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Issues Concerning Direct Payments in the Republic of Ireland

A Report for
The Person Centre

David Egan, November 2008

Introduction

For the purpose of this paper, *Direct Payments* are discussed within the context of people with disabilities and specifically people with disabilities who use personal assistants. *Direct Payments* have applications for many groups of people who are not disabled and can be used to provide a broad range of services.

Direct Payments are cash paid to individuals to enable them to employ, either directly or indirectly, individuals to assist them with their everyday tasks.

Direct Payments operate in a number of EC countries including Britain, Sweden, Austria, Finland, Belgium, Holland and Germany.

Over the past 20 years *Direct Payments* have become a key part of UK social care provision. The 2005 Cabinet Office Strategy Unit report 'Improving Life Chances of Disabled People' called *Direct Payments* "the most successful public policy in the area of social care."

This policy initiative resulted from disabled people (mostly with high level support needs and many of them in residential or nursing homes) demonstrating that cash payments were both an effective way of meeting their needs and an efficient use of public resources.

The Terms of Reference for this report, as set out by The Person Centre, are to produce a paper that clarifies the following:

1. Outline *Direct Payment* approaches/models in other jurisdictions.
2. Describe a *Direct Payment* approach/model that would be appropriate in the context of the Republic of Ireland.
3. Identify the possible advantages and disadvantages of *Direct Payment* for people with disabilities in the Republic of Ireland.
4. Describe possible advantages and disadvantages/concerns that might arise from the introduction of a *Direct Payment* scheme for public service bodies with responsibility for resource allocation and relevant policy-making.
5. Describe possible implications of *Direct Payment* for current service providers.
6. Identify conditions that might need to be in place to combat possible disadvantages and allay concerns of people with disabilities and other stakeholders.

Overview of Direct Payments in Northern Ireland

“Outline *Direct Payment* approaches/models in other jurisdictions”

The first recognisable payment scheme occurred in the UK in 1979 when a group of Cheshire residents, later known as Project 81, negotiated local authority funding by way of an 'indirect payment' to a Trust Fund. The monies were used to purchase personal assistance to enable residents to live in the community in lieu of the institutional service received. Project 81 led to the establishment of the first Centre for Independent living in Britain. Since then, there has been a steady increase in the availability of indirect and direct payment schemes throughout the UK. However the legal status of such payments remained unresolved until 1997.

In 1987 the Government announced the introduction of The Independent Living Fund (ILF) to compensate, in part, for the withdrawal of the 'Domestic Care Allowance.' The ILF had a dramatic impact on the availability of Direct Payments to purchase personal assistance and represented the first large-scale opportunity for people to use cash to satisfy their support needs. The establishment of the ILF resulted in two distinct funding bodies for Direct Payments, local government and the ILF, a situation which remains to this day.

In 1989 '*The Direct Payment Campaign*' was launched by the British Council of Disabled People (BCODP). BCODP obtained funding from the Rowntree Foundation and contracted the Policy Studies Institute to research the cost implications and effectiveness of Direct Payment schemes and how they improve user satisfaction and quality of life.

A year after the publication of 'Cashing in on Independence' the Government introduced Direct Payment legislation which was enacted in the UK in 1997. The Direct Payment Act 1996 made it legal for local authorities to make Direct Payments.

Primary legislation concerning Direct Payments in the UK is not generic. England, Wales, Scotland and Northern Ireland have distinct legislation passed by their National Assemblies and Parliaments. On the island of Ireland, Direct Payments are available to people living in Northern Ireland. The legislation concerning Direct Payments in Northern Ireland is 'The Carers and Direct Payments Act (Northern Ireland) 2002.'

Direct Payments are available to disabled people over the age of 16, disabled parents, parents of disabled children, and carers over the age of 16 for services to meet their own needs and people affected by mental health.

According to the Department of Health the aim of a Direct Payment in Northern Ireland “is to give more flexibility in how services are provided to many individuals who are assessed eligible for social services support. By giving Individuals money in lieu of Trust Social Care Services people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered.”

A Direct Payment can be used to employ individual staff, to contract with people who are self employed, to buy a service from an agency or to combine a Direct Payment and a service.

Qualifying people can employ relatives to work as their personal assistant with the exception of close relatives living in the same household. Exceptions can be made by the local Health and Social Service Trust provided the Trust is satisfied, that to do so, is in the best interest of the qualifying person. Spouses, partners, parents, grandparents, aunts, uncles, sons, daughters, brothers, sisters or their spouses are considered to be close relatives.

In Northern Ireland the assessment for personal assistance hours is carried out in most instances by a Social Worker employed by the local Health and Social Care Trust of which there are four in Northern Ireland. Inland Revenue do not regard Direct Payments as taxable income. No upper limit exists for the number of hours allocated to an individual to meet their need. However, Direct Payments are subject to the same budgetary constraints which impact across all social services provided by the Northern Ireland Health Trusts. Assessors can and do differentiate between critical and non-critical need.

'Means testing' is applicable to qualifying persons for a Direct Payment but the scheme does allow some discretion. Generally, people under the age of 75 can be means tested for what are regarded as 'core services' such as help in the home. People who require supports which are significantly in excess of core services are unlikely to be means tested.

Service users are allocated a number of hours of personal assistance per week based on their assessed needs. A flat rate hourly payment, which is decided by the Health and Social Care Trusts (payment rates can vary slightly within Trusts) is paid directly to the service user. Typically the hourly payment to service users varies between £8 and £10 per hour. There are no incremental payments for night work or Sunday work. The payment is intended to pay the wages of a personal assistant including holiday pay, unsocial hours and to cover certain administrative overheads associated with Direct Payments.

There is no defined payment rate for a Personal Assistant. Service users who employ a Personal Assistant are obliged to be familiar with tax and employment legislation including the statutory minimum wage which, in Northern Ireland, is currently £5.52 for people aged over 20 and £4.60 and those aged between 18 and 20.

Service users are required to account for their Direct Payment. Service Users sign an agreement with their Trust which outlines how the Direct Payment should be used and how they are expected to account for the payment. Weekly time sheets signed by the service user and the Personal Assistant are required to be returned to the Trust on a monthly basis. Detailed guidance is set out in the document: Accounting and Monitoring requirements for payments made under the Carers and Direct Payments Act (Northern Ireland) 2002.

The total number of Care Packages in Northern Ireland subject to Direct Payments was 1,144 at the end of March 2008 up from 117 in March 2004.

Of the total number of Direct Payments 30% were used by elderly people, 3% supported people with mental health, 22% supported people with a learning disability, 42% supported people with a physical disability with the remaining 2% being used by carers over the age of 18.

Centre for Independent Living Belfast provide a range of support services including a payroll service for 400 people on Direct Payments across all disability categories and for older

persons who do not have a disability.

People with Disabilities (PWD) in any part of the UK, including Northern Ireland, who have been approved for a Direct Payment and still find they have an unmet need around personal assistant hours can apply to an Independent Living Fund (ILF) as mentioned previously.

The ILF is a non Departmental Public Body which was established in 1987. ILF provide a 'Direct Payment' in the form of regular four-weekly payments to individuals that enables people to purchase care from an agency or pay the wages of a privately employed Personal Assistant.

The original Fund was superceded by two new extension funds in 1993 which eventually came together in 2007 to form the current ILF. The ILF continue to support existing users and new applicants. There are currently 21,000 people using the ILF across the UK.

Eligibility criteria for new entrants are stringent. Residents in Northern Ireland must be in receipt of at least £325 (from the 1st July 2008) per week from their local Trust in services or Direct Payments, must have capital of less than £22,250 (including any capital a partner may have), and be in receipt of the highest rate care component of the Disability Living Allowance.

Those who qualify for the highest rate care component of the Disability Living Allowances are asked to contribute half of that payment towards the cost of their service.

From the 1st April 2008 the ILF have introduced budgetary and prioritisation measures which include giving priority to new entrants who work at least 16 hours per week.

The ILF assessment procedure is distinct from the local Trust and the ILF employ 170 staff and 80 self employed regionally based ILF assessors. In certain circumstances local Trusts may be asked to verify information received from applicants. Service users in Northern Ireland are accountable to their Social Care Trusts for both payments.

Overview of Direct Payments in Sweden

Sweden has traditionally been seen as the 'gold standard' on Direct Payments since the introduction of 'The Personal Assistant Act' in 1994. Sweden remains the singular EC country which confers a right in law to a Personal Assistant without regard to cost. The Assistant Act includes personal assistant cover for all assessed needs including personal assistance, assistance at work, household work and assistance associated with parenting.

Other significant features of the Act are the absence of means testing and a payment for the administrative costs associated with Direct Payments. Needs assessed are expressed in the numbers of hours required to meet that need. A tax free payment enables assistance users to purchase their personal assistance from any service provider or to employ personal assistants directly. There are no upper limits on the number of hours to which an individual is entitled. Twenty-four seven personal assistance is a feature of the system. For those who qualify under the Personal Assistant Act there is one centralised source of funding – The National Social Insurance Fund.

Each assistance user has his or her personal assistance needs assessed by the local government or the National Social Insurance Fund. The need is expressed in the number of hours of service required per week. The local government or the Insurance Fund pay each qualifying person a monthly amount that consists of the number of hours that he or she has been assessed for multiplied by the flat rate that the government determines each year as the remuneration for one hour of personal assistance services. The amount is to cover wages, wages for unsocial hours, employer's social insurance costs, insurances for the employee, the user's and assistants' training costs (if deemed necessary by the user), the cost of accompanying assistants in the form of travel costs or entrance fees, meals, etc. The money is paid into the individual banking account or to their service provider's account, depending on the assistance user's preference. The funds can be used for personal assistance only and have to be accounted for by showing proof of the number of hours used. This proof is provided by sending each month the 'time sheets' of all one's assistants signed by them.

Some Swedish commentators suggest The Assistance Act 1994 has two major shortcomings. The Act does not extend to PWD over the age of 65 at the onset of their personal assistant need (those who qualified for Personal Assistance prior to their 65th year retain their assessed hours). Secondly, the hourly rates of pay to Personal Assistants is not indexed linked.

An interesting feature of the Act is that PWD who are assessed as needing less than 20 hours of personal assistance per week do not qualify for personal assistance under the Personal Assistance Act. In Sweden less than 20 PA hours per week is not considered 'independent living' under the Act and PWD's whose needs are assessed at less than 20 hours per week have their needs met from a home help service provided by their local municipality.

A PWD cannot directly employ a family member with whom they live as their personal assistant. However, a wife who wants her husband as her PA could ask a service provider to employ her husband as her PA.

The following extract is from a Government information sheet – Care and Services for People with Functional Impairment.

“There are certain conditions that make an individual eligible for personal assistance. These conditions are that the person must need personal assistance for certain basic needs in daily life, such as help with personal hygiene, dressing and undressing, eating, communicating with others, or other assistance that requires detailed knowledge of the person’s specific functional impairment. If someone needs assistance with these fundamental or basic needs for more than 20 hours a week, the person is also entitled to assistance with other Personal support in daily life, such as activities like going shopping, going to the cinema, and during holiday trips. Children as well as adults can have personal assistance. A person must be younger than 65 years old when receiving assistance for the first time. When they are 65 or older, they can keep the same number of hours that they were granted, but the hours may not increase. If a person needs more help as they age, it can be provided through the home help service.”

In 1987 a pilot project undertaken by the Stockholm Co-Operative for Independent Living (STIL) supported 22 individual personal assistant users to live independently within Stockholm County. All of the PA users were members of STIL. STIL calculated wages, hired personal assistants and administered the pilot Scheme which was hugely popular and led indirectly to the Personal Assistance Act seven years later.

The STIL model still runs today and many of the features pioneered by the co-operative have been adopted by service providers in Sweden and further afield. STIL’s belief in ‘growth through personal responsibility’ led to the development of core principles around self advocacy, self representation, peer support and the training and support necessary for individuals to manage their own service and participate fully in society. This was in contrast to traditional service providers who believed no demands should be placed on service users. STIL is recognised today for its high quality of service, its high user satisfaction and its cost effectiveness.

By the year 2002 seventy percent of service users were buying their services from local government (municipalities) who traditionally had provided a ‘home help’ type service. 15% of users were getting their service through co-operatives while another 15% chose commercial companies.

In Sweden today there are approximately 300 municipalities, 450 private organizations (for profit companies and cooperatives) plus around 500 individuals who employ their assistants themselves. Each organization offers different policies and schemes.

12% of the currently 14,000 entitled persons manage their services through co-operatives, 55% buy their services from local government and 30% from commercial companies. Only 4% of the 14,000 act as direct employers of their personal assistants.

Sweden V Northern Ireland

While Northern Ireland and Swedish Direct Payment policy enjoy a degree of commonality particularly in the areas of accessibility, accountability, choice and control, there are, none the less, substantive differences in key policy areas.

In Sweden PWD have a right in law to a Direct Payment without regard to the cost of the payment for the number of assessed hours and without regard to the means of the applicant.

In Northern Ireland PWD have a right to access a Direct Payment within the restrictions of the Trust budget. There is a provision for a test of means. Access to the ILF is subject to applicants meeting certain criteria and service user contributions to the cost of the service may be requested.

Sweden applies differing criteria to PWD applying for personal assistance that require more than twenty hours of service per week and those who require less than twenty hours. Northern Ireland Direct Payment policy does not make this distinction.

Sweden has one source of funding for those receiving a Direct Payment. In Northern Ireland and throughout the UK there are two sources of funding for a Direct Payment.

Pay rates for Personal Assistants are set nationally on an annual basis in Sweden. In Northern Ireland Personal Assistant rates of pay are elective for the service user within the parameters of minimum wage legislation.

Funding agencies and legislation in Sweden demonstrate a clear understanding of the role, purpose and function of a Personal Assistant. In Northern Ireland the emphasis is placed on the purpose and function of a Direct Payment.

Direct Payments in the Republic of Ireland

Currently disabled people in the Republic of Ireland do not have a right to a Direct Payment which would enable them to employ a personal assistant.

The Department of Social and Family Affairs operate a number of Direct Payment schemes to qualifying people with disabilities and to qualifying carers of people with disabilities. Examples of these payments include Disability Benefit, Invalidity Pension, Carers Allowance, Carers Benefit and Domiciliary Care Allowance. A Motorised Transport Grant and Mobility Allowance is paid directly to qualifying persons by the Department of Health and Children.

Personal Assistant services for people with disabilities are provided by a number of service provider organisations including the Irish Wheelchair Association, Cheshire Ireland, Enable Ireland, Centres for Independent Living and RehabCare. These services are funded primarily by the Health Service Executive (HSE) and to a lesser extent by FAS. The HSE also provided some personal care services directly to people with disabilities.

The Home Care Support Scheme (also known as the Home Care Support Package) is an administrative scheme, operated by the HSE.

In some parts of the country, services under the scheme are provided directly by the HSE, in others it is administered by service provider organisations on behalf of the HSE. According to the HSE document, Home Care Support Scheme for Carers, “Packages may also consist of direct cash grants to enable the patient’s family to purchase a range of services or supports privately. In some parts of the country, the package may consist of a combination of direct services and cash payments.”

The main priority of the Home Care Support Scheme is older people living in the community or those who are in-patients in acute hospitals at risk of admission to long term care. However, there is evidence to suggest that the purpose of ‘Care Packages’ is liberally interpreted by the HSE. West Limerick Centre for Independent Living is one of a number of service providers contracted by the HSE to administer ‘Care Packages’ for the purpose of supporting PWD through the provision of personal assistants.

Anecdotal evidence suggests that a number of PWD are receiving cash directly from the HSE under the Home Care Support Scheme to support their needs including personal assistants. At the time of writing this report it has not been possible to identify such individuals.

As the Home Care Support Scheme is still largely in its infancy there are no national guidelines regarding admission to the scheme. The scheme does allow for means testing and each HSE Administrative Area has responsibility for the operation of its own scheme. The HSE is currently working on standardising a national needs assessment of all individuals. In the meantime however, there is no standard assessment of the needs of people who apply for the scheme and no rules about how any assessment is carried out. The Home Care Support Scheme is not yet a national scheme and is not established in law. As it is an administrative scheme there is no automatic right to the scheme.

The HSE are currently working with a number of other Government Departments including the Department of Health, the Department of Social and Family Affairs and the Department of Environment, Heritage and Local Government to ensure that the Packages being delivered are flexible and include a structured cash payment and other supports.

The National Economic and Social Forum are undertaking a review of the Home Care Support scheme as a case-study of policy implementation, viewed from the perspective of outcomes. The Department of Health will also shortly begin an evaluation of the Home Care Support Scheme.

Approaches to Direct Payment Models in the Republic of Ireland

“Describe a *Direct Payment* approach/model that would be appropriate in the context of the Republic of Ireland”

Given the evolutionary evidence around how Direct Payments emerged in other jurisdictions it would seem logical that a Direct Payment approach/model in Ireland may emerge, initially, on a pilot basis.

The purpose of such a pilot would be to provide the basis for an evaluation of Direct Payments as a cost effective method of delivering a service and as a measure of user satisfaction around the outcomes.

Personal Assistance is a means to an end and that end is a person centred independent living approach to disability. This approach places the PWD at the centre of the decision making process which will determine how that person will choose to live their life. It would be important to establish, at the outset of any pilot, that person centred independent living should be an option for all persons with a disability including persons with sensory, mental health, physical and intellectual disabilities.

The purpose of any pilot would be to test a number of different approaches/options for service users around how they purchase their services. Looking at the Swedish and Northern Ireland models of Direct Payment, options include individuals directly employing staff, contracting a self employed person, contracting a service provider or a commercial company, contracting with a state agency, purchasing services through a collective or combining a service with a Direct Payment.

Taking all of the available options and testing them in a single pilot within the four disability categories would be challenging. To succeed the pilot may require a more narrow focus.

Having regard to the current services that are available to PWD around personal assistant provision it may be more realistic to look at a small target group of existing service users which would have the effect of confining the pilot, largely, to people with physical disabilities. However there is evidence to suggest that there are a number of people with intellectual disabilities and their families who are currently working with ‘Microboards’ (a small group of committed family and friends who join together with a PWD to create a non-profit society) who would be in a position to take part in a pilot on Direct Payments. A recent evaluation of Microboards published by the Microboards Association of Ireland called for a pilot study to be undertaken to determine the effectiveness of Direct Payments in an Irish context.

Any pilot may also have limitations imposed on it by service provider policy regarding the client base of the provider which may be confined to a singular disability category.

Buy-in from all stakeholders including existing service providers and statutory funding agencies would be preferable from the outset. Consideration as to how the pilot might be mainstreamed and an exit strategy would need to be a central part of the process.

Considerable funding would be required to undertake such a pilot for any meaningful period. Funding sources might include statutory agencies, philanthropic organisations, cross border funding, existing service providers or a combination of the above.

Below is a brief outline of two scenarios which could form the basis of an approach to Direct Payments.

Option A.

Consideration could be given to the potential that exists within the HSE Home Care Support Packages (HCSP), which is in itself a pilot, to test Direct Payments to PWD for the purpose of employing a Personal Assistant.

The HCSP is open to cash payments as it is currently operated but guidelines and criteria for participation by PWD on a 'cash payment' basis are still being developed.

In this scenario a cash payment would be made to participating members of the pilot by the HSE through the HCSP to enable them to employ a Personal Assistant.

The amount paid to the individual (individual person, limited company to support the individual, Microboard, etc.) will be based on an agreed hourly rate of pay to a Personal Assistant. The hourly rate of pay will also include a payment to cover certain agreed overhead costs associated with employing an individual. These are likely to include employers PRSI contributions, an allowance for unsocial working hours, cost of PA cover during holidays and bank holidays, training of PA's and service users, employers liability insurance and costs associated with payroll administration.

The number of hours of personal assistance service to be provided to an individual on a weekly basis will be decided by assessment. Service users could choose to have part of their service provided through cash while remaining with their existing service provider.

The payment will be made directly to a bank account of the individual which will be used exclusively for that purpose, or paid to a service provider nominated by the individual.

The pilot participants will be obliged to be a member of a legal entity (Limited Company, Co-operative, Trust) for the duration of the pilot.

The purpose of such an entity would be to provide support and services including assessment, to the individual, either directly or through out-sourcing. The costs associated with such an entity would be met, in part, through service user contributions.

Service users, or their representatives, would form part of the entity which would allow them maximum input into the development of their support services and to whom they would be accountable.

Support services to individuals will reflect the capacity and needs of the person and would be elective, except where there is a mandatory requirement, within the rules of the entity.

Option B.

Piloting Direct Payments in partnership with an existing service provider may also be an option.

Existing service providers have a wealth of experience in delivering personal assistant services. The challenge in this model would be to harness the experience and support of the service provider while providing maximum intellectual and financial autonomy to the service user.

In this model the service users could choose to receive cash payments from their service provider in lieu of services. The payment would be made directly to the individual. Service users could choose to continue to receive part of their service from the provider and to buy-in the remainder with cash. The cash element of the payment will need to recognise all of the overheads described in Option A.

Service users participating in the pilot would be entitled to aspire to having 100% cash payment in lieu of directly provided services within the lifetime of the pilot.

Service users would continue to use their providers for hard supports such as contracting with a PA, conflict resolution, PA training (health and safety), payroll and insurance.

Service users participating in this model would form a Collective for the purpose of supporting individuals around the use of the cash element of their service. This would give service users the opportunity to begin testing their abilities in a supported environment to hire PA's. The Collective would also be used to develop soft services such as peer support, personal development and growth through responsibility.

The Collective would be an independent entity and the costs associated with its administration would be met, in part, through service user contributions.

Accountability for the cash element would be to the service provider. The Collective would work with the provider to develop appropriate robust accountability practices which could be transferred into a mainstream environment. Some service providers currently have such accountability practices in place.

The exit strategy proposed for the end of the pilot is a migration by service users, who choose to do so, towards direct funding from a primary source.

The Option A and Option B models described above are intended to give an overview of a Direct Payment approach that would be appropriate in Ireland. Both models require considerable further analysis and consultation to develop in greater detail an appropriate approach which would be embraced by all stakeholders.

Having regard to a Direct Payment policy that would be appropriate in the context of the Republic of Ireland, delegates attending an Independent Living Conference in Dublin in 2007 set out a number of essential criteria for a National Policy on Direct Payments.

- Personal Assistant (PA) policy must be enshrined in legislation
- Clear definition of a PA's role and function
- A right in law to a PA service without regard to means
- A right in law to a PA service without regard to cost
- Direct Payments to be index-linked

- Direct Payments to include associated overheads
- Models of PA service delivery giving users choice and control
- Standards and quality monitoring
- Funding to attach to the individual
- Policy must recognise training needs for service users and PA's
- Payments must emanate from one source
- PA service should follow the life cycle of the service user
- Assessment should be person centre
- Portability of service nationally and internationally

Possible Advantages and Disadvantages of Direct Payments for Service Users

“Identify the possible advantages and disadvantages of Direct Payment for people with disabilities in the Republic of Ireland.”

User satisfaction among personal assistant users is generally good. The ‘service provider’ model which operates in the ROI is seen, by many of those who have access to a service, as an excellent model of service delivery. Currently, there does not exist a groundswell of dissatisfaction among service users or a national demand-led campaign for alternative models of service delivery including Direct Payments.

The advantages of the current model include the fact that there is no test of means for the service and there is a fear that any review of the existing service may throw up the spectre of means testing.

However, there is a realisation among some service users that the increasing cost of providing their current service will inevitably lead to calls for competing models and better value for money for service users and funders. This ‘loose’ group of service users has made sporadic requests to statutory agencies, service providers and to Government, to review existing services in the context of a national policy on Personal Assistant Services. Underpinning this campaign is the notion of funding following the service users rather than the service provider. Such a policy, it is believed, would have the effect of ensuring “choice, control and funding” would reside with PWD.

Some PWD and their families believe they could obtain better value for money and better personal outcomes from a Direct Payment. Direct Payments seen purely as an economic solution does however set off a series of alarm bells. Service users fear ‘a race to the bottom’ in terms of quality of service with service users using minimum wage to extract maximum hours in an unregulated market with little support and no recognition of the significant overhead required to administer such a model.

This ‘free for all’ approach reflects most closely the British model, in contrast to the more regulated Swedish model where a national pay rate for PA's is struck on an annual basis.

The same concerns which are being currently expressed about the lack of regulation and quality monitoring in HSE funded NGO's will also apply to Direct Payments.

The concept of 'growth through responsibility' has not gained traction in Ireland among service users who have become accustomed to a service with minimal personal responsibility. This can be seen both as an advantage and a disadvantage of Direct Payments depending on the capacity of the service user. Service users include third level graduates in full-time employment, former residents of institutional care with little exposure to the main stream, and people with intellectual disability. A more regulated environment may well suit the latter groupings. PWD with the capacity, ability and confidence to self advocate may find the 'Swedish model' over regulated.

Direct Payments are a means to an end and it is important to ensure that the administration of the Direct Payment does not become an end in itself. Equally, an over burdensome administration requirement will act as a significant deterrent to participation in Direct Payments

A lack of in-depth information among service users and families of PWD of what a Direct Payment implies has lead to a 'fear factor' among some PWD who feel they will be isolated and left 'to fend for themselves.'

In Northern Ireland Direct Payments have grown in popularity through 'word of mouth' among PWD meeting in informal networks. Those informal networks do not exist to any significant degree on a cross border basis. These networks are significant as they give assurance to would be users of Direct Payments through first-hand experience within a peer context.

The service provider model offers a large degree of comfort to service users around administration, continuation of service, back-up service, conflict resolution and statutory compliance.

A report by the Northern Ireland Department of Health, Direct Payment Policy and Practice Review, highlighted a number of motivating and de-motivating 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 i.e.:

- Where existing services did not meet an identified need.
- Where a service did not exist to meet an identified need.
- Where the service recipient feels 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 e.g. rural areas, 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.

Possible Advantages and Disadvantages of Direct Payments for Public Service Bodies

“Describe possible advantages and disadvantages/concerns that might arise from the introduction of a *Direct Payment* scheme for public service bodies with responsibility for resource allocation and relevant policy-making.”

Currently the HSE provide the lion's share of resources to support PWD to live independently in the community.

Statutory agencies are obligated to ensure public funds are fully accounted for and used by individuals and organisations for the purpose intended.

The potential to misuse funding should not be underestimated. If a Direct Payment is made to a PWD living in a family setting there is a risk that the payment may become part of the 'family budget.'

Were that the case and the individual was not benefiting from the Direct Payment as intended it may leave the funding agency 'open' to charges of not fulfilling their statutory obligation.

Currently, funding to employ personal assistants, flows through the provider organisations. If Direct Payments were to emanate from a State Body directly to PWD, and were this to

become an established model, it may prove more difficult and politically unpalatable, to limit or cut back on budget allocations during periods of economic downturn.

If a State Body were to implement a model of Direct Payment there would be costs associated with policy formation and with the building of the architecture necessary to support and administer the scheme.

Direct Payments may form part of the solution towards the unmet need for PA services. The Annual Report (2006) of the National Physical and Sensory Disability Data Base stated that there were 418 PWD assessed and wait-listed for a PA service. According to the report a further 7,553 people are waiting for assessment for personal assistants.

PWD who are currently residing in 'inappropriate' settings but who cannot live in the community because of service provider waiting lists may be in a position to organise their own services. A Direct Payment would circumvent any waiting list and free-up hospital and nursing home beds.

Equally many parents of people with intellectual disabilities feel their children are 'shoe horned' into existing services with poor outcomes for the service user. Increasingly these parents are asking policy makers within State Bodies to give them the means to design and implement their own service plans. Direct Payments would allow such State Bodies to be proactive in meeting these demands.

Currently there is no legislation in Ireland which sets out a framework within which Direct Payments might work. Direct Payments can operate without specific legislation as exemplified by the HSE Home Care Support Scheme described previously. Public Service Bodies will take their own view on whether legislation in this regard would be an advantage or a disadvantage.

Those who favour a 'light touch' regulatory regime which encourages maximum flexibility and innovation among service providers and State Bodies may see legislation as over prescriptive. The alternate view is that a National Policy on Direct Payments set within a legislative framework confers a right on PWD to a Direct Payment, clearly defines the responsibilities of State Bodies, and removes the minefields that can be 'interpretation' and 'discretion' at the point of delivery.

An advantage of a Direct Payment for statutory funders is the potential to get better value for money from the service and better outcomes for PWD.

Should the Direct Payment cease for any reason the allocated resource would revert to the funders.

However, the potential for cost savings should not be over stated as there is a substantial overhead associated with a good Direct Payment model.

Direct Payments are an opportunity for growth through responsibility and the full realisation of Independent Living. Confidence and competence are associated with Direct Payments which encourage PWD to push out their own boundaries towards education, employment and greater socialisation, with all of the implicit knock-on effects for the well being of PWD, an inclusive society and the associated economic benefits which accrue to the Exchequer.

Research in Britain, where Direct Payments are seen to allow the full expression of Independent Living, suggests that the positive economic effects go far beyond any immediate saving which might accrue from an Independent Living model of service delivery. “Interestingly, as opposed to the case for conventional support, case study and consultation evidence suggests that, on a macro-economic level, Independent Living is a cost effective option. This conclusion is premised on the assumption that Independent Living will permit far more disabled people to contribute tax and national insurance payments and that the benefits bill will also be reduced. Moreover, in the long term the demand on other public services particularly health service, is expected to be considerably less,” (The Costs and Benefits of Independent Living).

At a minimum the introduction of Direct Payments will allow funders to benchmark competing models of service provision (Direct Payments to support independent living, direct service provision to support independent living) as cost effective solutions and in outcome terms for service users.

A system of Direct Payment in the ROI has been a consistent, if sporadic, demand of the independent living movement to State Bodies and to the legislature. While Direct Payments are widely acknowledged as not being for everyone, none the less, for many, Direct Payments are seen as the key to giving people control and it is unlikely that this demand will diminish. How vociferous, voluminous or collective that voice may become in the future remains a moot point but it is unlikely to go away.

Increasingly, State Bodies will feel the weight of mandatory compliance with policy emanating from international bodies of which Ireland is a member.

The Council of Europe 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 signaled its intention to ratify the UN Convention on the Rights of Persons with Disabilities including the right to the “personal assistance necessary to support living and inclusion in the community” and the right of PWD to “control their own financial affairs.”

Access by PWD to a system of Direct Payment for the purposes of employing a personal assistant would ensure State Bodies are seen to comply with the spirit of the provisions of the UN Convention and the EC Disability Action Plan.

Implications of Direct Payments for Service Providers

“Describe possible implications of *Direct Payment* for current service providers.”

Providers working in the area of personal assistant service provision include the Irish Wheelchair Association (IWA), over twenty autonomous Centres for Independent Living (CIL’s), the Cheshire Foundation and a number of other organisations.

The IWA Assisted Living Service is the single largest provider delivering 984,627 hours of personal assistance to over 1,444 PWD throughout the 26 counties during 2007.

The IWA Assisted Living Service incorporates two models. In the Self Direct Service model the service user 'directs' the PA and reports to the IWA Co-ordinator. In the Support Service model the service user and the PA both report to the Co-ordinator.

The Irish Wheelchair Association 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 larger CILs are based in counties Offaly, Tipperary, Cork, Limerick, Mayo, Donegal and Galway. West Limerick CIL delivered 57,800 hours of Personal Assistant Services to 110 people with disabilities during 2007.

Within the CIL model, generally, CILs are the employer of the PA and the service user is the 'line-manager.'

A number of other user led organisations, who align themselves along the same principles as CILs, deliver personal assistant services in Counties Roscommon and Leitrim.

The Cheshire Foundation provides community based services to PWD in their own homes. This service, which is evolving, currently gives PWD support with daily living. Over the past decade the Cheshire model of service has moved away from a residential setting towards a person centred independent living approach. Currently, more than one-third of Cheshire service users live in self contained accommodation with daily support.

The average rate of pay for a Personal Assistant in Ireland is €13.47 per standard hour. Rates can double for week-end and night work. Typically the HSE might pay anything between €20 and €28 to a service provider per standard hour of personal assistance (more for unsocial hours or an aggregate payment for standard hours and unsocial hours). Rates paid by the HSE to service providers for personal assistant services vary between organisations and around the country. The HSE payment recognises the costs associated with administration, employers PRSI contributions, holidays, training and bank-holiday pay.

The implications of Direct Payments for current service providers would depend on the policy framework within which Direct Payments might be set. In the absence of such a framework it is difficult to say with any certainty what the implications of Direct Payments might be for service providers in the ROI.

Some commentators have suggested that the introduction of Direct Payments would involve service users moving away from traditional providers. However, the experience in Sweden illustrates that when consumer choice was introduced through Direct Payments there was no mass exodus away from service providers. This remains the case today with 96% of qualifying persons choosing some form of third party to deliver their personal assistant service.

In Northern Ireland and Britain generally the uptake of Direct Payments has been slow. It has been suggested, anecdotally, that the rates of payment to service users in Northern Ireland are not sufficiently high to allow contracting by individuals of organisations or

commercial companies. Conversely, it has also been suggested that the preference of service users in Northern Ireland who use Direct Payments, including parent of children with disabilities, is to directly employ Personal Assistants.

The current rate of between £8 and £10, quoted as being the average payment by the Northern Ireland Care Trusts to service users, would be unlikely to be a sufficient level of payment to allow service providers in the Republic to continue delivering a quality service.

While the Northern Ireland model would provide consumer choice in theory, in practice, it would be difficult to employ a personal assistant directly or to contract with a third party based on Northern Ireland rates of pay.

If Direct Payments attracted the same rates as are currently paid by the HSE to service providers (€20/€28) and thus offered PWD a sufficient level of finance to use their Direct Payment to contract a service provider, a commercial company or to become an employer, then it could be envisaged that Direct Payments would meet with a degree of success. In this case some individuals may choose to employ a PA directly rather than using a service provider.

However it should be noted that the Swedish experience suggests PWD would not want the 'hassles' associated with directly employing a personal assistant. The policy framework in Sweden, described previously, encourages PWD towards service providers while remaining consistent with the principle of choice, control and funding residing with the service user.

If Direct Payments were introduced within such a policy environment service users may choose to contract with their existing provider. The implications for the provider are that the contract will now be with the individual, with accountability to the individual, rather than to the HSE. The advantage for the service user is the assurance of a quality service in which they, the user, have choice and control while the provider remains responsible for the service.

Implicit in Direct Payments is consumer choice which would mean service users moving between different providers. A consequence of such a consumer model could give rise to commercial companies looking to compete in the sector.

Preparing the Ground for Direct Payments

"Identify conditions that might need to be in place to combat possible disadvantages and allay concerns of people with disabilities and other stakeholders."

Direct Payments may fail if the correct supports are not in place. This applies particularly to PWD who choose to become direct employers. However, even in the indirect employment model a high degree of support will be necessary for many PWD.

The question of who should support PWD on Direct Payments is a matter of ongoing debate. The basic support requirements might be as minimal as providing a payroll service which could be outsourced. However, most PWD will require to 'dip in and out' of a full

range of supports including advise on interviewing PA's, hiring and firing, employment legislation, health and safety legislation, insurance, conflict resolution, PA back-up service, allowances and benefits which can be used in tandem with a Direct Payment, rules, regulations and criteria around Direct Payments, advise on accountability process, information and preparation in advance of assessment, communication, equipment grants, transport, housing, rights, peer support and advocacy around all of the above.

It is the view of some commentators that these supports should be available, locally, to PWD through user led organisations.

In 2005 the UK Government strategy document 'Improving the Life Chances of Disabled People' recommended that by 2010, "...each locality should have a user-led organisation modeled 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. Techniques such as Person Centre Planning enable the views and preferences of individuals to drive assessment of need. Such forms are effective both in terms of enabling disabled people to play their full part in society and make effective use of public funds."

In Ireland these supports are not available in the setting described above. This type of support service would be necessary to give comfort to any PWD considering taking on a Direct Payment. Other stakeholders would also welcome such supports and statutory funders may insist on them.

State Bodies would require assurances that there is no recourse to them by the employee or by the contracted agency of the service user once a Direct Payment is put in place.

Any model of Direct Payment would be required to clearly state that PWD participating in a Direct Payment are obliged to undertake all of the responsibilities of an employer, or where PWD use an agency or self employed person to provide their service, that responsibility would rest with the contracted party.

State Bodies would therefore need to assure themselves that qualifying persons have the capacity to take part in a Direct Payment or that they have the necessary supports to enable them to do so.

Any funding agency responsible for allocating state resource would be required to demonstrate parity of access to all PWD, and perhaps also to non disabled people qualifying for certain HSE services, who wish to participate in Direct Payments. To ensure the process is fair and equitable may require national standards around all of the criteria including assessment for personal assistant hours. The statutory funding agency responsible for making a Direct Payment would be required to put in place all of the structural architecture necessary to underpin such a national policy.

This would include the necessary checks and balances to ensure that funds are used for the purposes intended and that they are fully accounted for. These checks and balances are features of Direct Payment models in other jurisdictions.

There may be a perception by potential funding agencies that they will be overwhelmed by applicants for a Direct Payment were such a scheme introduced, although this has not been the case in other jurisdictions when such schemes began operating. To allay these concerns,

and to allay the concerns of providers who fear they may lose clients, it may be preferable to introduce Direct Payments on an incremental basis.

Funding agencies will need to assure themselves that the scheme offers value for money to the exchequer when compared with other schemes and that outcomes for PWD are in line with Government policy on disability.

Standards and quality monitoring of service would also need to be built into the model. This may give rise to certification process for providers. Such a process would be advantageous for organisations who have built up good practices from long experience of service delivery. It would also assure service users that their provider meet with the criteria set out by the statutory funders.

A policy environment in Ireland where the duties and functions of a Personal Assistant are defined, and where a national rate of pay attaches to such a defined role, would go some way towards ensuring service providers remain central players.

Individuals may choose to contract with providers who can offer them a service which is tailored to their particular needs. Service providers would therefore need to be highly flexible in offering services to a multiplicity of service users requiring very different levels of support.

It could be envisaged that service providers may respond to such an environment by providing two distinct personal assistant services. One in which highly developed skill sets attach to the personal assistant and one in which the personal assistant is required to have basic training only. The rates of pay for Personal Assistants would be commensurate with their skills and training.

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