



2GoDirect

**The experience of two people
using a direct payment to employ
a Personal Assistant**



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ABBREVIATIONS

CIL	Centre for Independent Living
HSE	Health Service Executive
PWD	People with Disability
PA	Personal Assistant
PCP	Person Centred Planning
IWA	Irish Wheelchair Association
UNCRPWD	United Nations Convention on the Rights of Persons with Disabilities
ROS	Revenue Online Service
CRO	Companies Registration Office
PAYE	Pay As You Earn (Income Tax)
PRSI	Pay Related Social Insurance
IL	Independent Living
DHSSPS	Department of Health, Social Service and Public Safety (Northern Ireland)
ENIL	European Network on Independent Living
ILI	Independent Living Institute

ACKNOWLEDGMENTS

The author is grateful to Una Traynor of Breffni Integrated Ltd for initiating this report and for her unflagging support for the duration of the project. The Centre for Independent Living, through their Chairman, Michael McCabe, have been participative partners and co-funders of the project since the outset.

The publication of 2GoDirect would not have been possible without the wholehearted support of Damien O'Reilly who is a pioneer of Direct Payments in this country and who actively participated in all phases of the action research. Damien and his supporters willingly and openly shared every aspect of their journey through the achievement and administration of a direct payment over a period of twelve months.

John Dwyer (not his real name) has been equally keen to share his knowledge, gained from first hand experience, of directly employing a personal assistant. John's long experience of living independently and his use of a direct payment in conjunction with a provider service brought valuable new learning to the report.

The opinions expressed by Damien and John in their personal accounts are their own views.

The author also wishes to acknowledge the other members of the initial research group who were not in a position to continue with the project.

Finally, thanks to Dr. Colin Barnes, Professor of Disability Studies at the University of Leeds, for generously agreeing to write the Foreword.

David Egan

FOREWORD

Since their emergence in the 1970s direct payment schemes, sometimes referred to as state funded self operated support systems, have proved to be the most cost effective and user friendly way of delivering essential services to people with impairments and high support needs. Developed by disabled people and their organisations as a response to traditional dependency creating services run and controlled by non disabled professionals, direct payment schemes provide disabled individuals with funding to pay for the support they need to live independently in the community. This may include purchasing technical aids and equipment and, or more commonly, the employment of personal assistants to do the things they are unable to do for themselves due to the effects of their impairment.

Traditional services are generally controlled and run by non-disabled professionals. They often involve a host of different people, many of whom will be unknown to the disabled person. They are also frequently overly dependent on the good will of relatives and friends for additional support. The inevitable tensions that often accompany this enforced interdependence can lead to family discord and eventual breakdown. As a result the disabled person is usually put into residential 'care' of one form or another and their dependence is compounded and assured for the long term.

By way of contrast direct payment schemes give disabled individuals unprecedented levels of choice and control over their support needs. In so doing they enable service users to achieve greater autonomy and independence within the context of the family and or the wider community. Further by giving disabled individuals the responsibility for organising their own support, they inevitably acquire new skills and aspirations and their self esteem and self worth is enhanced. Thus they are empowered to participate in the everyday life of their local community. For many this results in the search for paid or voluntary work.

But the social and economic benefits of these schemes are not limited to individual service users and their families and friends. Disabled people with particularly high support needs may employ as many as four or five personal assistants over the course of a week. Consequently apart from freeing relatives and friends from caring responsibilities and so enabling them to pursue a career of their own, the role of personal assistant to a disabled person provides flexible and rewarding employment opportunities for non-disabled people who may otherwise be unemployed. Research in the UK indicates that these schemes are particularly welcome in rural areas where conventional services are in short supply and unemployment among the general population is disproportionately high.

Moreover in the interests of geographical mobility the organisation of these schemes must be centrally determined, but administered locally, ideally by organisations controlled and run by disabled people themselves commonly referred to as Centres for Independent Living (CILs). This is important because research from a variety of sources around the world indicates clearly that the successful implementation of user led self support schemes is best achieved in areas where service users are supported by people with direct experience of independent living and its implications. Indeed in most countries the overwhelming majority of disabled people, in common with their non-disabled peers, have neither the experience nor the skills to manage and operate direct payment schemes successfully without training and support. Therefore CILs provide work opportunities for disabled individuals who may otherwise be without it.

There is now clear evidence from across the world that the concept of independent living has provided both a philosophy and practical solutions to the problems encountered by people with impairments and labelled disabled. CIL type organisations and self operated support schemes are now a common

feature of state sponsored services in most economically developed countries including the USA, Britain, Canada, Europe and Japan. These services have empowered thousands of disabled people to participate fully in the economic and social life of their communities.

There can be little doubt therefore that where these services are not provided politicians and policy makers have a responsibility to make available sufficient resources to make these services available to everyone who needs them. As this report

demonstrates there is a growing demand for the further development of independent living services, particularly used led self support schemes and CILs, in Ireland. To ignore this demand is likely to prove both economically and socially disastrous for the Irish people whether disabled or otherwise.

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DIRECT PAYMENTS - CONTEXT, APPLICATION AND POLICY

‘Direct Payments’ is a generic term used to describe the provision of funds by the State, directly to people with disabilities, for the purpose of purchasing a range of supports and services. These services typically include personal assistance, therapies, and aids and equipment.

Direct payments enable people with disabilities to employ individuals, directly or indirectly, to assist them with their everyday tasks.

These tasks may include:

- Personal services: help with getting up, using the toilet, bathing, dressing, preparing food, eating etc.
- Domestic services: cleaning, washing, shopping and looking after children
- Social activities: socialisation, visiting family and friends, leisure activities, holidays and travel
- Employment and education: assistance getting to work, assistance in the workplace or at college

A Personal Assistant is an individual who is employed to assist with all of the above duties, both inside and outside of the home, and at the direction of the service user.

People with physical, intellectual and sensory disabilities can participate equally in direct payments provided they are given the capacity and supports necessary to assist them to make decisions and to sustain them within the employment model they choose.

Currently in Ireland direct payments are not formalised and do not operate in any meaningful context. In certain exceptional cases people with disabilities have negotiated a direct payment with the Health Service Executive (HSE), and in some cases with a service provider, for the purpose of employing assistance, including a Personal Assistant. There is evidence that some people are receiving small cash payments for the purpose of purchasing assistance. The evidence would suggest that these arrangements are quite informal. There are also some examples of people with intellectual disabilities, supported by their families, receiving cash payments from their service providers for the purpose of purchasing assistance.

Direct Payments to qualifying people with disabilities for the purpose of employing a Personal Assistant is part of social policy in many EU countries including Sweden, Finland, Britain, Austria, Belgium, Holland and Germany. Legislation conferring a right in law to personal assistance and direct payments has been in effect in some European countries for over a decade (Sweden: The Personal Assistant Act 1994; Britain: Direct Payment Act 1996; Finland: Services and Assistance for the Disabled Act 1987; amended 2008).

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BOX 1

DIRECT PAYMENTS EMPLOYMENT MODELS

In countries where Direct Payments, for the purpose of employing a Personal Assistant, have been in operation for a number of years, different employment models have emerged.

Self-Employ Model

PWD use their direct payment to employ a third party as their Personal Assistant. In this model PWD are the employer and are responsible for hiring and firing, interviewing, training, insurance, PRSI and PAYE tax deductions, employment legislation, holiday cover, rostering, accountability to the funder and generally for all of the responsibilities which would normally attach to any employer.

Self-Employed Model

The Self Employed Model is similar to the Self Employ Model except in this model the individuals employed as a Personal Assistant are themselves registered as self-employed persons. Self-employed persons are responsible for managing their own tax affairs and social insurance, and may also be self-insured. In other respects the model is similar to the Self Employ Model outlined above. In the context of Irish policy on taxation it is unlikely that a Personal Assistant could register as self-employed if they were working for one person only.

Provider Model

PWD use their direct payment to contract with a company to provide their personal assistance. The company may be a private 'for profit' company or a 'not-for-profit' company similar to IWA, CIL, Enable Ireland or Cheshire.

The Provider Model allows PWD to choose their provider and to control who works for them as their Personal Assistant but without the responsibility of being an employer. The provider remains the legal employer while the PWD controls the service to the extent they choose.

User Co-operative Model

A User Co-operative is one in which the membership is comprised of those PWD who use the services of the Co-operative. The management of the Co-operative is overseen by a Board of Directors who are elected by the members. PWD employ their own Personal Assistants and use the services of the Co-operative to assist them with their administration and other supports which they may require. The rules and regulations of the Co-operative are determined by the members.

Supported Model

A Supported Model is a small group of persons who come together to support an individual to use a direct payment and to manage their service. A Supported Model is usually comprised of family members, friends and appropriate persons from the local community. Examples of such groups are Microboards and Circles of Friends. These supported models use Person Centred Planning (PCP), a process designed to assist someone to make plans for the future. PCP is a life planning model which enables PWD requiring support to increase their personal self-determination and improve their own independence.

The Microboard model has been developed to an advanced stage in Ireland.

Since the introduction of the Personal Assistant Act (1994) in Sweden, qualifying persons are entitled to a direct payment for the purpose of employing a Personal Assistant without regard to the cost of the service or the means of the service user.

The Finnish Services and Assistance for the Disabled Act (1987, amended 2008) outlines a number of mechanisms through which people can organise their personal assistance: “by way of compensation for the severely disabled person of costs incurred in employing a personal assistant, including compulsory fees and compensations for the employer and other reasonable and necessary costs caused by employing the assistant.”

Figures revealed by the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS) indicate the number of people using direct payments for the purpose of employing personal assistance in Northern Ireland has risen from 797 in 2007 to 1,890 in December 2009.

The report, *Direct Payment Policy and Practice Review*, published by the DHSSPS in April 2005, highlighted a number of motivating and demotivating factors for participants in Direct Payments. The prime motivating factor for people requesting a Direct Payment was dissatisfaction with directly provided services. This could be for a number of reasons even if the quality of service received was good, for example:

- Where existing services did not meet an identified need
- Where a service did not exist to meet an identified need
- Where the service recipient felt that too many staff were involved in providing a service
- Where there was a lack of flexibility

People also sought a Direct Payment to achieve:

- Independence
- Choice
- Control
- Flexibility

- Privacy
- Added value for money
- Possible reduction in numbers of staff involved in delivering service

People were less likely to want a Direct Payment when:

- There was a lack of information, or that information was confusing
- The process was perceived as too complicated and long drawn out
- There was a heavy burden of paperwork/bureaucracy
- There was an anticipated difficulty in recruiting staff, for example in rural areas, and in making formal employment arrangements

Direct Payments give the opportunity to be independent and not reliant on family and friends. This has resulted in better relationships at home, enabling families to also live their own lives.

Receiving Direct Payments increased people’s feelings of self-respect, and dignity, particularly in relation to the empowerment experienced by being an employer.

Direct Payments recipients valued their power to decide who works for them. This was particularly relevant where personal care or support for a child is involved.

Direct Payments had directly enabled people to return to work. Support provided by the Centre for Independent Living had been valued by Direct Payments recipients as independent and comprehensive.

The Irish Wheelchair Association, which is the largest provider of personal assistant hours in the State, in its *Strategic Plan 2008–2011* states, as an objective, “working with members to explore alternative models of assisted living services including direct payment options to develop new models to increase the choice of services available to members.” The IWA have made significant progress with their consultation process.

The evaluation report of the Microboards Project in 2008 recommended a pilot study on direct payments for the purposes of employing assistance.

Speaking in April 2010 following the annual general meeting of Inclusion Ireland, the national association for people with intellectual disabilities, Minister of State for Disability Issues, John Moloney TD, said individualised payments were the way forward: “As far as I’m concerned, this is the future. I want to drive this idea and as part of a policy review, I hope to bring proposals on this area to Cabinet before the end of the year,” he said.

At a meeting in Leinster House on 29 April 2010 the Centre for Independent Living called on the Minister to introduce a Personal Assistance Act which would “set out who qualifies for personal

assistance, the purpose of such assistance inside and outside of the home, how such assistance is to be organised, and the right of people with disabilities to be part of their assessment for personal assistance. The Act would have regard to all models of service delivery including direct payments to people with disabilities for the purpose of employing, directly or indirectly, personal assistance, and provide the necessary policy context for the delivery of such services.”

Speaking at a conference organised by New Options Alliance in Portlaoise on 13 May 2010, Bairbre Nic Aongusa, Director of the Office of Disability and Mental Health, stated, in relation to the Review of Disability Services under the *Value for Money and Policy Review Initiative 2008–2011*, that “personal budgets will signal the direction of travel.”

RECOGNISING PERSONAL ASSISTANCE

A Personal Assistant is an individual who is employed to work at the direction of the disabled person. The work can vary and may include personal care such as dressing and grooming, housework, driving, assisting the client at work, at college, during social activity or while travelling.

Finnish legislation (Services and Assistance for the Disabled Act 1987, amended 2009) defines personal assistance as the “necessary assistance of a severely disabled person at home and outside the home:

- In activities of daily life
- In work and studies
- In hobbies
- In social participation
- In maintenance of social interaction.

In Ireland, and internationally, the term ‘Personal Assistant’ has achieved a high degree of recognition within the disability sector. A Personal Assistant differs from other forms of assistance (home help, home care attendant, nurse, carers) in that it is less restrictive. Personal Assistants offer support in every aspect of the disabled person’s life, irrespective of when or where the need arises, inside of the home and outside of the home.

Limerick Centre for Independent Living describe their personal assistant service as “essentially a

service for persons with significant disability who need assistance in aspects of daily living, at home, travelling, at work, college or socially. The individual first identifies what their needs are, whether by self-assessment, or often where they have not been in a position to make decisions about their own lives heretofore, facilitated assessment. The identified need then determines the level of service required (i.e. number of hours and how many PAs each person needs) to enable an individual to achieve independent living.”

The Council of Europe’s *Disability Action Plan 2006–2015* sets out a number of key objectives and specific actions to be implemented by member states. Action Line 3.8.3. says member states are required to “promote schemes which will allow disabled people to employ personal assistants of their choice.”

The Irish Government has also signalled its intention to ratify the UN Convention on the Rights of Persons with Disabilities, including Article 19, ‘Living independently and being included in the community’. The Article stipulates the right of PWD to the “personal assistance necessary to support living and inclusion in the community” and that State bodies “shall take effective and appropriate measures to facilitate full enjoyment by PWD of this right.”

A BRIEF INTRODUCTION TO INDEPENDENT LIVING

Independent Living is a philosophy and a lifestyle choice which enables people with disabilities to make and implement decisions about how they wish to live their lives. Independent Living adheres to the social model of disability which places disabled people at the centre of a process of self-determination, as participative and equal members of society. This contrasts with the more historic medical and charitable models of disability which traditionally saw disabled people as passive recipients of care and services.

Independent Living (IL) is a worldwide movement of people with disabilities who work for self-determination, self-respect and equal opportunities.

According to the Institute of Independent Living, IL “means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and interests, and start families of our own. Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves – just as everybody else.”

Independent Living is an interpretation of a philosophy by individual people with disabilities, some of whom come together as Centres for Independent Living (CIL) to collectively advocate for the migration of the Independent Living philosophy across every level of society. In Ireland there are over twenty-four CILs that actively engage in advocacy and service provision.

In Europe there are twenty countries that are affiliated to the European Network of Independent Living (ENIL). ENIL represents a forum intended for all people with disabilities, independent living organisations and their non-disabled allies on issues of independent living.

Despite differences in terminology, there is general agreement amongst the international disability community and their supporters that the philosophy of ‘independent living’ is founded on four basic assumptions.

1. That all human life, regardless of the nature, complexity and/or severity of impairment, is of equal worth
2. That anyone, whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices
3. That people who are disabled by societal responses to any form of disability – intellectual, physical, sensory or mental health – have the right to exercise control over their lives
4. That people with disabilities have the right to participate fully in all areas – economic, political and cultural – of mainstream community living on a par with their non-disabled peers

Independent living is given effect through identified needs which are the building blocks of an independent life. These ‘identified needs’ are subject to constant review but there is general recognition that there are certain key pillars which must be in situ if independent living is to be attainable by all people with disabilities. These include:

- 1) Housing, an appropriate place of choice to live
- 2) Personal Assistance/Personal Assistant
- 3) Transport, mobility options
- 4) Information, knowing what options are available
- 5) Peer support, encouragement and guidance by other people with disabilities
- 6) Access to the built environment and access to services
- 7) Technical aid and appliances to support self-reliance and independence
- 8) Education, training and employment
- 9) Advocacy
- 10) Income support

BOX 2

A NATIONAL POLICY ON PERSONAL ASSISTANCE

Delegates attending the 'Your Life, Your Choice' Conference in 2007, organised by the Centre for Independent Living in Dublin, set out a number of parameters for a National Policy on Personal Assistant services, including:

A national policy on Personal Assistants (PA) to be enshrined in legislation

A right in law to a PA service without regard to the means of the qualifying individual

A right in law to a PA service without regard to the cost of the service

Clear definition of a PA's role and function

A right to choose to receive a service from an approved provider, to contract with a provider or an individual, or a combination of both, and funding to attach to the service user

A right to an assessment, including self-assessment, and any assessment to take into account identified overheads associated with employing a personal assistant over and above the wage costs

Cost of PA service to be index-linked

Standards and quality monitoring of service

Policy must recognise training needs, and costs associated with training, for service users and PAs

Funding for personal assistant services to be centralised in one Government department not associated with health, recognising that Independent Living should be rooted in social policy

PA service should follow the life cycle of the service user

Portability of service nationally and internationally

DAMIEN GOES DIRECT

by Damien O'Reilly

Introduction

My name is Damien O'Reilly, I am 30 years of age and I have cerebral palsy. I have a high degree of disability and impaired speech, leaving me wholly dependent on a Personal Assistant (PA) service for all of my daily living needs.

I live in a rural part of county Cavan in my own purpose-built independent living apartment, which is attached to my family home, with a separate entrance. The apartment comprises a kitchen, bedroom with ceiling hoist and en suite wet room. In the past I have been involved in many disability organisations and was a representative for Disability Federation of Ireland on the Health Service Executive's (HSE) North East Coordinating Committee for Physical and Sensory Disability for over five years. I was also Chairman of the North East Leader Forum, a group of local people with disabilities who used PAs. I have an active social life and I am a keen sports fan; I particularly enjoy watching Gaelic games, soccer and rugby. I also enjoy swimming, painting (mouth painter) and gardening with the assistance of my PA.

Why Direct Payments?

I attended the local primary and secondary school, where I relied heavily on the support of my friends and classmates. It was not until I was in the middle of my Junior Certificate year that I negotiated for a classroom assistant with the Department of Education. The assistant worked specifically with me as a scribe and an interpreter. This was my first experience working with a PA. On completion of my Leaving Certificate I applied to Dublin City University but was unable to attend due to the lack of a personal assistant. It was this lack of independence that motivated me to find out information about how I could obtain a PA service.

Through my involvement with Disability organisations I had heard about the Direct Payment system and had read many reports on how it worked. To me none of them addressed the basic steps one would take in order to set up this model of service or indeed how one would go about negotiating it with the HSE. There was little information in the public domain about Direct Payments in an Irish context. I knew that if I was going to approach the HSE I would need to plan and research how I was going to manage any hours which were allocated to me; otherwise I would not be in a position to negotiate.

The capacity measure I undertook included completing a Certificate in Training with the National University of Ireland, Maynooth, undertaking a business course with Cavan Partnership, writing up a work safety statement and researching sole trader and limited companies.

My next step was to complete a self-assessment and a daily work schedule to determine how many hours of service I required per week to live independently. The total emerged at 112 hours per week. Equipped with all this information I organised a meeting with the HSE. Eventually after a long negotiation period the Health Service Executive responded positively and I was offered 40 hours per week. I was given the choice of negotiating with service providers, including the HSE, to get best value for funding and to find a service that met my needs.

As there was no service provider within the county providing a PA service I contacted the Irish Wheelchair Association and Enable Ireland to see if they were in a position to administer my hours which were allocated by the HSE. However, through discussions with both organisations it became obvious that it was not going to be economically viable for either organisation to administer my service. For a time the Centre for Independent Living administered my PA service. This did not work out

for numerous reasons but it did make me realise that the level of control that any service provider would have over my resources was not acceptable to me. I also tried a local commercial agency but this proved to be costly. It was at this stage everything started to point toward direct payments.

After coming to the conclusion that Direct Payments were the only viable option further negotiations with the HSE took place. This resulted in the HSE agreeing to fund me directly to employ a PA.

However my PA hours are very small for the level of support I need, only 40 PA hours. I need to use them for basic daily living tasks like getting up every morning, having something to eat, even having a clean shirt to wear. Socialising or even being involved in an organisation simply eats up my PA hours. I find I am constantly prioritising how I use my precious hours. Therefore to do the things I enjoy I have to constantly fall back on family for support. I am defiantly on the road to independent living, but only at the start, I hope it does not take as long to get to the end of the road as it took me to get on it.

How the Payment Works

After securing the Direct Payment many other objectives still remained which needed to be addressed. An agreement of the rate of pay which would adequately cover the wages of my PA, my overheads and the costs associated with setting up and administering the Direct Payment. I submitted an estimate of the cost of the service I required, including a proposed PA timetable, and a list of activities and other resources that I felt were needed.

The figure I arrived at contained the gross wage cost, including PRSI contribution, employers' insurance liability, an administration cost of one-and-a-half hours per week and an allowance to cover the outsourcing of an accountant for the payroll and end of year accounts. The HSE agreed to provide PA training for manual handling and lifting.

I registered as a sole trader with the Central Registration Office (CRO) and set up a separate bank account for the business 'Independent Living Options' (ILO). I created ILO invoices, time sheets, medical clearance forms and safety statements. I keep weekly time sheets, jointly signed by me and my PA, which are open to inspection. I am required to invoice the HSE on a monthly basis. Payment is made by direct debit into my company account. My accountant produces monthly pay slips for all my PAs, deducts tax and PRSI, and makes monthly returns to the Revenue Commissioners in addition to attending to any other matters to ensure I am tax compliant.

Hiring a PA

I have been using a Direct Payment system since October 2008. Initially I employed my PAs through a local commercial agency; however this service proved to have a lot of restriction. Subsequently in March 2009 I employed my PAs directly through the company. Initially I advertised for my PAs through local papers but now I tend to use the FÁS website. It is more effective and saves money.

I do my own PA training and direct my service. My mother interprets my speech at the start of training. She also assists with training, particularly around health and safety. My first priority is to get my PA to a point where they can understand and interpret my speech. I estimate it takes a new PA about three weeks to become an interpreter.

I roster my PAs on a weekly basis. I divide my hours at the moment between two people. I think this at least gives me some cover if somebody is sick.

Salary and Overheads

I pay my PAs the same standard rate per hour as the HSE pays their support staff. Other overheads associated with employing a PA are mentioned in the 'how the payment works' section.

However, the funding which I receive from the HSE does not recognise other overheads associated with employing a PA, such as meal costs for a PA when out, public transport costs for accompanying PAs, or the associated costs of going to the cinema or a concert, all of which are activities where I require to be accompanied by a PA. In addition the Direct Payment is not index-linked and any increase in payment will have to be negotiated with the HSE on an annual basis.

Trying to get employers' liability insurance was difficult. Many of the insurance companies did not understand the concept of a Personal Assistant or the nature of their work. I approached a lot of companies; I knew it was a key issue which had to be addressed. Eventually FBD Insurance offered me business multi-peril policy for a nominal fee.

Support

I acquired most of the information through self learning, trial and error and my lived experience. There was an instance when I was notified by the HSE that my funding had exceeded a certain limit and therefore they could not administer any more funding to my account until I submitted a tax clearance certificate. There was no problem obtaining the certificate, it just took time. I was extremely worried that I would not have sufficient funds in the account to pay salaries and expenses. Both the HSE and the revenue department that I dealt with were very supportive and everything worked out fine. If I had of known about it, it would have saved me a lot of worry. It was times like this I missed peer support. However I enjoyed strong support from my immediate family who have worked closely with me through the entire process.

My PAs are employed through my company, Independent Living Options (ILO). However, I do

not use their assistance with any work related to ILO. Like any other business, it is private and confidential. For someone like me with a similar disability who does not have the support of family members this could present a problem. I believe peer support groups are absolutely necessary to sustain and promote Direct Payments, particularly to pool knowledge.

Into the Future

I am adamant that Direct Payment works for me. There is no third party involved. I have more responsibility. I have to comply with a lot of laws and regulations, but I also have the freedom to direct my own service. I acknowledge that there is a big 'fear factor' about Direct Payments, some of which I feel have been created by disability organisations.

As the Direct Payments system is already used in Northern Ireland, Britain and many other European countries I believe that it is only a matter of time before Ireland follows suit. I feel we need to prepare for this. I acknowledge that Direct Payments are not going to be for everyone and will require many different formats tailored to the individual in question.

I have identified seven structures that would need to be in place to make it easier for many people.

1. A standardised model/policy for the Direct Payments system in Ireland
2. A shared accountancy service
3. A shared payroll service
4. Group insurance
5. Peer groups for PA employers
6. Peer groups for PAs
7. Hours provided should be based on the level of assistance that each individual requires

BOX 3

SOLE TRADERS

Both Damien and John have chosen to set themselves up as Sole Trading Businesses for the purpose of employing their Personal Assistants. Damien has registered his business as Independent Living Options. John trades under his own name. It is relatively simple to set up as a Sole Trader. Your main legal obligation is that you must register as a self-employed person with the Revenue Commissioners. If you wish to use a business name you must register that name with the Companies Registration Office. Sole Trading Businesses are not companies limited by guarantee.

It is not a legal requirement for employers to become a legal entity, a limited company or a sole trader, for the purpose of employing a Personal Assistant. However, in Ireland employers must register with the Revenue Commissioner for PAYE purposes if they pay €40 or more to employees, including domestic employees.

BOX 4

EMPLOYERS' LIABILITY INSURANCE

Employers' liability provides insurance cover if an employee suffers physical injury. In the event that an employee sues the employer for compensation the employers' liability will cover any compensation, as set out in the policy, that may have to be paid out along with the associated legal costs.

Through his company, Independent Living Options, Damien pays for employers' liability insurance through a multi-peril policy which he negotiated with FBD Insurance. John has extended his general household insurance, which covers domestic employees, to afford himself maximum protection but he is not entirely happy with the arrangement.

Employers' liability insurance is not compulsory under Irish Law. In the UK where employers' liability insurance is mandatory, Fish Insurance are just one company who specialise in Independent Living Insurance policies. According to Fish, "while direct payments provide welcome freedom and choice, they also bring responsibilities and potential liabilities." A Fish policy covers employers' liability and gives "24 hour telephone employment law advice on issues such as disciplinary matters, dismissal, absenteeism, health and safety, change of duties and harassment." The policy covers legal costs to resist and defend a case and awards which may be made against the employer.

The basic employers' liability policy offered by the Fish Independent Living Insurance Policy is £20 million for a premium payment of £76.65 (€90.42 www.xe.com 20/07/10). A more comprehensive policy is available for £134.40 (€158.60 www.xe.com 20/07/10), which in addition to employers' liability, also covers personal accident, personal accident of employee, errors and omissions by employee, additional expenses, infidelity of employee, employment tribunal costs, indemnity to others, employment tribunal awards and compensation.

JOHN GOES DIRECT

by John Dwyer

Introduction

I was born with muscular dystrophy and as a result I depend on the provision of a PA service to assist me with all aspects of daily living. Now in my mid 40s, I live independently in my own apartment in Dublin's city centre. I have a long experience of using PAs and was actively involved with the Centre for Independent Living in the early 1990s. I work part-time, have an active social life and I spend a lot of time in the West of Ireland, where I originally came from.

Why Direct Payments?

I first moved into an independent living environment in the late 1990s where I lived for approximately 10 years in an apartment which was owned by the Cheshire Foundation. I had 120 PA hours provided by the Irish Wheelchair Association (IWA) which was adequate at the time as Cheshire provided me with an on-call service at night time to complement this. In October 2006 I moved into my own apartment and this resulted in me losing the on-call service provided by Cheshire. This left me in a vulnerable position during the night so I applied to the IWA for extra PA hours but they were not in a position to provide an enhanced service at that time. Cheshire offered to provide a 'drop-in' service at intervals through the night but this did not offer the peace of mind or security which I needed.

I therefore applied directly to the Health Service Executive for an extra 20 hours of PA hours per week. The HSE were not in a position to meet this request but did offer me a payment of €10,000 per annum for the purpose of purchasing PA hours and made this payment through Cheshire Ireland on a quarterly basis. In 2010 I was informed by Cheshire that this payment was being cut by 8 per cent in line with HSE cutbacks.

I now manage my PA service through the 120 hours a week I receive from the IWA, combined with the hours I buy with my direct payment.

How the Payment Works

In order to receive my payment and to ensure accountability I agreed with the HSE (as indicated) to route my payment through Cheshire. I was required to set up a limited company as a sole trader and to open a separate bank account which would be used specifically for the payment.

The payment is made by the HSE to Cheshire and by Cheshire to my company bank account. Once I received my payments I agreed to provide Cheshire with monthly time sheets which showed the number of hours worked by my PA. I also provided quarterly spreadsheets outlining details of income and expenditure.

To assist me with taxation, PRSI deductions, and to ensure I was fully compliant with taxation and employment legislation, I retained a professional accountant for a nominal monthly fee. I e-mail him my PA's monthly timesheet and he makes all the necessary deductions and e-mails me back a pay slip which shows the nett monthly payment due to my PA. He also registered me with the Revenue Online Service (ROS) and put in place a standing order to ensure that my quarterly returns were made to the Revenue Commissioners on time. He also looks after any other necessary associated work and answers and/or deals with any queries which I am unsure about to ensure that all is in order.

This works for me, as all I want is the responsibility and the control of my service. I don't want the headaches of being an employer. By employing an accountant it helps me to understand and be fully compliant with all aspects of employing someone. It's what I'm paying him to do.

Hiring a PA

To advertise for the position of a PA I usually use the *Evening Herald* and a community website called Gumtree which takes free classifieds. I use a simple job description and reluctantly avoid the words 'Personal Assistant' but instead use the term 'Personal Care Assistant' as words like Personal Assistant has previously resulted in some 'suits' turning up to be interviewed for the position of a Personal Assistant in the business sense. I conduct my interviews on my own in a local hotel and never use my home to interview.

In short listing my interviewees, my preference is to work with males due to the personal nature of the job. My only other requirement is that my PA must be mature and have a full clean driving licence to drive my van.

As a Personal Assistant user of long experience I prefer to do my own induction and training (with new PAs working alongside experienced ones). The mandatory training requirement for Manual Handling and Lifting etc. is provided and invoiced through Cheshire when required. Garda clearance is also sought through Cheshire.

I used a standard service provider Employment Contract with terms and conditions and adapted the contract where necessary to meet my requirements and had it proofed by my accountant.

Direct and Indirect Costs

When I employed my first PA via direct payments, I set the rate of pay at the equivalent level paid to my PAs by my service provider at that time, which was €13.50 per hour. Since then most service providers have a paid salary increase under the Social Partnership Agreements. I have not been able to match this pay increase as my HSE payment is not index-linked. This is a very real problem for me as I now have a number of PAs doing the same work but on different rates of pay.

Regarding insurance, I have extended my domestic insurance to cover employing a PA (as a domestic employee) as I was unable to get a company to quote me specifically for PA employer liability. I am not very comfortable with this arrangement as it is a very grey area when manual handling is involved. Because I require my PAs to drive my van, I also must have an open drive insurance policy which costs €2,500 per annum.

The accompanying costs associated with PAs apply equally to people using a direct payment and those receiving a service from a provider. For example, when I go on a sun holiday with two PAs their wage costs are covered for the holiday. However, the cost of flights, accommodation, meals etc are not. I am expected to pay for these. My direct payment includes no overhead to meet such costs. Typically my holidays can cost me twice as much as the average person. If I go on a week-long package priced at €800 it costs me €2,000. I therefore don't go too often for obvious reasons.

Support

As there are very few people with disabilities using a direct payment there is consequently limited knowledge in the area and no organisational support as such. I would keep in touch with Cheshire who have been hugely encouraging and supportive. I have also built up a close network of peers who provide me with mutual support with issues concerning personal assistants and independent living generally.

Direct Payments – Is it working?

I have enjoyed the flexibility of using a direct payment. While my direct payment represents less than 10 per cent of my total PA hours, nonetheless, it has presented me with opportunities to set aside some funding to meet my PA overheads and to bank some hours (for holidays etc) if I choose. However, as I would only get paid for the hours I use the opportunity to bank hours is very limited. But that

said, if I had to, direct payments gives me the flexibility on occasions to stay at home unsupported for periods during the day in order to build up some hours for a particularly busy time or for holidays, which is a great advantage.

A disadvantage at present however is the uncertainty and a lack of security with regards to my direct payments. I do not have a contract in place regarding these payments. I do not receive my quarterly payment by direct debit and I often need to send 'reminders' that the payment is due. This has become critical in recent months as one missed payment would put my account into the red. I have nothing in writing, which is something that I would like for my own peace of mind and security.

The lack of indexation also means that the number of PA hours I can purchase with my direct payment will shrink as wage costs rise.

Into The Future

The Philosophy of Independent Living is about us (as people with disabilities) being in control of our own destiny. It is about us having the right to choose how to live our lives. I believe that a direct payment option is one such significant choice that must be available to those who choose to go that route. It is one of the key elements which, in my opinion, if implemented, would suggest that service providers and the HSE are finally beginning to understand the thinking behind the Philosophy of Independent Living. Such a choice would help enhance our quest for a meaningful independent living service and give us full and total control of our lives.

Of course, systems need to be put in place to ensure accountability and protection for all concerned. We as people with disabilities can be trusted and should be given the chance to prove it.

CONCLUSIONS & RECOMMENDATIONS

1. *National Policy on Personal Assistance and Direct Payments*

Both participants in this project negotiated their direct payment outside the parameters of any national policy on personal assistance. The direct payment was negotiated in both instances through the goodwill of the HSE. The HSE do not currently provide any guidelines on direct payments for the purposes of employing a Personal Assistant.

Personal assistance needs to be regulated through a Personal Assistance Act which would set out who is entitled to personal assistance, the purpose of personal assistance inside and outside of the home, how such assistance is to be organised and the right of service users to be part of their assessment for personal assistance. Personal assistance should be provided on the basis of assessment of need to live a full and independent life as equal and participative members of society, without regard to the cost of the service or the means of the service user.

The organisation of personal assistance should have regard to all models of service delivery, including direct payments to people with disabilities for the purpose of employing personal assistance. Direct payments models include directly employing personal assistance or contracting with a third party (a service provider or a private company) for the purpose of providing personal assistance, or a combination of both.

Direct payments should emanate from one source within a Government department, with a built-in accountability process to that department. The department should reflect that personal assistance is part of social policy rather than health policy.

2. *Peer Support for Direct Payment Users*

Both participants in this study feel isolated and vulnerable as direct payment users. There are no support organisations with practical experience of employing a personal assistant through a direct payment. Equally there is no peer network of direct payment users. Both Damien and John were required to go through each step of the process on their own and to self-learn through trial and error which was an exhausting and lonely experience.

PWD who act as employers should have access to support agencies that are available to assist them to manage their service and to provide peer support. From the outset it was recognised that PWD or their families and support groups, to use direct payments effectively, need appropriate support services. This may include advice on advertising, recruitment, wages, accountability processes, management skills, employment law and conflict resolution. User Led Organisations are often best placed to offer these services within a peer context. This model is widely used in Britain where the Government strategy document, *Improving the Life Chances of Disabled People*, published in 2005, recommended that by 2010, 'each locality should have a user-led organisation modelled on existing Centres for Independent Living. Disabled people are best placed to take the lead in identifying their own needs and in identifying the most appropriate ways of meeting such need.'

In Sweden, Co-operatives are the model of choice for direct payment users who wish to employ assistance in a peer supported environment.

In an Irish context the most effective way forward, initially, may be a national organisation to support people using direct payments. As the number of direct payment users rises, more localised organisations would be better placed to support direct payment users.

3. *Personal Assistant Insurance*

Both Damien and John have insurance but neither succeeded in identifying an insurance provider who specialised in personal assistance insurance, inside and outside of the home, for the purpose of independent living.

There is an urgent need for the insurance industry in Ireland to respond with cost competitive policies for this emerging market. The insurance industry in Ireland needs to be fully informed of the purpose, role and function of a Personal Assistant within the context of Independent Living.

4. *Associated Services*

Services associated with the administration of a payroll, including tax and PRSI deductions and returns to the Revenue Commissioners, and other accountancy services, are available locally to both Damien and John but they are not independent living specific services.

In Northern Ireland, the Belfast Centre for Independent Living (CIL) offers a number of services to clients, including a payroll service which is available through a subsidiary company of Belfast CIL.

In a direct payment environment it is preferable that service users are afforded the maximum choice and

flexibility to buy in support services which are cost effective and mainstreamed, or to acquire such services within the context of a supporting agency such as a User Led Organisation.

A pilot scheme, where an existing organisation that is also user-led, would establish a subsidiary company for the purposes of supplying support services such as payroll administration, available nationally on an e-commerce basis, would fulfil an emerging need and provide learning for all of the stakeholders.

5. *Indexation*

Both participants in this study have been receiving a direct payment for a period in excess of 18 months. During that time there has been no increase in payment from the HSE for the cost of the service. John has had his payment reduced.

The years 2009 and 2010 have been periods of recession and retrenchment with pay cuts in both the public and private sectors. It has also been a period of deflation.

During periods of normal economic growth, direct payments, for the purpose of purchasing personal assistance hours, need to be index-linked to protect their purchasing power and to ensure that the number of PA hours is not reduced.

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What is Independent Living, Independent Living Institute

About ENIL, European Network of Independent Living

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