

Direct Payments Schemes

for
People with Disabilities

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

Bray Partnership
Disability Research Steering Committee
May 2003

'Direct payments are cash payments by local councils direct to individuals, or parents of disabled children who need services. Direct payments are able to bring about improvements in the quality of life of people who would like to manage their own support. They promote independence and they aid social inclusion by offering opportunities for rehabilitation, for education, leisure and employment.'

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**Bray Partnership Disability Research Steering Committee
May 2003**

EXECUTIVE SUMMARY

This research project commenced initially in August 2002 and was initiated by the Disability Cluster Group – a network of local disability groups and service-providers, facilitated by Bray Partnership. The Group established a Research Steering Committee to oversee and guide the project with the core objective of exploring and moving forward the agenda relating to direct payments in the East Coast Area Health Board (ECAHB).

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. The concept of direct payments developed against a background of creative tension between the medical and the social models of disability. According to Oliver (1996), 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. Humphrey (1998) captures the core argument well when he comments, "... the social model sequesters impairment from disability and vests control of the latter in disabled people themselves". Therefore, the social model firmly places the 'cause' of disability in the various social, economic, political and physical environments within which disabled people operate and rejects the notion that the problem of disability is located within the individual's impairment.

The research is essentially qualitative in nature and the methodology included conducting focus groups with key stakeholders within the ECAHB (Bray area), individual interviews with members of each of the stakeholder groups, a literature review and a small comparative cross-border study of both service users and providers. From the outset the project placed considerable emphasis on participation by disabled people in all stages of the research process.

The report offers an analysis of the current literature as

well as a perspective from various European countries that currently operate direct payments schemes. It also presents the findings from the various stakeholders perspective. An analysis of the literature and research findings indicates that there are a number of significant advantages to operating a direct payments scheme as well as substantial challenges for the individual service user and their family, service providers and the funding administrators/the health board.

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 practiced 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.

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 it 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 – some thing 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 with in families and challenge the 'traditional' role of the family in providing 'care' to the individual with the disability .
- ▲ To date, 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.

The research offers a number key recommendations for consideration including:

The 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.

One/two of the health boards in the Eastern Regional Health Authority should commence planning for the introduction of a direct payments pilot research programme, engaging a small number of disabled people for one year in the operation of a direct payment scheme. The evaluation of the pilot programme would allow for significant learning in terms of establishing direct payments as a mainstream social policy response.

Additional research (to supplement the pilot research programme) should be undertaken focusing on a variety of issues including examining the implications for administrative and legal structures, the challenge of monitoring and assessment and the implications for core services when only some users opt for direct payments.

INTRODUCTION AND BACKGROUND

This research project commenced initially in August 2002 and was initiated by the Disability Cluster Group – a network of local disability groups and service-providers, facilitated by the Bray Partnership. The Disability Cluster Group established a Disability Research Steering Committee for the project which, in turn, employed 80:20 Educating and Acting for a Better World – a non-governmental development education organisation – to undertake the research.

The core objective of the work is to explore and move forward the agenda relating to direct payments in the East Coast Area Health Board (ECAHB).

OBJECTIVES OUTLINED

The primary objective of this qualitative piece of research is to identify the key elements necessary for the introduction of a direct payments scheme for people with disabilities in the ECAHB. More broadly, the objectives are to:

- ▲ Comprehensively describe a direct payments scheme.
- ▲ Identify the key elements of what constitutes a direct payments scheme, including its advantages and disadvantages.
- ▲ Analyse the perceived and actual barriers to key stakeholders in implementing direct payments.
- ▲ Present a comparative analysis of service-users who use and do not use a direct payment scheme in Ireland and Northern Ireland.
- ▲ Comment on the administrative arrangements necessary to implement a direct payments scheme.¹
- ▲ Present potential costs based on a 'typical' or likely scenario for each of the four types of disability.²

The 'stakeholders' in this research include people with disabilities (both users and non-users of direct payments), service providers from the community and voluntary sector and the health board, as the key statutory agency responsible for the delivery of community services. The services referred to in this research relate to community-based services, as currently defined by the East Coast Area Health Board to include – home-care attendant services, home-help services, occupational therapy, physiotherapy,

speech and language therapy, psychology, psychiatry and nursing.

It is important to note at this stage that the 'cost of disability', identified in the Report of the Commission on the Status of People with Disabilities (1996), is a separate issue, which is currently being looked at in Ireland by an inter-departmental group, headed by the Department of Health and Children. The 'cost of disability' payment relates to covering the additional costs associated with having a disability. As described by Conroy (2002:8) 'a cost of disability is a cash payment to take account of the extra and unavoidable expenditure incurred by people with disabilities who wish to participate in everyday activities.....A cost of disability payment aims to provide individuals with disabilities with some of the means to be self-sufficient and to participate equally and at an adequate level, in society.'

Direct payments refer exclusively to the purchase of services – these do not fall under the heading of 'a benefit' as would be the case with a 'cost of disability' payment.

RESEARCH METHODOLOGY

The research focused primarily on qualitative research methods of data collection including:

- ▲ An extended literature review, including a national, European and international perspective.
- ▲ Conducting structured focus groups of stakeholders within the ECAHB (Bray area) including service users (disabled people), service providers (community and voluntary groups) and the health board.
- ▲ Individual, one-to-one semi-structured interviews with members of each of the stakeholder groups - in particular, service-users.
- ▲ Engaging in a comparative cross-border study of those receiving direct payments in the Northern Ireland and service-users East Coast Area Health Board (Bray area) not receiving direct payments.
- ▲ Interviewing the relevant Northern Ireland agencies operating direct payments programmes.

It was intended from the outset that the research would be as participatory as possible, despite its difficulties and challenges. This was achieved in a number of ways. In the

¹During the course of the research, it became clear that the process of identifying the administrative arrangements required much more substantial research and is therefore only commented upon throughout the report and not comprehensively addressed.

²Ditto in terms of the costing issue.

first instance, the Bray Partnership Disability Research Steering Committee, which managed and directed the research process, engaged two disability activists in the group. In addition and following a comprehensive literature review on direct payments, a small focus group of service-users was held to establish the issues in relation to direct payments for disabled people in an Irish context generally and in the ECAHB in particular. The issues identified subsequently informed the development of the agenda for the focus groups and the structured interview schedule for direct payments service-users in the North and those in the South not using direct payments. Disabled people played a significant role in directing the focus of the research from the outset.

The following Bray-based community and voluntary groups³ were engaged in the focus group and in in-depth interviews. They cover the areas of physical and sensory impairment, learning disability and mental health issues and provide a broad range of community-based services, day care, training and support employment in the ECAHB region:

- ▲ Connect Employment – training and employment support for people with learning difficulties
- ▲ Enable Ireland Wicklow – full range of services including schooling for children and adolescents with physical disabilities and their families
- ▲ Irish Wheelchair Association – home-care attendant services and personal assistant services for people with a range of disabilities
- ▲ National Training and Development Institute – training and employment support for people with a range of disabilities
- ▲ New Dawn – training and employment support for people with mental health issues
- ▲ Open Door Day Care Centre – day placement for people with a range of disabilities
- ▲ RehabCare – sheltered employment and training for people with learning difficulties and mental health issues.

These service-providers also supported access to service-users within their organisation for interview. In-depth interviews were also held with service-providers and Health Board (Trust) staff in Northern Ireland for comparative purposes.

In-depth interviews were held with 18 service-users – 13 in ECAHB (Bray) area and 5 in the Northern Ireland, using a semi-structured interview schedule - interviews lasted between one and one and a half hours.

A particular difficulty with interviews in Bray needs to be acknowledged at the outset - only 2 service-users (both of whom were physically impaired wheelchair-users) had heard of direct payments prior to the interview. For the remainder, the questions on direct payments were necessarily hypothetical, despite basic information about direct payments being provided by the interviewer. It is difficult for service-users to articulate the practical implications of a concept i.e. asking someone about the perceived advantages or disadvantages of something they have never tried is, at best, theoretical. The same difficulty was clearly apparent (and admitted) in service-provider interviews.

PARAMETERS OF THE STUDY

This is primarily a piece of qualitative research focusing on the many elements that make up a direct payment scheme from a number of stakeholder perspectives.

In terms of the cross-border comparative element of the research, 10% of the total number of direct payments users in NI were interviewed. Given low overall numbers of direct payments service users, this figure is too limited for any significant statistical analysis. Instead, they serve to highlight some of the issues, experiences and challenges associated with introducing direct payments for a number of people with disabilities in Northern Ireland and allows for a range of conclusions to be drawn out.

³While these groups are providing services in Bray, some are also part of a national organisational structure.

CHAPTER ONE

THE LITERATURE REVIEWED

Direct payments essentially involve relevant statutory agencies giving cash to people with disabilities to purchase their own support services directly. Direct payments 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. Currently in Ireland, an individual with a disability receives a monthly mobility allowance – a cash payment from the health board to ‘buy in’ mobility services. In effect, this practice reflects the core ethos of a direct payments system. However, direct payments in relation to providing purchasing power to service-users is a new concept in Irish social policy and, to date, has not operated here.

Direct payments are made to individuals in a number of countries throughout Europe, the U.S. and Canada, to pay for independent living and assisted living schemes (including personal assistance). The discussion that follows the direct payments literature review relies heavily on the UK experience. The UK model is probably the most applicable to an Irish context, as service delivery tends to be similar with one or two caveats. In the UK ‘social’ services are quite clearly separate from ‘health’ services. Direct payments are used to purchase community care, which is part of the social services remit. It therefore covers ‘personal social services’ and not medical services.

THE MEDICAL MODEL AND THE SOCIAL MODEL

“The medical model had been in operation all around us. It was incumbent upon us to educate service providers that there was a new way of doing things, which meant bringing people with disabilities to the decision-making level.” (Florence Dougall, Opening address at CIL Conference ‘Independent Living Towards a New Millennium’ (April 2000))

The concept of direct payments developed against a background of creative tension between the medical and the social models of disability. According to Oliver (1996), 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. Humphrey (2000) captures the core argument well when he comments, “... the social model sequesters impairment from disability and vests control of the latter in disabled people themselves”.

The social model defines disability in terms of a disabling environment rather than as impairment solely. It argues that it is society that disables and not the actual impairment, thereby placing disability within the broader context of society as a whole. Furthermore, it re-positions disabled people as citizens with rights, thereby shifting responsibility for overcoming what Humphrey calls ‘disablism’.

The medical model, which had been the dominant philosophy in the care of the disabled for many years, draws much criticism both from disabled people themselves, their families and from able-bodied people working in the field of disability. Their primary criticism centres around the fact that the medical model does not leave enough space for discussion of the experience of disability and focuses with clinical detachment on the perceived ‘sickness’ of the individual. Those with impairments are given no control over decisions taken by professionals - decisions that greatly affect their lives. The limitations and inadequacies of the medical model have been increasingly highlighted since the late 1970s. McConnell (1999) has argued that the medical model is “... woefully inadequate for policy formation and for understanding what disability is all about”. Similar comments can be found in the numerous debates on the subject both in academic and in disability activist discourse.

The social model however, also draws criticism from some commentators because it does not acknowledge the role played by impairment and consequent illness in determining the life experiences of very many disabled people. Furthermore, it is considered by some to be too narrow in scope and therefore prone to marginalisation because it does not adequately address the issues relating to certain types of impairment – in particular, learning disability and mental health. Part of the problem with the social model is that it tends to view impairment in entirely physical terms (see, for example Dowse 2000 and Chappell 1997). Finally, the social model, as it is interpreted by disability activists, is seen to create a dichotomy of oppressor (able-bodied) and oppressed (disabled) thereby undermining partnership and inclusiveness (see Humphrey, 2000).

Hartley (2001) views the tension between the medical and social models as positive, because it is beginning to create a way forward in the form of a 'universal or comprehensive model'. Although it might be assumed, on first reading, that proponents of the social model are looking for two paradoxically opposed states – namely, empowerment and autonomy leading to independence on the one hand and community inclusion, which necessitates interdependence on the other. Hartley (2001) points out that it is common for people to desire opposing states because:

“they want to belong, they yearn for a sense of identity, they wish for good co-ordination between themselves and at the same time they desire discretion, autonomy and the freedom to make their own decisions”.

Hartley (2001) does not see this apparent paradox as specific to disabled people in community settings. She concludes that creative tension is necessary for development in all organisations and systems that are functioning well, while the challenge is to harness this tension constructively. In disability practice, this would lead to professionals combining an understanding of medical and social models in an integrated and comprehensive form. Direct payments might well be considered an example of constructive development arising out of the 'creative tension' between the medical and social models.

THE HISTORICAL POLICY CONTEXT

‘The net result of the welfare state is that disabled people are denied the opportunities to live autonomously’.
Gooding, C. (1994)

McConnell (1999) calls for a more inclusive disability paradigm, claiming that “disability policy today is largely a failure”, and will remain so until such time as professionals, providers, family members and policy makers recognise the equal right to participation of disabled people. Humphrey (2000) finds that disabled people are in the best position to speak about the experience of disability and their experiential knowledge should guide all debates about disability, yet historically, this has not been the case.

Gooding (1994) analyses the two classic state responses to disability – welfare provision and segregation. He sees 'disability' as a product of capitalist and industrialist society, in which people are defined, primarily as forces of production. Those who could not conform to a certain level of productivity were ascribed a category of need e.g. elderly, children, disabled etc., all of which are premised on exclusion from the labour market and subsequent inability to earn a living. Disability therefore became synonymous

with dependence and inability to work and Gooding claims that this is perhaps the most powerful impact of the welfare state on the meaning of disability.

He further claims that the medical profession, through their function as gatekeepers of the welfare state, came to hold great power over disabled people's lives. This was because the key concept in the new welfare system, when referring to disabled people, was that of 'need' and the control over defining the needs of disabled people and stipulating how such needs were to be met, was placed in the hands of professionals (usually medical professionals). According to Gooding, this system is based on the assumption that disabled people are incapable of running their own lives and, in turn, forces them to become passive recipients of those services, which other people think they ought to have. Needs assessment is therefore an exercise in power and Gooding cites numerous studies, which show that clients are unhappy about the way professional assessments have distorted or denied their needs, with the effect that needs remain unmet or inappropriately met. The right to define the needs of disabled people has therefore developed as one of the key issues in disability politics.

The desire of both disabled people and rehabilitation professionals to escape the confines of medical model thinking led to the foundation of the Independent Living Movement (ILM) in the late 1960s and the creation of the Centre for Independent Living at Berkeley in 1970. The IL movement takes issue with the 'sick role' and the 'impaired role', which exempt disabled people from 'normal' social activities and responsibilities on the basis of dependency. The Independent Living philosophy rejects the behavioural expectations created by these roles and states that the disabled do not want to be relieved of their familial, occupational and civic responsibilities in exchange for childlike dependency (see, for example de Jong 1983). The Movement recommends that in order to overcome environmental and societal barriers, a disabled person must swap the patient or client role for the consumer role.

The new consciousness around disability issues in the early 1970s led to the emergence of the Disability Movement in the UK and the development of the social model of disability. According to Oliver (1996), the Social Model became “the central concept around which disabled people began to interpret their own experiences and to organise their own political movement”. This in turn led to disabled people demanding rights to appropriate welfare services to meet their own self-defined needs, rather than having their needs defined and met by others (ascribed need).

DISABILITY RIGHTS - ASCRIBED NEED AND SELF-DEFINED NEED

Handley (2000) summarises the critique of ascribed need as follows:

- ▲ Rather than empowering disabled people and enhancing their autonomy, ascribed need contributes to dis-empowerment by neglecting the role that disabled people should play in planning their own lives on the basis of what they see themselves as needing.
- ▲ Consequently, ascribed need only maintains and enhances society's existing power structures, which oppress disabled people by ensuring their dependency upon others and exacerbating their powerlessness. Moreover, it also tends to reproduce a culture of dependence, from which it is difficult, if not impossible to escape.
- ▲ Additionally, it tends to keep disabled people marginal to the rest of society with all the attendant problems this involves, such as poverty and inferior educational and employment opportunities.

According to disabled activists, service provision based on ascribed need has, in the past, led to an invasion of privacy by professionals who offer "services that the State thinks you should have or is willing to pay for, rather than those that you know you need" (Oliver, 1996). However, Handley (2000) claims that the idea of self-defined need implies that disabled people know absolutely and completely what they need to enhance their life choices and chances without any mediation from professionals, while in reality, people rarely know absolutely what they need – only what they want or prefer. Self-defined needs are therefore a subjective notion, 'precariously close' to wants or preferences.

Handley (2000) argues that the concern of disability activists is to diminish the role of professionals in the daily life of disabled people, to do away with ascribed need and take greater account of self-defined need. However, he contends that everyone is only autonomous to varying degrees and that even able-bodied people are not entirely autonomous. Social inclusion implies inter-dependence. Despite this, he does not necessarily see a friction between ascribed need and self-defined need but suggests that disabled people should be involved in a 'deliberative approach' to the assessment of need with professionals, where negotiation could take place so that the self-defined needs of the individual are taken into account and they have a greater sense of, and actual empowerment in, their own life.

THE SOCIAL MODEL AND LEARNING DISABILITY

"It's very convenient for people with apparent disabilities or impairments to operate a social model which says 'we don't want to discuss things in terms of 'impairments'. Because these people have got priority anyway, and impairment-related provision... The trouble with it [the social model] is that it's very difficult... for people with learning difficulties or other conditions ... which are not catered for ... to raise their concerns as things which need dealing with on a service level, without feeling that they're breaking the law and talking about impairments".

(Quote from an interview with a disabled person in Humphrey, 2000)

Some would argue that the social model, with its emphasis on self-advocacy and self-defined needs has worked at cross-purposes to broader objectives – in the field of learning disability, for example Dowse 2000. Various stakeholders have called the applicability of the social model to those with learning disabilities and mental health issues into question and this has important implications for a cross-disability implementation of direct payments.

The principle of 'ordinary living' (O'Brien, 1987), suggests that people with learning difficulties should live, work and spend their leisure time in their local communities using ordinary facilities. This is very much in keeping with the thinking embedded in the social model. However, Humphrey (2000) notes that a type of 'purism' has emerged from the social model, whereby some impairments are 'privileged' over others. Learning disability does not 'fit the bill' and so there is a sense of exclusion within disabled society itself. Humphrey (2000) finds there is also a danger that the political principles of more powerful disabled actors can be prioritised over the personal perceptions of less powerful disabled actors. She does not suggest however, that medical model thinking resolves the issue for those with learning disabilities, rather that practitioners should work towards a more inclusive model.

Because the social model is seen to fall short of addressing the issues relating to learning disability and mental health, Coles (2001) notes that there have also been calls in psychology for an integration of models of disability. He finds evidence of social model thinking in service provision to people with learning disabilities. Such evidence "may take the form of humanist or empowering approaches, which seek to offer choice, rather than control and are based on the service user's needs and wishes

rather than professional judgements and imperatives". Coles' research emphasises the significance of the social model in relation to the social care of people with complex support needs and suggests that its practice as well as its policy implications can and should be drawn out.

Van Loon and Van Hove (2001) also find that it is possible to apply social model thinking to service provision for people with learning disabilities, and stress the importance of 'outcome-based evaluation' in this process. In this concept, the values of the client as a consumer are emphasised, with reference to self-determination, personal development, quality of life, empowerment and inclusion. Van Genneep (1997, in Van Loon et al) outlines some principles of this new paradigm in the concept of care for people with learning disabilities:

- ▲ the service user, as a citizen in his own right, determines to a certain extent the conditions under which his/her care is provided - this will lead to a declassification of the care
- ▲ citizens with learning disabilities should also be able to choose where and with whom they want to live, work and spend their leisure time, as well as those who will be supporting them, where and how
- ▲ the concept of 'care' is being replaced by the concept 'support'. Important in this matter is the notion that someone does not necessarily have to be 'ready' in order to be admitted to a certain living and occupational situation
- ▲ quality of life implies the opportunity to give shape and content to one's own existence complying with general human and specific fundamental needs, under ordinary living conditions and according to ordinary living patterns.

Quality of life is viewed as a key issue for people with learning disabilities and the question, which follows naturally for service-providers, is what constitutes a good quality of life? Views regarding 'quality of life' diverge widely. Some stress objective and measurable factors while others refer to the subjective experience where the most important aspect is the way an individual experiences the world (Van Loon et al., 2001). Schalock (1996, in Van Loon et al) finds that the following themes are important in this regard.

- ▲ the quality of life for people with disabilities is composed of those same factors and relationships that are important to all persons
- ▲ quality of life is enhanced by empowering persons to participate in decisions that affect their lives

- ▲ quality of life is enhanced by the acceptance and full integration of persons into their local communities.

Van Loon et al (2001) acknowledge that self-determination for people with learning disabilities, in particular those with an intensive need for support, is often a difficult concept to work with in practice. This is because a tension arises between dependence and self-determination when autonomy is considered from the liberal perspective where the freedom of decision lies completely with the individual, assuming that individual is in a position of competence, awareness and rational ability, which many people with learning disabilities are not. They suggest the concept of 'practical, communicative and relational autonomy' in order to overcome this problem.

According to this concept:

dependency does not have to restrict someone's autonomy as long as the person can identify with the choice made, feels good with what he or she is doing and can adapt to or feel comfortable with the circumstances the way they are (**practical autonomy**)

the decision making process should not be seen as the result of individual conscious choices, but as the fragmented outcome of prolonged processes reaching consensus and of conflict in which several parties are involved (**communicative autonomy**)

decisions are not made individually, but result from the communication of all those involved because we are not individual independent beings. We are by nature dependent on one another (**relational autonomy**).

This concept may hold the key to an implementation strategy for direct payments that could include people with learning disabilities.

DISABILITY AND MARGINALISATION

Humphrey (2000) contends that issues around discrimination cannot be articulated or altered without tackling issues and traits that disabled people share with other disadvantaged people. This is because the politics of redistributing resources is important to all people and because no movement can be furthered without a shared ideology about what constitutes a better world. Consequently it makes sense to combat shared discriminations as a variety of people suffer from problems with poverty, housing, transport, education, employment, health services and media-representation. In addition, pooling resources enhances consciousness-raising and campaigning, while staunchly guarding a specific identity e.g. the disabled identity, leads to isolation. These views are echoed by

O'Shea (1996) who place considerable weight and emphasis on efficiency, equity and values.

According to Murtagh (1997), the social model focuses on the barriers society places in the way of people with disabilities, which force them to live their lives on the margins of society. These barriers include environmental factors but also include the direct and indirect discrimination that disabled people face when they interact with Irish society. However, because the definition of disability used in both the Employment Equality Act (1998) and the Equal Status Act (2000), is based on the medical model, Murtagh claims that in an anti-discrimination context, disabled people have already "lost half the battle". This view was further endorsed with the publication of the Report of the Commission on the Status of People with Disabilities in 1996 – A Strategy for Equality. The Commission identified people with disabilities as the 'neglected citizens of Ireland' and itemised, inter-alia, issues of access, information, transport, lack of co-ordination between service providers and the difficulty of accessing entitlements. In particular, the Commission referred to 'deficits' in education, employment, income support, health and personal support. These issues have also been identified by the Combat Poverty Agency as key contributing factors to the persistence of poverty amongst people with disabilities.

Many of the broad issues identified in the literature reviewed above – those of isolation, discrimination, poverty and the high cost of care subsumed by families have been noted and commented upon by Eamon O'Shea of the Centre for Ageing Studies in Galway. In the context of ageing and dementia, O'Shea (2000) emphasised the primary role of families in providing support and the lack of adequate or coherent service provision. The needs of carers (particularly as regards the financial hardships experienced by those providing home care) and the need for 'consistent and longer-term' funding arrangements is a significant issue for care in the community. Commentators have been particularly concerned to highlight their fear that, in the context of health care in Ireland, stated government policy of encouraging 'community care' has become, in effect, family care as a direct result of the failure to provide effective or adequate realistic measures of support. The essential concern is that while there may be a philosophical shift at national level, it has not been manifested in the effective practical instruments.

DISABILITY RESEARCH

"To be empowering, the research must be designed with the group of people who have decided to obtain power".
(Sample, in Oliver, 1996)

Historically, disability research has been a source of great frustration to disability activists. Oliver (1992) states that research on disability has had little influence on policy and made no contribution to the lives of disabled people and that such research is viewed by disabled people as:

"... a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances or quality of life"

Researchers have therefore been called on to ensure that their research is more participatory and more accountable to disabled people. Humphrey (2000) claims however, that researchers have been required to go beyond their duty of accountability to disabled participants in order to give an account, which adheres strictly to the social model. Nonetheless, she notes a growing appreciation of the fact that disablism cannot be tackled by disabled people alone, because "cross-cultural dialogues are capable of producing insights, which may have eluded 'insiders' on their own".

According to Zarb (1994), participatory research should be used as a tool for improving the lives of disabled people, who themselves should work together with researchers to identify and address disability issues. Participatory research allows subjects to function as 'co-researchers', who generate the focus of the research, as well as the research questions. The subsequent findings address needs and issues that have been identified by the subjects as priorities, and that can produce practical conclusions and outcomes such as service improvement. Hartley (2001) concludes that this "requires an equality of participation between all the stakeholders involved, particularly disabled people and the communities in which they live".

However, despite this recognition, Humphrey suggests that even when the ethic of partnership governs the research project, there are other problems because stakeholder groups include policy-makers, service-providers, service-users, academics and activists and their interests are divergent. Translating needs and demands into practical measures is therefore at the mercy of politicians and managers.

As indicated, this piece of research was keen to be participatory in nature with disabled people engaged at all levels of the research process including the research design and management, the methodologies and active subject in the 'stakeholder' role.

CHAPTER TWO

DIRECT PAYMENTS IN EUROPE - AN OVERVIEW

INTRODUCTION

Direct payments is a term used widely throughout Europe and elsewhere to refer to a range of approaches which directly fund disabled and older people to employ their own personal assistants and organise their own care. According to an initial mapping study, (edited by John Halloran on behalf of the European Social Network in 1998), the introduction and development of direct payments is not only enhancing the independence of disabled and older service users but is also significantly changing the traditional relationship between service provider and service user in Europe.

According to the Social Network report, the last decade has seen widespread change in social policies across Europe, of which the most significant feature has been the shift from institutional to community based living for those with a range of disabilities. Parallel to this development, services for older people have also progressively moved away from the widespread use of long-term hospitalisation to social and health based community care. Halloran (1998) notes that:

'Whilst these developments have been welcomed by service users, they have nevertheless remained largely service-led responses to individual need with little, if any, control exercised by the users themselves, so that whereas most of us experience life as active citizens and consumers, the experience for most clients had remained relatively passive.'

Despite the fact that a declaration on the right to personal assistance, known as the 'Strasbourg Resolution' was agreed by 14 countries in the European Parliament in 1989, the concept of disabled people taking on the responsibility of managing their own personal assistance is a relatively recent development. The introduction of direct payments has been achieved by a combination of new and updated older legislation to make provision for cash payments.

In short, direct payments means that a service user is funded to pay for their own service directly through cash, cheque or vouchers or in some cases, directly authorising payment to a personal assistant or service provider. In many cases this involves service users directly employing their own personal assistants. Where the service user has difficulty managing this responsibility, some national or local systems allow a member of the person's family to exercise this role. In some circumstances, a number of service users have organised themselves into self-help

co-operatives (Centres for Independent Living), to provide information, advice and support.

TYPES OF DIRECT PAYMENTS IN EUROPE: ISSUES AND CHALLENGES

Halloran (1998) identifies 3 types of direct payments:

1. As in Germany, direct payments are part of a national insurance system providing a financial alternative to a range of direct health and social services, for those with a health and/or social need irrespective of disability or age.
2. The second, influenced by the disability movement, focuses specifically on services for physically disabled people and their need for personal assistance. In Sweden, the introduction of the Support and Services Act 1994 (for persons with functional impairments) introduced a voucher based system and has become a model for others in this regard. This type tends to emphasise individually tailored care plans and a relatively non-standard approach both to payment and services. It should be noted that such schemes also often include those with learning disabilities but tend to have an upper age limit (upon application) of 65 years or the equivalent pensionable age. Existing service users are however not excluded from continuing to receive direct payments upon reaching the pensionable age.
3. The third type of direct payments is designed specifically for older people. This largely differs from the second type in that it is essentially a community alternative to residential nursing or care home for very dependent older people.

Whilst eligibility criteria reflect differences across user groups, national legislation and traditions, the past number of years have witnessed the emergence of more or less standardised procedures using clearly defined criteria. The German social insurance model defines categories of need and allocates hourly costs accordingly. The issue of scale also features in the design of systems and whilst the French approach is not an insurance based model, its national scale (100,000 service users after 12 months of operation) means it shares many of the standardised features of the German model.

According to Halloran (1998), most countries utilise eligibility thresholds either in terms of a minimum required

service time or level of dependency. In Germany, the threshold is 1.5 hours of personal assistance per day and in Denmark 20 hours per week.

Individual need may be assessed within either a health and/or social care framework and accordingly eligibility for assistance may be uniquely related to personal/health care at home or to a wider range of assistance for 'work, leisure or cultural participation'. Where services are focused on older people and on significantly disabled people (e.g. France, Germany and Denmark), health plays a stronger part in the assessment. In Germany it is essentially a health-led assessment and monitoring (6 monthly) process. In France the assessment is carried out by both health and social professionals working together and in Denmark the local authority may also involve a nurse. Schemes, which enable personal assistance to be used outside the home – in Sweden, the UK and Denmark - tend to have social/ community model of assessments.

Responsibility for assessment and quality control also tends to reflect the needs and interests of the funding agency. For insurance-based systems of funding, in Germany Austria and the Netherlands, assessments are carried out by independent agencies appointed by the care insurers.

In the UK, France, Finland and Denmark it is the local authority that takes responsibility, whereas in Sweden it is the local authority for needs of less than 20 hours per week and the Social Insurance Office of central government for over 20 hours per week. In Sweden, quality control is the responsibility of national government via the National Board of Health and Welfare, delivered on a regional basis.

How the quality of direct payments is best monitored, given that it has been established to promote service user independence, is problematic. The well-being and protection of the user (and their assistants), together with the need to ensure financial priority, has to be taken into account. Current approaches tend to involve annual home visits, but there is concern that this may not always be sufficient and that adequate preparation followed by on-going monitoring and support also needs to be built into the system. Many disabled service users argue that they should be able to carry out self-assessment of their own needs in the first instance, and then negotiate with the local authority as to which direct payments they need to enhance their capacity to achieve independence.

'MARKET' RESPONSE TO DIRECT PAYMENTS

The growth of a new independent 'care market' appears to

have been stimulated by direct payments in Germany, Austria, Netherlands and France and to a lesser extent in Sweden and Denmark. In all countries this is regarded as a relatively fast growing though piecemeal market development of small companies and individuals. Service users in the above countries have taken to engaging or directly employing personal assistants or companies themselves or through agencies. Uniquely in the UK system, direct payment clients cannot exclusively use their local authority as the sole provider of their personal assistance, but must seek independent services or individuals. They can however use the local authority as part of a package of care.

According to Halloran (1998), it appears that service users in the Nordic countries generally retain such a positive attitude towards their public services, (regarding them as reliable and of high quality) that when given the choice (although limited) of independent providers, service users tended to prefer the local authority. Nordic countries, particularly Sweden, have made extensive use of co-operatives and one of the consequences of direct payments has been that some co-operatives have been able to pool their income from this source to employ their own administrative and care staff in agreement with the local authority. In relation to 'employing' family members under a direct payments scheme, different countries respond differently, as the following quotes illustrate:

'In many countries traditionally unpaid care has been provided by family members and sometimes friends and neighbours and regarded as a natural duty although in reality this responsibility fell largely on women and often the daughter or daughter-in-law. In most countries family members can now be paid to care.'

In Sweden, for example, a parent can be employed to care for their disabled children. This can however mean that the parent's employment career for example and financial well-being becomes dependent on their supporting their child, who may one day wish to leave home and live in a group home, thereby depriving the parent of that income.'

In France, in contrast, whilst relatives can be employed, this cannot include the client's spouse (or partner if unmarried). The similar dilemma can occur where an elderly parent is being cared for by the daughter, for perhaps 10 years, after which the parent dies and the daughter ceases to be paid and worse, is unskilled and unemployable.' (Halloran, 1998)

The Social Network report notes that whilst the advent of

direct payments has undoubtedly brought benefits to service users, there are consequences for employment in the home care sector. On the positive side, the development of direct payments has provided a large number of work opportunities particularly suited to people already caring in families, in local neighbourhoods and people wanting part-time and perhaps short-term employment.

There are, however, concerns about potential future dangers for both service users and workers (eg. Personal Assistants) from an unregulated home care market based on an untrained, fragmented and vulnerable work force. The Network report, however, notes that the development in the UK, of new non-government organisations or companies run by service users to provide employment services, insurance, help lines and training may offer one appropriate model of support and development for service users and workers.

PAYING FOR DIRECT PAYMENTS

It is difficult to comment effectively on the funding implications of direct payments due to the myriad and complex funding arrangements employed in different countries. The complexity is found for example, in the way personal assets such as housing are valued and then related to the allocated budget and again hourly payments depend both on the level of need and type of assistance and also the qualification of the assistant or other personnel.

Halloran (1998) in his review has identified 3 principle methods whereby direct payments service users can pay for their care package:

1. They may choose a particular service from an approved provider and the provider bills the funding authority and is then paid by them directly. This is the case in Germany, France and Denmark.
2. A second approach offered in Scandinavian countries is to issue a voucher for payment to a provider of their choice.
3. The third approach is to provide the client with cash with which to pay for services. This is now possible in the UK and Denmark, but in countries where users may opt for cash (France, Germany, Austria and the Netherlands) they receive a smaller sum than the in kind value of the service they would otherwise receive from a nominated provider. Despite this, 8 out of 10 German clients choose cash payments and in the Netherlands, once the budget is agreed, 20% is deducted for administration savings for those taking up direct payments. In Denmark the price of a

unit of service is the same whether it is paid for in cash or comes in kind from a private or public provider.

Only France and Netherlands undertake specific financial assessments with regards to direct payments. Particularly rigorous is the French system where charges may be made on the assets of future generations of the service user's family.

'In pure insurance schemes (e.g. Germany), allowances are calculated according to a pre-set national table of need and cost per hour with no financial limits on local authorities. In France local authorities administer this national scheme but are financially subject to managing within their budgets. In Sweden, the regional authorities pay for care if the service user is assessed as needing more than 20 hours of care per week, if less it is the responsibility of the local authority. They have discovered that as in Denmark that although there had not been a dramatic growth in numbers of direct payment service users that the cost per user has been higher than predicted.' (ditto)

The Social Network report notes, importantly, that:

'For the future, should direct payments become a mainstream and larger scale activity in European countries where that is not presently the case, ensuring equity within fixed local authority budgets may become a significant issue.' (ditto)

In conclusion, the European Social Network, following the research, is firmly of the view that direct payments have a number of important benefits to service users and to social services. The principal advantages identified include its value in increasing people's independence, self-respect and responsibility and better targeting of services on individual need rather than on institutional capacity and agendas.

However, the report concludes:

'Whilst many view direct payments as a success for adult physically disabled people willing and able to manage their own personal care, there were some doubts that it could easily be extended to such services where clients might have experienced considerable problems in managing their own lives in the first instance.'

The overall view however, was that this option should be available to all those who can adequately benefit from it, regardless of age or disability. In that context more work probably needs to be done to evaluate the experience of

existing service users and the social services in those countries responsible for implementing and monitoring mainstream Direct Payment services, particularly for older people.'

Whether direct payments is more expensive than directly provided services also received a mixed response with the general view being that it is at least as expensive with many countries indicating that they had experienced increased costs in terms of more hours being assessed per client (Austria and Sweden), fewer total clients than anticipated in Sweden and France and more complex administration in Germany and Denmark. Other specific issues noted included that any concerns about the possible misuse of public finances by individual service users did not cause undue problems. It was felt that better preparation of service users to take on their 'employer' responsibilities was necessary and better quality monitoring and ongoing support were considered important.

The report concludes with a number of key questions requiring additional research and consideration:

1. How best should systems of direct payments be financed in the future to ensure service equity?
2. How can service users best participate in their own service assessment and quality?
3. How can the longer-term employment prospects and protection of the workers, including paid family members, be best promoted?

DIRECT PAYMENTS IN NORTHERN IRELAND

In Northern Ireland, the application of direct payments differs slightly from the rest of the UK. This is because local health boards (entitled Hospital and Community Trusts), as opposed to the local authority, are responsible for the assessment of individual community care needs and the provision of such services, either directly or through direct payments. As with the UK, it is applied differently depending on the Trust area - Care Managers in some Trusts promote it more than others.

Individuals are assessed for their community care needs irrespective of whether they are going to receive a direct payment or receive services directly through social services. The care assessment involves the consumer, the care manager and, possibly, a family member or an advocate.

During the research, a number of additional points were

made concerning the operation of direct payments in Northern Ireland.

- ▲ Initial discussion focuses on what support are needed and this is translated into necessary hours per week with payment set at a maximum of £7.50 per hour. (2002 figure) There is no question of replacing day placement (provision of day care services) with direct payments. Different types of need are taken into account in deciding the scale of direct payments (e.g. a person might need help with getting out of bed, shopping, leisure activities etc.) - this is added into agreed hours.
- ▲ There is a distinction between 'health services' and 'personal social services' - health services (such as therapy) cannot be funded by direct payments. Personal social services are about support for every day life and are, in effect, mostly about personal assistance.
- ▲ The take-up of direct payments in Northern Ireland is quite low with about 65 people involved. The take-up in the mental health area is very low - only about 4 or 5 participants but this is likely to increase soon because of the introduction of micro-boards - effectively a 'circle of friends'- family members, a solicitor etc. - who look out for a person's best interests (see below). They set up a Trust to help people get involved in the community and they can also administer direct payments.
- ▲ Belfast Centre for Independent Living does not provide a pool of Personal Assistants but provides support to those hiring a PA and also provides advocacy for people in the care assessment process.
- ▲ In Northern Ireland, there is a Commissioning Board, which assesses the needs of the population. This then gives funding to local Community and Hospital Trusts, to meet those needs in their local area. In the past, the Trusts were accountable for their service-provision to the Commissioning Board but now they are self-governed

MICRO-BOARDS IN NORTHERN IRELAND - A CASE STUDY

In recent years, micro-boards have become increasingly important - they are used to support people with learning disabilities in using direct payments - this is likely to raise the number of people with learning disabilities using direct payments. Essentially, a micro-board engages a number of key people involved in the disabled person's life who will oversee the management of the direct payments scheme on his/her behalf. The micro-board is the

'employer' of the workers on the individual's behalf. Such boards are not used in the rest of the UK. Trusts in the North are now beginning to require families of those with learning disabilities to set up micro-boards in order to apply for a direct payment. Belfast CIL disagrees with this policy and does not think micro-boards should be a prerequisite as the administrative and legal element may be onerous. However, it does recognise that micro-boards are an innovative development.

Valerie McCarthy was the founder of micro-boards in Northern Ireland and now works for VELA - an organisation for support of micro-boards. Valerie was the first to set up a micro-board in Northern Ireland - she did this for her daughter who has a severe learning disability. There are now five people with learning disabilities using the micro-board method to work a direct payments scheme and VELA now assists others in taking up the scheme. The purpose of micro-boards is solely to look out for individuals and their families. Those with experience of micro-boards in Canada are working in Northern Ireland with a view to increasing their use - this experience could usefully be considered in the Republic.

Micro-boards adopt a particular form of assessment: essentially it is done through Person Centred Planning (PCP) in the form of a 'map' or 'PATH' - there should be a PCP process for each individual aged fifteen and upwards. A facilitator, who is an independent person trained by VELA carries out the assessment and completes the PATH with a recorder to draw or map the needs arising. VELA (NI) hopes to train every social worker in PCP. Each PATH takes about three hours and is about putting the map or the path of a person's life down on paper. The process begins by reviewing where the individual has come from and where they would like to be in three months, six months, a year etc. and looks at the person's strengths and gifts. In turn, it looks at what needs to be done to achieve such goals and what is needed in terms of support. The end result is an action plan.

The relevant Trust may or may not accept PATH as an assessment or they may decide they want a separate one. The family will usually have identified the people they want to sit on the micro-board, which is voluntary but which hires paid staff. Those sitting on the Board must have a relationship with the individual and should not be representative of funders or government.

Every Board member is a director. Each micro-board (MB) has its own constitution, designed specifically for the individual. The constitution is signed by each board member and uses the set of by-laws established for all voluntary

organisations. It is important to have relevant input from appropriate people in each case - in that of Valerie's daughter Julie, it was decided that none of the staff employed would be over 30. But decisions like this are completely based on the individual concerned. Each micro-board is individually insured (including staff) - this costs around £40 per year.

Direct payments is much more cost-effective for the Trust. Service-provider Agencies get about £15 per hour, but, in most cases, their staff are paid the minimum wage - around £4.80. Whereas, with direct payments, by cutting out the agencies, a board can afford to pay employees more - e.g. £6 plus a certain amount for travel. Families can apply for an administration cost to cover paperwork including, for example, the hire of an accountant.

CHAPTER THREE RESEARCH FINDINGS

This chapter presents the findings of the research carried out and looks at the issues that need consideration in terms of a direct payments scheme for service-users in the Republic of Ireland (EACHB/Bray area). The chapter is divided into three sections: Section 1 presents the issues from the service user (disabled person) perspective, both in Northern Ireland and Bray (ROI). This section presents a profile of service users, examines personal outcomes and discusses the advantages and disadvantages (perceived and actual) according to service users; Section 2 presents the findings from the service providers (community and voluntary sector) perspective including their perception of the key issues and implications of direct payment schemes for their service and organisation; Section 3, the

final section, relates to the views of the East Coast Area Health Board as the key statutory agency with responsibility for providing services to people with disabilities.

SECTION 1: SERVICE-USERS (DISABLED PEOPLE) PERSPECTIVE (NI AND ROI)

PROFILE OF SERVICE-USER INTERVIEWEES

A total of 18 disabled people were interviewed as part of the research. The following tables give a breakdown in terms of age, gender, type of disability and range of services they access.

**Table 1.
Gender and Age**

N = 18

	15-21	30-39	40-49	50-59	60+	Total
Male	2	4	4	2	2	14
Female			2	2		4
Total	2	4	6	4	2	18

**Table 2.
Disability Type**

Disability Type	N
Physical Impairment	7
Sensory impairment	1
Learning difficulty	3
Mental health issues	2
Mixed disability *	5
Total	18

*** Mixed disability combines learning difficulties or mental health issues with some form of physical or sensory impairment**

**Table 3.
Services currently used**

Service	ROI *	NI *	Total
Home-care attendant services	1	1	2
Home-help services	1	0	1
Occupational Therapy	2	3	5
Physiotherapy	5	1	6
Speech and language therapy	1	0	1
Psychology	2	1	3
Psychiatry	3	0	3
Nursing	3	1	4
Employment Support	5	0	5
Employment training	3	0	3
Personal Assistance **	2	5	7
Chiropody	0	1	1

*** ROI = Republic of Ireland; NI = Northern Ireland**

**** Personal Assistance in NI includes home-care attendance and home-help services**

PERSONAL OUTCOMES – SECTION I

Service-users both North and South were given a range of statements regarding their perception about their lives at present, including level of independence and autonomy.

The objective of this section is to compare, as far as possible, the perceptions of users of direct payments in the North with the perceptions of those in the South who do not use direct payments. Although it is not possible to establish the statistical significance of the findings, based on a small number of service-users, the results of the exer-

Table 4. Service-users' perception about life at present %

Statement	Strongly Agree		Agree		Disagree		Strongly Disagree	
	ROI	NI	ROI	NI	ROI	NI	ROI	NI
	%	%	%	%	%	%	%	%
I feel completely dependent on others	23	20	8	-	31	40	38	40
I feel in control in making decisions about my own life	31	80	46	-	15	-	8	20
I feel that life goes on around me but that I am not a part of it	8	-	15	-	62	40	15	60
I am able to participate in the life of my family friends and community	61	40	31	40	8	-	-	20
I am confident in my ability to perform everyday activities	38	60	54	20	8	-	-	20
I am happy to allow others to decide what services I need	8	20	31	-	38	-	23	80
I decide what services I would like to avail of ^a	33	40	59	40	8	-	-	20
I am able to participate in employment and / or training with the support I currently receive ^b	41	50	25	25	17	-	17	25

N = 18

N=17:

a. One service-user in the South who has learning difficulties felt unable to answer this question

b. This question was not applicable to one service-user in the North because of the extent of her physical impairment and to one service-user in the South because he is still attending school

cise allows for a relatively clear comparison of perception. As can be seen from Table 4, there is no clear overall pattern in the responses of interviewees in relation to personal outcomes. However, an interpretation alongside qualitative evidence may give a clearer picture. It should be noted at this stage that the parents of one direct payments-user in the North, Peter (not his real name), were interviewed on their son's behalf, as the severity of his learning difficulties rendered him unable to respond to questions himself: their answers distort the quantitative evidence to some extent, as discussions with them revealed that they themselves, as users of the direct payment on Peter's behalf, are far happier with the greater level of control they now have over the services their son receives and the impact this has on his development and quality of life.

There is no apparent difference in the level to which people feel dependent on others irrespective of direct payments. However, those in Bray were slightly more likely to agree with the statement, "I feel completely dependent on others." The level of dependence experienced by individuals North and South may not differ because even those employing their own PAs feel dependent to a large extent on their PAs. Nonetheless, anecdotal evidence suggests that the difference is in the relationship they experience with their PA, whom they are employing, by comparison with those who are dependent on family members, 'carers', or PAs hired by someone else to look after them. In the employer/employee relationship, the emphasis is more on support and less on care.

The pattern in relation to level of control is slightly clearer. Those in the North receiving direct payments are more likely to feel in control over decisions about their own life. In fact, the only users of direct payments in the North who strongly disagreed with this statement were Peter's parents, who make the decisions about their son's life themselves. They acknowledged, however, that they have a far greater level of control over their son's development and consequent quality of life than they did prior to taking up a direct payment.

All respondents in the North either disagreed or strongly disagreed with the statement, "I feel that life goes on around me but that I am not a part of it." All claim to have been in strong agreement with this statement prior to taking up direct payments. By comparison, twenty three per cent in the South either agreed or strongly agreed with this statement, while only fifteen per cent strongly disagreed.

Most users in the North and South agreed or strongly

agreed that they are able to participate in the life of their family, friends and community. The service-user in the North who strongly disagreed with this statement said that this is because of the physical environment rather than any personal issues. She is simply unable to go to the same places as her family and friends because of physically disabling environmental barriers.

Most interviewees were also confident in their ability to carry out everyday activities. The sixty per cent in the North who strongly agreed or agreed with this statement said their confidence came mainly from the support they receive through their PAs. Once again, the strong disagreement in the North comes from Peter's parents. Some service-users in the South confirmed that they are also in a position to carry out everyday activities either through their PAs, paid for through the Irish Wheelchair Association or through their carer, usually a family member.

As expected, those using direct payments are in strong disagreement with allowing others to decide what services they require. Peter's parents commented that their son is happy to allow them to decide what services he requires and that they are happy to be in a position to do this through direct payments, although they were previously not happy with allowing others to decide on services for their son. Nearly 40 per cent of those in the South either agree or strongly agree that they are happy to allow others to decide what services they require, while less than a quarter strongly disagree.

As expected, all direct payments users (including Peter's parents) are more likely to decide what services they would like to avail of as this is the purpose of direct payments. However, a majority of service-users in the South also claim that they decide what services they will avail of, with only one respondent disagreeing with this statement. This respondent, who has learning difficulties, was unsure whether or not he decides about the services he receives.

With regard to employment and training, the majority of those interviewed, claim that they could participate in employment or training with the support they currently receive. However, a number of respondents both North and South felt that the severity of their condition would impede any participation in employment and training irrespective of the level of support they receive.

PERSONAL OUTCOMES – SECTION II

This section relates to the experience of the five service-users in the North currently operating direct payments. Four of these respondents operate a direct payment by

themselves, all of whom have an acquired physical impairment. Peter's parents operate his direct payment on his behalf. Three of these service-users claim to have had reservations prior to taking up a direct payment.

As all of these respondents use their direct payment for personal assistance, their reservations relate primarily to issues around becoming an employer, such as tax and insurance and receiving money directly into their bank account for which they have to be accountable to the Trust. All of them suggested that there would be a real advantage in talking to people already using a direct payment, prior to taking up this option, in order to reassure

and boost confidence. Peter's parents claim to have had no reservations regarding direct payments because "we had such a bad experience with care before, we were willing to try anything". Four of the service-users avail of an Independent Living Fund (ILF) payment, which they operate in tandem with their direct payment.

In order to ascertain whether direct payments users in the North have perceived a benefit from using direct payments, they were given a number of statements comparing the 'before and after' experience. They were asked again to agree or disagree with the statements as appropriate.

Table 5. Experience of using direct payments in the North

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree
Since operating direct payments, I am.....	N	N	N	N
Less dependent on others	3	-	1	1
Better able to participate in the life of my family friends and community	3	2	-	-
More confident in my ability to perform everyday activities	4	1	-	-
More in control in making decisions that are important in my life	4	1	-	-
Able to have a better quality of life	5	-	-	-
More likely to decide what services I need	5	-	-	-
Better able to participate in training and / or employment	2	1	1	1
More confident in my ability to operate a Direct payments scheme	3	2	-	-

N=5

Three respondents strongly agree that they are less dependent on others since taking up direct payments. Peter's parents do not feel this is the case but are much happier with employing the PAs on whom Peter is depending, than they previously were when Peter was in day care or receiving PA support through the Trust. The other respondent, who does not feel less dependent, says that this is due to the severity of her physical impairment but, again, she is happier to depend on the PAs she has employed herself rather than on strangers sent by agencies employed by the Trust.

All five either agree or strongly agree that they are better able to participate in the life of their family, friends and community, including the interviewee who responded that she is generally unable to participate because of environmental barriers. Direct payments has enabled her to better participate in the sense that her PA can support her to do things she was previously unable to do.

The four respondents with acquired physical impairments feel more confident in their ability to perform everyday activities and more in control in making decisions that are important in their lives. Peter's parents also agree with

these statements to a certain extent and acknowledge that the direct payment has been very beneficial in this regard. The two most beneficial aspects of direct payments for all users are being able to decide what services they want to avail of and the better quality of life they enjoy through their new-found autonomy.

All agree that they are now more confident in their ability to operate a direct payments scheme. Again, the issue of training and peer support is considered paramount in this regard. All respondents stated that operating a direct payments scheme is not as daunting as it first appears and people should be encouraged to take it up and be given the support they need to continue with it.

Three of those with physical impairments either agreed or strongly agreed that they are better able to participate in training and/or employment with the support of their PAs. Peter's parents feel that no amount of support would enable him to participate in training or employment and that this is not applicable to him. The respondent, with a physical impairment, who disagreed with this statement, did so on the basis that her impairment is so severe as to preclude her from participating in employment.

ADVANTAGES OF DIRECT PAYMENTS FOR SERVICE-USERS IN NORTHERN IRELAND

One of the greatest advantages for users of direct payments in the North is "the ability to continue with as normal a life as possible." Individuals find themselves able to do things that they had previously not been able to do or had given up because of their impairment. One respondent tells how having PAs employed by him as opposed to being employed by the Trust has changed his life by allowing him to have a relationship.

"It suits my needs socially. I am now able to have a relationship, which wasn't possible before. I was able to develop a relationship because the times are more suitable. Previously, there were set times for everything, like getting up and going to bed. I also have independence from my partner, which means my relationship works well."

The sense of freedom from obligation is clear from all interviewees and is exemplified by one respondent who says:

"I don't feel obligated to people because it's a different relationship. You can build up a relationship with a PA you're paying that is more of a friendship. It's so much better than having a PA through the health service. When it's strangers who are coming in, you have to keep explaining yourself. This means I can live as much of an independent life as I can. I wouldn't want to be back where I was."

Not being dependent on or obligated to family members or partners is particularly important to respondents as it allows them to have a better relationship with their loved ones.

Another distinct advantage of direct payments is the ability to avail of employment, either part- or full-time with the assistance of PAs.

"I am able to work full-time because people can get me up at 6.30am. Previously, I had to get up whenever the agency decided was the time for me to get up"

The self-confidence, self-worth and dignity that individuals feel from being in a position to work are evident in some of the responses.

"It has given me back my life – given me back what I lost when I acquired my disability. I now have my self-worth. The disability is still there but now I can give something back."

This sense of self-worth gives an added quality to life for disabled individuals.

"My disability doesn't seem as bad. Quality of life is a lot better. It makes me feel equal to others. I'm able to work, so financially I'm much better off. I was able to get out of the poverty trap because I can get out to work and I'm contributing to the economy, which feels good. I have a much better outlook on life."

For Peter's parents, this improved quality of life applies to both Peter and themselves. Not only does Peter enjoy the opportunity of having a wider circle of friends, his parents can also enjoy the freedom from responsibility with peace of mind. They enthusiastically comment:

"It has improved our quality of life as carers. It gives our son a change of company. Previously it was always us. Now he has exposure to a lot more people."

The flexibility of employing a PA for themselves to suit their own needs is a real bonus for all respondents. It means that a job description can be put together as a negotiated package between employer and employee. According to respondents, PAs who come through agencies are bound by certain rules – mainly to do with insurance. So, for example, an individual might wish their PA to help them with housework or paperwork. A PA who has been employed directly is free to do this, while a PA employed through an agency might not be able to do so if this does not fall within their remit from the agency. One respondent finds employing his own PAs more efficient both in terms of cost and time:

“Deciding who comes to the house, deciding what they do within agreed limits, flexibility, sense of being in control of my own life, more efficient use of time – mine and the PAs.”

An important aspect for Peter’s parents is the continuity which direct payments can give them. Some respondents claim to have had up to sixteen different PAs coming to their house within the space of a week. This situation is particularly unsuitable for individuals with learning difficulties as they may find numerous strangers disturbing. Peter’s parents are much happier to have the choice of who is going to look after their son and to be able to limit the number of people whom he has to get to know. What they get from direct payments is “Continuity of care and choice of who is looking after him. People have to know him and he has to know them”.

The overwhelming enthusiasm with which all respondents spoke about direct payments was almost tangible during interviews and they were keen to encourage other people to take it up if given the opportunity to do so. This enthusiasm is captured in the following statements:

“I no longer feel like a child. It has given me freedom of choice.”

“It gives me greater independence, which is the ultimate.”

“If I’d never been given direct payments, I wouldn’t have had the opportunity to do all the things I’ve done. It opens doors I didn’t even know were there.”

ASSESSING THE DISADVANTAGES OF DIRECT PAYMENTS FOR SERVICE-USERS IN NORTHERN IRELAND

The greatest disadvantage mentioned by users of direct payments is the paperwork involved - four of the respondents also use the Independent Living Fund (ILF), which they say is far less complicated. As all of the respondents use their direct payments to employ PAs, they say that the responsibility of becoming an employer can be quite daunting at the outset, because there is a need to learn about tax, labour law, social insurance, health and safety etc. However, support is available from the Belfast Centre for Independent Living and one respondent comments that even though she has five PAs and the paperwork is time-consuming, “it’s worthwhile to do it in order to be able to live the way I’m living now”.

Another possible disadvantage is the difficulty of organising cover if regular PAs are on holiday or sick. However, one respondent suggested that by obtaining PAs through different sources i.e. directly through direct payments as well as through agencies with the ILF, it is easier to ensure that he doesn’t get stuck without cover.

GENERAL COMMENTS

In a general discussion with Northern Ireland interviewees on direct payments, respondents had some interesting points to make about the way the system works.

In general, respondents find that the whole attitude towards service-provision in the North has changed because of direct payments. One respondent claims that it used to be a case of, “This is what’s available – will that do?” but that now it’s a case of “What is your problem and how can we help?” Respondents say this is because they now have the money in their own pocket so they can “call the shots”.

Respondents feel that direct payments is primarily suited to the provision of PAs, because they find that independence is “not necessarily doing something yourself, it’s about choosing how things are done”. However, they do not see PAs as being in any way exclusive to those with physical impairments. All of the respondents comment that there are some things you need, such as personal social services, where it is much more important to be able to choose the person who is going to support you e.g. “who is going to come into your house to give you a bath”. This, according to interviewees, has to do with consumer rights. Consequently, the problem with the old way of doing things is that there was no choice and people’s dignity was damaged as a result.

All respondents recognised the scope of direct payments for those with learning difficulties and feel that it should not be exclusive in any way to a particular type of impairment. Having a PA allows a person with learning difficulties to meet a wider range of people rather than “sitting in a day centre with people with similar problems”.

The direct payments scheme is generally considered by users to be more beneficial for the Trust. It takes the burden of organising support away from the State, particularly in more complex cases where mainstream services are not suited to the individual in question. It is also considered to be more cost-effective in terms of supplying PA support (which is primarily what direct payments is used for in the North) because the agencies or ‘middlemen’, as respondents refer to them, can be done without.

At present, direct payments users are not entitled to purchase services such as PAs from agencies supplying the Trust. The rationale for this is that there is no merit in providing a direct payment for a service which can already be bought through the Trust. In addition, the Trust can, in theory, buy that agency’s services more cheaply because they do not have to pay VAT, whereas an individual service-user buying an agency’s services would have to do so.

However, some respondents feel that they should be able to purchase services through an agency as they are entitled to do with the Independent Living Fund. They feel that the very fact of having purchasing power and becoming consumers gives them much greater authority and empowerment in dealing with agencies. Their experience of purchasing services through agencies with the ILF has been more positive than obtaining these services through the Trust. This is because they can oblige the agencies to provide the quality of service they are looking for once they become consumers. The Trust cannot do this and therefore has less power to demand a better quality service for its clients. Respondents feel that the more people have choice the more the agencies will "have to get their act together".

In terms of the services being provided by agencies, respondents find that evaluation is crucial and that there is a need for training policies to be transparent so that service-users can be sure of the service they are getting. According to service-users, part of flexibility is about having a routine and this is almost impossible with current agency-provision. Training in customer service is therefore a necessity for agencies.

Most of the respondents feel that direct payments should also be used for therapy services. Currently these services cannot be purchased through direct payments as they are available through the Trust. However, respondents could see the value of having a choice with regard to physiotherapy etc. and, in particular, an occupational therapist, who is not affiliated to a Health Board or to a specific manufacturer. In practice, according to Belfast Centre for Independent Living (CIL), these services are simply not available outside of the Trust in any case, so that even if users were to be given a direct payment to purchase the service, they would end up buying back into the Trust. However, respondents feel that if service-users became consumers with regard to therapy services, such services would, over a period of time, become available in private practice, thereby enabling users to choose.

Respondents are quite happy with £7.50 (2002 rate) per hour for each care hour they are assessed as needing. They also find that budgeting in administration costs and social hours to their direct payment is very beneficial. However, they feel transport is a big problem, particularly in rural areas. Proponents of direct payments have always claimed that the direct payment for a PA should cover everything other employees receive. Currently, everything is covered except travel. While respondents accept that ordinary employees do not get paid for travelling to and from work, they say that being a PA is a different type of work and other workers do not travel to and from work four or five times a

day. Therefore, by not allowing for travel in a direct payment, people are put off applying for the job of PA, which limits competitiveness and choice, particularly in rural areas. Respondents did agree, however, that part of the £7.50 per hour could be used for travel if employees were paid £6.50 per hour for example. This would still be well above the minimum wage and in most cases, more than an agency pays employees.

It is considered most important by service-users that payments are used up in the way they were intended. This is why the assessment is so important. If service-users are assessed as needing a certain amount of care hours based on the needs outlined at assessment, it is essential to use the payment in this way. If there is money left over, their needs will be reviewed and they may not be assessed as needing the same amount of support.

The ILF is considered by those who receive it (four out of the five respondents) to be a big boost, especially because it is less bureaucratic than the direct payment and involves less paperwork. They feel the administration for direct payments should be a little bit more flexible, like the ILF, in particular for those who are receiving a relatively small amount. A number of the respondents use the ILF to subsidise their direct payment so they can afford to pay their PA more, thereby making the job more attractive and competitive. They recognise that the ILF is like a "catch-all", which allows them to make up for deficits in the direct payments scheme.

Support and encouragement is considered essential for people in using direct payments. This is the case particularly for individuals with learning difficulties, where families might feel intimidated by the prospect of dealing with more work. Training and reassurance needs to be given so prospective users can see that support is available. There are many ways to deal with the burden of work involved and an administration fee can be applied for as part of the direct payment. Three of the four respondents who have physical impairments suggested that users of direct payments with physical impairments could, for a nominal fee, undertake the administration that is involved in a direct payment for a person who has learning difficulties. This would, in addition, create employment for people with physical impairments.

Respondents consider that direct payments is a learning process, it is about learning how to make decisions and possibly mistakes as well. Prospective users of direct payments are encouraged to try and see if it works for them. Interviewees claim that the only way to find out if it will work is to "give it a go and see how you get on". In this regard, peer support is seen as being crucial.

THE VIEWS AND PERSPECTIVES ON DIRECT PAYMENTS OF SERVICE-USERS FROM BRAY

Respondents in Bray were asked how they would feel about operating a direct payments scheme if it were to become an option. This section is based on a 15- minute introduction

to direct payments by the interviewer, using the Department of Health (UK) user-guide. Although the responses are necessarily hypothetical, they give some insight as to how service-users in Bray feel about the prospect of directing their own service-provision.

Table 6. Attitude of service-users in the Bray to direct payments

Statement	Strongly Agree	Agree	Disagree	Strongly Disagree
Since operating direct payments,	%	%	%	%
I feel confident that I could participate in an assessment of my own needs with professionals ^a	67	33	-	-
I feel confident that I could operate a direct payments scheme by myself ^b	50	17	25	8
I feel confident that I could operate a direct payments scheme with the help of a family member or advocate	69	31	-	-
I do not feel confident that I could operate a direct payments scheme either by myself or with help	-	-	62	38
I would like to try to operate a direct payments scheme ^a	42	50	-	8
I do not think direct payments would be suitable for me ^c	-	8	59	33

N=13

- N=12: One respondent with learning difficulties answered that he did not know to both of these questions
- N=12: One respondent with learning difficulties said he could not answer this question as he has never tried to operate one.
- N=12: One respondent with mixed disabilities was unsure how to answer this question

All respondents feel confident that they could participate with professionals in an assessment of their own needs. This is particularly important as the assessment of the support required is an essential part of operating a direct payment. Direct payments users need to be clear when assessing the services for which they require direct payment.

Two thirds of respondents feel confident that they could operate a direct payments scheme by themselves, while one third do not. All respondents feel confident that they

could operate a direct payments scheme with the help of a family member or advocate. This is very encouraging as advocacy and peer support are an integral part of any direct payments scheme, as long as the individual is willing to take on the payment.

Nearly all respondents would like to try to operate a direct payments scheme and only one interviewee feels that direct payments would not be suitable for him because he is content at the moment to have somebody else look after services for him.

PERCEIVED ADVANTAGES AND DISADVANTAGES OF DIRECT PAYMENTS FOR SERVICE-USERS IN BRAY

Respondents then asked about the perceived advantages and disadvantages of direct payments. Because this question is somewhat hypothetical, interviewees were prompted with a list of advantages and disadvantages encountered by direct payments-users in the UK. All of the respondents agreed with the advantages and noted that the major disadvantage would be the paperwork involved in running a direct payment. However, most felt that if they were to receive help with this task, they would be able to handle the responsibility.

The most commonly perceived advantages of direct payments are empowerment, autonomy, control, independence, choice and flexibility. Comments such as, "It would give me more control of my own life," were frequent. The idea of tailoring services to suit themselves appealed to many respondents. For example, one respondent has a long way to travel and felt that if he could get services closer to home, rather than having to travel to his service-provider, this would be a big help. Another respondent, who has a sensory impairment, claims, "It would improve my independence and would be less expensive for me. I currently have a friend who gives me personal assistance for about ten hours a week – unpaid. I would like to be able to pay her properly."

The responsibility, although daunting, presented many of the respondents with a real challenge, which they would like to accept. Some simply want to do things for themselves rather than relying on others: "It's a lot better than depending on the Government or my service-provider – it's better to go out and do it for myself". Others see it as a means of becoming more involved in the community.

Despite recognising the manifold advantages of direct payments for service-users, most respondents recognise the necessity of speaking to individuals who are currently using direct payments. They feel that this would give them the confidence to go ahead with a direct payment and make the best of it.

A significant number commented that they could see no disadvantage, which might constitute a 'barrier' to taking up a direct payment. They noted that as long as they could go back to the way they were before if it didn't work out, then there is "more to lose by not giving it a try".

None of the service-users were unaware of the responsibility involved in taking on a direct payment. However, only one service-user felt that direct payments would not

be suitable for him because he finds it easier to have everything done by someone else. Most respondents, on the other hand, felt that with support and training, they could overcome their doubts about their own ability to manage. Some felt that it might be "difficult to make the leap," because they have been used to having everything done for them. In this regard, service-users might be "nervous about making decisions in unfamiliar circumstances" without assistance. One of the respondents with mental health issues worried that he might "have a lapse and get to the point of not being in control".

Transport was identified as an issue by one or two respondents who currently use the transport provided by their service-provider. They queried how they would cover transport if they were paying for services directly. Another issue of particular concern to a small number of respondents was that of social welfare entitlements. However, as long as direct payments would not affect their entitlements in any way, they would be happy to give it a try.

Finally, the question of evaluation was raised by one respondent, he was concerned that he would find it difficult to evaluate different services as a consumer and queried the level of support and advice that would be offered to those purchasing their own services.

When asked how direct payments would affect or change their lives, respondents again used words like choice, flexibility, control etc. Many felt that direct payments could open new doors to them, for example in terms of educational courses. "I could make my own decisions about where I would go for physiotherapy, about the courses I would attend, about the help and support I need." Some also felt that direct payments would enable them to regain their dignity and one respondent commented, "It would give me more choice and more dignity. You have to re-establish your dignity when you acquire a disability. Autonomy and control on a personal level is very important." Independence and control were seen as being central in the operation of direct payments, again with the proviso that proper advice and training would be given. All interviewees felt that it might change their lives for the better if they were to try it and that their quality of life would undoubtedly be improved.

GENERAL COMMENTS

Some additional issues were raised in the service-user focus group. With regard to options for accessing a payment, service-users were concerned that many disabled people do not have access to a bank account - a particular concern for those with learning difficulties. Service-users queried who would control the payment in such cases.

There were also queries over advocacy and whether a monitoring system would be in place to ensure that the money is being used properly if an advocate is operating the direct payment on an individual's behalf. In addition, the banking options would have to be flexible for those with restricted mobility e.g. internet-banking etc.

Service-users were also concerned that the responsibilities, which come with direct payments for Personal Assistants would be clearly outlined e.g. becoming an employer, PAYE, PRSI, tax returns, holiday pay, health and safety etc. Finally, some service-users queried how much advice an individual would receive around using a direct payment. Fears were expressed that they would be left 'out in the cold' with a direct payment but no advice on how to use it. One service-user commented, "People with a disability are not the same as people without a disability, no matter what anyone says. I wouldn't like to be thrown into a rat-race with able-bodied people."

SECTION 2: SERVICE PROVIDERS PERSPECTIVE (COMMUNITY AND VOLUNTARY SECTOR)

VIEWS AND PERSPECTIVES OF THE BRAY-BASED SERVICE-PROVIDERS

Community and voluntary service providers in the ECAHB area were consulted to discuss the practical implications of direct payments in terms of advantages or disadvantages for them with regard to the services they provide including day care, supported employment services, training and community services. Many noted the difficulty of assessing the practical implications of a concept. However, nearly all had heard of direct payments in some form prior to the focus group. On the basis of information obtained through the focus group, five service-providers across the range of disabilities gave in-depth interviews to discuss issues, which they felt would be most likely to impact on their service-provision.

In general, participants found relatively few benefits for service-providers but were very positive about the benefits for service-users in terms of increased choice and user-empowerment. However, it was also noted that direct payments effectively remove the 'comfort zone' for both service-providers and users and where service-providers may have to make decisions on a cost basis rather than for ethical reasons, this could leave service-users in a vulnerable position.

Some felt that direct payments might be well suited to 'single-dimension' service-provision, such as personal assistance, but that where the needs are more complex, a multi-

dimensional service-provider might be more appropriate. All acknowledged that the introduction of direct payments across a range of community-based services outside of the assisted living services (home-help, home-care attendant and personal assistant) would involve a huge upheaval in terms of philosophical and organisational change but that the benefits to service-users might outweigh these considerations. The issues that arose for service-providers fall mainly under the following headings.

- ▲ Competition
- ▲ Funding
- ▲ Additional costs
- ▲ Evaluation and accreditation
- ▲ Assessment
- ▲ Monitoring and accountability
- ▲ Organisational and attitudinal change

COMPETITION

There is currently relatively little choice for consumers so that even if they are given direct payments initially, they will still have very little option i.e. some service-providers have a monopoly over a particular service because of the way the system has evolved. Naturally, a monopoly makes it easier for service-providers to operate in any particular area because they enjoy economies of scale from which they would not otherwise benefit.

Direct payments will create competition, which is perceived as good for service-provision in the sense that it improves the service being offered if people can simply take their money elsewhere. There is a feeling that in a market economy dictated by direct payments the current 'large' service-providers will cease to exist in their present form because they will not be able to compete with smaller more innovative service-providers that would emerge. However, current providers have capital assets and an existing staff-base, which it will be more difficult for new small service-providers to acquire. This gives those already in the market a slight edge, even if they do have to change the service to meet the requirements of a more competitive market. Small service-providers already operating may do well in comparison with the larger providers.

One service-provider commented however, that they are at present restricted by the State, as they are not allowed to spend money on advertising and promotion. If they moved to a market economy, they would have the reserve funding to 'wipe out' the competition. There would therefore be no competition and nobody to regulate. This could be a serious disadvantage for service-users.

If the client base is subject to fluctuation, this could make

it very difficult for service-providers to operate e.g. if twenty individual consumers all decide to leave one service-provider in the space of a year, this would make it very difficult for that provider. However, because of the present monopoly situation, there is very little scope for 'hopping around' from one service-provider to another. There is a need to research how this operates in other countries, but large urban centres in other countries that practice direct payments cannot be compared with most of Ireland (even Dublin) and certainly not with rural areas in Ireland. Providers in large urban centres with a proportionately large disabled population might be better able to absorb fluctuations in their client base than would service-providers in smaller areas that require a monopoly – or at least a very definite client base - in order to remain viable.

Direct payments was seen by the group to be the equivalent of privatisation, in the same way as care for the elderly was effectively privatised with the introduction of privately run nursing homes. Privatisation invites the question of cross-subsidisation. Service-providers, once they have choice, can decide not to offer certain services because they are not lucrative. At present, voluntary and community service-providers offer services that can be described as 'loss leaders' i.e. services that are not profit-making for the organisation. If they were to become cost-effective and competitive, they would no longer do this. Service-provision, particularly in rural areas, would become a cost-benefit issue.

In relation to this, there is a concern that the bigger providers will 'cherry-pick' the most lucrative services. In rural areas, this could be a particular problem. It would simply not be feasible for service-providers to operate in areas where there isn't a large enough client base for a particular service or where they are in competition with other providers of a similar service for the same client base.

Some service-providers suggested that the problem of rural service-provision in a direct payments environment could be addressed by outreach services. Central organisations could identify demand for particular services in certain areas and, rather than providing a full service, just provide the ones that have been identified. Geographically, it could be difficult, particularly in terms of isolation for outreach workers, but it could work, provided the outreach workers have close links with the main organisation to ensure quality control. If the Health Board accredited a service-provider, the Board would need to ensure that all outreach services from that organisation work to the same standard.

One of the perceived benefits of competition is that serv-

ice-providers would not be overloaded with referrals. They would be in a position to choose the clients that best match the service they're offering. There would also be better personal outcomes for service-providers and practitioners, as clients will have chosen them rather than just 'ending up' with them. However, the corollary of service-user choice is that service-providers will also have a choice as to which service-users they want to provide a service. This could be a disadvantage to service-users. For example, if there is a complex case requiring a high degree of support there could be an issue of demarcation – who should provide the support? If service-providers are being paid directly, they can opt not to take the client. So, for example, if there was a wheelchair-user who also had a learning disability, a service-provider could claim it doesn't provide services to people with those needs. Currently, there is a statutory obligation to provide a service. This gives protection for service-users because someone has to take responsibility.

This would not change however, for voluntary service-providers who do not have a statutory obligation to take clients at present. Currently, some service-providers accept clients on a needs basis after assessment. If they feel unable to meet the needs of the client concerned, they do not accept the individual.

FUNDING

Direct payments may affect funding in a number of ways both directly and indirectly. Planning for the delivery of services is very important and currently there is a budget for this. The budget is based on full-time equivalents (FTEs) so each service-provider needs a certain quota of FTEs to maintain their budget. Day Place funding, whereby service-providers receive per capita funding for service-users, would no longer apply to direct payments users, as consumers would not necessarily be attending the service on a full-day basis but might be buying in to specific services offered by the service-provider. Some providers envisage difficulties in maintaining their budget and therefore their planning capabilities if there are large fluctuations in demand.

However, there is a general consensus among service-providers that funding should not be an issue if they are offering a quality service. Service-users will want to use their service if it is good, therefore the client base should not fluctuate too much and, consequently, funding should not be reduced. Direct payments would be welcomed by many service-providers as they feel it would encourage them to be more cost-effective and focused.

On the other hand, participants recognise that once a voluntary organisation moves from being funded to being

paid by consumers, the language will automatically turn from service-provision to cost analysis. The profit margin will become a significant issue and there are concerns about the possibility for innovation within this context. At present the drive for innovation comes from the state. Needs for specific services are identified by the state and providers are obliged to provide them if they are state-funded, irrespective of whether they are profit-making services. They would not do this if the state no longer had any say because it would not make sense for them. They would simply cut the services that are not profitable and stick to the ones, which bring in the most money.

ADDITIONAL COSTS

Transport arose as the major cost-factor if direct payments are introduced. Currently, service-providers supply transport for a group of people on a full-day basis but if this is to be done on an individual basis to ensure that each individual can reach the service he or she wants to attend, this will add a major cost in terms of transport. This will be the case to an even greater extent in rural areas. One service-provider pays €30,000 per year extra in taxis for only 10 people. If they were to become competitive in a market economy, this service might be at risk.

Participants feel it may therefore be the case that direct payments would only work in Ireland in relation to Assisted Living services because other services would simply be too difficult to access for individuals in terms of transport. Again, this cannot be compared with other countries where transport systems are infinitely better and adapted for travel by disabled individuals. Ireland is very different from the UK with a very big rural population.

However, there is a question mark over whether direct payments would improve the situation or make it worse in terms of therapy services. For example, individuals accessing direct payments could buy in therapists to come to their homes. Alternatively, they could use a PA to help them attend a therapist. Currently, they are in a position to access such services only through a service-provider to whom they have to be transported on a day-basis. Training, on the other hand, generally requires transport to and from some form of centre for training, unless an individual can avail of distance learning, and there is no way around this without incurring additional costs.

If direct payments were to increase the number of part-timers for some service-providers, this could make it more difficult to run a programme. There is the same amount of work in putting together an individual service plan for a part-time person as there is for a full-time person, so the workload and costs, would increase accordingly.

EVALUATION AND ACCREDITATION

Evaluation will become an issue for consumers receiving direct payments. Who will advise consumers and ensure that quality of service is maintained? With direct payments, an individual (or a group of individuals) would have to do the research on service-provision. They might not know how to go about getting a better service so there would need to be some sort of supports in place to assist them with evaluation of service-provision.

Concerns were voiced over how accreditation would be given to service providers and by whom. Some participants queried whether practitioners in complementary health would be accredited for use of direct payments or just mainstream practitioners.

Providers noted that direct payments would positively affect accreditation practice; a monopoly is not good for the service-provider in terms of accreditation. At present, it is very difficult to get accreditation from an outside body if you are the only service-provider of a particular service in a given area. The accrediting body will say they have nothing to compare with. A service-provider cannot get proper accreditation if there is no choice.

ASSESSMENT

There is a concern about the assessment process. Who will ensure that the money is being spent on what is best for the client? At present, service-providers generally offer a package of services. With direct payments, individuals might pick only one or two options from the package. There could be a conflict of interest between what people think they need and what they're assessed as needing. This could be the case in particular with children, where parents think they need something else.

Many service-providers have begun recently to offer individual service plans. These are based on an assessment of individual needs. The assessment typically involves the client, family members or advocates, if appropriate, and a team of professionals. With many service-providers, personal outcomes are central to the philosophy underpinning the assessment process. In this way, service-providers feel that the needs of clients are being genuinely addressed more so than ever in the past. Some feel that direct payments might hinder this process if the assessment is carried out elsewhere (e.g. the Health Board) and clients pick services across a range of providers, who are then not in position to look at the individual in a holistic manner. In addition, it was noted that some service-users prefer service-providers to do the whole package. It suits them better and takes the burden from them as long as they are participating in the process.

Service-providers stressed the need for the assessor to have some knowledge of the type of disability with which they are dealing in any given case. For example, it is difficult to assess the needs of someone with mental health issues without some background knowledge in that area. This issue is overcome in the UK by having a panel of professionals available for assessment so that the care manager doing a given assessment is relatively au fait with the area or at least has professional input from others who have in-depth knowledge.

In addition, service-providers noted that there would be a need for flexibility in the assessment process. Sometimes there can be a change in an individual's life and issues emerge for clients that weren't initially apparent. There would have to be a possibility for review of the assessment. They also queried whether a service-provider would be allowed to do a re-assessment of an individual if they were unhappy with the assessment carried out by the Health Board.

There is concern among service-providers about an assessment of people who cannot articulate clearly and where an advocate has the authority. All commented on the need for measures to ensure that no one person has all the power in any assessment situation.

Participants acknowledged that there is a learning process involved both for service-providers and for individual consumers. Individuals will learn how best to use the resources for their own benefit. They will learn to take their own decisions, to make mistakes and to learn from those mistakes. Service-providers on the other hand must learn to let go of the control as long as there is a proper monitoring system in place.

MONITORING AND ACCOUNTABILITY

Service-providers are concerned about the accountability of a direct payments scheme. Who will ensure that the money is spent on the services it was intended to pay for? This is of particular concern where advocates or family members may decide, despite the assessment, what is best for the client. Family control is a problem even with the present system, particularly for those with learning difficulties. A monitoring system would need to be in place to ensure that the money is spent on the services a person is assessed as needing.

In addition, participants expressed concern about the possibility of fraudulent claims on the part of any stakeholder. Some service-providers commented that there are currently problems with such claims and that this would also have to be a consideration when looking at monitoring. The experience in the North, however, shows that moni-

toring procedures are so stringent as to be quite burdensome to the clients involved and there is no scope for abuse of the system in this regard.

ORGANISATIONAL AND ATTITUDINAL CHANGE

Service-providers feel that direct payments will require a major change of philosophy or mind-set and a major reorganisation of large service-providers in particular. The current philosophy has prevailed for so long that the status quo has itself become a barrier to change. Professionals have been educated and gained their experience in a setting where they make the decisions regarding needs etc. Direct payments across the full range of services would require such a major change that it is threatening, not only in terms of funding and competition but also in terms of loss of control. Years of the top-down approach 'we know what's best' will be difficult to change. Participants stressed that all decisions are made by professionals with the best interests of the client at heart, while recognising that clients may want to make their own decisions. Some participants expressed fear that clients might make the wrong decisions with regard to their own well-being.

Sunbeam House Services' Personal Outcomes philosophy, which allows clients to assess their own needs, is an example of changing a mindset and having to reorganise a whole system within the organisation. This philosophy has made staff realise that the status quo is not enough. The boundaries have to be pushed out and they have to allow it to be service-user driven, even though the staff might be used to having control. Participants agreed that, although changing the philosophy and practice of service-provision across a range of services is a mammoth task, it is achievable with the right approach. An advantage of direct payments is that it opens up the possibility for a more flexible approach to meeting the individual needs of service-users.

Organisational change would be inevitable in terms of job-losses and re-training if direct payments were introduced on a large scale. Large service-providers, who currently maintain a full multi-disciplinary staff, may find that it is no longer viable for them to do so if service-users decide they only want certain services. This would affect employment contracts for workers. These organisations would effectively become referral agents for self-employed practitioners. In this scenario, doubts were expressed about prioritisation. On what basis would individual practitioners decide on whom to take clients from? There is, however, no reason why practitioners could not remain affiliated to particular service-providers, with clients choosing their service-provider on the basis of the practitioners to whom they have access.

One of the advantages of voluntary organisations is their structure, which means decisions do not have to go through layers of bureaucracy and management. Decisions are therefore taken more swiftly. For example, what might start out as a concept could become a pilot project within a few months in a voluntary organisation. By contrast, in a corporate environment there are layers of cost-analysis to go through before anything can be passed. This might impact on the scope for innovation within an organisation. Cost issues will take the place of funding issues, thereby reducing the leeway for establishing new services e.g. home-help and transport services started out as pilot projects. These would never have got off the ground in a corporate environment.

Development of new services might also suffer of necessity because no one is going to fund research and development in service organisations. However, research and development is necessary to develop appropriate services for disabled people and it would suffer in a 'cost' environment. This could be balanced by the possibility that, in a market-driven situation, needs and gaps in services will be more readily identified by potential service-providers and filled more quickly.

Change is not necessarily an issue just for service-providers. It might also be difficult to change the mindset of service-users. Sometimes it is almost more difficult to ask service-users to make a choice. A lot of the time, people will say they're happy with the service they have because they don't want to 'rock the boat'.

OTHER ISSUES

Confidentiality was raised as an issue that might affect both service-providers and service-users. Participants asked who would keep the records of an individual if the Health Board does an assessment and then service-providers do their own assessment as well, particularly if an individual is accessing a number of service-providers. This relates also to concerns around child protection. Would the Health Board still be the recipient of any reports relating to child protection or would this change?

It was noted by one service-provider that direct payments is, in effect, 'putting the cart before the horse' as there is still no disability rights act in Ireland and while direct payments would be an important step towards user-empowerment there is, as yet, no legislation to underpin such a policy development.

Service-providers consider it important that an understanding of all types of disability is built into any pilot proj-

ect for direct payments. If the scheme is implemented, it should be done in the context of all disabilities to ensure that no one is excluded from participating.

Finally, the view was expressed that direct payments removes the comfort zone for both parties and can leave both vulnerable. However, this has to be weighed against the obvious advantages of consumer-directed service-provision.

SECTION 3: THE EAST COAST AREA HEALTH BOARD PERSPECTIVE

THE CURRENT ROLE OF THE HEALTH BOARD

At present, the Health Act (1970) obliges health boards to provide 'services' but does not specify actual provision – health boards have considerable freedom in this regard and can use both voluntary and community agencies instead of providing the service themselves. In this sense, the health boards have an advantage over the Trusts in Northern Ireland in that the boards do not provide the services but 'farm them out'.

Currently, considerable expenditure on services for people with physical disabilities is incurred by the ECAHB for both residential care and the personal assistance service through the Irish Wheelchair Association (IWA)⁴. The ECAHB is also covering (in part) the core costs incurred by the IWA in providing the service. If the health boards were to redirect that funding towards a direct payments scheme this would compel IWA and other service providers to function as a business and promote competition between the agencies. If funding was made available for a direct payments scheme the health board would still have to provide services for those who choose not to use direct payments. There is the possibility of a 'gradualised' process in terms of introducing direct payments schemes and when a critical mass of service users use direct payments then the current funding arrangements could be reviewed. Existing community and voluntary groups could remain as the service-providers for those who want to receive a service directly. The issue of rural service-provision would also need review in such a scenario.

ENGAGING PEOPLE WITH LEARNING DISABILITY

Health board officials have some concerns about those with a learning disability and how they would be included within a proposed direct payments scheme – in the current system people with a learning disability cannot get a

⁴The Irish Wheelchair Association is providing personal assistance services to 70 people in the ERHA area. These are people with disabilities who wish to achieve an independent living lifestyle. All three health boards in the ERHA contribute to the funding of the service.

personal assistant, home-help etc. and if direct payments were to be introduced for these services, learning disabled people would be excluded.

ASSESSMENT, MONITORING & EVALUATION

The Board considers monitoring and evaluation as key in any direct payments scheme. A direct payments scheme effectively involves providing an assessment, giving the funding and providing an evaluation of the service-providers. Currently, the health board does everything except give the funding directly to the service-user, although there have been precedents in the past e.g. a Readers Scheme for the Blind administered by the National Rehabilitation Board.

One of the problems the ECAHB envisages is around the difficulty of assessment. How best should this be undertaken and with what consequences (both legal and financial)? There are serious financial issues to be considered in relation to the introduction of direct payments and Board staff are not currently clear about them.

The ECAHB does not see itself giving direct payments for overall residential care as this is the most expensive form of care. The Board envisages a situation whereby people who are currently in residential care, or may have to use residential care in the future, could opt for direct payments for assisted living so they could remain at home. It was pointed out that this would still be cheaper for the health board than residential care. It was suggested that the difficulty is the need to find ways of reallocating money from residential care to direct payments.

The Board does not envisage itself losing its relationship with the voluntary agencies as a significant proportion of disabled people will continue to want to receive their services directly through the health board. There is unlikely to be resistance to direct payments from the therapists, as they would be happy to have some of the burden taken from them by people using direct payments for private practice. Resistance may come from the Department of Health because of its legal and budgetary obligations.

In other health boards, 'assisted living' encompasses home-help, home-care attendant services, personal assistance and home-based respite. In the ECAHB, they are still separate services but one way to implement a pilot programme would be to combine these four services under the heading 'assisted living services' and offer direct payments for these services first. Then it could be introduced for therapy services.

BUDGETARY AND ADMINISTRATIVE CONSIDERATIONS

In principle, ECAHB officers would welcome a pilot scheme on direct payments focused in a limited number of areas – PAs, certain therapies etc. In the course of this research, they expressed considerable concern regarding budgetary implications and administrative requirements. Their specific concerns related to the costs of such a scheme and its impact on core budgets as well as budgets required to maintain services for those who would remain outside a direct payments scheme. They also expressed worries regarding the ability of potential direct payments users to actually access needed services, as the Board itself currently experiences difficulties in this regard, and it might take an appreciable length of time for the 'market' to respond to opportunities presented by direct payments. In their considered view, much more needs to be done on the supply side before direct payments could become successful here.

GENERAL COMMENTS

A point made strongly by the officers of the Board (and which has implications for this project) is the need for detailed information on the nature, character and delivery of direct payments elsewhere, as well as its impact. There has already been some contact between officers of the Board and colleagues in Liverpool and such an approach could be extended and expanded.

There is considerable interest in the Board regarding the potential role of advocacy groups in assisting those interested in exploring direct payments and its delivery. Such an approach could assist not only with the design and delivery of a scheme but also with the establishment of appropriate standards – a matter of concern at this stage. Board officers were also concerned with the crucial issue of assessment – who should make them and what their status would be as well as their implications – legally and administratively. The issue of the appointment of Care Managers is also of interest. Officers of the Board also stressed the need to explore the issues and implications around direct payments with colleagues in the Department of Social Welfare.

Overall, those we consulted with in the ECAHB would favour additional research on direct payments and to create opportunities to discuss and debate it further with experienced colleagues outside the Republic. In addition, they identified that a pilot scheme engaging a small number of disabled people in using direct payments could assist with moving the debate and policy development further forward.

CHAPTER FOUR

CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS

The core conclusions of the research are as follows:

- ▲ 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 with in 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 this 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.

RECOMMENDATIONS

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 its 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. 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.

APPENDIX 1

CASE STUDIES ON DIRECT PAYMENTS SCHEMES IN THREE EUROPEAN COUNTRIES

(This material has been extracted from Halloran (ed) (1998) Towards a People's Europe: A report on the Development of Direct Payments in 10 Member States of the European Union)

Case Study One – the Netherlands – Frits Van Brussel

In the Netherlands the equivalent of direct payments is called 'Persoonsgebonden budget (PGB)', which means that each person has his/her own budget to be spent personally. In 1996 the system of direct payments was introduced into the nursing and care sector and for mentally handicapped people. For elderly people and physically handicapped people there are limited possibilities for direct payments. Direct payments are rare in the total care sector and the PGB share in nursing and care services is still only 4% and for mentally handicapped people this share does not even exceed the 2% level of the financial resources within the law.

As is the case in other countries, the Dutch social security and care system is a mixture of state-controlled and (semi) private provisions. Central government makes the laws and monitors the regulations with either semi-private organisations or local authorities being responsible for implementation. For this reason it is difficult to speak of one uniform system in the Dutch situation.

The care sector in the Netherlands is run mainly by private organisations and semi state-controlled institutions. The Dutch take out care insurance as needs which are difficult to insure are subject to social insurance e.g. admittance to a nursing home and the care of handicapped and elderly people. In a number of cases, the central government puts the implementation of parts of the care system in the hands of the local authorities. Examples include the implementation by local authorities of transport and adapted houses for handicapped and elderly people.

In order to have a link between the two separated subsystems, it was decided in 1997 to cluster the eligibility assessment for both the governmental and semi-private sector into regional organisations. Local authorities are obliged to set-up and preserve local eligibility assessment bodies and in this way local authorities are influencing the admittance to the care system and the decisions as to PGB initiatives.

Starting in 1996, direct payments have been applied in the fields of nursing/care and mental handicap. The advan-

tage of a PGB is that the service user, as budget holder, can choose the care provider, the number of working hours and the kind of care provided. The independence and self-determination of the budget holder is therefore much greater than before. However, PGB also entails disadvantages including:

- ▲ the service user must recruit one or more care providers and has to tackle employment legislation which can be very complicated
- ▲ payments to the care providers are handled by de Sociale Verzekeringsbank (SVB) which is a Bank for social insurance
- ▲ the budget holder has to reach a written agreement with the care provider in order for the SVB to pay the care provider.

There are different agreements possible within these arrangements ranging from an agreement with a care providing organisation (called a service contract) and an agreement with one or more individual care providers in which the budget holder is the employer. Within this framework, there are different types of working contracts – a usual work contract, a call up work contract (this agreement can be used for asking help without specifying when it has to be provided) and a replacement agreement in case of the care provider goes on holiday or is off sick.

People with physical handicap and chronic diseases who live at home and need long-term care (longer than 3 months) are entitled to the PGB. This can comprise nursing and personal care called ADL (= general everyday life) and HDL (= every day housework).

Applicants need to sign on with a regional bureau, no matter how they are insured. The PGB is based on the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ). Once you have applied, you are placed on a waiting list (it can last more than one year before it is your turn). After acceptance of your application, someone from the care office to find out what kind of care she/he needs assesses the client.

Together they set up a care programme which sets out the care and nursing needs. This programme is then sent to the care office. The applicants will then be notified that they are entitled to a PGB and how much they will receive to purchase their care. An agreement stating the rights and duties of each party is also sent. The amount of

money allotted and the starting date of the arrangement are mentioned in this agreement. By signing the latter you are member of the association of Budget holders which is named in the agreement.

Care providing organisations can be a home care organisation, a private home care agency, a private nursing agency, and a mediation agency. Individual care providers can be a friend, a neighbour, a self-employed nurse, in fact anyone who can do the work required. It is possible and indeed quite common for a service user who has a budget for nursing, social care and housework to decide to use an organisation for social care, use a friend (employment contract) for household duties and a self-employed nurse (a freelance contract) for nursing.

Service users can also choose for an individual budget, based upon achieved performance. For professional care, care providers have several standards:

Once a client decides to be no longer dependant upon professional assistance and prefers to choose for a PGB, the same standard figures will be applied. However, before calculating the budget, the costs in-kind are reviewed, followed by a 20% deduction. So, if a client prefers a PGB, only 80% of the (former) care in-kind will be paid as a PGB.

Under the 1994 Provisions for Handicapped Act, local authorities are responsible for the implementation process while municipal social services are frequently the actual implementers. This Act enables the handicapped and elderly people to access adjusted wheelchairs, to use adapted public transport, to adapt a house according to the disability needs. Normally these are offered as in-kind provisions but a number of municipalities decided to allow a PGB for transportation purposes. The budget holder (i.e. the service user) receives a certain annual amount of money to arrange transportation.

Case Study Two: Sweden - Lars-Göran Jansson

Demands for greater independence amongst those with disability led, in 1967 to new legislation for persons with learning difficulties and, in 1985, to another law – Omsorgslagen - giving handicapped people improved legal status. The two pieces of legislation of importance for people with disabilities are the Social Services Act (Socialtjänstlagen), and the Health and Medical Services Act (Hälsa- och Sjukvårdslagen), which set out the responsibility that county councils have for health and medical care.

The Support and Service for Persons with Certain Functional Impairments Act - LSS (Lag om stöd och service för vissa funktionshindrade) - came into force in 1994

and focused on rights issues. It sought to create equality of opportunity and control with able-bodied people. The law is also about the availability of a personal assistant, someone who can act as an escort wherever necessary. It deals with support to families with handicapped children so that they have time and energy to enjoy a normal family life aside from the extra work that looking after a handicapped child entails. It deals too with the right to suitable housing and the provision of services to enable one to live away from home, as others do, when one grows up.

The legislative reforms improve the options for relatives to be paid for care. LSS also gives a right to relatives to get help from personal assistants, or be assistants themselves. LSS also states the right to an individual plan which co-ordinates the activities from different actors. The position of disability organisations has been affected because of that the legislation now states that both municipalities and counties must co-operate with them. The role of cooperatives established and run by disabled people is important as they provide appropriate advice and support and was the main route for the development of independent living in Sweden.

The local authorities are responsible for 9 of the 10 rights stated in the law (not 'advice and personal support' – these are national responsibilities) and for the co-ordination of activities for the other actors. Counties are responsible for, rehabilitation and handicap equipment and also for 'advice and personal support', but this activity can be transferred to the municipality.

A National Board of Health and Social Services has the nation-wide responsibility, but in practice it is delegated to Länsstyrelsen, the governments regional organisation. A new authority, Handikappombudsmannen, has been founded as a result of the disability reform. The task of this authority is to take initiatives to promote handicap issues. The ombudsman cannot however refer issues to court. Appeals against decisions must be referred by the handicapped person themselves - the court can overrule the decision made by the local authority.

The LSS-law applies to those who will benefit from these rights are persons with severe disabilities, namely, persons who are mentally handicapped or autistic, persons who have impaired mental ability as a result of brain damage in adulthood, persons with other permanent and severe physical or mental disabilities if they have considerable difficulties in their daily lives and need constant care and attention.

This disability reform covers the whole of Sweden and although prior to the reform it was estimated that about

100,000 people (about 1% of the Swedish population) would be covered by the 10 activities of LSS (of whom 40,000 were people with intellectual impairments), in practice only 43,000 people used LSS-activities in 1997. Of these, 22,000 sought it for advice and personal support and 12,000 for personal assistance. In total the reform has been less expensive overall than expected although the cost per client has been more expensive than expected.

One interpretation of the less than expected take up could be that the need for 'new' groups has been exaggerated. If so, the reason for the discrepancy would be that persons with intellectual impairments are satisfied with the measures already provided mainly under the Social Services Act and the Health and Medical Services Act.

The experiences of LSS by disabled clients has been very positive, with the exception of people with mental illness. They have asked for personal assistance to a smaller extent, and the assessing authorities are not used to this group of people.

The situation for personal assistants has however raised some issues for whilst it has generally worked well, some assistants have found themselves in difficult situations with their client as employer, where for example, an employer with a drink problem has requested they buy alcohol. There is no single role for the assistants, and the work can be lonely. There is also a risk that the possibility of employing relatives can create 'home-daughters' – a mother who takes care of her child all her life, which at the same time means that she can have no life of her own.

Case Study Three: The UK - James Murphy

The NHS and Community Care Act of 1993 gave local authorities the key responsibility for identifying and assessing need for care and purchasing and monitoring the delivery of that care. In addition to this care management role, local authorities were required to undertake wider joint planning and consultation, including with carers and service users. These reforms also required new contracting arrangements, complaints procedures and inspection and regulation functions.

This Community Care (Direct payments) Act came into force on 1st April 1997 and gives local authorities the power, though not the duty, to make direct payments between 18 and 65 years of age. This is instead of directly providing people with the community care services they have been assessed as needing under the 1990 legislation. Direct payments may be substituted for any community care service, except permanent residential care and payments are made only via local authority social services

departments.

Eligibility to access Direct payments is established by:

- ▲ being willing and able to manage your own care;
- ▲ being over 18 and under 65 years of age;
- ▲ payments not to exceed the maximum cost of residential care;
- ▲ payments cannot be made to employ close relatives; and
- ▲ certain exclusions, including people with severe mental health difficulties and those under Home Office restrictions that are ex-offenders.

Independent Living in the UK is supported through Central Government by way of the Independent Living Fund. Local authorities in the UK are placed to establish clear consultation mechanisms with service users, including disabled people. For the most part, where local authorities have responded enthusiastically to developing direct payment schemes, this has been based upon close consultation with disabled people and concerted pressure being exerted by disabled people.

One model which has been successful in the UK prior to legislation has been for schemes to be administered and controlled by organisations of disabled people. Such schemes included a range of independent living services such as peer support, training information, advice, and other infrastructure services such as payroll, emergency support and sometimes a register of personal assistants. Now that we have the new legislation a new model is being explored. This early example of direct payments gives the service users greater influence over the local authorities implementation of the legislation. In January 1996 Manchester City Council launched a 3-year independent living development programme based on the general principles of:

- ▲ empowering service users to manage their own assistants
- ▲ involving service users in the design and development of the project
- ▲ full consultation with service users and their organisations.

The Manchester scheme pre-dated the direct payments legislation, which came into effect in April 1997, but was able to incorporate the implementation of the new Act locally. To date there are 44 disabled people accessing direct payments with a further 25 waiting to join the scheme. The scheme also provides support and adminis-

tration for two other local authorities.

Early experience in the UK suggests that the overall cost of support packages for younger disabled people increases with direct payments, although the cost to Local Authorities may decrease. This is because the complex systems of benefits in the UK that allows access to additional centralised funding services within the direct pay-

ments regime. Whilst the total increase in costs may be justified in individual cases by the greater quality of life experienced by the direct payments users, the overall impact on the public purse of widespread extension of direct payments could vary greatly in the absence of a national framework.

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