in terms of choice of employment, education and Personal Assistants;

“If a PA can move, why can’t I?”

Three Leaders expressed a fear of losing their Direct Payments system of individualised funding in the future as they feel that the future of Direct Payments is uncertain.

It was outlined in Section 7.6 that the Direct Payments model has given a number of Leaders the flexibility to take up employment. Several Leaders indicated that the experience and confidence instilled in them through the running of their own company has prompted them to seek employment however there is a reticence among Leaders to take up full time employment as they would risk losing their medical cards and potentially other benefits;

“it’s a drawback, if I work I lose my medical card. It’s not worth it. I’m on so much medication that if I went back to work I wouldn’t be able to afford to buy it, it’s too expensive. That’s where people are caught. They stop people from helping themselves.”

In general, Leaders are positive about the Direct Payments model of service provision indicating²⁶ that “It’s important that we give Direct Payments every opportunity to advance” and though Leaders believe that the Direct Payments model of individualised funding will not suit the needs of every person with a disability, they “wish it could become the norm.”

9. Costs, Cost-effectiveness and Cost-Savings

This section presents the findings with regards to costs to the Government, Section 39 service providers and Leaders directing their own payments with the support of ÁT with regard to the provision of hours of Personal Assistance. Overall the Direct Payments model of individualised funding Facilitated by the ÁT network leads to cost savings and cost efficiencies. An analysis of the hours of Personal Assistance that eighteen Leaders direct through ÁT show that efficiencies in the Direct Payments model amounts to Leaders getting 58.5 hours of extra Personal Assistance per week or 3,042 hours per annum compared to when they received their services through the traditional service provision model. Furthermore, the Service Level Agreements negotiated on behalf of each Leader by ÁT show a cost saving of €1,214.43 per week and a total saving of €63,150.50 in 2016.

A combination of sources have been used to estimate the unit costs for the support services used by the Leaders in this evaluation. As outlined in Section 5.2 service level agreements are in place between the HSE and Section 39 organisations such as Cheshire, the Irish Wheelchair Organisation and Bluebird Care who usually provide persons with disabilities with Personal Assistants. Typically, Section 39 organisations receive €23 per standard hour of personal assistance. Rates paid by the HSE to service providers for personal assistant services vary between organisations and by location however as one Section 39 organisation delivered approximately 78% of all Personal Assistance hours in Ireland in 2016 at a cost of €23 per hour, €23 per hour of Personal Assistance is used as the hourly cost of an hour of Personal Assistance for the purpose of this analysis.⁴ The HSE payment of €23 per hour of Personal Assistance to Section 39 organisations recognises the costs associated with employers PRSI contributions, holidays, training and bank-holiday pay. As already noted in Section 4, ÁT negotiate a Service Level Agreement, on behalf of each Leader, with the HSE. Each Leader is different, has varying needs and is located in a different part of the country therefore the rate of pay per standard hour of personal assistance is different for each Leader and varies from €20.70 per hour up to €24.62 per hour. The HSE payment per hour of Personal Assistance to each Leader recognises the costs associated with administration, employers PRSI contributions, holidays, training and bank-holiday pay.

9.1 Cost Efficiencies

Of the eighteen Leaders that receive Personal Assistance through the Direct Payments model of individualised funding, eight Leaders reported that they have more hours of Personal Assistance with Direct Payments (DP) than they had with their traditional service provider. The general feeling from Leaders is that they “get value for money” since they transitioned to the Direct Payments model and almost all of the Leaders interviewed noted that the flexibility within the budget permits cost savings to be made;

“fourteen hours of care and one hour of shopping assistance has expanded to seventeen hours with ÁT.”

Another Leader pointed out that since moving to the Direct Payments model of individualised funding, they now have 5% more hours of Personal Assistance. One Leader indicated that since they moved to the Direct Payments model “I have more hours, way more hours” of Personal Assistance.

Cost efficiencies are achieved in a number of ways through the Direct Payments model. Transferring the majority of the administrative burden to the Leaders has resulted in cost savings as well as savings that are derived from payroll being completed by the Leader. Further efficiencies are gained through Leaders hiring Personal assistants with varying skill sets to meet their individual needs. This enables Leaders to hire Personal Assistants on varying pay scales, depending on the level of skill of the Personal Assistant and the level of skill that the Leader requires from their Personal Assistant. For example, a Leader may need a highly skilled Personal Assistant to carry out certain tasks with them on a certain number of hours per week but may need a less skilled individual to aid them with other tasks for the rest of their hours of assistance in a given week. One Leader pointed out that

⁴ Irish Wheelchair Association (2017). Annual Financial Statements for the Year Ended 31 December 2016. Available at http://www.iwa.ie/downloads/information/publications/annual-reports/1499_WEB_IWA_2016_Financial_Accounts.pdf, Accessed August 11th 2017.

“on some occasions having someone to drive, to cook, to do the more social things, I would benefit more from having a PA without a medical or caring background because things can actually get confused. what really I need for most of my needs is an understanding of hygiene or care or supports for physiotherapy that need to be supported.”

Being able to recruit Personal Assistants on varying pay scales and skill levels combined with the administrative efficiencies achieved through Leaders adopting much of the administrative burden, has permitted Leaders to stretch their budgets much further in terms of Personal Assistance hours. It was also noted that all Companies directed by Leaders operate under and adhere to the national employment law framework. ÁT plays an important role in making sure that all Leaders are knowledgeable regarding company law and employment regulations.

Table 9.1 demonstrates the cost effectiveness of the Direct Payments model in terms of Personal Assistance hours. The first column Total PA Hours/Week as Negotiated with the HSE shows the number of hours of Personal Assistance per week that ÁT negotiated with the HSE on behalf of each Leader in 2016. The second column Actual PA Hours Available to Leader/Week lists the actual number of hours of Personal Assistance per week that each Leader was able to purchase using their budget. Column 3 illustrates the number of additional hours of Personal Assistance per week that each Leader received using their Direct Payments budget. The last column shows the number of additional hours of Personal Assistance per year that each Leader received using the Direct Payments model.

The results show that of the eighteen Leaders, eleven were able to stretch their Direct Payments budget and increase the number of Personal Assistance hours they received per week by a total of 58.5 hours or an average of 3.2 hours across the eighteen Leaders. This translates to an extra 3,042 hours of Personal Assistance per year. Using the standard Section 39 organisation rate of €23 per hour of Personal Assistance, this equates to a cost efficiency of €69,966 per year across eighteen Leaders.

Table 9.1: Total and Actual Hours of Personal Assistance

Leader	Total PA Hours/Week as Negotiated by ÁT	Actual PA Hours Available to Leader/ Week	Variance in Total Weekly Hours (Actual - Total)	Variance in Annual Total PA Hours (52 weeks)
1	15.0	17.0	2.0	104.0
2	53.0	54.5	1.5	78.0
3	19.0	24.0	5.0	260.0
4	37.0	49.0	12.0	624.0
5	31.0	31.0	0.0	0.0
6	24.5	24.5	0.0	0.0
7	90.0	104.0	14.0	728.0
8	17.5	18.5	1.0	52.0
9	87.0	94.0	7.0	364.0
10	12.0	12.0	0.0	0.0
11	80.0	80.0	0.0	0.0
12	17.5	18.5	1.0	52.0
13	70.0	70.0	0.0	0.0
14	84.0	84.0	0.0	0.0
15	120.0	120.0	0.0	0.0
16	91.0	92.0	1.0	52.0
17	62.0	72.0	10.0	520.0
18	32.0	36.0	4.0	208.0
Total:	942.50	1,001.00	58.50	3,042.00

Leaders reiterated what has already been reported in previous research into the cost effectiveness of the Direct Payments model, that Leaders have the added incentive to “use your payments and set up your company in a way that you get the most out of it.” One Leader indicated that the incentive to allocate the Direct Payments funding wisely is because;

“we have to get out of bed in the morning. If we spend all night in the pub having a hoolie and spend all our budget, then we cannot get out of bed in the morning because we will not be able to afford a Personal Assistant to help us. Our independence depends on us.”

At least five of the Leaders noted that the flexibility and confidence that the Direct Payments model has given them has prompted them to look for employment with one noting

“It gave me belief in myself because after I left work I began to think I was a bit stupid even though I knew I probably wasn’t... .. when I started doing Direct Payments paperwork I realised I could get a job again ... got back my confidence.”

One Leader noted that their job requires them to travel internationally but however “PAs travelling with me was a problem from my old provider” but this issue has been solved by the Direct Payments model of service provision;

“I can ask my PA to do a two-week shift on and a two week shift off, it suits them and it suits me.”

9.2 Costs within the Individual Funding Package

As outlined in Section 6 ÁT acts as the intermediary between the Leader and the HSE and negotiates a personal budget on behalf of the individual which is outlined in a Service Level Agreement. In most cases, prior to transferring to ÁT, Leaders are in receipt of a dedicated number of hours of Personal Assistance per week and this service is usually provided by a traditional service provider. The budget for these hours is negotiated by ÁT, debundled from the service provider, transferred to ÁT and finally transferred to the Company belonging to the Leader. The Service Level Agreement rate per standard hour of Personal Assistance is negotiated by ÁT on behalf of the Leader is different for each Leader.

In Table 8.2 Column 1, Average PA Hours per Week as Negotiated by ÁT, shows the average number of hours of Personal Assistance per Leader per week negotiated by ÁT on behalf of the eighteen Leaders. These range from 12 hours per week to 120 hours per week for one Leader with particularly high care needs. Column 2, Average Service Agreement Rate per Hour of PA with ÁT, illustrates the average rate per standard hour of Personal Assistance as negotiated with the HSE. Column 3, Service Agreement Rate per hour of PA with Section 39 Organisation, is the rate per standard hour of Personal Assistance that Section 39 organisations get from the HSE to provide one hour of Personal Assistance.⁵ Column 4, Average Cost of PA per Leader per Week with ÁT, shows the average cost of providing 52.4 hours of Personal Assistance to each Leader per week through the Direct Payments model. Column 5, Average Cost of PA per Week with Section 39 Organisation, shows the average cost of providing 52.4 hours of Personal Assistance to each Leader per week through the traditional Service Provision model. Column 6, Variance in Cost of PA per Week, shows the average cost savings to the HSE per week for one Leader when receiving their Personal Assistance through the Direct Payments model compared to the traditional service provider or Section 39 organisation. Spreading this cost saving across the eighteen Leaders, a saving of €1,272.35 per week is made from the Direct Payments model of service provision. This translates to a saving of €66,162.10 per year for eighteen Leaders.

⁵ Irish Wheelchair Association (2017). Annual Financial Statements for the Year Ended 31 December 2016. Available at http://www.iwa.ie/downloads/information/publications/annual-reports/1499_WEB_IWA_2016_Financial_Accounts.pdf, Accessed August 11th 2017.

Table 9.2: Personal Assistance Budget

Average PA Hours per Week as Negotiated by ÁT	Average Service Agreement Rate per hour of PA with ÁT	Service Agreement Rate per hour of PA with Section 39 Organisation	Average Cost of PA per Leader per Week with ÁT	Average Cost of PA per Week with Section 39 Organisation	Variance in Cost of PA per Week Cost Savings
52.4	€21.65	€23.00	€1133.59	€1204.28	€70.69
<i>Total Weekly Savings for 18 Leaders:</i>					€1,272.35
<i>Total Annual Savings for 18 Leaders:</i>					€66,162.10

It is important to note, when comparing the Service Agreement rates per standard hour of Personal Assistance as negotiated by ÁT and that of a Section 39 organisation, that the rate per hour of Personal Assistance as negotiated through ÁT covers training costs, PRSI contributions, holidays, administration costs and bank holiday pay. A minimal fee is also required by ÁT in order for the core staff of ÁT to provide support and expertise to the Leaders. ÁT requires a fee of €1.875 per hour of Personal Assistance from each Leader in their first year. During year 2 through to and including year 5 ÁT request a fee of €1.675 per standard hour of Personal Assistance and in year 6 this decreases to €1 per hour of Personal Assistance. Therefore, the longer that a Leader is with ÁT, the less support and expertise they will need and the lower the fee they must pay ÁT.

9.3 Transparency

As well as giving Leaders greater value for their allocated funding, the Direct Payments model facilitated by ÁT provides considerable more clarity as to precisely how and where public funds are spent when compared to the traditional service provision model. For example, if ÁT negotiate an individualised funding package for a Leader at a cost of €22 per standard hour of Personal Assistance, this €22 includes the fee that ÁT gets for support, the costs associated with administration, employers PRSI contributions, holidays, training and bank-holiday pay, it is all encompassing. The transparency of the Direct Payments model is something that the Governments Programme for Government 2011 - 2016 acknowledged when it made a commitment to

'move a proportion of public spending to a personal budget model so that people with disabilities and their families have the flexibility to make choices that suit their needs best. Personal budgets also introduce greater transparency and efficiency in funding services'

(Department of the Taoiseach, 2010, p53)

Furthermore, the Leaders felt that there is a need for transparency in the flow of funds to persons with disabilities with one Leader noting that 'transparency is key' to making sure that the individuals that are most in need of support get it. Many of the Leaders discussed how the reporting and accounting mechanisms within the Direct Payments model address concerns that the Government and the HSE may have regarding the accountability of funding allocation because

"returns are creating accountability, you can see the opening and closing balance, payroll and bank charges." One Leader suggested that one reporting period per year may suffice as they felt that the frequency of reporting was tedious.

10. Conclusion and Recommendations

The importance of having control over one's support was evident throughout the interview process. The Direct Payments model of service provision facilitated by ÁT places Leaders at the centre of the decision-making process, recognising their strengths and preferences and gives them the confidence, support and means to shape the way in which their care is provided by transferring choice and control over funding decisions to them and allowing them to identify their unique individual needs. In line with Flemings' (2016) findings, the Direct Payments model offers Leaders far greater flexibility and more choice and control over their service provision, leading them to be more confident, empowered and independent as individuals. The Direct Payments model of individualised funding offers value for money through cost savings and cost efficiencies. Cost efficiencies to the value of €69,966 were made in 2016 from eighteen Leaders being able to stretch their budgets further in terms of hours of Personal Assistance and a saving of €66,162.10 was made by eighteen Leaders receiving their Personal Assistance through the ÁT model of Direct Payments when compared to a Section 39 organisation. While the cost saving element of Direct Payments is to be commended, the potential introduction of the Direct Payments model should not be seen only as a cost saving measure, as this may ultimately deny persons with disabilities a real choice.

This report has highlighted the key benefits of the Direct Payments model for individuals with disabilities. It is evident from the research that there is a significant need for a policy change in Ireland and an emphasis on a change to the current model of service provision in Ireland. There is strong evidence that indicates that the Direct Payments model of service provision gives those directing their own services a greater sense of control and empowerment. Having control of ones' support needs is an essential part of well-being and active citizenship. An important aspect of the Direct Payments model that was identified during the interviews was the support that ÁT provides to Leaders. As an organisation, ÁT was found to provide a high level of guidance, advice and knowledge to Leaders which ensures that they do not have to go through the process of setting up and managing a company alone.

One could assume that should Direct Payments be made available to every person with a disability in Ireland, persons with disabilities would move away from traditional service providers. However, the experience in Sweden illustrates that when consumer choice was introduced through Direct Payments there was no mass exodus away from service providers as service providers are still used to purchase services. The findings from this report show that Leaders are very open to using their personal budgets to purchase services directly from service providers and this may lead to efficiencies in the system in the long term.

If a model of Direct Payment were rolled out across Ireland, its success would depend on a range of factors including a standardised needs assessment tool, a pool of personal assistants from which to hire, a health system that recognises the merits of the Direct Payments model, changes in the routine practices and organisational culture of traditional service providers and supportive organisations such as ÁT to make sure that persons with disabilities have access to the appropriate documentation, advice and support.

10.1 Recommendations

Given the advantages of the Direct Payments model of Individualised Funding facilitated by ÁT and the growing emphasis, both from a public and policy point of view, for change in policy and legislation relating to the current system of service provision, this report finds that it is vitally important that the ÁT Direct Payments model continues to be funded by HSE, at the very least until such time as a clear national strategy and framework is agreed in the area of Direct Payments. It is equally important that persons with disabilities in receipt of services through the traditional service provision model be provided with the relevant advice, information and guidance to establish if the Direct Payments model of service provision is suited to their needs and is compatible with their aspirations for independent living. Every person with a disability in Ireland should be afforded the opportunity to direct their own services and those wishing to transition to the ÁT model of direct payments should be supported to take this step.

As there is no standard assessment tool by which person with disabilities are assessed in terms of their care needs, a single assessment tool is required to evaluate individuals' resource allocations based on the individual's goals, the impact of their disability, their family circumstances, their living arrangements and so on. The absence of a standardized assessment tool means that there is little clarity in the way that resources are allocated to persons with

disabilities in different parts of Ireland and this brings a sense of inequality to the system. The lack of a standardised assessment tool also means that the changing needs of persons with disabilities are not correctly being monitored and subsequently reviews and revaluations of needs are not being carried on a regular basis.

This report finds that persons with disabilities in receipt of disability services perceive that their movement from one CHO to another is restricted as there are significant bureaucratic hurdles to be overcome for them to receive disability services in a different CHO. A need exists to transform the disability service provision model to permit persons with disabilities to more easily move their service provision from one CHO to another should they need to for personal, employment or educational reasons.

At present, Leaders can use their budgets to purchase Personal Assistance. However the budget should be extended to the purchase of equipment, aids, and other goods and services that relate to the healthcare needs of the individual following an assessment. According to Kremer (2007) this would give further choice and control to the individual, decrease the time that it takes for persons with disabilities to receive certain goods and services, create demand in the private market and drive a more efficient system of service provision.

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