

Direct Payments Schemes

for

People with Disabilities

'A new and innovative policy approach to providing services to disabled people in Ireland.'

A SUMMARY GUIDE

Bray Partnership Disability Research Steering Committee

May 2003

This information leaflet is based on a comprehensive piece of research carried out by Bray Partnership and managed by the Disability Research Steering Committee. A full copy of the report is available from Bray Partnership or can be downloaded from the Partnership's web-site: www.braypartnership.ie

This leaflet is available in Braille, large font, on cassette or disk on request.

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INTRODUCTION

The information contained in this leaflet is based on research carried out by Bray Partnership in 2002 entitled 'Direct Payments Schemes for People with Disabilities'. The aims of the leaflet are; to provide a range of stakeholders (disabled people, service providers, community and voluntary groups and statutory agencies) with information on what direct payments are; to create awareness of the concept of direct payments; and to commence the process of lobbying for the introduction of a direct payments pilot research programme. This leaflet implements part of the first recommendation of the research report around devising an information and dissemination strategy on direct payments schemes.

WHAT ARE DIRECT PAYMENTS?

Direct payments essentially involve relevant statutory agencies giving cash to people with disabilities to purchase their own support services directly. They are designed to offer individuals with a disability significant choice and control over the type of service wanted and/or needed and, in turn, to enhance independence and autonomy. Direct payments primarily relate to the delivery of community care services, but employment supports and housing grants are also relevant and suitable to a direct payments system. Direct payments schemes are a new concept in Irish social policy and to date have not yet operated here. However, they are currently operating successfully in the US and many European countries.

WHY DIRECT PAYMENTS?

The concept of direct payments developed against a background of creative tension between the medical and the social models of disability. The social model arose as a reaction against the medical model, which reduced disability to impairment so that disability was located within the body or mind of the individual, whilst the power to define, control and treat disabled people was located within the medical and paramedical professions. In the social model, impairment is the physical or mental manifestation while disability is the daily experience of life with that impairment. Direct payments emerged through disabled people's activism to promote increased service-user choice, control and capacity to achieve independent living.

WHAT ARE THE POTENTIAL ADVANTAGES?

- The available evidence suggests strongly that for those who do/can avail of direct payments their capacity to choose and control needed services is greatly increased. This, in turn, can lead to greater autonomy and capacity to achieve independent living.
- Direct payments encourage and require the development of individualised 'care plans', thus ensuring greater focus on and attention to individual needs rather than those of the 'care system'.
- In many European countries to date, direct payments schemes have assisted with the bypassing of cumbersome and often un-

coordinated central, regional or local care services and have, effectively, challenged such service provision by placing the primary focus on the individual.

- Direct payments have assisted, to some degree, with the broader objective of greater social inclusion for those with disability both nationally and within Europe - a stated objective of official care policy at both levels.
- The experience of direct payments to date suggests that they encourage individuals, society and systems to place disability and care issues in their broader social and economic contexts.
- In effect, direct payments acknowledge that 'impairment' is as much 'social' as it is 'medical' and this contributes to a broader awareness of many of the challenges surrounding disability within the community.
- Depending on the particular model utilised, direct payments have contributed to challenging and ending isolation as they significantly reduce segregation in care for many individuals with a disability.

- Direct payments schemes achieve the objectives of many disability activists in challenging the decision-making context and control of health care administrators and medical professionals.
- Direct payments not only emphasise the rights of those with disability, they also acknowledge their responsibilities particularly with regard to employment, care plan development and monitoring and assessment.
- As practised thus far, direct payments have been a potentially key step in the transition from a 'care' framework to one based on rights/support in the overall context of disability.
- Despite the many difficulties in the context of family, direct payments, as administered in many European countries, have recognised the central role of the family in the provision of support services.

WHAT ARE THE POTENTIAL CHALLENGES?

- On the basis of current evidence, direct payments are best suited to those with a physical disability

ADVANTAGES – SUMMARISED

Increased **choice** and **control** for the user
 Focus on **individual** needs
 Challenge existing '**care**' systems and service provision
 View disability as a **social** not a medical issue
 Increased **social inclusion**
 Reduced **segregation** and **isolation**
 Challenge traditional **decision making processes** and **control** of 'care'
 Emphasis on **rights** of disabled people
 Acknowledge central **role of the family** in providing support

who are in a position to manage their own lives and are not as suitable for those with learning disabilities.

- Users of direct payments to date have found sometimes difficult to fulfil their obligations as employers. Support and training is required to meet this need.
- On the basis of available European evidence, the take up of direct payments so far has been slower than anticipated for a variety of reasons including inadequate information, satisfaction with 'traditional' care provision and the complexity of some systems.
- The administration of a direct payments scheme is not as simple as it might, at first sight, appear to be – it requires a range of 'administrative' dimensions from employment to planning, monitoring and assessment if it is to be fully individualised – not all users have found these dimensions simple and straightforward.
- On the basis of the evidence so far in Europe, costs associated with direct payments are at least as high as those of 'traditional care systems' and, in many cases, appear higher than at first anticipated.
- Direct payments users have often found it difficult to access their care and support needs within current private and public structures and procedures – direct payments often do not 'fit' with national, regional and local structures.
- Direct payments have encouraged the emergence of a private

'independent' care market which, to date, remains un-regulated and un-coordinated – something which is of concern to many users and traditional service providers. In some cases, the 'market' has not responded effectively and there may be a need to examine other possibilities – user groups, co-operatives, etc.

- The areas of monitoring and assessment have proven to be problematic as users may not be familiar with the requirements of individualised plans or where there have been disagreements about both needs, rights and the role of 'outside' assessment.
- In the case of family support, careful planning and preparation is required to ensure the a direct payments mechanism is used in the manner for which it was developed to avoid disagreements within families and challenge the 'traditional' role of the family in providing 'care' to the individual with the disability .
- So far, the development and application of direct payments has not been consistent across Europe – this has led to the emergence of a complicated system which has the capacity to frustrate the objective of an 'inclusive Europe' for those with disability.

WHAT DID THE BRAY PARTNERSHIP DIRECT PAYMENTS RESEARCH CONCLUDE?

There is a clear **information deficit** regarding the potential and value of

CHALLENGES – SUMMARISED

Not as suitable for people with **learning disabilities**

Difficulty for user to fulfil **employer** role

Inadequate **information**

High level of **complexity**

Significant **administration** attached

Do not readily 'fit' into **existing structures**

Care market may be **un-regulated** and un co-ordinated

Market may not respond effectively

Monitoring and **assessment** can be problematic

Significant level of **inconsistency** in service provision across Europe

'**Cared for**' mentality needs addressing particularly in family context

direct payments schemes – at least amongst those engaged in this research. Time and time again, those consulted within the research expressed the need for a wide range of additional information on almost all dimensions of direct payments from structures to budgetary implications to user and provider experiences.

Evidence from the research is that the direct payments schemes as currently implemented in many countries in Europe (and as researched in Northern Ireland) have **(many very positive outcomes and advantages for service users)** as well as many **challenges**.

Direct payments schemes present significant challenges for health boards and service providers with a broad range of **(legal, administrative, philosophical and budgetary**

implications) to be addressed.

Viewed from the perspective of the rights and needs of many (but, by no means, all) of those with disabilities, direct payments clearly work and have bestowed real and tangible benefits especially when measured against criteria of **independence, self-esteem and control**.

Direct payment schemes appear to operate best for those disabled people who wish to lead an **independent living lifestyle**. To date, the utilisation of direct payment schemes has been dominated by people with physical disabilities operating personal assistance services to achieve independent living.

There are **difficulties and concerns** related to direct payments in the context of **learning disabilities** but it is felt that these can be tackled if there is

commitment and interest. However, in arguing the case for direct payments, one cannot understate the challenges associated with either its introduction or the creative possibilities for overcoming them.

Training and peer support for direct payment service-users is essential to ensure effective use of resources and that the responsibilities of the service-user to the funders are met.

Direct payments are not a 'cheap' alternative or about replacing existing services; they must be seen as being part of a **continuum of services**, offered as an **option** for those disabled people who wish to engage in operating a direct payments scheme.

WHAT DID THE BRAY PARTNERSHIP RESEARCH RECOMMEND?

Recommendation 1(a)

There is a need for an information/awareness-raising and dissemination strategy to provide a comprehensive understanding of what direct payments schemes are, stimulate debate among key stakeholders and influence the local and national policy-making process. A summary of the findings of this research should be widely distributed as an initial information provision exercise. There is considerable need to initiate a discussion and debate among potential key stakeholders in order to create conditions in which

direct payments could become a viable proposition.

Recommendation 1(b)

An **explanatory leaflet** around the value of direct payments with clear and precise information on direct payments *per se* should be prepared and used in a structured manner for lobbying purposes. It is clear from this study that many potential stakeholders remain significantly 'ignorant' of direct payments in all their dimensions. This is particularly so as regards the benefits to users in terms of human dignity, respect and control. The argument for direct payments needs to clearly encompass the non-financial and administrative dimensions. Such a leaflet could also address the 'holistic' nature of assessment in the UK and Northern Ireland and its value as against more limited 'piecemeal' assessments.

Recommendation 1(c)

The promoters of this research should begin to plan and structure a **North-South Seminar** on the value and impact of direct payments. Such a seminar could take place in 2003 with a view to using the outcomes to assist in the planning and structuring of the pilot scheme proposed below.

Recommendation 2(a)

Planning work should begin on the possibility of introducing a **direct payments pilot research pro-**

gramme in the Eastern Regional Health Authority area engaging a small number of disabled people for one year in the operation of a direct payment scheme. The East Coast Area Health Board and one other health board should be engaged in developing and implementing the pilot research programme. Wicklow represents an excellent opportunity to encompass both urban and rural contexts. In addition, the ECAHB is relatively well pre-disposed to the idea and already has a level of understanding and knowledge in the area of direct payments. The pilot research programme should set out to comprehensively monitor and document the challenges as they arise as well as the benefits and disadvantages for both users and service-providers. It is likely that setting up such a project will take time; therefore, initial planning and networking to establish the parameters of the direct payments pilot research programme should commence as soon as possible.

Recommendation 2(b)

There is a strong case for **further research work** to be undertaken in the case of direct payments in the Republic of Ireland to include examination of the necessary administrative structures and their implications, the challenge of assessment and the implications for core services when only some users opt for direct payments.

This research should be viewed in the context of an extension of the pilot project proposed above.

Recommendation 2(c)

The dimension of the costs of direct payments as well as the **financial and administrative implications** need to be addressed at a national and health board level.

Recommendation 3

It is important that those promoting direct payments tackle the need for a **broader focus on disability rights legislation in Ireland**, as the scope for direct payments remains very limited under current community care legislation and service provision. A number of 'like minded' voluntary organisations need to address this issue in order to 'push-out' the boundaries of the current debate in Ireland. The forthcoming Disability Bill is an important element of this work.

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Bray Partnership

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