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
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.

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
- 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
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 BRA Y PARTNERSHIP
DIRECT PAYMENTS RESEARCH
CONCLUDE?

There is a clear information deficit
regarding the potential and value of
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 sig-
ificant 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 cri-
teria 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 utilisa-
tion of direct payment schemes has
been dominated by people with phys-
ical disabilities operating personal
assistance services to achieve inde-
pendent living.

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

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
commitment and interest. However, in arguing the case for direct payments, one cannot underestimate 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 programme** 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.

**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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