

Extending^{the} Boundaries

...I was a crying child. I always knew what is what. I believe people knew too, even though I often heard people whispering that I will never be able to think, walk or talk. This fogged my mind, as I was a thinking human being long before I learned to read, climbing mountains of discoveries of my little big world. I always knew more than people credited me. Radio and music cushioned me. This gave me a fringe of a world I was living in but not yet part of.

I remember being asked 'Where is God?' I was always blessed with a sense of humour. I couldn't help thinking what a question to tease me with. I flapped my palm hinting I didn't know, hoping people could understand my monkey language. I often laughed silently, how do I know when I never met him yet? I always talked to him for comfort but he was never a pop star I wall the walls with

**Our Experience
of Independent Living**





Extending the Boundaries

Our Experience of Independent Living

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With

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long before I learned to read, climbing mountains of dis-

PREFACE

It is now thirteen years since the Personal Assistance Services started in Ireland. Before that the only options open to disabled people, who needed assistance, was to rely on family members or go into residential/institutional care. True, there was a service called the Care Attendant Scheme and the Home Help Scheme, but these were focused around family relief and/or bare minimal assistance. None of these options or services provided significantly disabled people with the opportunity to aspire to a quality of life that everyone else took for granted.

The early pioneers of Independent Living learned about the new Personal Assistance Service model and everything that goes with it, from their peers abroad in the US, Sweden and the U.K. When these informed pioneers met with health officials, such learned executives said that the State could not afford such a service and that it would never work. Well thirteen years on we in CIL wanted to see exactly how well Personal Assistance Services do work. Do they truly facilitate Independent Living? How far has Independent Living come?

With these questions in mind we sought and gratefully received funding from the Department of Community, Rural and Gaeltacht Affairs to commission independent research. The following is the outcome of the skilful work of Ralaheen Ltd whom we chose because we believe they understand what Independent Living is all about.

We sincerely thank the participants for giving so fully and honestly of their views, the team in CIL Carmichael House, who oversaw the research, and finally Dr. Pauline Conroy and Niamh Murphy of Ralaheen for their expertise.

*Eugene Callan
Chairperson
CIL Carmichael House*

people credited me. Radio and music cushioned me. This

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Dr Pauline Conroy

Niamh Murphy, B.Soc.Sc. M.Soc.Sc.

List of Acronyms

| | |
|-------|--|
| BCODP | The British Council of Disabled People |
| CE | Community Employment |
| CIL | Center for Independent Living |
| DPI | Disabled Peoples International |
| ENIL | European Network on Independent Living |
| HSE | Health Service Executive |
| IL | Independent Living |
| ILF | Independent Living Fund |
| IWA | Irish Wheelchair Association |
| MS | Multiple Sclerosis |
| NDA | National Disability Authority |
| PA | Personal Assistant |
| PAs | Personal Assistants |
| PAS | Personal Assistance Services |
| STIL | Stockholm Cooperative for Independent Living |
| UPIAS | Union of Physically Impaired Against Segregation |
| UN | United Nations |
| VAT | Value Added Tax |
| WTORS | Wheelchair Tie-down and Occupant Restraint Systems |

CHAPTER 1

THE BEGINNING OF INDEPENDENT LIVING

By Sarah Dixon (CIL Carmichael House)

Introduction

This chapter will examine the development of the Independent Living Movement in the USA to its emergence in Ireland. The chapter begins with an overview of the history of the Independent Living movement and continues by tracing its inception in the United States to its spread across Europe. It concludes by presenting the reader with an overview of the emergence of Independent Living in Ireland in recent decades.

A Historical Overview

During the nineteenth and twentieth centuries medical disciplines dictated the prognosis and outcomes for people with disabilities in Western society¹, with long stay hospitals and institutional care being the norm for disabled people considered unable to care for themselves. In the nineteenth century the emergence of an increasingly secular society, Darwinism, and an increasingly competitive industrial economy led to a climate in which impairment of any kind was seen as deviant. In the decades following the war a new more paternalistic way of viewing disability began to emerge, which saw people whose impairment made it difficult for them to compete in modern society as being in need of a cure, rehabilitation or, if all else failed, care. An industry soon arose around the disability issue, employing medical staff, therapists and administrators in Government, private and charitable organisations.

In the 1960s ideas began to change.² The shift in emphasis came from disabled people themselves, and was a result of a growing awareness of Civil Rights issues. According to Malhotra, the disability movement, as an entity run by and for disabled people only became established in the 1960s, as the 'New Left' began to emerge, characterised by movements such as the Civil Rights movement, the gay and lesbian movement, the movement against the war in Vietnam and the women's movement. The progress and politics of these movements gave disabled people a new way of expressing their own needs and aspirations.³

In the 1970s more radical political movements also emerged, such as Disabled in Action, established in 1970. These groups sought to heighten the political awareness of disabled people about the barriers that existed to full participation in US society. During the 1972 presidential elections disability groups joined with groups of disabled and highly politicised Vietnam veterans to demand dialogue and a voice in the political arena. The Vietnam veterans, within the Paralysed Veterans of America organisation,

¹ Barnes, Colin. (2003) 'Independent Living, Politics and Implications'. Available at: www.independentliving.org/docs6/barnes2003.html.

² Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future*, London: Routledge.

³ Malhotra, R. (2001) 'The Politics of the Disability Rights Movements', in *New Politics*, 8(3, New Series). Pg. 65-75.

were an extremely influential group, and were not afraid to use radical tactics to promote awareness and bring about political change. While they did succeed in raising awareness through a number of high profile protests in the early 1970s, the movement had little cohesion or long-term vision. Many of its actions were condemned by movements such as the Independent Living Movement, which felt that its political connections and lack of long term vision sometimes endangered progress being made elsewhere for the Disability Movement.⁴

In the post Second World War decades a new approach to disability was put forward, one which did not negate the importance and beneficial effects of medical interventions, but which brought social issues to the fore. This 'Social Model' underlined the fact that physical impairment is a subjective concept, and that it is cultural, social and economic barriers which 'disable' people. Overcoming these barriers requires society rather than disabled persons to change.⁵ The social model, which originated in Britain in the 1970s, has become influential in the legislation of many countries, including Japan, Sweden, the USA, South Africa and Britain.⁶

The Early Days: Berkely, California

In 1962 Ed Roberts, who was a polio sufferer, enrolled at the University of California in Berkeley. Initially, the Californian Department of Rehabilitation refused to sponsor his enrolment in university, believing him to be 'too disabled' to become a productive member of society. Roberts turned to the media, and successfully galvanised public opinion in his favour. However, whilst his application met the required academic standard, Roberts was informed that his disability was too great, and that there was no place suitable for him on campus. Eventually he was offered a dormitory place in the University's Cowell Hospital. Roberts and other disabled students began to hire and train assistants to allow them to become 'independently dependent'.

Roberts became involved in the Civil Rights movement that was emerging in the US, and began to see parallels between the discrimination against minorities such as African Americans and the experiences of disabled people. As more disabled students began to enter Cowell Hospital a group was formed to try and discuss ways of changing the segregated nature of life on campus.

In 1970 Roberts and his group achieved funding for a Disabled Students Program on campus. The aim of this program was to take disabled students out of the hospital environment and into the wider University community. The demand for these services, which treated disabled people not as patients but as consumers, quickly extended

⁴ Malhotra, R. (2001) 'The Politics of the Disability Rights Movements', in *New Politics*, 8(3, New Series). Pg. 65-75.

⁵ Barnes, C. and Mercer, G. (2003) *Disability*, Polity Press, Cambridge.

⁶ Barnes, Colin. (2003) 'Independent Living, Politics and Implications'. Available at: www.independentliving.org/docs6/barnes2003.html.

beyond the University and into the community at large. Roberts, seeing this demand, responded by setting up the first Center for Independent Living in 1972. By the mid 1970s Independent Living centres were springing up across California and beyond, to cities like Houston, New York and Boston.

THE EUROPEAN EXPERIENCE:

Sweden

According to Adolf Ratzka, the situation in Sweden in the 1970s while appearing relatively enlightened at first glance, had robbed disabled people of independence, dignity and pride. The Swedish tradition of redistributing wealth to all members of society meant that individual disabled people were given access to funding to adapt their living conditions. However, problems of equality of access to public amenities such as public transport and public buildings were largely left unaddressed.⁷

During the 1980s, Ratzka became involved in the Swedish Disability Movement and introduced the concept of Independent Living; the idea of direct payments to disabled people who could then become independent consumers rather than passive recipients of charitable ventures. In December 1983 he organised the first Conference on Independent Living in Stockholm, which was addressed by Ed Roberts.

After this conference a group known as the Stockholm Cooperative for Independent Living (STIL) was established, based upon the principles of Independent Living. Its primary goal was to introduce a new idea of '*personal assistance*', a service that would be funded by direct payments to disabled people. The users of the service would then be in charge of recruiting, training, supervising and firing of their own personal assistants (PAs). STIL's proposal met with hostility from various quarters, including government parties, disability organisations and disabled people themselves; many of whom, although unhappy with the service they were receiving, seemed unable to take on board the concept of self directed services. Notwithstanding the opposition, a pilot project was established in 1986 in which a direct payment was made to each service user involved after an initial assessment of need, which was to cover all expenses including the wages of the PA.

In 1989 the pilot project was accepted as successful, and the scheme was mainstreamed. This meant that those organisations that had been put off by STIL's radical image felt able to come on board. During a talk at the Japanese Ventilator Users Symposium Adolf Ratzka outlined his view of the situation in Sweden since the

⁷Ratzka, A. (2002) quoted at <http://homepage.tinet.ie/~andyh/cil/about.html>.

introduction of the Independent Living Movement. He acknowledged the fact that disabled people in Sweden are still more likely to have lower levels of psychological well being, and to have less opportunities to work, contribute politically or have a family, than other non-disabled members of society.⁸

The United Kingdom

During the late 1970s there was growing disillusion with the services available for disabled people in the UK. People began to look toward the USA and the experience of Independent Living there. In the early 1980s a number of key individuals, including Vic Finkelstein who is the founder of the Union of Physically Impaired Against Segregation (UPIAS), travelled to Berkeley to observe the Independent Living movement in action.

In the UK a rising tide of pressure from disabled people living in institutions, led to the establishment of Project 81. During the early 1980s the group managed to persuade their Local Authority to provide disabled people with payments agreed through assessments, so that they could pay for their own personal assistance and hence begin to move out of institutionalised care.

As in all countries where the Independent Living movement began to take hold, the biggest battle was in convincing the authorities that disabled people were capable of taking on the responsibility of running their own service. In addition, there was a learning process for disabled people themselves which involved confidence building and the development of skills, so that they would feel able to take on the responsibilities of Independent Living. In 1984 the Hampshire Centre for Independent Living, the first of it's kind in the UK, was set up and developed along the same lines as the Berkeley CIL.

The core work of the early CILs became identified as the '*Eleven Basic Needs*'. These were housing, personal assistance, mobility/transport, access, peer counselling, information, technical assistance, employment, education and training, income/benefits and advocacy.

In the early days of Independent Living the CILs were supplemented by volunteer schemes, whereby volunteer PAs allowed some disabled people a route out of residential care, and gave them a taste of Independent Living. At the same time some universities began to build specially adapted accommodation, which allowed disabled people to enrol in third level education. While these schemes were not initiated or run by disabled people themselves, they did allow a greater level of choice and were an

⁸ Ratzka A. (2004) 'The Swedish Personal Assistance Act of 1994', Independent Living Institute, Presentation in Helsinki, Finland.

intermediate step on the way to an American style ethos surrounding Independent Living. The movement began to gather pace in Britain with the emergence of more CILs, which used the 'social model of care' and Independent Living theory to focus upon the local needs of local people.

In 1987, following outrage at the cutback of an allowance called the '*Domestic Care Allowance*', which had allowed many disabled people to live independently, the British Government introduced the Independent Living Fund (ILF). This allowed for direct payments to disabled people for personal assistance. This fund was a great asset to the IL movement, it allowed greater flexibility and choice for those already receiving personal assistance services (PAS), and also allowed people living in areas where Local Authorities still felt that cash payments were illegal due to 1948 legislation, to become involved in Independent Living.

In 1989 the British Council of Disabled People (BCODP) began its 'Direct Payments Campaign'. The BCODP was set up in response to the uneven spread of Direct Payments and Independent Living practice across the UK. The launch of this campaign coincided with the setting up of the European Network on Independent Living (ENIL). ENIL was established in 1989, after a group of over eighty disabled people from fourteen different countries, congregated in Strasbourg. The founding of ENIL was the beginning of a co-ordinated and integrated approach to Independent Living across Europe.

According to John Evans '*the development of Independent Living schemes, which now are more commonly known as Direct Payments schemes, was probably one of the most crucial developments in strengthening the infrastructure to mould the schemes into the framework of the social policy systems of the Country*'.⁹

The Irish Experience

The Independent Living Movement as a philosophy was adopted in Ireland, as in other countries, as a reaction against a tradition of institutional or family based care, which were the only options of care open to disabled people at the time. The rise of the Independent Living Movement within Ireland has allowed for the increased and genuine participation of disabled people within the community, and at the level of policy decision-making. In Ireland these two developments coincided with the establishment of the Forum of People with Disabilities in 1990.

The 1990s saw a period of profound change in policy, legislation and, to a lesser extent, service provision in respect of disabled people. New thinking emerged as a

⁹ Evans, J. (2003) 'The Independent Living Movement in the UK'. Available at: www.independentliving.org/docs6/evans2003.html.

result of influences from the USA and Europe, which challenged the perceived wisdom of the medical model of disability that had been dominant during the previous decades. The Independent Living Movement in the USA and the establishment of Disabled Peoples International (DPI), with its close cooperation with the United Nations (UN) in formulating the World Programme of Action Concerning Disabled Persons from 1983 to 1992, can be considered watersheds during this time.

A new impetus was given to the promotion of a social model of disability and equal opportunities for all disabled citizens. There then followed the establishment of the Department of Justice, Equality and Law Reform under the Programme for Government in 1992 and the subsequent establishment of the Commission on the Status of People with Disabilities. There was also a reshaping of public thinking on equality at this time and a growing consensus that equality and discrimination were two sides of the same coin.

As in other parts of the world, the historical approach to disability in Ireland was to treat the disabled person as a patient. Most disabled people either faced living in an institution or being cared for in the family home by other family members. In most cases such choices were made by medical professionals or by the family of the disabled person. From the 1940s, with the discovery of cures for polio and tuberculosis, treatment of disabled people began to move toward a rehabilitation model. This remained a purely medical approach to disability, where the focus was on 'curing' the individual, or at least making them 'fit' enough to contribute in some way to society. However, in the 1940s, some visually impaired and blind people began to question this approach, and argued that they did not need rehabilitation, but rather needed education. This initiated the first movement in public policy away from the medical model to a social model of care for disabled people in Ireland.

The State response to the issue of disability in Ireland has traditionally been piecemeal, with the emphasis on medical diagnosis and a lack of attention to the whole person. In most instances care for disabled people fell to non-government agencies, such as religious groups, secular philanthropists, or concerned people, such as parents' groups. In more recent times the State has taken over completely in certain areas, while in others it has entered into partnership with non-government organisation, with the State providing funding while the non-government groups provide the services and expertise.

In 1992 the first Center for Independent Living was set up in Dublin in response to the growing frustration of disabled people regarding the lack of control they were able to

exercise over their own lives. A group of disabled people educated themselves about the principles of Independent Living, and set about introducing this philosophy to others. The Center for Independent Living went on to develop the first PAS in Ireland. This pilot project, known as INCARE, ran for two years.

The success of this project led to a demand from other disabled people for PAS. Once the concept had been accepted the provision of services was entrusted to regional CILs, and to organisations such as the Irish Wheelchair Association (IWA) and Enable Ireland. The provision of services is funded either by the Health Boards or by FÁS through the Community Employment (CE) Scheme. There are now twenty-six regional CILs operating throughout Ireland with approximately three hundred and fifty Leaders countrywide, receiving services, or awaiting these services.

While the experience of Independent Living has been broadly accepted as a positive one for disabled people, there is a concern over the uneven spread of this service provision, and a worry that the philosophy of Independent Living, which should underpin service provision, is being diluted.

CONCLUSION

Independent Living does not imply a life led in self-sufficient isolation. It means that a person with a disability is afforded the same right to choice and self-determination within the wider community that all other adults take for granted. These choices often require that a disabled person be supported, either by assistive technology, environmental adaptation or by the physical help of another individual. It is the element of choice and the fact that it is the disabled person who chooses and directs his or her own support services, which underpins the Independent Living approach to disability.

Independent Living is not necessarily an easy solution to the way in which society views disability. It is a challenge, both to societal attitudes, and to the attitudes of disabled people themselves. Independence brings many benefits, allowing disabled people to participate, to explore their individuality and to develop their potential. Disabled people have already become more confident and vocal, as evidenced by the growth in disability organisations in recent years, for example the Forum for People with Disabilities and regional CILs. In addition, the language and discourse surrounding disability has shifted from one of pejorative terminology and charitable patronage to an increasingly rights based approach. Disabled people are far more visible in the community, and segregation and institutionalisation have largely been accepted as contrary to best practice.

The following chapter will trace the theoretical reasoning behind Independent Living and aims to examine its emergence in various European States. The potential barriers to its growth and the often-delicate relationship between employer, Leader and personal assistant are also considered.

CHAPTER 2

How has Independent Living Shaped the Development of Contemporary Irish Strategy Around Policy?

By Cathy McGrath (Disability Federation Of Ireland)

Introduction

This chapter presents the detailed findings of an extensive literature review, conducted during the initial stages of exploratory research. The analysis gives an overview of the main theoretical propositions underlying the Independent Living literature, which when combined form the backbone of this work.

The widespread growth in the demand for Independent Living in recent years has attracted significant attention from both academics and practitioners alike. To fully appreciate the research findings, which follow it is necessary to discuss the theoretical reasoning behind this phenomenon as well as the potential barriers to its success.

The Philosophy of Independent Living

Independent Living is:

*'The right of all persons regardless of age, type or extent of disability to live in the community...with all the duties and privileges that this entails.'*¹⁰

Independent Living, as embraced by disabled people and their representing organisations, is based on four main assumptions; that each life is valuable; that regardless of a person's disability they have the ability to choose; that people have the right to practice control over their own lives regardless of the oppressive attitude and practice of society and finally, that each disabled person has the right to fully participate in society.¹¹

The Structure of Centers for Independent Living is a practice result of the consolidation of disabled people who joined together around the aim of ensuring that disabled people had the opportunity of achieving Independent Living within the community.¹² Indeed CILs have been described as tilting the balance of history in favour of a fairer and more equitable future of disabled people.¹³

It is important to clarify the difference it makes for disabled people to have access to 'Independent Living' as opposed to living independently. When individuals live independently they are given instruction in carrying out their daily needs without

¹⁰Ratzka, A. [2002] quoted at <http://homepage.tinet.ie/~andyh/cil/about.html>.

¹¹Morris, J. (1993) *Independent Lives*, Tavistock, Macmillan.

¹²Mc Gettrick, G. (2003) 'Health services and disability' in Quin, S, Redmond, B., (eds) *Disability and Social Policy in Ireland*, University College Dublin Press, Dublin. Pg 79.

¹³Oliver, M. (1990) *The Politics of Disability*, Macmillan, London. Pg. 42.

assistance.¹⁴ Independent Living focuses on supporting all disabled people, especially those with high service needs to develop a way of life with assistance that ensures they have the power of control over their own care and own lives.

The Social Model and PAS

Under the social model people with physical and sensory disabilities receive either or both residential or support services with PAS being a support service akin to day, respite, home help and home care services. The remit of a PA extends to all areas of life assistance for a disabled person, from their personal, home, social, educational or employment lives. A disabled person, who is referred to as a Leader, instructs the PA. PAS fundamentally provide for mainstreaming by enabling disabled people to fully participate in life - through the workforce, the education system or to lead a fulfilled social life.

There are different types of PAS in existence in alternative countries, but fundamental to them all, as highlighted by the National Disability Authority of Ireland in their recent study of international personal assistance programmes, is the importance of placing personal assistance within the broader context of Independent Living as outlined above.¹⁵ Independent Living defines disability in terms of the barriers which are inherent in society that prevent disabled people from full and equal participation. Such an approach has been successful in connecting with the policy arena and highlighting the diversity of the issue, and how any measures around positive action or mainstreaming, taken at a policy level, need to take this into account.¹⁶

The example used here of PAS, highlights the complexity of disability. With a full and dedicated system of PAS disabled people are given the capacity to enter into the workforce, the community and society as a whole in a way, which would not otherwise be possible. Within Ireland the first PAS was developed in 1992 with a pilot programme called INCARE. Following the roll out of this two-year programme funding was allocated under the Eastern Health Board, with services to be provided by the Irish Wheelchair Association as the direct personal assistant provider. Personal assistance ensures that disabled people can have the opportunity to live independently, and moving on from this, it supports the capacity of disabled people coming together around important policy campaigns over issues which are just as vital to true Independent Living, from areas of housing, transport, and education to that of employment and environmental access.

¹⁴De Jong, G. (1979) 'Independent living: from social movement to analytical paradigm', in the *Archives of Physical Medicine and Rehabilitation*, Vol. 60, 3: 436- 446, Elsevier, Orlando.

¹⁵National Disability Authority (2004) 'International Practice in Personal Assistance Services for People with Disabilities', in *Disability Agenda*, Issue 3, NDA, Dublin.

¹⁶Mc Gettrick, G. (2003) 'Health services and disability' in Quin, S, Redmond, B., (eds) *Disability and Social Policy in Ireland*, University College Dublin Press, Dublin. Pg. 80.

Assessment of PAS

Following on from the inception of INCARE a number of reports have been carried out on PAS. The 1994 evaluation of INCARE was extremely positive, and as mentioned above paved the way for PAS to be rolled out around the country.¹⁷ Participants of the INCARE Programme felt they were no longer dependent on family or friends to cater for their personal needs and in the same way the responsibility and capacity to decide what direction their lives took was no longer in the hands of someone else. Ultimately it was ensuring they had the same independence which is second nature to the rest of the population.

Other more recent reports on similar PAS echo this. A 1996 report on PAS in Ireland points to the dynamic elements related to the service, where the benefits include, for example, a reduction of previously necessary statutory care provision as well as a notable increase in employment of the disabled.¹⁸ Across the country any cessation or withdrawal of the PAS would clearly impact negatively on the lives of Leaders.

However, the growth of Independent Living within Ireland, through CILs and other organisations, must be reviewed within a context of Government policy as outlined above. According to the NDA towards the end of 2004 there were still 645 people on waiting lists for personal assistants.¹⁹ This brings into question the success of Government attempts to provide fully for the diverse needs of disabled people.

The Tripartite Relationship: Employers, Leaders and Employees

In 1989 fourteen European Countries agreed the Strasbourg Resolution, under which the rights of disabled people to a personal assistance service was agreed. In countries where this has become a reality the service is facilitated through Direct Payments. This service allows Leaders to employ a PA through the availability of an allowance. Where an individual is unable to take on the responsibility of running his or her own service a third party can take on this role. In most cases cooperatives such as the CILs in UK and Ireland, or similar organisations in Sweden have developed into support systems for service users. However, Direct Payments do not exist in Irish Disability Policy.

PA Services in Ireland

As already stated, the Personal Assistance Services that are now available in Ireland came into existence in 1992 with a two-year pilot project that was initially run by the

¹⁷McGettrick, G. (1994) 'Nothing About Us, Without Us: Evaluation of the INCARE Personal Assistance Service Programme', Center for Independent Living Carmichael House.

¹⁸O'Shea, E. and Versieck, K. (1996) *Personal Assistance Services in Ireland: Context, Process and Outcomes*, UCG, Galway.

¹⁹National Disability Authority (2004) *Pre-Budget Submission to Government for 2005*, NDA, Dublin. Pg. 5.

first Irish Center for Independent Living. It was recognised that in order to further the Independent Living Movement in Ireland, a consumer controlled Personal Assistance Service would be essential. This was envisaged as a service which would assist disabled people in all aspects of daily living, provide assistance rather than care and is directed and controlled by the service user.

After the success of the pilot project the administration of Personal Assistance was entrusted to Service Provision Agencies, such as the Irish Wheelchair Association, and Enable Ireland, although some regional CILs remained involved with Service Provision. Today the Service Provider assesses a potential service user for need; the Leader is then allocated a number of PA hours by taking into account his or her individual requirements and the number of service hours available to that user. Once a Leader has been approved for funding and his or her requirements have been established, the Leader enters into a contract with the Service Provider, undergoes a period of training, and then Personal Assistants are either employed directly by the Leader or recruited through the Service Provider. While the Service Provider directly employs the Personal Assistant, the Leader acts as line manager, and directs the work of the Personal Assistant.

A European Comparison

The Irish system is based upon, but not completely comparable with systems in other countries where Leaders receive Direct Payments, and employ their own Personal Assistants, invoicing their funding agencies for the cost of the service. This alternative system places a higher burden of administration and responsibility upon the service user, but is seen by many as a more correct interpretation of the Independent Living Philosophy, allowing more control and choice to the service user, whilst at the same time demanding a level of responsibility that any other member of society would be expected to show in an employer/employee relationship.

A study carried out by Nolan and Regan looked at the issue of Direct Payments and the advantages and disadvantages that might arise from an entirely user controlled service. Service users were largely positive about the idea of Direct Payments, but different parties raised several concerns. The majority of disabled participants in the study saw the strengths of Direct Payments as enhancing independence, self esteem and control. Direct Payments were seen as conforming to a rights-based approach to disability. All parties acknowledged that certain challenges will have to be faced in relation to people with learning and intellectual disabilities, and that it must also be

recognised that the Independent Living philosophy is not uniformly understood or embraced by all disabled people. Direct payments would need to be underpinned by a network of peer support and training. A Direct Payments Scheme cannot be seen as a cheap alternative, but as part of a commitment to the quality of life and choice of those disabled people in Ireland who wish to live independently.²⁰

The introduction of Direct Payment services for disabled and older people across parts of Europe is transforming traditional relationships between service users and service providers.²¹ In countries where Direct Payments are made, there appears to be a growing marketplace response to the demand for personal assistance. According to Halloran, the provision of direct payments has had a positive effect on several sectors of the workforce, including people who would have been caring in the home anyway, and those who wish to work part time. However, it is important that the sector does not become an unregulated, low skilled and low paid sector.²²

In Germany a central national insurance fund system provides Direct Payments so that individuals with social or health needs, regardless of their disability or age, can purchase services to meet their requirements. Schemes such as these usually categorise need and allocate hours of service accordingly.²³ Unlike the systems operating in the UK and Sweden, the German assessment process is largely health based, and assistance is concentrated in the home environment.

Eligibility for Direct Payments under the Swedish 1994 Personal Assistance Act is dependent upon an assessment of need which establishes that a person will require more than twenty-six hours a week of assistance with basic everyday tasks. Once this basic need is established extra hours can be allocated for assistance with work, communication and so on. Those who are over sixty-five when they begin to require PAS are not eligible for consideration under the 1994 Act, although those who begin using a Personal Assistance service before the age of sixty-five can continue receiving payments after that time.

For those who are not eligible under the 1994 Act, the 1972 Social Assistance Act allows for Local Government to provide services-in-kind instead of payment, with such authorities legally required to maintain a 'reasonable' quality of life, rather than a 'good' quality of life as in the 1994 legislation. The Local Government is only responsible for service provision within its own boundaries under the 1972 legislation,

²⁰Nolan, Ann and Regan, Colm. (2003). *Direct Payments Schemes for People with Disabilities: A new and innovative policy approach to providing services to disabled people in Ireland*, Bray Partnership, Co. Wicklow.

²¹Halloran J. (ed)(1998), *Towards a People's Europe: A Report on the Development of Direct Payments in 10 Member States of the European Union*, Brighton, UK: European Social Network.

²²*Ibid.*

²³Nolan, Ann and Regan, Colm. (2003). *Direct Payments Schemes for People with Disabilities: A new and innovative policy approach to providing services to disabled people in Ireland*, Bray Partnership, Co. Wicklow.

while under the 1994 legislation the service provision follows the individual, even if they move overseas to work or study.²⁴

The Movement and Government Strategy

The impact of the Independent Living model on disability policy in Ireland can be traced from its initial formation through targeted policy initiatives springing from the 1996 Commission on the Status of People with Disabilities. *A Strategy for Equality* is generally acknowledged as a watershed and a key catalyst in shaping new thinking around disability in Ireland. Until this point disabled people, through their various representative groups and non-governmental organisations, had been struggling to have their voices heard. The guiding principles of the Commission on the Status of People with Disabilities Report were equality, maximising participation and enabling independence and choice through a social model of disability. However, this Strategy did not embrace the full meaning of a social model which places service users at the centre of their care. Independent Living and all its implications of independence and empowerment was only discussed as an option for people with a 'significant' disability.²⁵

According to Rule 15 of the UN Standard Rules on the Equalisation of Opportunities for People with Disabilities (1993), States have a remit around creating a legal framework for ensuring that persons with disabilities have a mechanism of achieving full and equal participation. These Rules are followed through the 402 recommendations made by the Commission in 22 target areas.²⁶ However, outside of this context of the legal system, Independent Living, which is seen as a core rule to the UN Standard Rules, has clearly been ignored by the Irish Government.

Ultimately, the question must be raised, if this report, juxtaposed other pieces of equality legislation around the 1990s, has succeed in achieving a rights based agenda for people with disabilities? The Government strategy was clarified as focusing on an overall strategy of mainstreaming of services for disabled people. It has been argued that such embracing of the social model as a framework for policy and practice has led in Ireland to an acceptance by Government, service providers, academics, and researchers of the social model and its attendant legislation.²⁷ However, from an Independent Living perspective, the Government has fallen far short in ensuring the rights of disabled people to live as equal citizens.

²⁴Ratzka A. (2004b) 'The Swedish Personal Assistance Act of 1994', Independent Living Institute, Presentation in Helsinki, Finland.

²⁵Commission on the Status of People with Disabilities (1996) *A Strategy for Equality – Report of the Commission on the Status of People with Disabilities*. Submitted to the Minister for Equality and Law Reform, Mervyn Taylor, TD.

²⁶Of relevance here in the context of the legal system are points 15.1 – 15.9 inclusive.

²⁷Lundstrom, F., McAnaney, D., and Webster, B. (2000) *The Changing Face of Disability Legislation, Policy and Practice in Ireland*, in the *European Journal of Social Security* Volume 2, No. 4. Pg. 379-397. Pg. 382.

Significant legislation has been passed in the last two decades, including the Equal Status Act, 2000, the Employment Equality Act, 1998 and the Equality Act, 2004. In 2000, the Government adopted mainstreaming itself and around this period services for disabled people were reorganised through the transfer of services, which were previously supplied by the National Rehabilitation Board to mainstream agencies, the re-creation of Comhairle and the establishment of the National Disability Authority.

In addition, FÁS along with the Department of Enterprise, Trade and Employment was given responsibility for labour market training, advice and supported employment for disabled people. Building on each of these pieces of legislation, 2004 brought the introduction of an overall National Disability Strategy.

The voice and participation of organisations representing disabled people within the decision-making area of the legal field has also grown, partly due to the legislative developments mentioned here.²⁸ This has been clear since the development of the PAS and its roll out across the country in 1992.

The development of the National Disability Strategy has its own roots of focused and organised lobbying by and on behalf of disabled people. In 2001 the Disability Bill was rejected by the disability sector as unacceptable and ineffective in answering the needs of disabled people. The weight and relevance of the policy goals and values which the disability movement advocated, were too important and too strong for the State to reject out of hand. This act of defiance necessitated a further consultation process between the State and the disability sector as a whole.²⁹

The current National Disability Strategy is made up of the Disability Bill, 2004, six Sectoral Plans, commitment by the Government to a multi-annual investment programme for disability support services and finally a Comhairle (amendment) Bill, 2004. Of particular relevance here, in considering Independent Living and PAS, is the Disability Bill, 2004, which provides for an individual assessment of health and education needs and a related service statement. Also incorporated as part of this Bill is an independent mechanism of appeal in relation to service provision. If a region of the Health Service Executive does not implement a determination made on appeal, the Appeals Officer has the power to enforce this determination, or arbitrate a settlement, through the Circuit Court on behalf of a disabled person.³⁰

²⁸ Colgan (1997), quoted in Mc Gettrick, G. (2003) 'Health services and disability' in Quin, S, Redmond, B., (eds) *Disability and Social Policy in Ireland*, University College Dublin Press, Dublin. Pg. 69.

²⁹ Doyle, A. (2003) 'Education policy' in Quinn, S, Redmond, B., (eds) *Disability and Social Policy in Ireland*, University College Dublin Press, Dublin. Pg. 22.

³⁰ Department of Justice, Equality and Law Reform (2004) *A Guide to the Disability Bill 2004*. Pg. 7.

IL Theory and Models of Service Delivery

The way in which disability policy has developed has invariably been contingent on the perception of the nature of disability to date. Making the link between Independent Living in theory and the practice of policy, needs to take into account the climate of thinking within which policy was previously shaped, and how that has changed.

The medical model of disability can be taken to refer to the model most commonly used within policy making in Ireland until recent years. This perception of disability considers and develops policy by placing people in isolation and considering them in terms solely of their specific impairment, implying that it is the disabled person themselves who are different. This leads to a scenario where to bring disabled people around to 'normality', they have to be helped or cured as much as possible. In essence the experience of disabled people under this model echoes that of other minority groupings where the body is classified as the deviant, not the society itself.³¹

The social model of disability counteracts this debate by focusing the debate on a critique of the social barriers in society, which serve to exclude disabled people. Within this model practices such as unequal job opportunities, segregated and insufficient education, environmental barriers, inadequate public transport and limited lifestyle opportunities are highlighted in how they deny disabled people full access to the social world. This shift in thinking highlights the need to consider disability outside that of the medical aspect, and expand the debate to consider environment and social control systems in general society.³²

The success of the social model can be traced directly to the collective efforts of disabled people themselves. Here, the challenge of the social model can be observed in the changing power relations from that of dependency, where the disabled person under the medical model faces an individual abnormal experience of disability within society, to that of the social model where exclusion from society is dealt with as a collective facing an oppressive system.³³

CONCLUSION

Independent Living benefits society by increasing the capacity and contribution of disabled people within the community. However, Independent Living also brings with it many challenges. Disabled people have to meet the responsibilities that come with developing their own services, and in many cases have to become experts in a variety of new and complex areas, such as employment laws and equality legislation.

³¹Stone, E and Priestley, M. [1996] 'Parasites, pawns and partners: disability research and the role of non-disabled researchers', in the *British Journal of Sociology*. 45, (4). Pg: 699-716.

³²Mc Gettrick, G. (2003) 'Health services and disability' in Quin, S, Redmond, B., (eds) *Disability and Social Policy in Ireland*, University College Dublin Press, Dublin. Pg. 78

³³Barnes, C. and Mercer, G. [2003] *Disability*, Polity Press, Cambridge.

Disabled people also have to be prepared to take the lead in the development and maintenance of their services, leaving behind a culture of passivity, which may be deeply ingrained.

The shift from a medical model to a social model of disability is not a smooth transition, but a series of steps that may have to be revisited and reassessed along the way. This is a process which has been led internationally by the determination and vision of disabled people themselves, but it is a long and difficult transition and needs the support of society at large. Undoubtedly there is still a long way to go in Ireland, as in other parts of the world, and there remains a long learning process ahead. While the situation in Ireland for disabled people remains less than ideal, it is unthinkable that we as a society would ever return to the paternalistic culture of passive dependency, wherein decisions were made for disabled people rather than by disabled people. The true value of society's attitudinal changes to the issue of disability will be reflected in the experiences of its disabled members.

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EXTENDING THE BOUNDARIES: OUR EXPERIENCE OF INDEPENDENT LIVING

CHAPTER 3

CASE STUDY METHODOLOGY

What is this Research About?

The purpose of this report, as stated in the research proposal, is to:

*'...document the development of Independent Living in Ireland in case study format, highlighting the true potential of the personal assistance service for integrating people with disabilities into the wider community, and thereby providing a viable reference source for policy makers, community development and disability organisations.'*³⁴

As stated above, the preferred methodology of this study was to use a case study format. There are a number of types of case studies that a researcher can use. Jensen and Rodgers outline a typology of case studies, which include:

- *Snapshot case studies*: This involves a detailed, objective study of one research entity at one point in time, with hypothesis testing by comparing patterns across sub-entities. This is the type of case study that is closest to the kind this research utilised.
- *Longitudinal case studies*: This type of case study is a quantitative and/or qualitative study of one research entity at multiple time points.
- *Pre-post case studies*: This is the study of one research entity at two time points separated by a critical event. A critical event is one which you would expect to impact case observations significantly on the basis of a theory under study. An example of this would be to undertake another case study on Independent Living in a number of years to assess the impact of the Disability Act, 2005 on Independent Living in Ireland.
- *Comparative Case Studies*: These are a set of multiple case studies of multiple research entities for the purpose of cross-unit comparison. Both quantitative and qualitative comparisons are made.³⁵

Case studies were chosen as the methodology for this report so that the development of Independent Living in Ireland could be explored in an in-depth, qualitative way. Only a small number of respondents were interviewed for the study to allow for this in-depth research. According to Becker et al (2005) case studies are:

*'A form of qualitative descriptive research [which] looks intensely at an individual or small participant pool, drawing conclusions only about that particular group and only in that specific context. Researchers do not focus on the discovery of a universal, generalisable truth, nor do they typically look for cause-effect relationships; instead, emphasis is placed on exploration and description.'*³⁶

³⁴CIL terms of reference, 2005.

³⁵Jensen, Jason and Rodgers, Robert (2001) 'Cumulating the intellectual gold of case study research', in *Public Administration Review* 61(2): 236-246.

³⁶Becker, B et al (2005) 'Case Studies', writing at Colorado State University Department of English.

In other words, case studies are not representative of entire populations and the case study researcher must be careful not to generalise beyond cases that are similar to the ones studied.³⁷

How will we do the Research?

Susan Soy outlines the six steps that should be used when undertaking a case study methodology:³⁸

1. Determine and define the research questions
2. Select the cases and determine data gathering and analysis techniques
3. Prepare to collect the data in the field
4. Collect data in the field
5. Evaluate and analyse the data
6. Prepare the report

The research questions should be targeted to a limited number of *'events or conditions and their inter-relationships'*.³⁹ To assist in formulating and targeting these questions, the researchers should undertake a literature review which *'establishes what research has been previously conducted and leads to refined, insightful questions about the problem'*.⁴⁰ Tellis recommends that the research questions should only be formulated following extensive relevant reading on the subject matter.⁴¹

It was agreed that the case studies should focus on particular themes around Independent Living. The themes were chosen and agreed upon by the Steering Committee and the researchers. Case study methodology does not utilise sampling techniques. However, it is important that the cases are selected carefully so as to maximise what can be gained from the research within the time constraints.⁴² The case selection should be theory driven, or in the case of this research, the cases should be selected on the basis of the philosophy or principles of Independent Living. According to Tellis (1997):

*'The unit of analysis is a critical factor in the case study. It is typically a system of action rather than an individual or group of individuals. Case studies tend to be selective, focusing on one or two issues that are fundamental to understanding the system being examined.'*⁴³

³⁷Garson, D. (2005) 'Case Studies'. See: www2.chass.ncsu.edu/garson/pa765/cases.htm.

³⁸Soy, Susan (1996) 'The Case Study as a Research Model' in *Uses and Users of Information*, LIS 391D.1.

³⁹Ibid.

⁴⁰Ibid.

⁴¹Tellis, W. (1997) 'Application of a case study methodology' in *The Qualitative Report*, Volume 3, Number 3.

⁴²Ibid.

⁴³Ibid.

The interviews were undertaken with people to whom the finalised themes were relevant. The participants were sought through CIL Carmichael House and the Leader Forum. Some people contacted Ralaheen in order to take part in the research after Dr. Conroy delivered a presentation on the research to the Leader Forum, while Ralaheen contacted others from a list of potential candidates.

Of the 18 candidates who were willing to take part, ten were interviewed. One of the participants decided that they did not want to take part in the research after they read their case study. The other nine participants all agreed that their case studies could be used in the research. Participants were allowed the option to change their name if they wished. Some participants opted to do this while others decided to use their real name. Often this depended on the sensitivity of the theme.

As well as interviews with the Leaders, a number of interviews were held with service providers. These included an interview with the Irish Wheelchair Association (IWA), Dublin City Council and a PA.

According to Kane (1995):

*'Interviews can take several forms, ranging from very informal exchanges to very structured, ordered sets of questions. The form you select depends on your research, the subject, the kinds of information you need, the setting of your research and the characteristics of the people to whom you are talking.'*⁴⁴

The interviews in this research were semi-structured in that a list of topics or areas that could be covered under the specific themes were used during the interviews. However, these were used only as a guide because often it emerged that there were more relevant and interesting topics (to the interviewees particular situation) to discuss. The discussions with the Leaders were all tape-recorded. This was so that direct quotes could be used when writing up the case studies and so that the interviewers could concentrate on the discussion rather than trying to take notes. All interviews were on a one-to-one basis with the participant and one researcher.

After the meeting the interviews were transcribed, analysed and written up into case study format. The case studies were then sent back to the participants to get their permission to use them. Once the participants agreed the text, verification of the information gathered was sought using peer review by a panel of CIL members.

A commentary of research and other documentation accompanies the case studies for increased validation. According to Tellis *'One of the most important uses of documents is to corroborate evidence gathered from other sources.'*⁴⁵

⁴⁴Kane, E. (1995) *Doing your own Research: How to do basic descriptive research in the social sciences and humanities*, Marion Boyars, London.

⁴⁵Tellis, W. (1997) 'Application of a case study methodology' in *The Qualitative Report*, Volume 3, Number 3.

E-mail paragraphs, based on the same themes as the case studies, were sought from Leaders who had not already taken part in the research. This was to allow for a wider group of participants to contribute to the research. However, due to the very low response rate these paragraphs were not included in the report.

CHAPTER 4

CASE STUDY:**EMERGENCE AND TRANSITION TO INDEPENDENT LIVING****Introduction**

John⁴⁶ had a serious motorbike accident when he was 21. He is now 33 and lives on his own in Dublin. It is six years since he began using personal assistants. Initially he used them to attend college and complete his degree, but now he uses them for many more aspects of his life such as personal care, social life and gardening.

Our discussion took place in John's house in Dublin. The views which follow are those of John.

Before Independent Living

Immediately after his accident, John moved into a residential care institution where he spent eight years:

'There was kind of a forward-looking institution, if you can call it an institution. Each of us had our own room; we had our own personal space. The services I need like physiotherapy, occupational therapy and transport and all were available at hand, which I would say was the good side of living in that particular institution...the financial constraints weren't as difficult as they are now'.

However, John believes that it is the fundamental human right of every individual to have the right to live in appropriate accommodation that respects their life as an individual and living in a residential home was not what John saw as appropriate accommodation for himself as a 21 year old.

Emergence to Independent Living

John went on the housing list after one year of living in a residential home. Psychologically, he did not find living in the home good for him and he wanted the challenge to see if he could live independently. However, John was on the local authority housing list for over seven years before coming across an interesting development in Dublin:

'I saw this development being built and then I approached the housing association that was building this housing estate and I asked them if one of the houses could be converted for my needs. And they said sure, as long as I had overall medical priority on the corporation listing. Then I worked with the housing association to design this house around my needs'.

⁴⁶Name changed to protect identity.

After his first contact with the housing association about this development, it took a further two years before the house was completed and John could move in.

Transition to Independent Living

The transition to Independent Living was slow for John so that he could get used to living on his own:

'...when the house became available I got the additional hours from IWA so we started to move in here in a slow transition and stay here three nights a week and make a slow transition from where I lived beforehand to here. And then try to get the services in place in the community to meet my needs and then apply for additional hours, PA hours, and eventually I am established here and this is my home at the moment and will be...'

Although John worked with the architect before the house was built there were a few hiccups when he first moved in. But generally the house is well constructed and very spacious with lots of room for a wheelchair.

Family and Independent Living

The time after John's accident was very traumatic for him and those close to him:

'It's very traumatic like for anyone. All the plans you had for your life ahead of you, when you're a twenty one year old one-day everything just changes, it's a very traumatic time. Your family don't expect you will be in need of care at twenty-one. Usually you're the one that they depend on at that time of your life...it's the time when you're expected to perhaps take control of your life and become independent and perhaps have others depend on you, instead of like becoming dependent on poor resources and family and friends and any relationships you have. It puts everything under great strain to say the least, along with coping with the accident and that at the same time.'

John believes that his family were a bit apprehensive around the time of his transition to Independent Living although this changed as they saw how well he coped with different situations:

'They didn't initially show it and I have always been someone who has managed most things in my life, I made the decisions myself like, and they didn't interfere. But I'm sure in the background they were quite [worried, but] they know me well and they know I can manage my life regardless.'

As long as John explained to his family what he was doing and that he planned things well, they trusted that he would be okay. Although there are occasional times when he

may need help, John's family have come to realise that he can cope in most situations by himself.

The Day-to-Day Experience and Challenges of Independent Living

Since John moved into his house he has a lot more freedom to do as he wishes.

However, this freedom does not come without certain challenges:

'Now I've got a lot more freedom in one regard but I have to cope with services in the community, which I don't see as that brilliant. I have to deal with everything; manage my own PAs, manage my own bills, manage my own entire lifestyle, which I find challenging to say the least, but it's good, it's a better situation. If I had to make a judgement on what lifestyle I would like for myself, its living in my own house...with a few snags to say the least.'

Before moving into his house, John had services such as full-time care, full-time nursing care and full-time occupational therapy to hand. Now living independently, these services are much more sparse, with a waiting list of over a year for an occupational therapist to do a home visit. John feels that he could live his life even more independently if a number of these community services were improved.

Another aspect of Independent Living that can be challenging is dealing with PAs and organising the service. Without realising it, one becomes an employer and it can be a challenge to organise 120 PA hours a week. A Leader has to provide PAs with contracts and may *'even have to sack them sometimes!'* But Leaders must take on this responsibility as an employer and this can be quite stressful, *'particularly when things are not working as well as you would like'*.

Around six or seven years ago, John undertook a course in Independent Living, as he knew this was something he was working towards. The training focused on areas such as management skills, financial skills and time management. John did not realise the challenges that lay ahead of him at the time but when he looks back now he can appreciate how this course helped him.

The Relationship with PAs

Although John has a professional relationship with his PAs, he also likes the relationship to be friendly:

'I think I'd be more on the side...that's more friendship level, but I try and keep it at a balance...the contract is for a year and then I suggest to them that they move on to

something else for their own well-being and a challenge in their life themselves...I like PAs that challenge themselves and that's what I say to them at the beginning, even though they might stay for more than a year.'

John has had a number of PAs from abroad. Although this works for the most part, sometimes there may be a language or communication barrier. Initially, it could take them a while to adapt to the Leaders grammar or slang or they may have different morals or ideas about how to live ones life, but mostly there is no problem.

CONCLUDING REMARKS

John's advice to any young person who wants to undertake the transition to Independent Living would be to do as much research as possible early on and before one moves ask other people who have gone through the transition about their experiences. It is also important to plan for the long-term and make provision for 'plan B' just in case it does not work out. Finally, do not be too proud to ask for as much assistance and support as one needs.

Case Study Commentary:

The Transition to Independent Living for Disabled People

There is no formal scheme to provide personal assistants for disabled people in Ireland. The Government information website on public services states that disabled people who want to avail of PAS should apply to their Health Service Executive (HSE) area or to a voluntary group that provides the service.⁴⁷ However, the current numbers on the waiting list for the PAS are very high. In 2004, some 6,621 persons with a physical or sensory disability were waiting for assessment for PAS or had been assessed and were waiting for PA hours to be provided.⁴⁸ This illustrates that it is not easy to make the transition to Independent Living.

Although the Commission on the Status of People with Disabilities (1993-1996) recommended that Personal Assistance Services should be provided for people with 'significant physical disabilities', the waiting list figures above show that this is not being implemented.

The following is an extract from the Commission report in relation to PAS:
'Personal Assistance Services should be provided for people with significant physical disabilities. A personal assistant, a concept coming from the Independent Living Movement, is somebody employed directly by a person with a disability to assist him/her in

⁴⁷See: www.oasis.gov.ie.

⁴⁸Health Service Executive (2005) *National Service Plan 2005*, Table 4.3.7.

participating in everyday life at home, school, work, or leisure activities. They are trained for their role through formal and informal training in which people with disabilities are fully involved. They facilitate Independent Living, which concerns empowering people with disabilities to live as they want, with the same choice as people without disabilities, using mainstream services and taking control over their own lives.⁴⁹

⁴⁹Commission on the Status of People with Disabilities (1996) *A Strategy for Equality – Report of the Commission on the Status of People with Disabilities*. Submitted to the Minister for Equality and Law Reform, Mervyn Taylor, TD. Page 165.

left my mouth on the plane. I wrote a letter to Dublin

EXTENDING THE BOUNDARIES: OUR EXPERIENCE OF INDEPENDENT LIVING

CHAPTER 5

CASE STUDY:**Personal Growth and Development as a Result of Independent Living****Introduction**

Pat⁵⁰ lives on her own and is currently undertaking a Research based Masters Degree, both of which she would be unable to do without the help of her PAs. Pat used to live with her parents but after she was on the housing list for four years, a house became available for her in 2000 and she has lived there ever since.

Our discussion took place in an accessible public house near Pats home in Dublin. The opinions which follow are those of Pat.

Before Independent Living

It was in 1993 that Pat first heard about Personal Assistance Services. At that time she was living with her parents and was very worried about where she would end up if anything happened to them. Having been in respite care on several occasions and having had some bad experiences, she was scared of ending up in a residential home: *'I mean if I hadn't had a PA I would be languishing in a [Home] somewhere, where all your possessions are in that one room and I wouldn't be able to pursue anything that I see as enjoyable...'*

In an effort to gain more independence Pat decided to undertake a repeat Leaving Certificate course. One of the other participants had a PA and this interested Pat. She saw how well having a PA worked for this participant so she asked him how to go about getting PAS herself. Later that year she was accepted into college so she decided to contact the Center for Independent Living, Carmichael House. She was asked to write a proposal on how many hours she would need and what she would need them for. Soon after this Pat was allocated a number of PA hours per week. It was a few years later that she moved out of her parent's house and into a house on her own.

Life Changes and Personal Assistance Services

Pat believed at this time that she could do what she wanted, when she wanted, now that she had a PA. However, she feels that she had to change her high expectations and *'come down to earth'* over the first couple of months of using PAs. Pat found it difficult to deal with the high turnover of PAs at first. However, Pat did like the fact that she now had the power to deal with difficult situations as they arose:

⁵⁰Name changed to protect identity.

'...I had the power to say to somebody this is not working out because of this reason so I think you should consider either thinking it over and deciding we can change things or leaving to work with somebody else.'

Pat describes having Personal Assistants as her lifeline. If she did not have PAS she would be in a residential home, as her parents are getting older and they would no longer be able to cope with providing all the assistance that she needs. Having PAs has made it possible to pursue her interests, which include painting and voluntary community work. Another major advantage of having PAS is that Pat was able to attend University and is now undertaking a Masters Degree.

Difficulties that Pat has Encountered Using PAs

Although Pat views the PAS as paramount to her living independently, not all of her experiences since she became a Leader have been positive. Over the years difficulties have arisen with a small minority of PAs and these have not always been easy to deal with. Pat believes that the burden of proof in such instances falls too heavily on the Leader and not so much on the PA. In 2002 a situation arose where Pat's lack of knowledge of employment law caused her problems. She informed a PA that the work relationship was not working out and that she no longer needed her services. Pat then proceeded to find another PA. However, she was informed that she could not hire someone else until the PA that had been let go was taken back to 'work out her notice'. Pat did not want to do this as she was having problems with this particular woman so she held out for five weeks without a PA for the allocated time slot:

'...during those two and a half days a week my mother had to come and help me. I found that rather bizarre because on the one hand I was being criticised for involving my parents but on the other hand I had no choice.'

Eventually Pat gave in and took back the PA so that she could work her notice. However, the PA walked out after working just one day. Pat began to have nightmares after this incident in which she was really ill at home and nobody knew because there was no one in the house with her. Only Pat and her parents live in Ireland. The rest of her family live abroad and as her parents are now in their seventies, being left alone is something that worries Pat. That is why the PAS is so important to her. She describes the PAS as:

'...so valuable that I can't put into words how much it means to me.'

There is a constant fear in the back of Pat's mind that she could lose her Personal Assistance Services because of the lack of permanent funding and this would be devastating for her:

'For me I'd rather fight to the death if I had to for my freedom, the personal assistant service has ensured my freedom, if I don't have the personal assistant service I would be in bed with bed sores, in one room, with very few possessions...life wouldn't be worth living.'

Changes for the future

From Pat's past experiences she has realised that the help of her family is important. However she feels that their involvement is somewhat frowned upon:

'Well I feel that the involvement of my family should not be so much frowned upon because I know in my case, when I have to deal with [my service provider] I clam up. I get so nervous that I can't speak and the PA can speak faster and coherently. They are able to tell their story...the situation of 2002, if that situation happened again the involvement of my family wouldn't be so much frowned upon and I would love to see the establishment of an advocate service that is there for people who can't even speak, what about them?'

Even though Pat sees her family as a valuable asset, she knows that they will not be around forever so she does not want to become reliant on them. Pat thinks that an advocacy service would be invaluable for both people with and without the help of their family members. For those who rely on family, Pat believes that an advocacy service would take much of the worry away for parents whose son or daughter is living independently.

In Pat's opinion, if the Government is really committed towards developing meaningful disability services then they must make sure that the PAS is maintained and enhanced and that the funding for the PAS is secured.

Case Study Commentary:

Advocacy in Ireland

Advocacy has recently become very popular in Ireland and abroad. Advocacy is a means of empowerment for vulnerable people and can take many forms, such as self-advocacy, citizen advocacy, peer advocacy, collective advocacy, family advocacy and professional advocacy. According to the National Disability Authority:

*'Advocacy is a practice carried out by or on behalf of an individual or a group, which tries to redress the imbalance of power in society. Advocacy is a powerful tool that individuals with disabilities can use to participate fully in society...Advocacy promotes social inclusion and heightens awareness across wider society to the obstacles faced by people with disabilities. Advocacy allows for all voices and opinions to be considered when services and policies are developed.'*⁵¹

In its publication *The Jigsaw of Advocacy*, Comhairle argue that Advocacy per se is not a prominent feature of Irish social policy. There have been some preliminary policy initiatives in recent years but besides these *'evidence of advocacy is scarce on the ground.'*⁵² However, the concept of advocacy is beginning to surface at the policy level with significant references to advocacy in a number of official documents.⁵³ Some voluntary organisations have started to recruit or employ advocates.

Advocacy may soon get a basis in law. The Comhairle (Amendment) Bill, 2004 provides for a personal advocacy service for disabled people. This is the first time that an advocacy service has been provided for in legislation. In the Bill, advocacy is defined as:

*'...including services in which the interests of a person seeking a social service are represented in order to assist the person in getting entitlements to such a service but does not include legal representation.'*⁵⁴

The Board of Comhairle - which is a public service body - must take its own financial resources into account and whether the person can get advocacy from another source, when providing for or arranging the provision of the service. The Board must take account of a number of other factors when assigning a personal advocate to a qualifying person, as they may have to set an order of priority among people who qualify for the service (See Box 1).

⁵¹NDA (2003) *Exploring Advocacy: Short Report*. Information Leaflet.

⁵²Weafer, John. (2003) *The Jigsaw of Advocacy*, Comhairle, Dublin, Pg. 21.

⁵³The Report of the Commission on the Status of People with Disabilities, *A Strategy for Equality*, 1996, *The Programme for Prosperity and Fairness*, 2000, *The Health Strategy, Quality and Fairness, A Health System for You*, 2001, *Report of the Public Consultation for the National Children's Strategy - Our Children, Their Lives*, 2000, The Disability Act, 2004, The Comhairle (Amendment) Bill, 2004.

⁵⁴Comhairle (2004) *Relate*, Vol. 32, No. 1. The Comhairle (Amendment) Bill, 2004.

BOX 1

Extract from the Comhairle (Amendment) Bill, 2004.

(3)The Board shall have regard to the following to determine the order of priority to be accorded to different qualifying persons in the assignment of personal advocates to such persons:

- (a) the needs of qualifying persons to have personal advocates assigned to them;
- (b) the degrees of risk of harm to the health, welfare or safety of qualifying persons if they are not provided with the social service or services that they are seeking to obtain;
- (c) the benefits likely to accrue to qualifying persons if personal advocates are assigned to them;
- (d) the availability to qualifying persons of advocacy services otherwise than under this Act; and
- (e) such other matters as the Board considers appropriate or as may be prescribed by regulations made by the Minister.

Source: Extracted from the Comhairle (Amendment) Bill, 2004.

The NDA believe that:

'Expanding Advocacy provision in Ireland will involve similar difficulties to those encountered in other international models. It is likely that the primary problems will arise from a failure to regard advocacy as a human and civil right and the lack of guaranteed funding.'

The Bill has addressed neither advocacy as a right nor guaranteed funding; the two issues mentioned by the NDA as important to expanding advocacy provision. This Bill does not legislate for advocacy as a right but rather as a need.

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EXTENDING THE BOUNDARIES: OUR EXPERIENCE OF INDEPENDENT LIVING

CHAPTER 6

CASE STUDY:

The PA-Leader Relationship (1)

Introduction

Eimear⁵⁶ began using PAs thirteen years ago. She lives on her own but she used to live with her sister, her sister's husband and their children. She frequently stayed with her other sisters to 'give them all a bit of a break'. Eimear worked part-time and enjoyed her life but she often found it difficult to have to rely on her family all the time, for instance, if she wanted to meet friends who lived far away from where she lived.

Since moving into her own home Eimear has changed a lot as a person. Before she was very shy, but her confidence has really grown. She lives nearer to her friends and she has made a lot more new friends. She enjoys socialising with them regularly; something she could never do before her transition to Independent Living.

Our meeting took place in Eimear's home in Dublin. The opinions which follow are those of Eimear.

Feeling Vulnerable during the Transition to Independent Living

When Eimear began the transition to Independent Living she was a little scared about moving away from her family and living with someone she hardly knew:

'Even though it was what I really wanted, it was difficult in the beginning, as I had to give instructions for all my personal care plus household duties. It was also hard having to tell my PAs not to bring their boyfriends in to my home, as it was their place of work. It was hard to deal with this situation and I was not sure what to do. When I go to bed I do feel more vulnerable as I'm unable to move and feel helpless, but with training and experience I began to enjoy life.'

As the years have passed Eimear has learned to deal with these difficult situations as they arise. And although she can still feel vulnerable at times, she is glad that she took the opportunity to live independently.

PAs and their Personal Problems

A Leader may have some personal problems in their life but it is important to recognise that the PA can have problems too. Eimear found herself in a scary position a few years ago when one of her PAs was dealing with a serious eating disorder:

⁵⁶Name changed to protect identity.

'...going back down the road one PA, about 18, who was not long with me, had a lot of problems. I would hear her getting up in the middle of the night raiding the fridge and all the food would be gone. I would say "what happened to the food?" I think she had an eating disorder. I did ask a friend of mine what I should do about her eating problem but he said she had to be the one to ask for help. Many times I did ask her if she had some problem, because at mealtimes she would eat very little. Then I had a box of money, which was for phone calls. I noticed the money was missing. I would ask her what happened to it. She would say she needed it as she was short of money. I told her that by taking money like that, it was stealing ...if she needed money to ask me for a loan. Each week I would loan her some money and she would pay me back when she got paid. She was a very nice girl though.'

These types of problems can affect both the PA and the Leader and can be difficult for the Leader to deal with.

Difficulties with Using PAs

Although Eimear was very positive about her experience with using PAs, she did mention some difficulties she has encountered:

'You really have to build up a trust with your PAs, especially when giving them your pin number to take out cash from the bank. I have to say I encounter no problems with that situation. I did have a PA running up my phone bill...also one item of my property went missing. I would have to remind my PAs also about using mobile phones, especially when I need their assistance to cook dinner or go to the bathroom and to turn off mobiles during the night. I would just remind them that this is a real job and when I'm in work I cannot use my mobile until my break. When I'm not busy then I have no problems with them using their mobile.'

Now when a PA begins to work for Eimear, she makes sure to explain carefully how she likes things done, so as to try and avoid any of these difficult situations arising in the first place.

Keeping the PA-Leader Relationship Friendly

Eimear believes it is important to get on well with your PAs. She describes herself as close to some of them, although not all of them:

'I've had great PAs over the years from Sweden, Spain, Canaries, Bosnia, Lithuania and many Irish. I still keep in touch with quite a few of them. I would meet some of them

during the year for lunch...also at Christmas. My present PAs and past PAs meet up and have a meal. It's great to keep in touch. Of course there are some PAs you will not get close too. That's the way it goes. I feel it's very important we get on well otherwise I don't think it would work for me. Of course every Leader works to their own agenda.'

Eimear became good friends with a few of her PAs. She regularly keeps in touch with one particular PA who was not from Ireland and has returned home. This PA still visits her every year and Eimear travelled to the PAs home country to attend her wedding. She does not like to keep a strict employer-employee relationship with her PAs.

'I have to say at present I have great PAs and they are great workers and always willing to help when another PA is on holidays or sick. If someone is with you for a few years...it nearly feels like being married to the person. You have to have respect for them... also they have to respect you. My PAs know my friends and also my family from attending social situations and I have also got to know their families. I wouldn't want to treat them badly that is the way I feel.'

Although Eimear likes to keep her relationship with a PA quite informal, she does recognise that this is not the case for all Leaders. For some Leaders PAs are simply employees.

Professional Boundaries

Keeping professional boundaries with a PA that she is quite friendly with is not a problem for Eimear:

'...I think if you have good PAs and even if we are friends... they do their work and they know what has to be done. They wouldn't falter on that like take advantage of me.'

If there is a problem with a PA, Eimear will tell them what is wrong. This is something that she feels has become easier over the years as she has become more assertive. Recently she had to have a chat with one of her PAs and tell them that there were things that she was not happy with. She would not be afraid to say this to any of her PAs even the ones that she is close to.

Training New PAs

Eimear has a routine when she has to hire and train a new PA:

'When a PA leaves then I have to advertise for a new one. It takes a lot of my energy and time answering phone calls and ringing people back. Then I would set up an interview and

meet with about two or three candidates and make a decision. I suppose I hate having to go through this procedure but it will be always part of my life. I would always have one of my regular PAs with me when I'm training them in. It also makes life easier for me.'

Eimear feels a little nervous during this training period, especially at night. But she would always get her present PA to stay the night as well during the new PAs training period.

CONCLUDING REMARKS

Eimear summed up her feelings around Independent Living and the opportunities that it has given her:

'I really have to say I'm very glad I got the opportunity to move to Independent Living and live my life to the full. I have to say I nearly did not take the chance but boy am I glad I did. I have such a busy life always rushing to work, meetings, socialising etc. I remember my sister saying many times there's not enough hours in the day for me. Now I'm saying the same to myself. Most of the time life runs smoothly but of course we all have some bad days but that is life.'

Eimear is really happy with her life using PAs. However, she does feel bad for all the people who are on waiting lists for PAS. She hopes that they do not have to wait too long for the service and get the same opportunities that she got.

CASE STUDY:

The PA-Leader Relationship (2)

Introduction

Jessica is using PAs over ten years. Although she was very excited about the service when she first began to use it, recently she is finding it harder to deal with all that comes along with being a Leader.

Our meeting took place in Jessica's workplace in Dublin. The opinions which follow are those of Jessica.

Using PAs – Past and Present

Jessica was very excited when she first started to use PAs. She was excited about what she was gaining from using PAs but she was also happy about the fact the PAS helped to create employment:

'It's not all about what I'm gaining, somebody else can gain out of this as well and that was big for me and that was in fact one of the points that we would have pushed towards the Government at that time...So I remember being excited from that point of view. I wasn't at all nervous about it at that point...I felt very strong actually at that time...'

However, Jessica believes that her feelings towards the PAS has changed somewhat as she has gotten older. Although she still recognises the value of the service, she does not have the same energy as she once had:

'Things have changed and I'm not so excited about it now. I actually find it is really hard work and I don't know whether that's probably because I'm that bit older. I just don't have that energy anymore...'

The Relationship between a Leader and their PA

Jessica has never seen her PAs as companions or friends. To her they are employees for a specific job. However, the PA may not always see the relationship in the same light due to the intimate nature of the work:

'...because I don't see them as friends, but depending on where they're at in their life they might see me as a friend, and also because maybe they're in my home you know, in an office it's structured – It's all kind of very cold isn't it?...But in your home it's relaxed and it's your décor but people who come in to work as a PA then they kind of take this on as very relaxed as well and that they can feel very comfortable in my surroundings.'

Jessica tries to keep professional boundaries in the working relationship so that despite the fact that the PA's work takes place in her home, the PA is fully aware that it is their place of work and not their place of comfort. Keeping these boundaries can often prove difficult:

'...I mean I have to keep kicking myself, keep checking that there isn't a kind of familiarisation you know between me and them...Just to give you an example like, I absolutely adore cooking. Now I can't physically cook but I am a good cook...But when you're in the kitchen I'm not just cooking dinner, I'm actually nearly eating as I'm cooking you know, I'm so excited about cooking like...because you're having a conversation and [the PA is] learning and sometimes they might be a bit excited even about it you know, then it can very quickly become a kind of fun time for them, so that's pretty difficult then, you know what I mean? Like that's just an example I'd give because I'm at my most excited, if you like, when I'm cooking...so that's where I find I'm most relaxed...and sometimes I just know that they sort of feel that this is the moment you know when she can be, she can chill out a bit...and then when I want to get back on target after dinner,

that's where I find it difficult because there has been moments of enjoyment for me and most likely for the PA and then you have to go back on track...'

Jessica does not consider it more difficult to keep professional boundaries with PAs that she has had for a long time. However, she does find it difficult to keep the PAs that she has employed for a number of years interested in the job and as a result of this it is harder to get the 'mundane jobs' done, such as ironing and washing.

Other aspects of the job can make keeping professional boundaries difficult. As Jessica and her PA work in such close quarters, sometimes younger PAs may express their private problems to her and this can make getting on with the job difficult:

'...you care about them but you can't carry it, you know. See it all falls back to because you're at home...they think that they can you know, express everything that is wrong in their life, you know what I mean? The hardest thing I find is if they have a sad story, like a genuinely sad story it's very hard to actually move on and still get your jobs done...I know myself if somebody comes in with a sad story and there's, just say there is eight people in the office, well okay all eight of us might be tuned into one person's story for a couple of minutes but then it's taken that they will go back to their desks and just get on with it, do you know what I mean? But it doesn't seem to follow through in your home...'

Jessica had a situation where she found it impossible to maintain these boundaries and the relationship with the PA broke down. Jessica explained what happened at that time:

'...the P.A. was herself from a very fragile, very insecure family. When my family members came to share precious moments with me, she could not remove herself from the gathering, I tried all the various tactics, but because of where she was coming from, she seemed to gain great comfort and strength from my family. I found this situation very difficult to deal with and tried to understand it from her perspective.'

This was a situation that she found very difficult to manage and it took a lot for her to pluck up the courage to tell this particular PA that she should 'start looking for a new job'.

The Different Experiences of Males and Females using PAs

In Jessica's opinion male and female Leaders have very different experiences of using PAs:

'Being a female leader employing a female PA is completely different from a male leader employing a male PA. Males are built stronger generally and don't find the physical

element of their job as difficult as women and aren't affected by the 'monthly's' and all the different moods these can bring and sometimes even an inability to work and are not at risk of becoming pregnant. Men in general can build up a relationship over drinks, discussing sport and anything else as long as it is not too deep, whereas women, and of course I include myself in this, find it difficult to open up in the company of a relatively new PA.'

Jessica feels that it can take much longer for women to find a 'common ground for discussion' than it takes men.

Other Issues That May Arise for the Leader When Using PAs

A number of other issues can arise when a Leader is using PAs. Firstly, it is not always easy to recruit a suitable PA. As Jessica works full-time she uses PAs after work:

'...I work full-time you know and I don't wish to go short on these hours. That's my problem. That's why I find it hard to find PAs because it has to be fitted in around my own work shift. It's very strange hours for somebody to work, but I'm not prepared to give up work, or reduce hours that's just the way it is you know. That defeats the purpose.'

A second issue that Jessica identified was in relation to trust. Jessica had a bad experience with one of her PAs and this has affected her overall trust in employing someone in her home. She also mentioned safety concerns that arise when first employing someone to work as your PA:

'I have to tell you, I am glad that I have my [family] and I don't know what I would ever do if [anything happened] or whatever. Really because I have no trouble now and I just think that it would be impossible for me to have somebody in my home and the fear that that creates you know, it's just so awful you know. I mean I don't even...interview PAs in my home or anything. I'd interview in a hotel so that they mightn't get to know where I live until I decide or choose them to be the one. And that feeling of somebody coming into your home, even for the first time when you have taken them on as a PA, it's a horrible feeling.'

The final issue that Jessica discussed was in relation to privacy. This can become a real problem for some Leaders, as the level of privacy that they would like in their life is not always a possibility:

'...you open your whole home to [PAs] you know...I mean I don't think people understand this; how private I wish to be but how private I can't be...It's huge and people say you know when your disabled for all of your life it mustn't really affect you when it comes to your

personal care and you know, in the bathroom. It really does and it affects you great like...You know straight away whether somebody has a problem with it as well and that's all in very close quarters in the bathroom you know. You can't decide, like when somebody's on trial, you have to go through every particular scenario, if you like, so that they can decide whether they want the job or not and I can decide whether they are going to be good enough in the job. And so you have to do all that and then they might say, "ah I don't want this job".'

Jessica finds that as a Leader she does not have the same energy that she once had and that makes it more difficult to deal with the different issues that may arise while using PAs. Despite this, she does think that the PA system is 'an absolutely fantastic system', albeit in need of a few changes.

The Future for PAS

Although Jessica stated that the PAS can take up a lot of a Leader's energy, she does still have complete faith in the PAS as a system for Independent Living. She feels that a policy of Direct Payments is 'absolutely the only way' for the future as this would help to alleviate many of the issues that arise in the Leader-PA relationship. In Jessica's opinion it would be clearer who is the PAs employer if she was paying the wages, giving Leaders more control. Although Jessica recognises that this would create more work for Leaders she does believe that the positives outweigh the negatives in this case.

Case Study Commentary:

The Complexity of the PA-Leader Relationship

A leaflet on the *Assisted Living Service*, which is provided by the Irish Wheelchair Association, describes the tasks undertaken by PAs. These tasks will vary depending on the needs of each individual and may include some or all of the following:

- Personal care, including showering, bathing, toileting, transferring to bed/wheelchair and so on.
- Essential cooking, feeding and domestic support.
- Social support, for example, trips to the shop, social events, outings and so on.
- Essential overnight/weekend services.
- Assistance for access to employment or education.⁵⁷

⁵⁷The Irish Wheelchair Association (2004) *Assisted Living Services Information Leaflet, Including Code of Good Practice*, IWA, Dublin.

This list of PA tasks helps to illustrate the sensitive nature of the PA-Leader relationship. ENIL state that it is important to remember the complex nature of the 'user-personal assistant relationship'. In most cases this relationship is one-to-one and can, on occasion, become very intense and personal.⁵⁸

Japanese Research on the Relationships Between Disabled People and their Personal Assistants

The relationship between disabled people and their personal assistants in Japan was outlined in a 2003 study. The research explains how the projects participants tended to characterise assistants in four different ways, which were 'instruments', 'employees', 'companions' and 'social assets'.⁵⁹

Personal Assistants as 'Instruments'

A number of the Japanese participants saw their personal assistants as functional extensions of themselves who react automatically to their instructions. This is revealed in statements such as *'I don't need a head, I need arms and legs' and in a desire that personal assistants are 'like the air I breathe'*.⁶⁰ However, participants recognised that their personal assistants were people who should be treated with respect and resisted any proclivity to treat the assistants simply as objects. Still, the participants believed that they should hold the control within any assisted transactions, while the personal assistants should provide the means of acting on the disabled persons decisions.⁶¹

Personal Assistants as 'Employees'

Only two participants in the Japanese research did not consider their personal assistants as employees. Fourteen of the participants used phrases similar to *'after all, I am the employer'*. Like in Ireland, payments to personal assistants are not made directly by the disabled person. Therefore, technically speaking, the personal assistants are not the direct employees of the disabled users. Nevertheless, the term 'employer' was *'used to indicate the feeling and belief that people held employer-like responsibilities towards assistants'*.⁶²

⁵⁸ European Network on Independent Living (1995) 'Controlling Your Own Personal Assistance Services'. Available from www.independentliving.org/doc2/enilbcodppayschemes.html (accessed 28/06/05).

⁵⁹ Yamaki, Chikako Kimura and Yamazaki, Yoshihiko (January 2004) "instruments', 'employees', 'companions', 'social assets': understanding relationships between persons with disabilities and their assistants in Japan" in *Disability and Society*, Vol. 19, No. 1, Taylor and Francis, London.

⁶⁰ Ibid.

⁶¹ Ibid.

⁶² Ibid.

Personal Assistants as ‘Companions’

The Japanese participants expressed a desire to develop friendly relationships with their personal assistants and some even stated that they felt close to them. All participants (to varying degrees) aspired to family or friend-like relationships with their PA, or had formed such relationships with them naturally. However, the research participants demonstrated a strong concern that they maintained a certain distance from their PAs with many taking precautions against becoming overly involved with them. This was for two reasons. Firstly, there was a concern that the quality of the personal assistance may decline if the user and helper were to become too involved or ‘*over accustomed*’. Secondly, some worried that they themselves may experience ‘*emotional imbalance*’ if they become overly involved.⁶³

Personal Assistants as ‘Social Assets’

Some of the participants in the Japanese research expressed a preference that their PAs served them exclusively. This can be a common preference for disabled people and is based on concerns that services would suffer or that private matters would not be kept private if their PA has divided obligations. However, a contrasting preference was stated by a number of the participants. These participants hoped to promote a broader understanding of Independent Living by introducing their personal assistants to others whom they might also assist. These participants were significantly involved in the Independent Living movement and they considered their assistants as a kind of social asset and sought to ‘*cultivate them as such*’.⁶⁴

Multifaceted Relationship

The relationship is a multifaceted one with different people emphasising different elements of the user-helper⁶⁵ relationship, that is:

*‘Some participants stressed their role as ‘employer’, while others stressed that of ‘friend’; some individuals commented on every aspect of the relationship, while other discussed only some’.*⁶⁶

The findings of the Japanese research recur in this Case Study which demonstrates that the PA-Leader relationship is complex and multifaceted and different Leaders stress different elements of the relationship as outlined above.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ User-helper, meaning Leader-PA, is a term used in the article.

⁶⁶ Yamaki, Chikako Kimura and Yamazaki, Yoshihiko (January 2004) ‘instruments’, ‘employees’, ‘companions’, ‘social assets’: understanding relationships between persons with disabilities and their assistants in Japan’ in *Disability and Society*, Vol. 19, No. 1, Taylor and Francis, London, P. 40.

CHAPTER 7

Case Study: Organising and Using Personal Assistants (1)

Introduction

Michael went to work as normal one morning in June 1991. He went out on the scrambler motorbike that he often used and while travelling across the bog he hit a soft spot and the bike jackknifed, throwing him off it. Michael was left paralysed from the neck down and spent the next 12 months in a rehabilitation hospital where he used up his time wondering what was going to happen to him and how he was going to provide for his wife and four children. Over these 12 months some of the power started to return to Michael's body and he is no longer totally paralysed below the neck.

Our interview took place in Michael's home in Offaly. The opinions which follow are those of Michael.

Using PAS – The Beginning

Michael found it very tough when he first came home from the hospital. At this time he could not push a wheelchair and he had to be fed. He found this very awkward for himself and his family. However, Michael undertook a lot of physiotherapy and exercise and the power began to return to his arms and legs.

The opportunity arose for Michael to study computers in a FÁS training centre. He studied there for 18 months undertaking a number of courses and he left with a Diploma in Computerised Accounts. When he completed his courses he got a job in research.

Around this time Michael's occupational therapist told him about the PA service in Dublin:

'...to make a long story short...I was introduced to the PA service in Carmichael House and I was called for an interview. I obviously passed the interview and I was offered PA time. I was the second person outside of Dublin to get a PA...So I got a personal assistant and it lasted about three months. It just physically didn't work out. I got a second personal assistant and that didn't work out and I got a third personal assistant and that didn't work out...to be honest about it, it wasn't all their fault. I come from a very active background...I was a member of the Offaly GAA, on the County Board...so I would have had a very active background and it wasn't their fault. I wasn't ready for a personal assistance service. So anyway, three or four months went by and I just had nobody and then eventually I interviewed another person. I took her on and she only retired last Christmas after ten years, so that was very, very successful.'

Michael believes that it was at the time of hiring his fourth PA that he really recognised the worth of the PAS. He made a decision that if Dublin could have a Personal Assistance Service then Offaly should have one too.

Setting up Offaly CIL

Michael went about setting up the CIL by organising a meeting with the Dublin CIL Director and people from four other counties. It was decided that five more CILs would be set up around the country. It was in September 1995 that Offaly CIL came into being:

'...we started out with a FÁS CE scheme with 11 personal assistants, a supervisor and ten leaders. And then you know, after three years, the people have to leave because they can only stay on the FÁS scheme for three years. So we applied to the Health Board for funding and we got the funding that enabled us to keep on our PAs.'

Since 1995 Offaly CIL has continued to grow and grow and at the beginning of this year they had over 60 PAs and 85 Leaders. Recently Offaly CIL took over the Laois CIL personal assistance service and now has over 100 PAs.

Younger and Older People Using Personal Assistants

Offaly CIL allows children and older people to avail of their PAS. Michael believes that it is important that children learn about Independent Living from an early age:

'I always look at it from a GAA point of view. You don't start to train young [All-Ireland] hurlers and footballers at 18 years of age...they started when they were children at two or three years of age, kicking a ball around. So we adopted the same philosophy in CIL. As soon as we hear of a child with a disability, if the parents are willing and want an independent lifestyle, then we move in. We have started with children as young as...four and five. Now saying that, the parents would be totally in tune with the Independent Living movement...the PA has to be under the jurisdiction of the parent when the child is under 18 but it has worked very, very well for us.'

Michael used the example of a teenager with a significant disability who uses PAs to illustrate the benefits of the service for young people. This particular teenager has been using PAs for a number of years now. His mother provided full-time care for him before this. Offaly CIL hired his mother, who used to be a teacher, to research and write a manual on mainstream education for disabled children:

'...she could not have wrote that manual if her son did not have a personal assistant. He has a personal assistant that takes him anywhere, he's into music...he's into

swimming...he goes on his holidays...his mother was free to work for us those three years...and it is a success story'.

This teenager is now in Third Level education and has a job secured for himself when he finishes college. It is Michael's opinion that if this person did not have a PA he would probably be on disability benefit and one of his parents would have to stay at home to look after him.

Offaly CIL also take on people over 65 to use the PAS. Michael described some examples of older people who are using PAs in Offaly:

'Now we have one Leader for instance, I'll give you an example, he's 81 years of age, he came to us ten years ago when he was 71 years of age. He is a wheelchair user for 60 years...he buys those ancient clocks...he buys them at auction...and brings them home. He has a workshop and he repairs them. One of the PAs, he has two PAs at the moment, one of the PAs...is an ex-fitter...he works with him and he makes the parts for the clocks and then when they get the clocks rolling again they sell them. They bring them out and they sell them, they put them in the shops and they sell them there you know. He also makes picture frames and he's pretty good at art and that's a man of 81 years of age. If he did not have a personal assistant he would be in an institution now doing nothing. So he's a man that's fulfilled, getting job satisfaction out of his work, his PAs are getting job satisfaction and that works very, very well. We also have an 87 year old, he's a retired botanist now... he's 87, his wife is 89 and about 5 years ago, ...they were here one morning and his wife said her husband was getting very cross and contrary and the reason was that he couldn't dig and sow his plants anymore in the garden. So I said "what about a personal assistant service" and after three weeks they accepted a personal assistant. So, he's back doing his plants and all that goes with that and there are tourists that come in every second week from all over the world...and they come in every second Sunday and eh, that's his life and at 87 there is still a spring in his step because, where he physically can't do the work he has a PA that acts as his arms and his legs and does the work for him at his direction, you know. That's some of the benefits now of the whole scheme.'

Michael believes that quality of life and independence are important no matter what age you are. In his opinion, the policy of taking on children, teenagers and people over the age of 65 has worked, and continues to work, very well for Offaly CIL.

Offaly CIL and the Community

Offaly CIL have built up a relationship with many organisations in the local community. Michael considers this as paramount to the success of a CIL and for the improvement of conditions for disabled people in general:

'...we got involved in quite a few things now, for instance, in Tullamore at the moment there is a big stadium being built, the GAA are building a big stadium and they asked me to do an access check on it before the building and I look at the drawings for them and that's how much things have changed...rather than them deciding for someone else, we decide now what we want...and with the local hotels in town it is the very same...in Tullamore the Ulster Bank now, for instance, where we deal, it wasn't accessible. I couldn't get into it and other wheelchairs couldn't get in...so I had a meeting with the manager and I went "look we put a million Euros through your bank and I need to get in here." So...to cut a long story short they gave us €50,000, they said "you do it for us", so we did. It didn't actually cost half of that...that's the sort of relationship that we have built up in the town. It's sort of a profile that we have built up and it's working well you know.'

Michael also believes that it is important to keep a close relationship with the local politicians. Members of Offaly CIL invite the local TDs to meet with them every year in order to keep them up to date on CIL activities and Michael feels that this has benefited them in different ways.

Michael's Personal Use of PAs

Michael is involved in fundraising and the development of Offaly CIL. He does quite a bit of this work at night on the computer. In the morning when his PA comes to his house Michael does weight lifting and other exercises while his PA checks the material that he wrote the night before:

'She got very much aware of the whole philosophy of Independent Living and the ethos of Independent Living and...she could correct all that for me...I would go into work nearly every day and she would take me in and I would have my lunch inside and she would take me home at 4/5 o'clock in the evening...If I'm going to...meetings, when I'm standing up in the morning my PA prepares all the stuff for me, gets the folders out, gets everything into a briefcase that I have, takes it to the meeting, sets the whole thing up for me.'

The PAS brings great benefits to Michael personally, but he feels that it also brings benefits for his family:

'...So it works very well from that point of view and from another point of view, from the family point of view. I have a wife and four in the family...they're all in their own jobs, they

all went to school and to college and done well for themselves...they're all paying their tax and their PRSI and they don't feel they have to be at home looking after me...And I think that is the most important part of the whole Independent Living movement. Not only has it created an independent lifestyle for me but it also creates an independent lifestyle for my family and [they contribute] to the exchequer in tax or PRSI'.

Michael explained that if he had had his accident more than 15 years ago, when there were no PAS, one of his sons or daughters would probably have had to stay at home and look after him. He feels that this would have left both him and his carer very unhappy people as he would feel dependent and they would miss out on their education and career. But the whole 'landscape of disability' has changed in Michael's opinion and a lot more disabled people are now able to work and 'draw their own wages' rather than receiving social welfare benefits.

Personal Assistance Services in the Future

The single biggest issue for the future of PAS, in Michael's opinion, is the securing of permanent funding. At present funding comes from a few different sources and is not secured in law. Michael describes this as a priority for Offaly CIL and he is confident that if you spoke to all the other CILs around the country it would most likely be a priority for them too. Michael is optimistic that this lack of permanent funding may change in the near future. In his opinion the PAS in Ireland works well, costing significantly less than institutional care.

CASE STUDY:

Organising and Using Personal Assistants (2)

Introduction

Kenneth began using PAs in 1995. He has a significant physical disability called Friedreichs Ataxia⁶⁷ which is getting progressively worse at a rapid pace. Between the ages of 16 and 20 Kenneth used a wheelchair on and off. At age 20 he had to use a wheelchair full-time. Now his Disability has progressed to the stage that he needs full-time PAS.

Two of Kenneth's brothers also have Friedreichs Ataxia. One is older and the other is younger. One now lives in a residential home full time.

⁶⁷ Ataxia is a blanket term for a loss of ability to control one's muscles.

Our discussion took place in Kenneth's home in Gorey, Co. Wexford. The views which follow are those of Kenneth.

Gorey CIL

Kenneth set up Gorey CIL in March 2000. He is now the Programme Manager.

According to Kenneth:

'Gorey CIL is in the business of empowering and enabling people with disabilities to achieve Independent Living and equal participation in mainstream society, by employing personal assistants to assist them and with the use of technical aids, for example, power-wheelchairs, computers, etc.'

All the work that Kenneth does for Gorey CIL is voluntary. He spends a lot of his PA hours a week undertaking this work. Although Gorey CIL is one of the smallest CILs around the country with only four or five PAs at any one time, it is very active in terms of campaigning.

PA Hours

When Kenneth first began to use PAs he had 70 PA hours per week. This was during his time at college in Dublin. Kenneth lived in Dublin assisted by two PAs while he was studying. This only lasted for a year and when the initial EU funding ran out his hours were reduced to 19½ hours. His PA time has increased by only ½ hour since and he now has 20 hours a week. Kenneth has tried to obtain more funding for the extra PA time that he needs. However, to date his efforts have been unsuccessful. Kenneth described what it was like when he first started to use PAs:

'...even at that stage my disability wasn't as progressed as much as it is today. I could go out; I could do what I wanted when I had that many hours. I was very independent. But now I have [twenty hours], I can't do anything because with my twenty hours I have I can't go out...I spend a lot of time working on Gorey CIL stuff...'

There is a full-time care service in Kenneth's home which consists of one carer for two people with disabilities. This is not what he wants or feels that he needs. Kenneth 'needs and wants' full time assistance, but on a one to one basis, in other words a PAS rather than a care service. What he means by "full time" is 168 hours per week.

Because Kenneth only has a few hours with his PA each day he spends most of this time on CIL work which includes letter writing for different campaigns that the organisation is involved in. Kenneth feels that he could benefit significantly if he had

more PA hours. However, he has been told by the Health Service Executive (HSE) that the funding is just not available for him to increase his hours. None of the Leaders in Gorey CIL have more than twenty PA hours per week:

'...If I had more funding yes I would increase my PA hours. When my disability first started it wasn't as bad, but my disability is progressive and it has progressed significantly...I could manage with so many hours for so long but now I [have] full-time needs...'

Kenneth's disability has progressed so significantly his only independence is for twenty hours a week when his PA is at his house. Although Kenneth has his own car, he needs a PA to drive it for him. As he has so few PA hours, he cannot leave his house for the remaining 148 hours a week:

'...on the days that I don't have a PA I'm just stuck here. I feel very much like a prisoner in my own home without the assistance of my PA. I get parole for 20 hours a week. I need to have someone to go out with me...'

Kenneth lives in a rural area so his car is his only means of transport. There are only minor back roads from his house so he cannot go out alone in his wheelchair.

Using PAs

As Kenneth has so few PA hours, organising and attending CIL meetings can sometimes be a problem. He needs to know about a meeting well in advance so that he can try to swap around some of his PAs hours if necessary. He explained that this is usually not a problem but it is important that he give his PA *'plenty of advance notice because they have a life as well'*.

Kenneth has one PA who has worked with him for eight years. He feels that they have a good working relationship:

'...from the beginning and even now after all these years I still have full choice, control, freedom and decision making in what I do, she is excellent.'

Kenneth described the relationship with his PA as friendly but he explained that even though he gets on well with his PA, at the end of day it is an employer/employee relationship.

CONCLUSION

Kenneth is soon to move to a new house in Gorey. When he moves he will continue to have the same care package even though he will be living alone. This time his care

service will be shared with his neighbour who also has a disability. This is not Kenneth's preference but he was not given any choice. Kenneth needs more PA hours to live an independent life, as *'there is a big world out there and lots to be explored'*.

Case Study Commentary:

The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities⁶⁸ in Relation to Personal Assistance and Personal Assistance Provision in Ireland.

The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities were introduced in 1993. The standard rules are not legally binding but they *'represent a strong moral and political commitment of Governments to take action to attain equalization of opportunities for persons with disabilities.'*⁶⁹ The rules were formulated to serve as an instrument for policy makers in the member countries.

The extract in Box 2 states that the provision of personal assistance and other services should be based on a disabled persons need, as an important measure to achieve the equalisation of opportunities. Unfortunately this is not the case in Ireland as the service is based on available funding rather than need. The case of Kenneth illustrates how a disabled person may be left without adequate PA hours due to a shortage of funding. Because of this, CILs throughout Ireland have been lobbying for the establishment of an ILF, which would ensure a secure, and consumer controlled fund from which Leaders could get as many PA hours as they require.

⁶⁸Adopted by the United Nations General Assembly, fourth-eight session, Resolution 48/96 annex of 20 December 1993. The 22 rules summaries the messages of the World Programme of Action and were adopted as guidance for action in 1994.

⁶⁹See: www.un.org.

BOX 2

Preconditions for Equal Participation, Rule 4: Support Services

§ States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily lives and to exercise their rights.

§ States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with disabilities, as important measures to achieve the equalization of opportunities.”

§ States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure time activities.

§ Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

Source: www.un.org

waiting on equipment to get repaired. I wouldn't say hav-

EXTENDING THE BOUNDARIES: OUR EXPERIENCE OF INDEPENDENT LIVING

CHAPTER 8

CASE STUDY:**A Woman's Experience of Independent Living****Introduction**

Karen⁷⁰ has been using PAs for eleven years now. She lives in her own home with the help of personal assistants and Karen believes that without this 'essential service' she would not have the quality of life that she now has. A number of years ago Karen completed a degree in college and she now works full-time. When she first started using PAs, Karen found it 'scary and fairly rocky' at times and she appreciates the fact that her family were still supportive of her despite this. She believes that the support of one's family is crucial and that it is also essential that they do not interfere in the relationship between a Leader and their PA.

Karen's view of independence is very broad. She sees it as being able to come and go as she wants, participate in society and the community as she chooses and being financially independent, as one's financial stability has a huge impact on the control and the level of autonomy that a person feels they have in terms of decisions and life choices.

Our meeting took place in Karen's workplace in Dublin. The views which follow are those of Karen.

Body Image and Clothes

Karen felt very strongly about the issue of body image and clothes for disabled women. She believes that disabled women are often made to feel like 'freaks' because they don't have the perfect body image. In her opinion body image is a very important issue for many disabled women and the clothes that are available for these women do nothing to improve their confidence:

'Like if we get back to the whole body shaping and body image and that, but if because of your impairment you have a curvature of the spine for example and you can't wear the tight fitting tops and whatever else, that's a huge issue for a lot of women and I know I have had trouble with it myself and I still do to a certain extent. It just frustrates me, it angers me when you go out and try to get clothes, you know sexy nice clothes that you feel comfortable in, that accentuate your good points and hide the ones that aren't so great. They're all for grannies...'

Karen feels that some of the clothes that are suitable for her to wear are very frumpy and unflattering and are clothes that would generally be worn by much older people. She finds it very hard to find fashionable clothes that fit her properly and she wishes that she had more choice available to her when shopping.

⁷⁰Name changed to protect identity.

The Sex of the PA

Karen believes that the dynamic in the relationship between a male Leader and their PA and a female Leader and their PA is different:

'I would have had a situation in the past whereby a PA would come in and basically unload [their problems] on me but I think yeh, the dynamic between two men and two women is very, very different and I've often noticed that at the times I've had, for relief, I've had a man, a male driving me or whatever and I quite like the kind of dynamic...between us...there is definitely a different kind of dynamic'

Although Karen has enjoyed having a male relief PA, she would have doubts about hiring a male PA full-time:

'This is something that I constantly toy with and ask myself about and you see in a work situation...I would actually like at times to have a guy but because I need personal care, there is just something that stops me from...having a guy as a PA when I need that level of intimate assistance. Now I don't know why...there was one occasion where I had somebody for a week, a Spanish guy, and somebody else at work provided me with the personal care. But I think because I kind of liked him and built up kind of a trust with him, if he'd been there for longer I may have...approached the subject with him and seen how he felt about it you know, if we came to kind of a consensus between us I may have tried it but I had to get to know him first and I don't know why that is...I always struggle with it in my head you know, wondering should I?'

Karen explained that using male PA's would also pose safety issues for her. She does not feel comfortable with giving a male PA 'access to your most intimate personal care'.

Relationships

In Karen's opinion there is a lot of stigma around disabled women having intimate relationships. Although she does not have a partner at the moment Karen has had in the past. There is one aspect of having an intimate relationship that she finds difficult to deal with:

'I think a very big issue for me is the fact that I need to use equipment to transfer, to move basically and basically I find that very intrusive in a relationship type situation, where it's something I don't think I'll ever quite get used to, you can learn to live with it but it kind of brings a lump to your throat when them situations arise. And the fact that...nothing is spontaneous and the fact that, especially in the early stages until you get to know the person well, a PA always needs to be involved in what is supposed to be an intimate moment or moments between two people and that for me is very, very difficult.'

Whenever Karen has been in a relationship in the past she has had to sit her PAs down and talk to them about it and see what they are comfortable with:

'So when I'm interviewing new PAs I would be very in tune and aware, watching their general openness and their body language...and because it is a huge issue and unless, you know, I feel comfortable in broaching it with somebody...the possibility of being able to be at home or whatever with a partner or even if it is a casual thing you know, that possibility needs to be open to me and they need to be willing to take me to someone else's house and to kind of know that this is very private and personal and know when to step out...'

It is important to discuss these issues with your PA early on when you hire them. It has never been an issue for any of Karen's PAs but she knows that it has been for some other people.

Reproduction and Motherhood

Karen believes that a lot of people do not think it is possible for disabled women to have children. People think that because disabled women need care there is no way that they could have a relationship or children themselves:

'I think the majority of people, a lot of people, can't see how it is possible, that if somebody with a physical disability needs assistance with their own personal care how can they possibly care for a child or baby and I am quick to point out that, there is a lot more to being a parent than providing physical assistance. And a baby is only a baby for so long and kids grow up and you know can be quite self-sufficient physically after a short period of time...I will be there when the tasks are being carried out and I will give instructions, of what I would like done, and the way in which I would like assistance in the same way as I do in all other areas of my life.'

People's attitudes towards disabled women having children are generally quite negative and this annoys Karen. Especially when non-disabled women who are obviously not in the right place for parenting because of issues in their life are not criticised for having children, yet disabled women are not deemed to be fit parents because of their physical impairments, for example, because their *'legs don't work!'*

The Invisibility of Disabled Women

Karen feels that as the wider society becomes more comfortable around issues of disability, many of the issues specific to disabled women remain invisible:

'Hollywood has become a little more comfortable in recent times in discussing and making movies around the theme of disability. Movies such as "My Left Foot" and "A

Beautiful Mind” have won international acclaim. More recently “*Inside I’m Dancing*” and “*Murderball*” have hit the big screen. However, not surprisingly the central characters in all four movies are male.’

Karen is disappointed that in the twenty-first century no one has had the ‘*foresight and the courage*’ to write a book or a movie which has a disabled woman (or women) as the main character. She feels that it is time that this imbalance is tackled.

CONCLUSION

Karen wonders whether gender equality is a ‘*reality or a mere fantasy?*’ She is not quite sure but she believes that disabled women have much to contribute to society both collectively and individually. Disabled women are not a heterogeneous group but they have the right to expression and freedom of choice in the same way as their non-disabled counterparts.

Case Study Commentary:

Disabled Women, Relationships and Motherhood

Relationships and motherhood are issues of great consequence for many disabled women. Robert Drake argues that obstacles are continually placed in the way of disabled people who want to ‘*recognise and enjoy their sexuality*’ and form loving relationships.⁷¹ According to Drake:

‘The hurdles were not only attitudinal (that sex for disabled people was wrong and to be avoided), but also concrete, as seen for example in the provision of no other arrangement than single-sex dormitories in residential care establishments and long-stay hospitals and in the lack of sex education and information to disabled people, in the lack of opportunity to socialise and make friends, in exclusion from leisure settings such as nightclubs and restaurants, and in the lack of funds necessary to pursue courtship and meet the costs of setting up a more permanent home.’⁷²

When disabled women do form long-term relationships they are ‘*frequently counselled by medical professionals against having children.*’⁷³ According to McPherson, disabled women are told that their child would suffer and that they would not be able to cope with medical emergencies if they arose. McPherson also states that even now disabled women, with intellectual and physical impairments, ‘*run the risk of involuntary sterilisation, usually carried out in conjunction with some other operation.*’⁷⁴

⁷¹ Drake, Robert. F. (1999) *Understanding Disability Policies*, Macmillan, London. Pg. 132.

⁷² Ibid.

⁷³ Ibid.

⁷⁴ Quoted in Drake, Robert. F. (1999) *Understanding Disability Policies*, Macmillan, London. Pg. 133.

When disabled women have children they are often undermined as parents, particularly in relation to the identification of their children as 'young carers'.⁷⁵ Morris argues that:

*'Children of disabled parents have been described as "little angels" who are forced to "neglect their schoolwork and friends" in order to look after us. However, if we apply the social model of disability to the situation of disabled mothers we can see that there are a number of social factors which create the situation where children might have to provide some help to their parents.'*⁷⁶

Poverty and discriminatory professional attitudes are two of these barriers. Morris contends that it is a failure to understand the social model of disability that '*lies at the heart of the dominant reaction to the situation where children are having to provide support to their disabled parent.*'⁷⁷ A challenge to medical model perceptions of disability and parenthood is necessary to overcome these barriers (See Box 3 on the following page).

A Norwegian study examined the experiences of 30 disabled mothers in Norway. In this report Grue and Lærum argue that the fact that disabled women are stuck in a discourse of disability makes it very difficult for them to be looked upon and treated as a mother, as the mainstream discourse of disability does not blend easily with the mainstream discourse of motherhood. The study indicates that there is still a long way to go before this will change as:

*'...disabled people on the whole are primarily still looked upon as being dependent on other people's help and care. In short, they are often looked upon by professionals and lay people as receivers (discourse of disability) and not as carers (discourse of motherhood).'*⁷⁸

However, the authors of this research argue that even if a woman's impairment does have some effect on her activity levels, the main problem faced by the women who took part in this study was other people's disbelief and the social and material '*framing*' of motherhood in Norwegian society.⁷⁹

⁷⁵ Morris, Jenny (1998) 'Feminism, gender and disability'. Paper presented at a seminar in Sydney, Australia, February 1998.

⁷⁶ Ibid.

⁷⁷ Ibid.

⁷⁸ Grue and Lærum (2002) 'Doing Motherhood: some experiences of mothers with physical disabilities' in [Disability and Society](#), Vol. 17, No. 6, Taylor and Francis, London.

⁷⁹ Ibid.

BOX 3**Disabling Attitudes and a Disability Rights Perspective to Parenthood**

| Disabling Attitude | Disability Rights Perspective |
|---|---|
| People who need help with the physical tasks of daily living are dependent | Independence is not about doing everything for yourself but about having control over how help is provided. |
| If your child helps you put your shoes on, this involves a reversal of roles – have become the child, and your becomes your parent. | The need for help with daily living tasks does not undermine your ability to love and care for your child. |
| We need to recognise the role of 'young carers' so that we can support these children in their 'caring responsibilities, experience and needs.' | Disabled parents should not have to rely on their children for help as they have a statutory rights to 'practical assistance in the home' and to the adaptations and equipment in the home. ⁸⁰ |
| Source: Morris, Jenny (1998) 'Feminism, gender and disability'. Paper presented at a seminar in Sydney, Australia, February 1998. | |

⁸⁰This is in relation to British legislation and does not refer to Ireland.

CHAPTER 9

Case Study:

Transport and Independent Living

Introduction

Dermot has been active in the area of transport and accessibility for a number of years. He mainly works as a Disability Consultant for Dublin Bus. He is involved in and with many groups that primarily focus on transport and Independent Living. Our discussion took place in the heart of Dublin city in Temple Bar in an accessible street level lounge with an indented parking space outside the door. The views which follow are those of Dermot.

How does Independent Living Impact on Transport?

Personally, Dermot would not be able to play the role he currently does in the development of transport without the services of a personal assistant. In relation to the wider population, people are now being empowered to be able to use different types of transport. Many people like Dermot own their own vehicle and use the services of a PA to drive them. Other people may need assistance using public transport.

Significant Developments

It is Dermot's belief that there have been two significant developments in the transport system that have had an impact on Independent Living. These are the increase in the number of accessible buses, which now stands at over 50 per cent of the Dublin Bus fleet, and the development of the enterprise *Vantastic*. In Dermot's opinion '*we came from nothing ten years ago*' and there has been some very important progress since then. However, Dermot believes that transport and spatial issues are treated separately. The '*accessibility chain*' which links transport and space is rarely considered as a whole. According to Dermot the accessibility chain means that you can: '*...get from your house to your car or to the bus or whatever, to your office and back home or to the pub or whatever. I don't think that people do understand it.*'

Choosing and Running a Car

An element of the Government's transport policy that Dermot called '*the best system in the world*' was the concessions that people with disabilities can get when they buy a car. If you buy a vehicle and it is adapted to your needs, all the tax and duty is refunded from the car as well as the duty on petrol. But Dermot believes there are some problems that people with disabilities face when they buy a car. One is the cost

of insurance, which may be up to four times higher than for a non-disabled person. Dermot brought his insurance company to the Equality Tribunal because his premium was so high. He won his case. Although he got a refund and a premium reduction, he still pays €1900 a year for insurance. Another problem that people with disabilities face is trying to find a vehicle that is suitable to convert for their needs. Dermot's car is quite an expensive car but that is out of necessity and not as a status symbol. It was the only car he could find to suit his needs. He even travelled to the UK to try and find a cheaper suitable vehicle but he could not locate one. Another problem people face is that if their vehicle is off the road for any reason it is almost impossible to rent an accessible vehicle.

Preferred Mode of Transport

Dermot does most of his travelling in his car, for which he uses a PA as his driver. He can travel on the bus, Luas or train independently. However, he has not used the train since he got his car in 1999. Before then he used the train all the time but he was never happy about some of their policies:

'If you're a wheelchair user and you want to go on the train you have to give 24 hours notice. Where is the equality in that? And if you arrive at the station there is a panic to locate a ramp to get you on to the train and you are only allowed to sit in the dining carriage, which in my view is segregation.'

Dermot explained that the three C.I.E. companies have a consultative group of people with disabilities to give them advice. However, the user groups are under the direction of the Department of Transport and they decide on the make-up of the user groups. Dermot's big problem with groups of this type is that the participants are representing organisations rather than just representing themselves as people with disabilities. Dermot meets a wide range of people of different backgrounds all the time and feels that he could identify a number of potential participants who could make a good input to a transport user groups but he has no say in the matter.

The Image of Transport for People with Disabilities

To Dermot, the image created by transport for people with disabilities is very important. In relation to this, he feels that a move away from specialised transport and a shift more towards public transport is necessary:

'I think we need to move away from specialised transport and move people into public transport. Certain buses that are wheelchair accessible are not seen as buses but are

classified as an ambulance. I think we need legislation so that you cannot make a bus into an ambulance...It creates the wrong sort of image of people with disabilities and it keeps the general public's mindset stuck back in the day when it was "those people need special this and special that".

Disability association and specialist transport services should be striving for equality. All people should be able to use the public bus service. However, association buses could still be run as a service for people with disabilities, rather than being labelled as an ambulance, which in Dermot's view is exactly what people with disabilities would like to get away from – the medical model. In his opinion, association transport should just be plain transport for everyday use, which means that the '*underused association buses*' would be used much more regularly.

Taxi Services are they safe?

Dermot never uses taxis as a mode of transport as he considers that there are no accessible taxis in the Dublin area that he has come across that would meet objective safety criteria. At the moment a wheelchair user enters a taxi from the side door and Dermot knows that this is not safe as usually there is no room to reposition the wheelchair so the wheelchair user can face frontward rather than facing the side, which is dangerous. Often, these taxis do not have the necessary chair restraints and even less seem to have the seat belt restraint. Dermot believes this could be as a result of their €400 price tag.

In May 2005 there was a transport show on in Dublin. After the show Dermot was out with some of the people who had stands at the exhibition. They were people from around Ireland and the United Kingdom who make safety equipment for transport vehicles. They had ordered a taxi to get home and when it arrived and the driver took out the ramp one of the guys asked Dermot if he thought the taxi was safe. Dermot replied that he did not think so and the taxi man turned to one of the other people that was there and said '*sure what would he know*'. The taxi man was very surprised to find out that Dermot was a wheelchair safety officer. When he asked the driver whether he had the proper straps for the wheelchair, the taxi man replied '*what straps?*' Dermot knew it was not safe but it was quite late at this stage and he needed to get home so he just had to take the chance and go in the taxi. Usually Dermot would not use the taxis and he feels that there are only two ways to get home from somewhere late at night if he doesn't have his car – by bus or in his wheelchair.

Transport Policy

The issue of transport for people with disabilities can be frequently left to linger far down the policy agenda. However, Dermot sees it as his job to try and keep it up the policy agenda

Dublin Bus uses U.K. bus regulations, as there are none in Ireland. This is causing problems as the newer low-floor buses meet these regulations but do not suit many people's powered chairs due to the position of a pole on these buses. Although this is being addressed at the moment, Dermot feels that we need our own regulations. He also feels that the people who make wheelchairs should work together with people designing vehicles.

Case Study Commentary:

Transport Safety Regulations

According to U.K. regulations, all vehicles that are intended to carry wheelchair users should include suitable Wheelchair Tie-down and Occupant Restraint Systems (WTORS).⁸¹ The exception is large public service vehicles, which provide a designated wheelchair space. As there are no bus safety regulations in Ireland, Dublin Bus uses U.K. bus regulations. However, regulations do exist in Ireland in relation to wheelchair accessible taxis. An excerpt from the Road Traffic (Public Service Vehicles) (Amendment) Regulations, 1997 outlines these requirements:

Requirements for Wheelchair Accessible Taxis⁸²

1. *The vehicle must have been constructed or adapted so as to be capable of accommodating a person seated in a wheelchair.*
2. *The vehicle must have seating accommodation for at least three passengers in addition to the person seated in the wheelchair.*
3. *The vehicle must have at least two doors giving access to the area in the vehicle where the wheelchair and its occupant is to be accommodated.*

Each of these doors must have an aperture height of at least 1300mm and an aperture width of at least 735mm.

4. *The vehicle must be provided at all times with a mechanism to permit the safe entry and egress of a passenger seated in a wheelchair. The mechanism must be capable of*

⁸¹ Medical Devices Agency (2001) *Guidance on the Safe Transportation of Wheelchairs*, MDA DB2001(03) June 2001.

⁸² As stated in the S.I. No. 193/1997: Road Traffic (Public Service Vehicles) (Amendment) Regulations, 1997.

transporting a combined wheelchair and occupant mass of 300kg minimum between the road and the vehicle interior without the assistance of any person but the driver of the vehicle.

5. *The wheelchair and its occupant must be accommodated in either a forward facing or a rear facing position in such an area of the vehicle that the occupant has an unrestricted view of the taximeter.*

This area must be at least 1350mm in height measured from the floor to the roof lining and have a length of at least 1200mm and a width of at least 750mm available for the exclusive accommodation of the wheelchair and its occupant.

6. *The area designated for the accommodation of the wheelchair and its occupant must be provided with*

(A) a restraint system which is fixed to the structure of the vehicle by an appropriate means for the purpose of securing the wheelchair, and

(B) a separate restraint system which is fixed to the structure of the vehicle by an appropriate means for the purpose of securing the occupant of the wheelchair.

The Department of Transport *Outline Sectoral Plan Under the Disability Bill, 2004* states that the Government is committed to continuing the process of making taxis wheelchair accessible:

*'However, a number of complex issues concerning implementation of an accessible taxi policy have yet to be decided on. These include improvements to the existing wheelchair accessible taxi specification, matters relating to urban/rural taxi needs and the cost of suitable vehicles.'*⁸³

The Department's overall goal and objectives in relation to transport for disabled people as illustrated in the *Outline Sectoral Plan Under the Disability Bill, 2004* is outlined in Box 4 next page.

⁸³The Department of Transport (2004) *Outline Sectoral Plan Under the Disability Bill, 2004*: Department of Transport, Stationary Office, Dublin.

BOX 4

Department of Transport Outline Sectoral Plan Under the Disability Bill, 2004: Goals and Objectives

High Level Goal

The Department of Transport is committed to the comprehensive development of accessible public transport services for the greatest number, and the largest categories as possible, of those with mobility and sensory impairments in the shortest possible time having regard to resources, technical and other constraints.

Objective

The Departments objective with regard to Transport Accessibility is:

'That all passenger transport providers should provide the highest possible degree of accessibility, subject to available resources and competing priorities and rules of practicability'.

The obligations arising from this objective will apply to all providers of public transport services, both public and private. This Plan has been prepared having regard to the likely life span and replacement costs of existing public transport vehicles infrastructure.

Source: The Department of Transport (2004) *Outline Sectoral Plan Under the Disability Bill, 2004*: Department of Transport, Stationary Office, Dublin.

CHAPTER 10

Case Study:**The Role of Assistive Technology in Independent Living**

Mags lives alone in Dublin. She was in residential care for 35 years before she started using PAS. Although it can be rough sometimes, Mags enjoys 'the road of Independent Living'. When she was living in residential care she had no control over her life and she had to rely on 'pocket money'. Her life is a lot more independent and enjoyable now.

Mags uses a *Lightwriter* to communicate so she had already prepared an article for the interview before it took place in order to 'save time'. The interview took place in Mags' home in Dublin. Mags wrote the following passage:

...I was a crying child. I always knew what is what. I believe people knew too, even though I often heard people whispering that I will never be able to think, walk or talk. This fogged my mind, as I was a thinking human being long before I learned to read, climbing mountains of discoveries of my little big world. I always knew more than people credited me. Radio and music cushioned me. This gave me a fringe of a world I was living in but not yet part of.

I remember being asked 'Where is God?' I was always blessed with a sense of humour. I couldn't help thinking what a question to tease me with. I flapped my palm hinting I didn't know, hoping people could understand my monkey language. I often laughed silently, how do I know when I never met him yet? I always talked to him for comfort but he was never a pop star I wall the walls with.

Learning to read tore my brain; in my mind I spelled listening to sounds of words which were never right. I had to hammer myself, making my mind a scrabble game every time I fingered new words. Kids today can use picture screens or picture bliss boards to help them spell, if their situation allows them to be able to spell. Seeing words is easier than playing scrabble in a hurry. Time is on everyone's back when the need to communicate is so great. It is hard for people watching your fingers flying about trying to remember the jazzy conversation. It is a bit like today with the smoking when a person leaves a pub during a good conversation, when he or she comes back the bones of what was being said is forgotten. The mind feels like rocks when people are lost as you are trying to express yourself. You don't want to waste their time saying nothing but in some cases this is important too. It fills your world with company even when it is a struggle putting holes in people's heads playing scrabble with a bliss board.

Humour was the cream of my personality even through the darkness of my day. I lost lots of cardboard mouths during my teens and twenties. I remember I went to Lourdes one time and left my mouth on the plane. I wrote a letter to Dublin Airport if they found my

cardboard mouth please post it to me. I am sure people thought I was from Mars. Where in the world is this nutcase from? I was dying to get a reply as I imagine people's eyes were hopping in their jaws. I got a letter back 'Lost property hasn't been found...' I remember another time I went away without my mouth, I had to point for two days. My mind was a bomb, I couldn't tell people I didn't know what I need. Okay, people had notes about me but it is nice to communicate because going on holidays people are different. It adds more fuel to their character and is usually more fun letting your hair down making new friends.

I liked school but got wired up over exams. I failed my Inter Cert, which turned me into a scribbler. My schooling stopped then in 1980. Sometimes it is great to fail because it allowed you to become who you really are. I loved being normal but it was hard coping. I had not even a powered wheelchair. I missed out at the beginning of every class because a teacher at the end of each class had to wheel me around. I never got on well with my classmates. They always ran away and forgot about me. Maybe being 5 or 6 years older than them didn't sew reality. I would never be the normal disco kid, I was 17 and they were 13 or younger...I often asked what would I turn out to be...You could have nothing and everything all at the one go.

You get many parking tickets in your way waiting on equipment to get repaired. I wouldn't say having the magic toys that are around today wouldn't have put more petrol into my life. Sometimes too much is too little. I believe that technology...pushes normality into my life making mobility possible. Though it is never a God I can rely on.

Buds in Winter

I feel like a dumb lame doll when I am not in my home environment. I was away last week. I wished I could piggyback my house. No computer, or wheelchair, or key to let me into my house. I know I wasn't here. When you rely on Technology you can't make the world move just because you need a holiday. I know all things are possible, but waiting for equipment to get fixed might take weeks to repair. I feel like a Cinderella using technology. I like to explore, but I live in hope my wheelchair or my Lightwriter to communicate with doesn't break down when I am out alone.

Having a disability is heavy. You have to make sure equipment gets charged to give you freedom you need – just to get by daily. You can't expect buds to grow in winter just because life is as it is. Responsibility is a test if you want to be equal. It is like playing football, you can never tell if you are going to win or lose. You only hope people will kick the 'specialness' out of you by treating you the same.

I am a clown when people stop me in town and they asked where do they get a talker like mine? Their parent might have had a stroke, but before I fingered the message they run. I feel like saying: 'In any toyshop. I think you get them in Penny's or Dunnes', I joke silently.

People must remember I am not the best one to ask. What suits me might not suit their mother or father. Another type, or none at all if their ability of spelling is gone. It is nice to be seen as a person of hope in someone else's dark world but it is funny watching people flying away before I can finger their answer. People must be assessed for the gear they need before buying equipment. Buying expensive equipment is a waste of money if it doesn't benefit the person who it is bought for.

Sometimes I feel like swallowing the sky seeing prices of disability equipment. I read parents hearts. They might jail themselves by giving their disabled loved one the best and might end up not really caring for themselves. They might have other kids biting into their wages too. I wish the Government would realise people need equipment and it hurts families to give if there are other children to rear. It is very important to start early as it gives people a better picture of the future and makes them more employable too.

Using technology can open many doors as well as shut down many others. I remember being locked inside my flat for six hours because my remote key wasn't working, as there was an electricity failure in the area. I often laugh seeing notices in elevators, 'don't use lifts when fire'. What must we do? Climb stairs! I once heard of a person who could not get into bed because her bed broke down and it was too late to expect a person to come out to repair it. Health and safety issues become out of fashion coping with your Cinderella world. No parent or relative would sleep comfortably thinking of their loved one that is nodding off in their wheelchair. It is terrible when you can't go to bed. Your prayers feel as if they were hanging off clotheslines in a rainy season. When this happens to me I ask God to put me to bed. He never does – but gives me a pressure sore instead. It is hard not to take these free offers. Technology only gives security when it doesn't have a P.M.S. mind.

A child talking to a person in a wheelchair who uses a touch talker:

'Why have you sore legs?'

'They are not sore'

'I am not able to use them'

'But why?' said the wee child.

Her mother whispering, 'She is a special person'.

'But mam, am I not special too?'

'Hurry up, drink that coke, we must go', mam said.

Why can't we stay to play with her "speak and spell"?'

'It has a funny voice. Look mam, she is laughing, yes, she is letting me use it'.

'Stop your whys and go'.

'Mammy if I play with it will I become more special to you?'

I got my first Lightwriter in 1989. It had no voice. It pushed me out into the world. I remember in the early 1990's darting to Tara Street on my own. I ended up in Bray. Nobody on the train knew what my machine was for. A woman said to me afterwards she thought I was just taking down notes. I laughed silently, 'Am I a spy?' Coming up to Christmas one year when I was really new communicating to people outside my environment a man asked me 'What will Santa bring?' I let a cheeky laugh, I pinpointed 'BIKE'.

I feel I have to be really quick in thinking of what I am going to say, as there is no such thing as a waiting game anymore. I wish there was because if people don't take the time to listen to what is being said a lot of frustration can nest in your head and it might not be easy for the person who is assisting you to cope with. We all need a dustbin. It is important to express our sadness as well as our joys when the need to communicate is so great.

I got my first talking Lightwriter in 1994. People thought it would be handy for the phone. It caged my mind even more. I felt like a space invader. My voice wasn't me. I had a chalky throat talking like a robot. The phone was a puzzle. For a long time I hated hearing myself talk. I felt I was in somebody else's body. I sounded more like a man than a woman. History hasn't turned the wheel. There is not much progress in trying to make the voice more human. I wished I had a Dublin accent. But hope is slow at coming and a lot of more important things need to happen first to make the voice clearer. Now I must say I like having a voice but would not mind a mouth transplant to make talking better. I am a wonderer at heart. I can never anticipate who I am going to meet during the day. Perhaps it is a person that is blind that is shouting at me to get out of his way. The reply has to be clear, as he mightn't know I am impaired with mobility and speech too. Time doesn't give me room to spell out my needs if my hand is on the joystick of my powered wheelchair. I can't talk and drive at the one time.

Case Study Commentary:**Accessing Assistive Technology in Ireland**

Assist Ireland was developed by Comhairle as an online resource that provides information on assistive technology and as well as a directory of products available from Irish Suppliers. It provides some useful information for disabled people and their families in relation to accessing assistive technology (See Box 3).

BOX 5**Assist Ireland Website: Accessing Assistive Technology**

Assistive technology funding varies widely across the country. Unlike other countries, disabled people in Ireland do not have any legal right to access funding and supports for aids and appliances. Therefore what provisions are made available, are open to adjustment in relation to other funding demands that are made upon the health services. The reality for many people is that the process of accessing equipment is unreliable and erratic which is extremely frustrating for users whose needs are left unmet. Essentially, there are currently two principle sources of funding available for equipment and housing adaptation in Ireland. These are as follows:

- *Department of Health and Children*
- *Disabled Person's Housing Grant'*

Source: www.assistireland.ie

If a person is unsuccessful in securing funding from these sources and they privately purchase an assistive device, they can seek a refund of the Value Added Tax (VAT) paid on certain aids and appliances from the Revenue Commissioners through the Private Purchase of Aids and Appliances VAT Refund scheme (VAT 61A). Examples of eligible goods, as stated on the Revenue form, are:

- Necessary domestic aids (e.g. drinking and eating aids designed solely for the disabled),
- Walk-in baths designed for the disabled,
- Commode chair and similar items,

- Lifting seats and specified chairs designed for the disabled,
- Hoists and lifters designed for invalids including stair lifts,
- Communication aids designed for those unable to speak.⁸⁴

However, privately purchasing assistive devices may not be an option for some people due to the high cost of this equipment. A recent survey by Fine Gael found that disabled Irish people and the HSE are paying on average 40 per cent more for basic disability equipment than their British counterparts. In one case an item was priced 100 per cent higher in Ireland. David Stanton outlined the survey in a recent press release:

*'We looked at a range of 19 items of basic equipment – such as mobility equipment, toileting aids and safety grab rails – which would assist people with disabilities in their daily living. We found that on average prices are up to 40% higher on those available in the UK. Of the 19 items surveyed, 5 were over 50% more expensive in Ireland. Only one item on the list was cheaper in Ireland than in the UK.'*⁸⁵

As the study explains, these price differentials need to be addressed so that necessary assistive devices are available to a larger number of people.

⁸⁴See the Revenue form: Claim for Refund of Value Added Tax (TAX) chargeable on aids and appliances for use by Disabled Persons under the Value Added Tax (Refund of Tax) [No. 15] Order, 1981.

⁸⁵See Fine Gael Press Release: 'People with disabilities Paying up to 100% Higher Prices on Basic Disability Equipment'. Available from: www.finegaele.ie

CHAPTER 11

The Contributions of Service Providers**The Views of a Personal Assistant****Introduction**

A number of the Leaders who took part in this research spoke about different situations that they have come across with their PAs; from finding the right PA to the relationships that they have with each other. It is important that these issues are discussed from the PAs point of view as well as the Leaders. For this reason an interview was sought with someone who has worked as a PA for a number of years.

The following interview was held with Joanne⁸⁶ who works part-time as a PA for a disabled woman in Dublin. The views which follow are those of Joanne.

The Day-to-Day Experience of Working as a PA

Joanne has worked as a PA for a number of years now. The main day-to-day tasks that she undertakes include personal care, such as showering and bringing people to the toilet, making dinners, doing shopping and sometimes, depending on the Leader, organising finances as well.

Joanne's work as a PA also involves bringing Leaders out on social outings. According to Joanne, the etiquette on these occasions depends on the particular Leader that you are working for:

'I have been in places where they don't want you there at all. I have been in places where they want you there consistently and I have been in places where they want you there but they don't want you to actually talk and actually say to you, this is my friends...you can listen in but don't get involved in the conversation...it really can vary, everyone is different.'

Joanne has never worked for a Leader who has not been open about what they wanted her to do in these social situations.

The PA-Leader Relationship

Joanne believes that a lot of PAs move from one Leader to another after around a year, as when you work with someone for quite a while the relationship goes beyond a PA-Leader relationship and can turn into a friendship. She feels that this is when problems can start. For example, Joanne explained that a Leader might ask their PA out for dinner outside of their work hours because they see them as a friend but the PA may just want to get home from work. This situation can be very difficult to deal

⁸⁶Name changed to protect identity.

with as the PA would not want to offend the Leader but they may not want to go out to dinner either. Joanne believes that you have to learn to be firm in a way that you can still get on with the person and it is important to find that balance.

Joanne does not find her work physically demanding but mentally she feels *'it's really draining'*, as you are with the same person all day and you have to do *'what they say when they say it'*. She finds it difficult that she has no work friends that she can talk to in order to *'let off steam'*. Joanne feels that PAs are *'very much alone'* and *'isolated'* and for these reasons she thinks that a lot of people move on from working as a PA after a short period of time.

Vulnerable Employment

Another issue that Joanne raised was in relation to the vulnerable employment position that many PAs find themselves in. According to Joanne:

'It is very hard if you're not happy with something to say it, because you're working with them. Even though you're working with the[service provider], they're your boss; they have the power to fire you. Lets say, my shift was finished at eight and at ten to eight they decide that they want to go to the shop and you're like well look I'm actually off at eight but they're like 'no, I've no milk, I'll have no milk all night'. And it's very hard to say well no I'm off at eight. You end up going to the shops and it might be half eight/quarter to nine...its very hard to [go to your boss] and say look no...that can be very hard and if you decided tomorrow you didn't like me for some reason...you have the power to fire me like that and that's not fair...'

Joanne feels that it is too easy to terminate a PA's employment, even when they may be doing their job well. It may be that the Leader does not like them for some reason other than their work performance and they are able to fire them *'very, very easy'*.

Other Issues for PAs: Training, Relief Work and Working Nights

There are three final issues in relation to working as a PA that Joanne spoke about. These are the training that PAs receive, working as a relief PA and working nightshifts.

1. Joanne thinks that it is very important that PAs receive training around how to handle emotional situations like the ones she described above. However, she never received any such training. When she first began work as a PA Joanne received a little training from her employer (the service provider) but she was mainly trained

by the Leaders that she worked for. Joanne mentioned that often when you begin work for a new Leader their old PA will help to train you in but when she first began work this did not happen for her because the Leader and her old PA had '*fallen out*'.

2. When a PA is doing relief work it is much more difficult for them as they are not sure how things are to be done. Each Leader is different and likes things done a certain way so every time you change Leaders you have to get used to a whole new routine.
3. Joanne used to work nightshifts but she does not anymore. She feels that it is not worth the money that you get paid. Payment for night work amounts to three hours normal hourly pay if you are undisturbed during the night and five hours normal hourly pay if you have to attend to the Leader during the night. Joanne has known of situations where a PA has had to sleep on the couch because there is no spare bed in the house or apartment. One PA that she knows had to stay on the floor of the Leaders bedroom as there was nowhere else for him to sleep, leaving neither of them with any privacy.

CONCLUSIONS

Some important issues that Joanne mentioned in relation to working as a PA included the occasionally problematic PA-Leader relationship and the vulnerability of a PA's employment.

She feels that it can be hard to keep the balance of a friendly, yet professional working relationship and this may be part of the reason why PAs do not generally stay long periods of time with the one Leader.

In relation to job security, Joanne thinks that it is too easy for a Leader to terminate a PAs employment and that this can leave a lot of people in a very vulnerable position because working as a PA is their full-time job and they may not find another position easily.

Dublin City Council and Independent Living

Introduction

Having a house or flat which is modified and adapted to the needs of disabled people is essential for independent living. Dublin City Council has two schemes to make this possible. One is a scheme to adapt the flats and houses of its own tenants and a second is for those who live in their own privately owned houses and flats.⁸⁷ Arriving in Dublin City Council offices to discuss their contribution to independent living, I was delighted to be met by Lorna and her Guide Dog who showed me up in the lift-accessible offices of the Grants Scheme for People with Disabilities.

Accessible Housing Schemes

Approximately 1,800 applications under the Grant Scheme to adapt houses and flats are processed each year. The Council financially supports applicants with a disability who need a downstairs shower or bathroom, a stair lift or ground floor adaptation.

The definition of disability under the scheme is very wide and includes many common health conditions. Applicants may have contracted Multiple Sclerosis (MS), arthritis or a heart condition. Medical evidence must be supplied when applying for a grant. Applicants can be any age – there is no age discrimination. Recently a couple who have a child with a serious health condition applied for a stair lift as the mother could no longer lift her growing child up the stairs. They had already received a grant for a downstairs bathroom when their child was small. But this was no barrier to applying for an additional grant for a stair lift as the child's needs changed. Dublin City Council uses its discretion in special circumstances.

When applying for a grant it is essential for the applicant to submit medical evidence from his or her General Practitioner. This is followed by a home visit from a Dublin City Council Inspector within two weeks. The inspector reviews the accommodation and discusses the necessary adaptation requirements with the applicant. He/she may request the applicant to obtain an occupational therapist's report. The occupational therapist can be engaged privately or through the Health Service Executive. There is such a long delay - running to months - in getting a HSE occupational therapist that many applicants use private occupational therapists. The Inspector may also request an Architect's Plan if the adaptation comprises the building on of an extension. There is only a maximum grant awarded to a household irrespective of the number of

⁸⁷The Housing Adaptation Grant is available through all Local Authorities and not just Dublin City Council.

disabled people in that household. The grant does not have to be repaid if the applicant dies within a short time after receiving the grant.

The Eastern Community Works Section of the HSE carry out some works free of charge such as providing ramps, grab rails, light electrical works, window and roof repairs. Where works of this nature are not included under the City Council's Grant Scheme, applicants are made aware that the Eastern Community Works Section provides this service. Dublin City Council provides 90 per cent of the cost of approved adaptations up to a maximum of €20,320 for a household. The maximum grant available for a bathroom conversion is €6000, a straight stairlift is €2,500 and a curved stairlift is €6,000. The remaining ten per cent has to be met by the applicants. However the Council points out that some applicants may be eligible for a refund of the VAT paid to a builder on essential and approved adaptations. The VAT can be reclaimed on Form 61A issued by the Revenue Commissioners.

Funding the Schemes

Dublin City Council spends €10.5 million a year on their revenue programme to enable people to continue living independently in their own homes. Only two thirds of this money can be recouped by the Council from the Department of the Environment, Heritage and Local Government. The remaining one third has to be funded by the City Council itself from its own revenue raising activities. If 80 per cent or 90 per cent could be recouped from central Government, more people might have a chance to live independently in their own homes.⁸⁸

Contact:

Dublin City Council,
Loans, Sales and Grants Section,
Block 2,
Civic Offices,
Wood Quay,
Dublin 8.
Tel: (01) 222 2195

⁸⁸Other Sources for this section are:

Information Brochure of Dublin City Council Housing and Residential Services Grants Scheme for People with Disabilities, 2005,
Revenue form: Claim for Refund of Value Added Tax (TAX) chargeable on aids and appliances for use by Disabled Persons under the Value Added Tax (Refund of Tax) (No. 15) Order, 1981.

The Irish Wheelchair Association (IWA) Leader Managed Assisted Living Service

Introduction

The IWA Assisted Living Service provides the services of a PA to individuals with physical or sensory impairments. The package is delivered in two ways:

1. **Self-Directed or Leader-Managed Package:** *'the person with a disability acts as the Leader or service manager for IWA. This involves recruiting their own personal assistants, organising their weekly rosters, returning their timesheets, arranging holiday cover, etc. The Leader can consult the service coordinator when necessary.'*⁸⁹
2. **Supported Package:** *'in the supported package the service co-ordinator takes responsibility for some or all of the management, delivery and operation of the service package. The level of responsibility undertaken by the individual is discussed and agreed at the commencement of the service.'*⁹⁰

An interview was held with a manager working for the IWA in their offices in Dublin. This interview focused on the first of these packages – the Self-directed or Leader-managed package. The views which follow are those of the IWA.

The Self-Directed or Leader-Managed Package

The IWA described the Leader-managed package as giving as much choice, autonomy and responsibility as possible to the Leader in relation to PA hours. However, the IWA has to be mindful of the legislation that governs the service.

There is an age limitation on the Leader-managed service. This limitation, which generally excludes those under 18 and over 65, is imposed by the IWA's funders and is not a policy of the IWA. Leaders are hardly ever under 18 years of age and although people who are already using the PAS and who reach age 65 can retain their service, people over 65 rarely enter the service for the first time.

The waiting list for this service is quite significant. According to the IWA the joint waiting list for the Leader-managed and the Supported Package is over 300 people. It is hard to reduce the waiting lists, as the funding of the service has not increased over the last few years. The core funding has stayed the same but the additional funding available for developments on an annual basis has decreased.

⁸⁹ IWA (2004) *Assisted Living Services Information Leaflet: Including code of good practice*, IWA, Dublin.

⁹⁰ Ibid.

Training of PAs and Leaders

There is joint responsibility for the training of PAs between the IWA and the Leaders. The IWA provide general training for PAs, such as manual handling, health, hygiene and safety, disability awareness and the philosophy of independent living. It is up to the Leader to provide the PA with additional, job specific or individual training.

The Leaders receive some training as well. This training runs for four days and is held every time there is a new intake of Leaders. It covers areas such as disciplinary procedures, recruitment and selection, management of timesheets and paperwork, and expectations and responsibilities of the Leader. The Leaders are also made aware of the areas that the PAs have been trained in. From time to time some additional training is supplied to Leaders. However, the IWA recognise that this needs to be more formalised.

Turnover of PAs

The turnover of PAs is quite significant. The average length of service of a personal assistant is between one and a half to two years. Some remain longer and a number of PAs have worked for more than ten years but generally they work for shorter periods of time. According to the IWA, this may be due to the intensity of the work, the lack of career progression for PAs or the fact that some PAs use this work as a stepping-stone into other areas of social care.

The type of people that are attracted to the work may also have an influence on the turnover of PAs. Many of the people who work as PAs are not Irish nationals and are employed on a work permit. These PAs usually return home after a few years.

The PA-Leader Relationship

The IWA described the relationship between a PA and a Leader as '*potentially a very difficult situation to manage*'. When you are working so closely with someone it can be hard to introduce boundaries. Some people have this skill and are better at managing than others. The IWA believe that the principle responsibility lies with the Leader when it comes to laying the boundaries of the relationship. They believe that the Leader needs to make the boundaries clear, as the PA might not have previously worked in this type of situation.

If a problem does arise between a PA and a Leader the IWA stress that they try not to get involved until they absolutely have to. They feel that it is not in keeping with the

philosophy of Independent Living and the autonomy of the Leader to intervene. One recent issue that has arisen is in relation to the legislation around short-term contracts. Because of the nature of the work it is sometimes best that the working relationship is terminated. However, because of new employment legislation introduced in 2004 this is not possible. This can be a problem as if a Leader and PA are not getting on and are finding it difficult to work in such close quarters. IWA together with the Leader consultative group are currently seeking to find ways to address this situation.

The Rights of the Leader and the Rights of the PA

In certain instances the IWA feel that some people think they put the rights of the employee or PA before the rights of the Leader. An example of this is in relation to hoists. A Leader could argue that it infringes on their rights to have to use a hoist even when they do not wish to. However, the IWA argue that they recognise this but they are bound by the legislation that states that a PA legally has to use a hoist in certain circumstances. According to the IWA, if they say that the PA does not have to use a hoist they would be held responsible if the PA injured him or herself. The IWA stressed that they are bound by the legislation that governs the service and they are in a difficult situation when it comes to introducing any legislation that challenges the autonomy that the Leaders seek under the philosophy of Independent Living. They believe that if direct payments were introduced the Leaders would find themselves with the same obligations that the IWA now has.

Conclusion

The IWA considers it very important that people are aware when they sign up to be a Leader that *'the philosophy of Independent Living won't always marry with the laws that govern the country'*. There is a lot of responsibility attached to becoming a Leader and the IWA say that they recognise that it can be very wearing on the Leader and outline that this is due to the onerous duties they sign up to. They believe that it is good if the service is challenged and state that this can be constructive for the service rather than destructive, which is welcomed by the IWA.

CHAPTER 11

Conclusions and Recommendations

This final section of the report will draw some conclusions from the preceding chapters. The conclusions will be based on the central issues that emerged during the course of the research. A number of recommendations will also be made in this section.

Independent Living in Ireland

The benefits of Independent Living are far reaching. Independent Living affords disabled people the same right to choice and self-determination that is experienced by non-disabled people. However, it is by no means an easy road and brings with it many challenges. These include the responsibilities that come with developing your own services, knowledge of employment law and equality legislation, recruitment, and building and maintaining professional relationships with your PAs.

These benefits and challenges to Independent Living in Ireland are the issues that were addressed in the case study section of this report.

Methodology

The case study methodology used in this report has proved appropriate to achieve the research aims of documenting Independent Living in Ireland and presenting an in-depth exploration of the experience of Independent Living. This report has demonstrated the value of in-depth work in relation to disabled peoples lives as all the participants were happy to have the opportunity to voice their opinions and experiences and to have a chapter dedicated to each of their contributions. Most of the participants felt at ease talking about their personal experiences of using PAS as the interviews were done on a one-to-one basis and the interviewees were given the choice to use a pseudonym if they wished.

The participants were able to read their case study before it was sent to the steering committee. This was so that they could clarify anything that they felt was not fully explained or remove any comments that they were not comfortable with having included. The participants were pleased with this level of involvement as they really felt like they were given a chance to let people know about their experiences in their own words.

Hiring a PA

The research illustrates the difficulties that some people face in finding a suitable PA. Most Leaders do a trial period with their PA's before offering them the job so that they can see if they are both at ease in the employment relationship. For instance, one Leader said that they have to go through every possible scenario during the trial period to make sure that the PA is comfortable with all the job requirements, such as personal care, and also to see if they are compatible with that particular PA.

Using PAS

Although all the participants were pleased that they have a PAS, using the service was by no means easy. A number of the Leaders said that they often felt exhausted trying to organise PA hours, hiring new PAs, filling out time sheets and dealing with their service provider. However, the participants felt that the service was worth the difficulties that came along with it. A number of the Leaders saw their alternative prospects as a concern in light of the absence of an ILF. Many of the participants mentioned secure funding as the most pressing issue for Independent Living.

Recommendation:

The introduction of a secure, consumer-controlled Independent Living Fund would ensure that regional differences in PAS provision are eliminated. Under this fund, the Leader should be able to get as many PA hours as they require.

Inconsistent Benefits of Using the PAS

The changes that Independent Living has made to the participants' lives is incalculable. However, the extent of these changes varies between Leaders. While some Leaders spoke about regularly socialising with their friends, for others this is still not a possibility. Some Leaders have a lot of PA hours which affords them the opportunity to live their life to the full. Yet, other participants have much less PA hours and do not have the same freedom. Any variations in the provision of PA hours between HSE Areas should be rectified.

Recommendation:

The PAS needs a consistent and systematic programme structure. Within this, it is necessary that there is recognition of the fact that PA hours alone do not provide the

capacity for Independent Living and that accessible transport, adequate housing and assistive technology are all vital elements as well. At present, the levels of support for each of these elements vary across the spectrum.

Independent Living for All

One of the participants gave an interesting insight into PAS for young people. Offering PAS to young children could have far reaching effects on the rest of their life. In Offaly CIL they have offered this service to a number of young people and it has worked well for them. One example is of a young man who has had a PA since he was a young. Because he had a PA he was able to attend mainstream school and is now at college. He has already secured a job for himself when he completes his course. His mother and father are both able to work and contribute to the exchequer, as they do not have to provide him with all of the care that he requires. And he will soon be contributing to the exchequer himself when he takes up his new job. If he did not have PAS his mother would be providing him with full-time care and he may not have got the chance to attend college.

Offaly CIL have also taken on Leaders over the age of 65, as they believe that independence is important no matter what the age of a person. Offaly CIL argue that in taking on Leaders over the age of 65 the Government is saving money as providing PAS is significantly cheaper than providing full-time institutional care.

Recommendation:

Age restrictions imposed on the PAS should be removed to allow for Independent Living no matter what the age of a person and to avoid age-based discrimination.

The Complexity of the PA-Leader Relationship

The complexity of the PA-Leader relationship was explored in this research. In keeping with previous research⁹¹ on this subject PAs were mainly characterised as 'instruments', 'employees' and 'companions'.⁹² The participants spoke about the PAs undertaking tasks such as cooking or gardening under their instruction (instruments). They spoke about the hiring and firing of PAs or keeping employer-employee boundaries (employees). Finally, a number of the participants spoke about their PAs as friends or someone that they got close to. One participant mentioned that she still stays in touch with some of her PAs and has a Christmas party with them every year (companions).

⁹¹Yamaki, Chikako Kimura and Yamazaki, Yoshihiko (January 2004) "instruments', 'employees', 'companions', 'social assets': understanding relationships between persons with disabilities and their assistants in Japan' in *Disability and Society*, Vol. 19, No. 1, Taylor and Francis, London, P. 34-35.

⁹²The Japanese research also characterised PAs as 'social assets' but this did not come up in this research.

The service providers also spoke about the complexity of the PA-Leader relationship. The IWA describe it as a potentially difficult situation to manage and think that when it comes to laying the boundaries of this relationship, the principle responsibility lies with the Leader as the PA may not have worked in this area before.

PA and Leader Training

Shortfalls were identified in the training of both PAs and Leaders. The formulation of a PA training brochure could work well as a reference for PAs after they have received adequate formal training. It is also important that Leaders receive adequate training in relation to employment law and their obligations and responsibilities to PAs under this law. Both the PA and a number of the Leaders identified this as a grey area where they are not quite sure where they stand.

PAs need to receive some training around how to handle the emotional aspects of working as a PA. This would be very beneficial to them when they first commence working with Leaders.

Recommendation:

The introduction of a PA training brochure would be beneficial as a reference guide for PAs who have received formal training. Increased levels of PA and Leader training are necessary including training around employment law, organising and managing PAs and ways to handle the PA-Leader relationship.

Safety and Gender

The issue of safety was mentioned by a number of the women participants. None of the female Leaders had a male PA and they stated that this was partly for safety reasons. One Leader said that she would not be comfortable with a man providing such intimate personal care for her, while another said that she felt vulnerable at night time even with a female PA so there was no way she would ever have a male PA. Only one of the female participants said that she would even consider hiring a male PA. However, she did say that she would find it difficult with a man providing her personal care.

Recommendation:

From this research it is apparent that there is a gender dimension to Independent Living and the different issues that Leaders face while using PAS. However, exactly

what this gender dimension involves is not yet clear and needs further exploration from both a female and a male perspective.

Gender differences should be taken into account in all research on Independent Living, as men and women have very different experiences of using PAS.

Transport

The case study on transport threw up some interesting issues. Truly Independent Living is only possible when a person has adequate transport as well as a PA. This transport could be a bus, train, Luas, taxi or a personal vehicle. Dermot believes that there are issues with the safety of taxis in Dublin and this should be explored further.

It is apparent from the interview in Gorey that a personal vehicle is crucial for Leaders who live in rural areas. However, as many Leaders need their PA to drive for them, adequate PA hours are also essential. As one Leader explained, he is confined to his house outside of his 20 weekly PA hours as he cannot drive his car himself and no public transport serves the area where he lives.

Recommendation:

It is important that issues of transport, accessibility and Independent Living are considered collectively and that the various Government Departments and bodies work together and inform each other about their relevant disability policies and future plans.

The issue of wheelchair safety in taxis should be examined further and appropriate action should be taken to eliminate any identified problems.

The Importance of Assistive Technology

The importance of assistive technology for Independent Living was discussed during the research. The extent of some people's use of and reliance on assistive devices was highlighted. When an assistive device breaks down Leaders can be left waiting quite a while for a replacement. For some people this makes it much harder to communicate and give instructions to PAs.

Recommendation:

The availability and maintenance of assistive technology should be improved so that people are not left without essential devices that they need for Independent Living.

Dublin City Council

There are around 1,800 applicants each year under the Dublin City Council Grants Scheme for People with Disabilities. Although applications for the scheme are dealt with in a short time period, there can be one major delay in that the City Council Inspector may request the applicant to obtain an occupational therapist's report. There is a long waiting list that runs to months to get an appointment with a HSE occupational therapist. Because of this, many applicants use private occupational therapists.

Dublin City Council spends €10.5 million a year on their revenue programme to enable people to live Independently in their own homes. However, they can only recoup two thirds of this money from the Department of the Environment, Heritage and Local Government and must fund the remaining third from the Council funds.

Recommendation:

If a higher proportion of the money spent on the revenue programme for tenants and homeowners could be recouped from the Department of the Environment, Heritage and Local Government, more people might have a chance to live independently in their own homes.

The Irish Wheelchair Association

The IWA stressed their opinion that although the Leader-managed package gives as much choice, autonomy and responsibility as possible to the Leaders in relation to PA hours, the IWA has to be mindful of any legislation that may govern the service. They feel that people should be aware that *'the philosophy of Independent Living won't always marry with the laws that govern the country'*. In other words, the ideal of Independent Living as set out by the philosophy of Independent Living may not be attainable in Ireland as it is, in their view, restricted by legislation.

The IWA say they recognise that the extent of the responsibility on a Leader can be very draining but that this is due to the onerous duties Leaders sign up to.

Personal Assistants

Just one PA was interviewed for this research as the main focus of this study was on Leaders. However, this interview highlighted that issues exist for the PA as well as the Leader and further research could be beneficial to improve the service/service provision for both the Leader and the PA.

The main issues identified in this interview centred around the vulnerable nature of being employed as a PA, the lack of sufficient training for PAs, the difficulties associated with working as a relief PA and the low payment for working nightshifts.

Further Research on Independent Living

Recommendation:

This research involved a small number of participants yet it succeeded in bringing a number of key issues to light that Leaders face when using PAS. These key issues could be explored in a national study involving a much larger number of people of diverse backgrounds from each region.

their answer. People must be assessed for the gear they

EXTENDING THE BOUNDARIES: OUR EXPERIENCE OF INDEPENDENT LIVING

APPENDIX 1**Appendix 1****Definitions:⁹³****Independent Living**

Independent Living is a worldwide philosophy and movement by people with disabilities seeking self-determination, equal opportunities and self-respect. Persons with disabilities wish to enjoy the same rights that their non-disabled peers take for granted. These include the right to live in the family home, the right to education, the right to a job that is appropriate to each person's education and abilities, and the right to access public, social and cultural facilities.

Historically disabled people have been excluded from full participation in society by attitudes, which saw disabled people in terms of their medical diagnosis or impairment. This medical approach meant that disabled people became the objects of pity and charity, and that their choices were limited to living as a burden to their families, or becoming institutionalised. This approach to the issue of disability restricted the power of disabled persons to self-determination, self-representation and full citizenship. The ideology of Independent Living is radical in that it is a direct challenge to the way in which people with disabilities have been viewed and treated by the rest of society. However, it is not simply a challenge to this way of thinking, it also offers an alternative ideological and practical approach to the issue of disability in society (Barnes, 2003).

In order to overcome the obstacles to independence, persons with disabilities have two fundamental requirements. The first is full access to the built environment, including domestic, educational, social and public areas, and the second is a Personal Assistance Service.

Personal Assistance

A Personal Assistant carries out the basic tasks of everyday living that a person with a disability would have been able to do for him or herself if it were not for the physical or sensory impairment. These tasks can be very varied, and include anything from domestic chores, such as shopping and preparing meals, to assistance in the workplace, school or social environment. A Personal Assistance Service is tailored to the unique needs of each individual, and is directed by the disabled person for whom the Personal Assistant is working. The Personal Assistance Service is designed, scheduled and controlled by the Service User, i.e. the person with a disability, and should meet the needs, capabilities, aspirations and circumstances of the service

⁹³Provided by CIL Carmichael House.

user. The service user decides who is to be employed, how and when they will work, and also has the discretion to terminate employment if he or she is unhappy with the service provision.

According to Adolf Ratzka, the term '*Personal Assistance*' cannot be truly applied to situations where the service is controlled and delivered by Local Government or Community Agencies. This is because of the hierarchical nature of such organisations and the fact that the service user is placed at the bottom of such hierarchies.

It is important that Personal Assistants have adequate employment protection and remuneration, in order that the service user can demand and expect a high quality, reliable service.

Personal Assistance puts a disabled individual back in charge of his or her own life. It allows a person to fulfil his or her potential, whether in terms of education, family commitments, social participation and public responsibility. A person with a disability who has access to the services which allow him or her to become educated, can then go on to become a tax-paying member of the workforce. The correct services can also allow a person to take on domestic responsibilities such as child rearing, and can free family members to pursue their own lives and aspirations.

Direct Payments

This is a central tenet of the Independent Living definition of Personal Assistance Services. When persons with disabilities receive payment in kind, i.e. services, direct from an Institution or Government Agencies, they become passive recipients, and are unable to control the quality, content and effectiveness of such services. In addition the bureaucracy involved diverts funds away from service provision itself. The alternative to this system is the system of Direct Payments. This means that the person with a disability is paid directly, and then has the discretion to choose his or her own service, or to organise the training and direction of his or her own employee.