LIVING IN THE COMMUNITY: SERVICES AND SUPPORTS FOR PEOPLE WITH DISABILITIES

March 2013

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Preface

The success in blurring the lines between inclusion and exclusion sometimes makes it difficult to see where the needs and responses associated with disabilities begin and end. Level or ramped pathways; automatic opening and closing doors; audible pedestrian crossings; destination announcements on transport; the availability of “hearing loops”; a guide dog’s head protruding from beneath a table in a restaurant; accessible toilets; and Braille on medical packs – all of these have been supported by the power of goodwill in the community.

The fuel for the engine of goodwill is derived from the work of voluntary organisations and people with disabilities. While some of the areas mentioned above now come under legislative requirements, they had their beginnings in campaigns by the voluntary sector, made up as it is from the people with disabilities themselves, their families and friends, aided by the professionals who help to interpret individual needs into person-centred solutions.

Voluntary organisations that form the subject of this study support the independence and person-centred rights of people with disabilities through various resources and supports. So invisible have these supports become to the uninformed observer that they might not be seen to exist at all but they are there in the episodic help with a life-style issue presenting today and which might not present again for months or years. The interventions of the organisations explored in this study form a type of virtual hyper-market where people with diverse forms of disabilities and very particular needs come for a specialism, a unique form of help or advice or hardware that sustains them as neighbours, participants, spectators and as engaged and disengaged as they wish to be.

The above is not the language of illness or health. Too often we continue even today to look at people with disabilities through a lens which sees them just emerged from the hospital, on their way to a rehabilitation centre or on their way back into medical care. In the last census, 595,335 people declared themselves as having different forms of disability. These are the people for whom the organisations in this study exist as facilitators of their independence and ameliorators of their disabilities.

It is true that there are people with disabilities currently living in inappropriate settings, and this needs to change. Equally true is the fact that there are many more people in the community who need disability specific supports and facilitated access to mainstream services to live ordinary lives. Community based services and supports make key public services like health, housing and education inclusive, in line with the National Disability Strategy, thereby contributing to the State meeting its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Planning to move people out of inappropriate settings into communities, without at the same time planning to support existing community based services and supports does not make sense. This research contributes to our understanding of the role of disability organisations in providing these kinds of services and supports that enable people to continue living independently in their communities.

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We are grateful too to Lillian Buchanan, of the Disability Federation of Ireland, who provided valuable information and other assistance.

Staff members of fifteen voluntary disability organisations made time in their busy schedules to participate in the research through questionnaires and interviews, and to provide additional documentation. Their commitment to the process was exemplary, as is their commitment to the people with disabilities they serve. Without their contribution the study would have been much poorer.

We learned a great deal from everyone we engaged with in the course of the research, and we hope the report does justice to the range and quality of the work of these organisations and of the sector as a whole.

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The research on which this report is based addresses a gap identified by the Disability Federation of Ireland and the Not for Profit Business Association, in the context of planned reform of disability services. They found in recent major policy statements, notably Value for Money and Policy Review of Disability Services in Ireland (DoH 2012), a lack of recognition of how voluntary organisations through their services and supports enable large numbers of people with disabilities to continue living in the community. They pointed out that the Value for Money and Policy Review concentrates on the high-expenditure services which support only a minority of people with disabilities, those living in institutional care, while the range and quality of the community-based services supporting the majority are not adequately acknowledged.

The study investigated the nature, scope, level and quality of community-based supports and services provided to people with disabilities and their families by voluntary disability organisations in Ireland. It also looked at relevant questions of value, and ‘value for money’. Its findings, presented fully in the main body of this report, are based on documentary research and detailed interviews with fifteen voluntary disability organisations. They demonstrate the vital and multi-faceted role of these organisations in supporting individuals with disabilities to live independently and well in their communities.

Voluntary organisations as mainstream disability specialists

In the National Disability Survey (2006), 18.5 % of the population reported a disability of some kind, and most of these people were living in their own homes. While national disability policy has a strong new emphasis on community settings, voluntary disability organisations have been providing community-based supports and services for decades, and, as this study shows, have evolved to become ‘mainstream disability specialists’.

Four intrinsic features make them a vital community resource: they are naturally person-centred; they have specialist knowledge and skills; they can innovate and adapt to change; and they have forged strong connections both within communities and beyond.

Naturally person-centred

Person-centredness is a core aspect of the ethos of the fifteen participating organisations. Many were founded by people with disabilities, and continue to be user-led. Others have developed strong consultation mechanisms to foreground the voice of their clients. This ethos is clearly reflected in the ways they plan and set goals with individual service users.

They are strongly committed to independence and autonomy for people with disabilities, through the provision of high quality personal assistant services,

training programmes, and assisting individuals to move from residential to independent accommodation.
Crucially, maximising independence often involves the organisations providing the necessary supports and services as flexibly as possible, and only when the individual needs them - often at critical points in their lives. Their holistic approach to clients' needs means addressing a wide range of practical and environmental issues, such as housing and transport, alongside more personal and social issues.

Specialist knowledge and services

Some organisations respond to gaps in mainstream health services by providing, or facilitating access to, specialised clinical interventions, and some employ dedicated support workers to help people with disabilities access the medical supports they need. Many organisations also regularly inform and train mainstream healthcare professionals, while all provide condition-specific information and advice to their clients, as well as information on relevant benefits and entitlements. The 'social model' orientation of voluntary disability organisations results in their knowledge and expertise extending across many fields, well beyond medical aspects of disability, and this is demonstrated in services such as personal assistance services, respite care, and assistive technology.

In addition, the organisations' insight into the risk of social isolation many people with disabilities face has led to provision of a range of community-based social supports and opportunities for participation and interaction, with an emphasis firmly on client choice.

In conclusion, voluntary organisations receiving State funding to provide disability-related supports and services see themselves as being both specialist and mainstream, and most definitely an integral part of the whole infrastructure which enables people with disabilities to live as well and as independently as possible in their communities.

Adaptive to change

These organisations have devised many innovative measures to address emerging or newly-identified needs, to improve services in response to client feedback, or to ensure that all of an individual's needs are met. Examples include: online support groups; setting up a supplementary private but low-cost personal assistant service; and the use of the 12 guiding principles of New Directions as a framework for eliciting service user feedback.

Adaptability is also an essential aspect of responsive, person-centred service provision for all those organisations who do not provide full-time support, and which operate on the basis that there can be 'a different scenario each time' they engage with a client.

In the context of reduced State funding, these qualities have also become key elements in budgeting, and all organisations have substantially reduced non-pay expenses in order to safeguard essential services. However, there is consensus now that cost-cutting opportunities are exhausted, and that any further cuts will have a serious negative impact on core services and supports, in contradiction of the new overall policy direction.

Connected and collaborating in the community and beyond

Across the fifteen organisations, there is very wide range of inter-connections: with other disability organisations; with statutory and voluntary agencies; community groups; local authorities; professionals in health and education; and with government Departments.

At an operational level, day-to-day collaboration with other professionals and agencies is central to their work, whether to resolve an immediate difficulty or to build up a long-term support network for an individual, which involves health and social services, their 'circle of support' of family and friends, local community groups, the education service and so on.

Their connectedness is strengthened through organisations' membership of national and international bodies (including research-focused organisations). This networking is hugely beneficial, resulting in shared expertise, experience and good practice models, and can also generate collective pressure for much-needed change.

QUESTIONS OF VALUE

Efficiency and cost-saving

While participating organisations have all maximised cost-efficiency in recent years, their services also make demonstrable savings for the State, perhaps by enabling a person with a disability to return to work and cease drawing welfare payments, or by keeping someone at home, rather than in a hospital or nursing home, through tailored supports.

Co-funding

The proportion of HSE funding received by participating organisations for the provision of services varies from 5% to almost 100% across the fifteen organisations. Hence, most are continuously seeking co-funding partnerships for their work and facilities, from sources such as FÁS, Pobal, EU project funding, National Lottery, Genio Trust, sales from shops, training and transport services etc., private and corporate donations, and fundraising.

Added value and value for money

Voluntary disability organisations, in contrast to most private concerns, bring added value to the services they provide on behalf of the State in many ways, including the huge contribution of volunteers, the flexibility and motivation of staff, and their generosity in sharing knowledge and expertise, and often the use of their premises.

Accountability, good governance, quality assurance

The Department of Health's Value for Money and Policy Review of Disability Services (2012) emphasised organisational accountability and good governance, and the achieving of quality in services. Participating organisations show themselves to be highly accountable: to their clients, boards, funders and other stakeholders. Their day-to-day practice is characterised by continuous improvement and quality assurance measures, and many are fully accredited within recognised European and Irish quality frameworks. Consultation and service user involvement, also highlighted in recent national policy statements, are significant features of these organisations.

Outcomes as measures of value and effectiveness

At national policy level, there is a determination to develop appropriate outcome measurement within an accountability framework. Voluntary disability organisations too are fully committed to demonstrating effectiveness by measuring client outcomes, and currently use a variety of frameworks and systems for this purpose.

However, they observe that their current Service Level Agreements focus on the more quantifiable aspects of a service, and do not adequately capture the very significant but less tangible outcomes achieved by individuals they support. Based on their own experience, they outline the challenges involved in developing a universal and comprehensive model of outcome measurement which also responds to differences among services and among service users, and express reservations about an 'over-quantified' or purely economics-based approach, particularly in relation to progressive disabling conditions. They also advocate exploring effective frameworks relevant to voluntary sector provision, such as the Social Return on Investment (SROI) model as developed in the UK.

Conclusion

The study highlights the voluntary disability sector's capacities, its community base and range of services, its responsiveness to individual need, and its value for all stakeholders. As 'mainstream disability specialists', these organisations play a critical role within the overall disability services framework. The sector can thus be seen as an essential resource for supporting people with disabilities to live independently in their communities and, as equal citizens in Irish society, to fulfil their potential and achieve their goals.

The report makes a number of recommendations, addressed to both policy makers and to the voluntary disability sector, which appear in Chapter 9, and also in the introductory report responding to this research, which has been published by DFI and NFPBA.

1. Introduction

1.1 Aims and purpose of the study

This report, and the research on which it was based, were commissioned by the Disability Federation of Ireland (DFI) and the Not for Profit Business Association (NFPBA). The research was carried out in September and October 2012 and the report was finalised in November 2012.

The study set out to explore in some detail the supports and services provided by fifteen different voluntary disability organisations, all of which are members of the Disability Federation of Ireland. Seven of them are also members of the NFPBA.
The overall purpose of the study, as set out in the Terms of Reference, was:

> to capture the nature, scope, level and quality of the community-based services provided to people with disabilities and their families by voluntary disability organisations[1].

The intention was to consider how these services, and the organisations themselves, are by their nature responsive to the individual needs, preferences and circumstances of people with disabilities. The study also aimed to focus on how these organisations function, not on the margins, but within the mainstream, as essential parts of a social/health infrastructure and continuum of supports which enable individuals with disabilities to lead lives which are as full and self-directed as possible.

A further broad aim was to illuminate aspects of the community basis of the voluntary disability sector, and their extensive record, over many years, of providing services which are firmly located 'in the community', and which support people with disabilities living mainly in their own homes.

The study came out of a particular context, and the decision to commission the research was a response on behalf of the voluntary disability sector itself to that context. This is the recent series of reviews carried out under the auspices of the Department of Health and the HSE, and the ensuing policy statements and decisions intended to reform and reshape provision for people with disabilities in the 21st century.

In particular, the July 2012 report, Value for Money and Policy Review of Disability Services in Ireland, was a catalyst for organisational and sector-wide thinking on the role and future of voluntary provision within a proposed future landscape of services which would be firmly located 'in the community' rather than in the

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[1] DFI and NFPBA: Terms of Reference, p.1

segregated institutions of an earlier era. This policy context is outlined below (Section 1.4)

It was acknowledged in the Review document that its analysis of the contribution of the voluntary sector was limited, and a number of practical, operational reasons were given for this. However, there is serious concern that new directions in policy and practice of disability services overall may now proceed on the basis of this analysis.

This report was commissioned to address this critical gap in evidence, and show how the voluntary sector has in fact pioneered many of the new approaches signalled in the recent major policy statements. It aims to contribute to redressing the balance by providing an overview and analysis of community-based services that is lacking in the Value for Money and Policy Review of Disability Services in Ireland.

1.2 DFI, NFPBA and the rationale for the study

The Disability Federation of Ireland (DFI) is the national support organisation for voluntary disability organisations in Ireland which provide services to people with disabilities and disabling conditions. The Federation acts as an advocate for the sector and it works:

> to ensure that Irish society is fully inclusive of people with disabilities so they can fully exercise their civil, social and human rights.

DFI has represented the 'disability interest' at national level through its role as a member of the Community and Voluntary Pillar within the Social Partnership process, and is a member of the Disability Stakeholders' Group (DSG) set up in 2006. The DSG works with government to monitor progress towards the vision of the National Disability Strategy, which is echoed in the national partnership 10-year strategy document, Towards 2016:

> An Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families and as part of the local community, free from discrimination. (p.66)

In 2012 DFI had a total of 127 member and associate organisations, addressing the whole range of disabilities: intellectual, physical, sensory, neurological, emotional and hidden, as well as mental ill-health (See Appendix A).

The eight largest disability service providers, who provide services mainly to people with physical and sensory disabilities, established the Not for Profit Business Association (NFPBA) as their representative body (also Appendix A). It engages with government and with the HSE on behalf of members and is also a member of the Disability Stakeholders' Group.

Its stated mission is the achievement of:

> a society where people with disabilities are enabled to participate as equal citizens and where our member organisations are recognised as leaders in the provision of successful efficient quality services to people with disabilities.

DFI and NFPBA are also represented on the HSE's National Consultative Forum, established in 2011, with the purpose of advising the HSE Management Team on the overall strategic direction, coordination, and monitoring of services to persons with disabilities.

Both bodies contributed substantial submissions and provided extensive information on behalf of their members to the Department of Health's reviews of disability services in Ireland, a process begun in 2009. They responded rapidly to the resulting report, Value for Money and Policy Review of Disability Services in Ireland, published in July 2012, and its stated intention:

> To contribute to the realisation of a society where people with disabilities are supported…to participate to their full potential in economic and social life, and have access to a range of quality personal social supports and services to enhance their quality of life and well-being. (p.xxvii)

Both organisations welcomed the person-centred principles and overall thrust of the new policy directions signalled in this and in the preceding reports published in 2011 by the HSE, notably Time to Move on from Congregated Settings: a Strategy for Community Inclusion (2011) and New Directions: Review of HSE Day Services and Implementation Plan 2012- 2016. Nevertheless, they felt that the picture these documents painted of the voluntary disability sector, and the conclusions drawn about the ways voluntary organisations provide day, residential and other services on behalf of the HSE, and funded by the HSE, was incomplete in a number of significant ways.

They argued in their submissions that the conclusions of the report on the Value for Money and Policy Review of Disability Services seriously underestimate and undervalue the overall role and significance of the sector, and fail to acknowledge how far voluntary disability organisations have already 'travelled the road' laid out in this set of crucial strategy documents. They have already achieved substantial reductions in the cost of services, through working innovatively and collaboratively, and themselves have been pioneers of the endeavour to:

> move away from institutional and congregated settings to a more inclusive society for people with disabilities, where services and supports will be tailored to meet the needs of the individual citizen. (NFPBA news release, July 2012)

In particular, they noted that, for various reasons including ease of data-gathering and cost estimation, the analysis in the Value For Money report focused on the older residential institutions which mainly serve people with intellectual disability, and on 'wrap around' day service settings. These are the 'high expenditure' areas of disability services, which cater for only a small proportion of the population with disabilities, while the majority live in their own homes in the community[2]. They argued that the challenges are very different in relation to the provision of adequate services for the majority already 'in the community', whose independence is sustained through a wide variety of supports and services from voluntary organisations working (often with HSE funding) in many different ways to address their individual circumstances and needs, most of them relating to physical, neurological and sensory disabilities.

DFI and NFPBA are concerned that, unless decision-makers recognise the significance of these services and establish ways to strengthen them, then both the overall mainstreaming agenda and the goal of self-determination for people with disabilities will be jeopardised. The not-for-profit services provided by voluntary sector organisations for people with disabilities are, in their view, both mainstream and specialised, and should be acknowledged and supported as such.

In addition, they have pointed out that the Value for Money and Policy Review of Disability Services classifies specific services which are fundamental to voluntary sector support for the independence and social inclusion of people with disabilities – such as housing, transport, 'environmental access' and assistive technologies – as 'indirect service provision', rather than assessing them as integral components of these services.

They also expressed concern that the Review's consideration of outcomes and value for money in disability services uses a 'unit cost' methodology appropriate to a fixed service pattern of institutional care, but not to the type of services covered in this research.

DFI and NFPBA took the decision to commission this piece of research in order to redress these imbalances in the Review, and to show how voluntary disability organisations in effect provide 'mainstream specialist' services which – including their own residential and day services – are all firmly based in the community. These services are bridges linking people with disabilities to statutory and other

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[2] The National Economic and Social Council recently estimated that disability services are being provided to approximately 50,000 people in the State, of whom approximately 4,000 receive full-time care in 'congregated settings'. These figures are based on the National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database (NPSDD). The NPSDD only includes information from people with a physical and / or sensory disability who are receiving or who need a specialised health or personal social service, and/or who are receiving a specialised hospital service, currently or within the next five years. It also does not include people aged over 66 years or over.

vital services and supports which may otherwise be inaccessible, enabling them to live as well as possible as equal citizens and as part of their local communities.

The later chapters in this report describe the many ways in which these aims are achieved, and the characteristics of voluntary sector organisations and their provision which now urgently need to be protected for the future.

1.3 Participants

The DFI member organisations which agreed to participate in the study are listed below, with their dates of foundation and statements of their missions, taken mainly from their websites.

Table 1: Participating organisations

Organisation	Date founded	Mission
Arthritis Ireland	1981	To help people live a good life with arthritis. Provide information and training for those with arthritis.
Epilepsy Ireland	1966	Committed to improving the lives of people with epilepsy in Ireland.
Cystic Fibrosis Association of Ireland	1963	To improve the treatment and facilities for people with cystic fibrosis in Ireland. To increase knowledge and awareness and give advice and support to people with CF and their families.
Cheshire Ireland	1963	Providing a range of support services for people with disabilities. Committed to empowering people with disabilities to live independently.
Central Remedial Clinic	1951	Leading the way for children and adults in Ireland with physical and multiple disabilities.
Enable Ireland	1948	To work in partnership with those who use our services to achieve maximum independence, choice and inclusion in their communities.
Headway	1985	To bring positive change in the lives of those affected by an acquired brain injury.
Irish Wheelchair Association	1960	A national organisation dedicated to the achievement of full social, economic and educational integration of people with physical disabilities as equal, independent and participative members of the community.

Organisation	Date founded	Mission
Muscular Dystrophy Ireland	1972	Muscular Dystrophy Ireland provides information and support to people with muscular dystrophy and related neuromuscular conditions, and their families, through a range of support services. Its objective is to promote, through practical empowerment, independent living for people with muscular dystrophy. MDI supports advocating for services to enable people with neuromuscular conditions to fully participate in society, and to live a life of their own choosing. MDI also aims to support and fund research into neuromuscular conditions.
MS Ireland	1961	To enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential. Providing information, support and advocacy services to the MS community.
NCBI	1931	To promote the independence of people who are blind or vision-impaired.
National Learning Network*	1995	Vision: A world of equal opportunities through learning. Mission: To promote equality by providing world-class training, education and employment access services and by actively influencing the creation of a more inclusive society.

Organisation	Date founded	Mission
RehabCare*	1996	Vision: Every person living life to the full and valued for and as themselves. Mission: RehabCare is the provider of choice of person-centred, health and social care services that facilitate people who are disadvantaged to participate in the life of their local community in ways that match their choices, aspirations and needs. Operates a wide variety of responsive health and social care services which reach into communities the length and breadth of Ireland.
County Roscommon Disability Support Group Ltd	1989	County Roscommon Disability Support Group Ltd (RSG) is committed to improving the quality of life and the standards of services to all people with disabilities, older people and children
West Limerick Centre for Independent Living	1997	Providing personal support services for people with disabilities to ensure that they achieve independent living and full participation in society.

**Both are members of the Rehab Group, which was itself founded in 1949.

1.4 National policy context

This report addresses current policy developments in relation to disability services. It is useful to briefly outline the main milestones in the development of policy (and practice) at national level over the last two decades, culminating with the very recent Value for Money and Policy Review of Disability Services in Ireland, which was the basis for the commissioning of this study.

Two very significant reports on disability services appeared in the mid-1990s. The first was A Strategy for Equality, from the Commission on the Status of People with Disabilities (1996), which recommended legislative change and proposed a redesigning of all disability services to enable provision ‘in the mainstream’. Shortly afterwards Towards an Independent Future: Report of the Review Group on Health and Social Services for People with Physical and Sensory Disabilities (1996) was published by the Department of Health. Referring to a wide policy context of United Nations and World Health Organisation guidelines, its stated aim was:

> To enable people with physical and sensory disability to live as independently as possible in the community. (Foreword)

These reports were the catalyst for the establishment, a number of years later, of the National Intellectual Disability Database (NIDD), and the National Physical and Sensory Disability Database (NPSDD), designed to gather data which could inform service planning. Many responsibilities for service provision were laid on the then Health Boards, and it was suggested they could consider implementing models of independent living accommodation themselves, such as those provided by the Irish Wheelchair Association and Cheshire Ireland. The recommendations of the Review Group (DoH, 1996) began by stating two important underlying principles:

> The objectives of health and personal social services for people with disabilities should be to enhance their health and quality of life.
> Research should be undertaken to develop outcome measures for disability services, so that their benefits can be evaluated.

It was the national health strategy document, Quality and Fairness: A Health System for You (Department of Health and Children, 2001) which consolidated the key concept of 'mainstreaming' in relation to services for people with disabilities:

> Services for people with disabilities should be the responsibility of those government departments and State agencies which provide services for the general public. (p.141)

This would entail rethinking services so they could accommodate a more diverse public, an approach labelled 'tailored universalism' by the National Economic and Social Council in its influential 2005 report, The Developmental Welfare State (NESC, 2005).
This approach was incorporated in further significant documents which established a new framework for disability services, with the aim of:

> Supporting equal participation of people with disabilities in society.

These were the National Disability Strategy of 2004, from the then Department of Justice, Equality and Law Reform, and the accompanying legislation, the Disability Act 2005. As a result, public bodies were now obliged to 'mainstream' their services and to provide equal access, including access to buildings and public employment, and to produce Sectoral Plans for their areas of responsibility, developed through consultation with people with disabilities. The new framework conferred important rights on people with disabilities, including the right to an assessment of need and statement of services to be received, though to date this has not been implemented in practice other than for children under five years of age.

There are a number of other important elements in the Strategy, including a legislative basis (the Education for Persons with Special Educational Needs (EPSEN) Act 2004) for improved educational access and progression for children with special needs, (though its provisions have not so far been implemented for economic reasons), and the establishment of the new advocacy service for people with disabilities. It also makes a commitment to supporting collaborative work between statutory and non-statutory agencies.

The State's intentions regarding its citizens with disabilities were encapsulated in the 'vision' set out in the National Partnership Agreement, Towards 2016, of:

> 'An Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life with their families as part of the local community, free from discrimination.'

This document utilised a 'life cycle' framework in its thinking about health and social services, in which people with disabilities, no matter what their age, are thought of as a specific category of potential service recipients with their own needs and rights to which resources should be directed in the interests of social justice.

Elaboration of the principles articulated in these earlier documents has recently taken place with the recent publication, by the Department of Health, of three significant policy and strategy statements addressing different aspects of disability services.

Time to Move On from Congregated Settings: A Strategy for Community Inclusion (2011) considers the situation of people with disabilities, largely intellectual, who have been housed in group-based institutional residential care, a scenario that runs entirely counter to the current vision of supported independence. The intention is a new 'care in the community' model and much greater autonomy: the old institutions will be closed, and their residents progressed into accommodation in community residential areas, where they will receive individualised services.

Soon afterwards came New Directions: Personal Support Services for Adults with Disabilities, which focused on changes in day service provision, to ensure it becomes more 'flexible, responsive and person-centred' (Foreword). A theme from earlier policy statements is prominent: the input that users of the centres should play in relation not just to evaluation of services, but to their design and implementation. The intention to support collaborations between services at local level is also restated. There is a strong focus on quality assurance and evaluation systems for outcome measurement, to be built into future service level agreements.

Building on these is the document most relevant as a context for this commissioned research, the Department of Health's final report on the Value for Money and Policy Review of Disability Services in Ireland (2012). Its points of departure are, first, the disjunction between stated disability policy, as outlined above, and a good deal of practice, particularly in relation to 'congregated settings', second, the fact that the system no longer responds to the wishes and aspirations of people with disabilities, and, third, the unsustainability of current costs in the system of disability services provision. It proposes:

> 'A fundamental change in approach to the governance, funding and focus of the Disability Services Programme, with the migration from an approach that is predominantly centred on group-based delivery towards a model of person-centred and individually chosen supports' (p.xvii).

It restates the overall vision of Towards 2016:

> 'A society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life, and to have access to the range of quality personal social supports and services to enhance their quality of life and well-being.'

And it aims to establish:

> a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities (p.164).

The Review, a very substantial document, covers areas such as efficiency, effectiveness, the shape of future service delivery, and improving the current system of 'performance indicators' for monitoring various types of service. It also looks forward to a new funding system based on individual budgets (already in place in other countries) which will support personal autonomy and choice.

Overall, the degree of change proposed is immense, and the pathways towards achieving such a radical transformation of services are yet to be fully articulated.
Those in the voluntary disability sector, who are already providing community-based services raised many questions about the Review and its

limitations, as outlined earlier, and about the place envisaged for voluntary organisations in the future landscape of services. These types of organisations perceive themselves to be almost invisible within the account of disability services presented in the report, although it considers itself well capable of contributing to a reshaping of the system and well placed to respond to the requirements for accountability, efficiency, effectiveness and developing appropriate outcome measurements. Chapter 8 of this study, on ‘value’ reverts to these themes.

1.5 The study: objectives and tasks

The Terms of Reference for the research set out the main objectives of the proposed study of these fifteen organisations – each with its own unique and clearly-defined role, remit, history, structure, modus operandi and relationships with clients, funders and other organisations and agencies. These objectives were:

- To explore the wide range of supports and services these voluntary/non-profit organisations offer to individuals with disabilities and to their families, and the modalities of their service provision.
- To investigate commonalities of approach, such as their person-centredness, both in the planning and delivery of service.
- To identify the different ‘specialisms’ inherent in the work of the different organisations, such as their specialist knowledge, specialist medical interventions, and specialist roles vis á vis statutory health services.
- To look at the links which voluntary disability services forge and maintain with statutory and other mainstream services in the localities where they operate.
- To investigate the value of the work of these organisations to all their stakeholders, as well as the ways in which they provide ‘value for money’ in relation to their HSE funding.

It was hoped that this research project, by means of a close engagement with a limited but very varied group of non-profit disability organisations, would highlight some of the most important characteristics of the sector as a whole, and would underline and reinforce both its current contribution and value and its future potential.

Planning the study

The intention from the outset was to study these and other key dimensions of voluntary disability organisations' work using primarily qualitative and exploratory methods. All DFI member organisations supporting people with disabilities to live in the community were invited to take part in the research. The sample selected fulfilled a number of criteria in terms of broadly representing the overall membership of DFI.

The participating organisations were requested to nominate a senior-level representative who could be interviewed on behalf of their organisation, and would also complete a pre-interview questionnaire and provide relevant documentation. A small Steering Group, with members from DFI, NFPBA and two of the participating organisations, was set up to liaise closely with the consultants and to guide the research.

Carrying out the research

There were two main elements to this study. Documentary research was first undertaken, involving: a review of the relevant research literature; a study of the national policy context and recent developments in relation to disability service; and a study of documentation provided by the participating organisations themselves.

Factual information about each organisation was obtained by means of a pre-interview on-line questionnaire, but the heart of the study was a series of fifteen lengthy in-depth interviews in which the central themes and topics of the research were explored with each organisation, and from their perspective.

The amount of detailed data produced was considerable, and required systematic study. A careful process of thematic analysis was used to produce the main findings, which are presented in chapters 5 to 8 below.

It should be underlined that this research, carried out over a relatively short period, did not in any sense set out to evaluate these organisations or their services. This would have entailed a very different approach from the exploratory, descriptive one that was employed. Instead, this report summarises, compares and brings together crucial evidence from the interviews and documentation, in a way which draws out their specific characteristics.

Each organisation nominated its own representative/s to participate in the study, and these individuals held a variety of posts: some were CEOs, while others were senior managers with responsibilities such as direction of services or strategic development. In addition, the participating organisations, varying in their focus, also varied greatly in size. This meant that not everyone was in a position to respond on all of the questions raised (for example, contractual relationships with the HSE). However, the wide range of perspectives contributed was in itself a source of rich data and a strong contribution to the research process.

The research findings illuminate important aspects of the voluntary disability sector as a whole, which perhaps have not been sufficiently highlighted by the organisations themselves, understood and recognised by policy makers, or taken sufficiently into account in recent policy debates, in particular the Value For Money and Policy Review of Disability Services.

The final task was to draw together the outcomes of the documentary study and the detailed work with this group of organisations into a report which will be of value to the voluntary disability sector and to policy makers at the highest level.

1.6 Outline of the report

The following two chapters put the research and its main findings in context. Chapter 2 provides an overview of international research literature on the supports and services provided by voluntary disability organisations, which play a key role in enabling people to live in the community. It also explores threats to the unique contribution of this sector, as presented in the literature, as well as the importance of measuring value for this sector, and the challenges involved, particularly in relation to governmental requirements for 'value for money'.

Chapter 3 profiles the fifteen participating organisations in relation to: their history; geographical reach; ethos; funding; supports and services provided; their personnel and staffing; and how they have been affected by the recession.

The second main section of the report presents the findings of the qualitative and documentary research, which illuminate the 'mainstream disability specialist' role fulfilled by voluntary disability organisations in the community. The four key characteristics highlighted in Chapters 4 to 7 are: a person-centred approach; specialist knowledge and skills; innovation and adaptive capacity; and connectedness both within the community and beyond.

Chapter 8, the final part of the report, looks at 'value' in relation to voluntary disability organisations, and considers a number of different value-related dimensions: accountability to stakeholders; issues and challenges in measuring outcomes for people with disability; consultation processes which enable responsiveness to clients' needs and preferences; 'quality assurance', or how organisations assess their performance and benchmark themselves against external standards; and finally the concepts of 'added value' and 'value for money', as viewed from the perspective of the voluntary disability organisations themselves.

Chapter 9, the final chapter, presents a summary of the findings of this research, concluding with a number of recommendations in relation to both policy and practice, based on these findings.

2. Literature review

This literature review was conducted with a view to finding and analysing existing international research that relates to the two core research questions of the present study: (i) the particular contribution made by voluntary disability organisations in supporting people with disabilities and their families in the community; and (ii) the issue of measuring the value of that contribution. This literature review was not originally envisaged as a component of this research, but early in the process it emerged that it was a necessary one. Its findings played an important role in informing the development of research tools and provided a useful framework for the analysis of findings. As is clear in subsequent chapters, it also provides considerable validation for the findings of this exploratory study.

While it does not claim to be comprehensive, a number of academic research databases were used in this search, including the Social Sciences Citation Index (SSCI), Academic Search Complete (EBSCO), and the Education Resources Information Center (ERIC). In addition, specific searches were made of two journals whose focus is the community and voluntary sector: Voluntas and the Nonprofit and Voluntary Sector Quarterly. This was supplemented by a search of online ‘grey literature’.

The parameters of the review, as outlined above, are very specific, particularly considering that the focus was on voluntary disability organisations, rather than the voluntary sector as a whole.[3] This meant that, while a significant and ever-growing body of research has been conducted on the voluntary sector as a whole, only a small number of studies were identified as being truly relevant to this study. What is interesting is the way in which relevant studies tended to emerge in contexts of political and economic change, when voluntary disability organisations found themselves under increased pressure or when their survival was under threat. For example, funding restrictions introduced by a neo-liberal government in Canada in the 1990s; a policy shift in Australia away from traditional forms of public assistance for vulnerable populations, and towards one based on contracting out services and competition; and more recently in the UK, increasing pressure from policymakers for evidence of a broad contribution from the sector.

2.1 A distinctive contribution

It is clear that the voluntary sector plays an important role in supporting people with disabilities who are living in the community. A UK report (Haugh and Kitson, 2007), for example, identified people with disabilities among the top five beneficiaries of voluntary organisations’ work in addressing social and environmental issues, improving access to employment and in providing goods

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[3] Focusing solely on literature relating specifically to voluntary disability organisations proved too narrow. The review was then extended to include research on voluntary organisations providing health and social services and support.

and services. Their contribution is also reflected in the finding of an EU survey that 28% of the public believed voluntary organisations were truly responsible for improving access to public spaces for people with disabilities (cited in Pillinger, 2003). Over the past twenty years, a body of research literature has explored the key traits of these organisations that enable them to play such an essential role in enabling people with disabilities to live in the community.

Innovation and capacity for adapting to change

Innovation has been described as playing a central role in the success of both for -profit and non-profit organisations (McDonald, 2007). This is particularly so in a changing environment, where a failure to innovate can lead to failure, whereas an innovative approach is positively linked to organisational performance (ibid.). A focus on innovation, reflected in a mission statement for instance, can create a climate in which innovative projects can emerge develop and thrive.

Innovation and flexibility also allow organisations to cater for diverse needs, in a way that would otherwise not be achievable (Hanlon et al, 2007). In the context of an ageing population and the increasing importance of providing care in the community, the Institute for Public Care (IPC) in the UK has recently stressed the urgent need for innovative approaches across care services that can deliver improved outcomes at good value (IPC, 2012). They argue that the nature of voluntary organisations that provide such supports make innovation and adaptability easier.

While innovation is a key feature of the voluntary sector, however, it is not an inherent one. The IPC set out five characteristics of the sector which make this characteristic more likely:

- A strong commitment to shared values at governance level, and an enthusiasm for sharing creative ideas and good practice from all staff.
- A commitment to reinvesting any surplus to enhance and develop services still further.
- The capacity to raise extra funding to support innovative practice or new projects through public giving and charitable donations.
- A well trained and committed workforce able to offer ideas about innovative practice.
- The capacity to share best practice through infrastructure and information sharing organisations.

Another UK study showed that innovation can arise as a response to the policy context (Osborne et al, 2008). A longitudinal survey, it found that the innovative capacity of voluntary organisations shrunk when the policy context in the 1990s moved away from one that privileged innovative activity and towards one that favoured the development and provision of specialist services.

Complexity as a strength

The voluntary disability sector is especially complex, diverse and therefore difficult to capture; the HSE's recent Value for Money and Policy Review of Disability Services cites lack of comparable data on the sector as the only reason for its exclusion.[4] Yet this does not mean that this complexity is a weakness. On the contrary, one influential UK paper (Billis and Glennerster, 1998) argued that the voluntary sector's core strength lies within its very complexity. After all, the sector is complex and diverse because each voluntary organisation arose to address a specific issue or meet the needs of a specific group of people.

Many disability organisations were founded by people with a disability, and have evolved to exhibit both the characteristics of statutory administrations as well as the features of a user-led, membership based organisation. These features enable voluntary organisations to respond more sensitively than other bodies (i.e. State agencies and the private sector) to certain 'states of disadvantage'. This particularly applies to potentially marginalised groups, whose needs are not adequately addressed by government, due to inadequate pressure from voters. For such groups, voluntary organisations can possess the required 'motivation, sensitivity and knowledge' (1998: 89) to address otherwise unmet needs. Being less bound by potentially limiting structures and rules can enable organisations to adapt quickly and effectively to changes, such as in funding or policy (HM Treasury, 2002). They can use diverse strategies for accessing and mobilising resources (Haugh and Kitson, 2007, Hutchinson et al, 2007). They can be adaptable in the context of changing circumstances, and can move the focus of their resources, as needed.

Independence and trust

Some studies highlighted that independence from statutory agencies can mean that organisations are not bound by structures or rules in the ways in which more traditional public sector agencies are (e.g. HM Treasury, 2002). They are independent and so can try to deliver services in new and innovative ways. They are free to offer responsive services which are user-centred as they are not driven by budgets and targets within the public sector. This has been associated with a high level of trust among stakeholders and the general public regarding the voluntary sector. This trust has been related to their perceived independence, the fact that they are more likely to be driven by a specific mission and the absence of profit-related goal (Hansman, 1980). Moreover, voluntary organisations tend to be perceived as being independent of government and therefore free to be unequivocally on the user's side (Pax and Pierce, 2005).
For organisations that are largely dependent on State funding, however, overly stringent accountability criteria and funding conditions can reduce their

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[4] In this regard, organisations emphasised that they provided all the information as requested by the Value for Money Review Group.

independence, and therefore their innovative capacity. Other authors point to the 'clear danger' that closer relationships with the State will undermine levels of trust, and to the way in which reliance on government funding potentially blurs the boundaries between the government and the third sector, in terms of governance and control.

Voluntary sector receipt of funding for the delivery of public services largely develops in the context of political and social inequality. Such a development inevitably leads to closer relations with the State, which can bring discontinuity between 'espoused purpose and values' and 'operative purposes and values'. In Australia for example, the voluntary sector became increasingly drawn on by the government to provide primary care services in the 1990s, under a doctrine of 'constructive compassion'. In this context, one research paper highlighted how this development served to undermine the 'comparative advantage' of the sector, as it required organisations to adopt increasingly formal structures and practices (Dollery and Wallis, 2001).

A similar development took place in New Zealand, where again research showed that if the voluntary sector is mandated to deliver basic services, competition amongst third sector organisations for financial and other resources can mean the pool of resources spent on other social supports might diminish (Crampton et al, 2001).

Recognising these risks, a HM Treasury report (2002) concluded that in contracting with voluntary organisations to deliver services, Government needs to ensure that regulation is proportionate and the independence of the sector is recognised. The greater the regulation, it notes, the greater the risk that the best features of the sector are smothered. Under the last UK Government, the Government moved to longer term funding terms for the voluntary sector, with the term determined by the objective the funding sought to achieve rather than by convention. This followed a report by the National Audit Office which showed that this kind of arrangement would not only give funded organisations greater financial stability but could also provide better value for money for the Government in the long run.

Naturally person-centred

Within the voluntary sector, disability organisations have a particularly strong history of being user-led, with many having emerged from the social movement of people with disabilities, with its mantra of 'Nothing about us without us'. Briefly, the social model of disability directly challenges traditional approaches to disability, whereby challenges associated with people with disabilities such as unemployment are addressed within a medical model (NDA, 2012). By contrast, those working within the social model of disability 'argue that solutions presented within this [medical] framework fail to link structural, economic, social and environmental arrangements of the given society' (NDA, 2005).

The grassroots-oriented and social model based provision of voluntary disability organisations means that they tend to be more responsive to the people they seek to support (Skocpol et al., 2000). Moreover, being closely connected to service users/clients means that disability organisations are less likely to display features of philanthropic paternalism and are more likely to take a truly empowering role and to be responsive to the needs of those they represent (Crampton, 2000). It has also been suggested that voluntary organisations can play an important role in enabling the mobilisation among people with disabilities (Acheson and Williamson, 2001).

A person-centred approach is grounded in the social model of disability (NDA, 2012). It has been described as 'a way of discovering how a person wants to live their life and what is required to make that possible' (NDA, 2012). The person-centred model of service delivery was developed because:

> people with disabilities often find it difficult to get the kinds of basic services, opportunities and experiences most people take for granted – and even when they do, they frequently find they are required to somehow fit into someone else's idea of what that service, opportunity or experience should be like and how they should act, think or feel in relation to it (NDA, 2012).

Not surprisingly, given the strong adherence to the social model of disability among disability organisations, person-centredness is a major feature of voluntary disability organisations. Such organisations tend to have evolved to be naturally person-centred, in the sense that the individual has always been at the centre of their mission and purpose. They play an important advocacy role, providing a voice to those groups that would otherwise be marginalised. This can also mean organisations are an important source of knowledge of user/client needs.

Social capital

Social capital has been described as being about 'the value of social networks, bonding similar people and bridging between diverse people, with norms of reciprocity' (Dekker and Uslaner, 2001, cited in IPC, 2012).

Examples might include making use of community contributions, providing the maximum opportunities for employing local people, promoting good links between people and organisations in a community and providing people with opportunities to volunteer (IPC, 2012). Voluntary organisations providing supports and services have been recognised as key players in developing local social capital (IPC, 2012).

2.2 Impact of funding pressure: some lessons from Canada

An economic downturn can threaten the value of the voluntary sector. This is because it can lead to increases in demand that outpace funding available from government and other sources, while at the same time constrained public funding causes increased competition for funding with the private for-profit sector as a result of State policies favouring market-based modes of service delivery. It can also cause difficulties in acquiring and adapting operations to high-cost new technology, as well as challenges in retaining skilled staff, as wage levels and working conditions deteriorate.

In Canada in the 2000s, neoliberal emphases on competition and privatization translated into an increasingly competitive environment of service delivery in which voluntary organisations bid against each other and against private sector firms to deliver health and welfare services. They were put under pressure to diminish levels of service provision to clients, particularly those in greatest need, reduce staffing levels and institute survival strategies that negatively impact working conditions. This led to organisations relying even more heavily upon volunteer labour, and modifying operations in a struggle to cope with harsh conditions (Chouinard and Crooks, 2008). Negative outcomes, though not necessarily intended by policymakers, did occur: many voluntary organisations experienced a decrease in their capacity to deliver services to people with disabilities. And while disability organisations were finding it increasingly difficult to deliver services and supports to an increasing number of people, in the context of this transition to a ‘mean and lean neoliberal state’, the State was failing to meet the needs of people with a disability (ibid.).

Another Canadian study of the impact of (politically related) changes in mental care and social assistance programmes in Canada (Ontario) in the context of the recession of the early 1990s highlighted a decrease in income supports and growing pressure on informal support networks (Wilton, 2004). Collectively, such developments signalled a shift in emphasis from individual control and empowerment to individual responsibility (an important distinction as often the two terms become conflated). Psychiatric patients were ‘free’ to be more responsible for their own well-being, but in a context characterised by fewer resources and greater professional authority and State supervision.

2.3 Measuring the value of voluntary disability organisations

Impact measurement is especially important where voluntary organisations spend public money, make claims of community responsiveness and/or have objectives that have implications for the community as a whole (Lecy et al., 2011). In the UK, concern has been raised regarding the evaluation capacities of, and processes used by, some voluntary organisations. However, when done properly and with the right support, measuring impact provides a number of potential advantages. Murtaza (2012) provides a useful synthesis of such advantages for voluntary organisations engaged in providing supports and services:

Advantages of measuring impact:

- Enhance incentives for improved performance, motivating and inspiring frontline staff.
- Improve services and supports for beneficiaries.
- Influence the debate on ‘what works’.
- Raise an organisation’s profile.
- Encourage voluntary organisations to become more closely aligned with community perspectives, and enhance shared learning about good practices and programmes.
- Provide greater assurance to donors and supporters, and help expand their support.
- Help achieve the morality and transparency considerations that NGOs subscribe to by increasing their credibility and influence, and enhancing their ability to influence larger stakeholders to become more accountable.

Finally, by initiating more effective accountability mechanisms, it has been argued that voluntary organisations can potentially avoid inappropriate and top-down accountability mechanisms being imposed on them by external stakeholders and protect themselves from politically-motivated attacks.

Impact measurement: challenges and concerns

Despite the importance and the potential value of impact measurement, research literature highlights a number of challenges faced by voluntary disability organisations in measuring impact, as well as concerns regarding its potential impact on their role and value. It is of concern that evidence from the UK, Canada and Australia suggests that an emerging emphasis on accountability, efficiency and competition can threaten to supercede a person-centred and personalised approach to supporting people, and to flexibility, as well as placing an undue administrative burden on organisations. For example, a UK-based study argued that the use of performance measurements can result in the standardisation of services, inhibit innovation, and ultimately result in ‘mission drift’. It also argued that the use of measurement is never neutral or objective, but that it emerges in moments of uncertainty and change. Another paper adds the point that traditional understandings of accountability in organisations are linked to ownership. Non-profit organisations do not have owners but ought to be accountable to their stakeholders.

2.4 Towards measuring value for money

In the context of a recession, externally imposed impact measurement requirements are more likely to focus on value for money. Yet concern has been raised regarding the application of one-dimensional measurements in evaluating the effectiveness of voluntary organisations. Lecy et al. (2012) identify a broad scholarly consensus that this approach is not useful or effective, despite being commonly used. Such formal structures or measurements may even serve to undermine the very strengths that give voluntary disability organisations a comparative advantage. As highlighted in an HM Treasury consultation exercise (cited in a 2007 report), a narrow focus on financial efficiency and value for money of some public funders in the UK caused unintended consequences for the sector's ability to truly transform services. In response to this, the Treasury called for acknowledgement of broader outcomes and a recognition of wider social gains from funders.

As one commentator concludes, 'some way must be found to reconcile the existing nature of voluntary organisations with public accountability'. But this emerges as a clearly difficult issue, with a lack of consensus regarding appropriate alternatives. Over recent years possible models have begun to emerge; one example is the Social Return on Investment (SROI) approach, as promoted by the UK government. This model aims to calculate the net financial value of a project by calculating in financial terms the total value of benefits against the cost of investment. It involves a detailed focus on outcomes, including the various ways in which people's lives are impacted and for how long, and has been praised for giving 'voice to intangible aspects of a project that might not otherwise appear in evaluation reports' (Marden, 2011). However, its limitations have also been flagged: particularly the way in which subjective feedback from service users/clients is translated by an evaluator into an approximate market value. A clear criticism here is that certain outcomes, such as increased self-confidence, are not always reducible to a monetary value.

In 2010, the UK-based think tank Demos published the report, Measuring Social Value (Wood and Leighton, 2010), which aimed to gain an insight into the capacity of the third sector (in the UK) to measure and communicate its 'social value'. It found that several diverse methods exist, and are being used by voluntary organisations to measure their value; this may relate to a 'poor penetration of social value reporting' in the sector.

The SROI model has been promoted as a tool for measuring social value by the UK government 'thanks to its unique feature of attributing monetary values to 'soft' outcomes'. However, while government policy has focused 'on making this complex and resource-intensive tool accessible and user-friendly to the third sector', their research suggests that the majority of voluntary organisations are not 'SROI ready'. Despite these concerns, at least one voluntary organisation in the UK (the Princess Royal Trust for Carers) has used the SROI method successfully. In an evaluation of its five carers' centres, they used it to show that together the five centres generate annual gains to society of at least £73 million (Baker Tilly, 2011).

2.5 Key findings

- Certain features of voluntary disability organisations make them particularly well placed to support people with disabilities living in the community. These include:
    - A capacity for innovation and flexibility.
    - Adaptability in the context of changing circumstances.
    - Independence (which creates trust).
    - A naturally person-centred approach, grounded in a social model of disability.
    - Social capital (in the sense of bringing people together and developing strong community networks).
    - A specific mission that relates to niche skills and expertise.

- These important qualities are potentially as fragile as they are valuable. For example, extreme levels of regulation can compromise their independence. Funding restrictions can significantly reduce disability organisations' capacity to provide needed services and supports.

- Measuring the impact of supports and services is an important responsibility of voluntary disability organisations. Done effectively, it can also bring many benefits to organisations, such as improving service standards, enhancing incentives to improve performance among staff, raising an organisation's profile and even influencing debates on what works.

- However, there are risks associated with impact measurement. Use of one-dimensional performance indicators can potentially lead to 'mission drift', and the broad consensus on this approach is that it is neither useful nor effective.

- Over recent years, efforts have been made to develop a means of effectively capturing the social value of supports and services provided by voluntary organisations. One example is the Social Return on Investment (SROI) model. It has been promoted as a tool for measuring social value by the UK government due to its unique feature of attributing monetary values to 'soft' outcomes. Yet not all outcomes can (or arguably should) be translated into a monetary value. One study described the SROI model as resource intensive. Nonetheless, it remains a model worth investigating; at least one voluntary organisation (for carers) in the UK has successfully used it to highlight the value of their work.

3. Fifteen voluntary disability organisations: an overview

3.1 Introduction

This chapter sketches an overall profile of the fifteen voluntary disability organisations participating in the study, contributing views, perspectives, and a wide range of illustrative information and documentation, to illuminate the key questions of the nature, scope, level and quality of the services they provide.

What stands out in this overview is the enormous variety among the organisations in dimensions such as their mission, makeup, operating structures, and the particular work they do. There is variety too in the range of experience, depth of knowledge and social and organisational connectedness built up by these organisations, and shared across the voluntary sector, over decades. What also stands out is how much they share in terms of their overall ethos, and the way in which this influences their work and practice.

Both this variety and these shared commitments and values are significant resources which could be drawn by the State as it begins to implement its new thinking on policy and future provision of disability services.

This chapter uses information drawn from pre-interview questionnaires, which was expanded in interview discussions, and supplemented by documentation provided subsequently. Organisations' own websites were also consulted.

The following sections outline similarities and differences across a number of dimensions: the organisations' history and ethos, their geographical reach, the disabilities they focus on, the supports and services they provide and their staffing and funding.

The final section reports on the impact of the recession on these organisations and their work.

3.2 History and ethos of voluntary disability services in Ireland

Voluntary disability organisations have been a notable part of Irish civil society for decades, and the history of the fifteen organisations, who participated in this research is broadly representative of the whole membership of DFI. More than half of the participating group were founded 50 or more years ago, and have become an almost taken-for-granted part of the Irish civic and social landscape, with a wide range of influence and connections.

Before organisations like these began to emerge, disability provision in Ireland was largely in the hands of religious bodies, who provided care on a charitable basis in large 'segregated' institutions.

The new entities were part of a broader development of lay organisations set up by private citizens to address social issues. In the case of disability organisations, their establishment might involve charismatic founding figures, people with disabilities themselves, their families, and physicians. This was a different not-for-profit model, one that was situated firmly within the community and the natural contexts of the person with disability: their family and other relationships, education, employment, and cultural and leisure activities.

Their focus was on people with primarily physical and sensory disability (though sometimes with a neurological basis), whose needs were largely not being met by the older models of care, or by State medical services. And their primary aim was simple: to achieve, through all means at their disposal, better outcomes and better lives for people with these conditions.

The first of the fifteen to be founded was NCBI in the 1930s, followed by Enable Ireland and Rehab in the 1940s. The 1950s saw the establishment of the Central Remedial Clinic, and in the 1960s Cheshire Ireland, Epilepsy Ireland (then known as the Irish Epilepsy Association), the Cystic Fibrosis Association of Ireland and the Irish Wheelchair Association were all set up, followed by Muscular Dystrophy Ireland, Arthritis Ireland, and Headway.

The County Roscommon Disability Support Group Ltd, and later the West Limerick Centre for Independent Living were both offshoots of a new international movement of people with disability: the Independent Living Movement, influential in Ireland from the 1980s.

Ethos – then and now

The ethos of many early initiatives in the voluntary response to disability in Ireland was characterised by a paternalistic approach and an emphasis on ‘care’, alongside a drive to overcome the stigma and isolation associated with certain diseases or conditions. Over time, the thinking and the languages of rights, independence and equality came to the fore, alongside significant changes in the population being served[5].

Two quotations from participating organisations exemplify the prevailing 21st century ethos among the non-profit disability sector:

> We are working with service users to help them achieve maximum independence, choice, and inclusion in their communities. Our core values include: a social model of disability, rights-based approaches, person-centredness, independence and the right to self-determination, equality, and integrity.

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[5] This arose in some cases because of improved medical treatment, and increasing longevity overall, leading to a much greater number of middle-aged and older people with certain disabilities. NCBI estimated that over half the people who contacted them for advice, support and practical services in 2011 were over 65.

> This organisation exists to enable and empower people …to live the lives they want to live.

There would appear to be little or no gap between this language and the language of the high-level ‘vision’ statements in the recent Department of Health policy and strategy documents. One of the key statements in the Introduction to the July 2012 Value for Money and Policy Review of Disability Services in Ireland, describes the characteristics of the HSE’s proposed new model of service delivery in this way:

> Choice, control, independence and community inclusion are the keys to an effective person-centred service. (ibid.p.xxiv).

3.3 Structure

One strand in the history of many of these organisations is that of their gradual extension beyond their original geographical base, and their incorporation in their own particular ways into the fabric of local life. Many organisations have built up a wide geographical reach and solid local ‘embeddedness’ over time, and consciously nurture this as one of their most valuable attributes.

Among the fifteen organisations, there are perhaps four main types, with regard to their geographical reach and catchment areas.

(a) Firstly, two of the organisations in the study, the County Roscommon Disability Support Group Ltd and the West Limerick Centre for Independent Living, are county-based, and have similar origins in the Independent Living movement, which aimed to provide services designed and managed by people with disabilities themselves, which would enable them to engage in employment, education/ training, or simply to remain an active part of their families, social networks and community activities. These organisations are consciously ‘in the community’ and in the Roscommon case, also consciously aiming to provide employment locally for non-disabled members of the community, as well as to make person-to-person links at a very local level.

The other thirteen organisations all operate at national level, but in different ways. One of the differences is that between organisations with a strong individual membership base, closely involved in principle in decision-making at local and national (Board) level, and those that do not, so are more properly referred to as ‘not-for-profit’ organisations.

(b) The ‘member-directed’ national organisations could be considered the second type in relation to their geographical presence. Of these, the Irish Wheelchair Association stands out with its 20,000 members across Ireland, while Epilepsy Ireland has 8,000, Cystic Fibrosis Association and Arthritis Ireland around 2,500. Muscular Dystrophy has almost 700 (all 2011 figures). In principle, all these members have the right to influence the direction and management of the organisation, and in practice they are its influential community base, organised into local branches across the country distinct from, but interconnected with, the national leadership and also with the supports and services the organisation provides in various regional locations. MS Ireland is a good example of the geographical reach of a membership-based organisation (see box below).

Box 3.1: National, regional and local structures: example of MS Ireland

MS Ireland has its headquarters and a national Care Centre in Dublin, plus community-based staff in 9 regional offices providing services to people with MS (advice, information and support, counselling, case work and 'living with MS' programmes). The regional centres are hubs within a network of 39 volunteer-based local branches, and in addition there is an individual membership system. Just over 4,600 members were registered in 2011.

The local branches, usually of 10-20 people, raise funds, but may also disseminate information, and act as a point of contact and support. The branches meet three times a year as the MS Council, which elects three members to the Board of the organisation.

(c) In contrast, organisations in the Not for Profit Business Association may not have an individual membership structure nor a significant volunteer dimension (the Irish Wheelchair Association is the most striking exception in relation to membership, while Enable Ireland has a 6,500-strong volunteer network). However, they all have widespread and well-established national networks of service provision, which are firmly integrated into their local communities. Some examples are (2011 figures):

- The 670 staff of the National Learning Network provide rehabilitative training to around 5,000 people with disabilities and mental health difficulties in 57 different locations across the country, many of them on high streets, in shopping centres and business parks, and close to the agencies and entities of greatest relevance (employers, VECs, local community groups etc.)

- In 2011 Cheshire Ireland, through its staff of 650, provide full-time care and support to around 400 individuals with significant levels of disability, of whom 43 are living independently in their own homes. Others live in the 20 residential centres based in communities across Ireland; small-group settings such as apartments in ordinary residential environments are gradually replacing older types of accommodation.

- NCBI, the main provider of services to people who have impaired vision or are blind (thought to total almost 250,000) has a staff of over 160 providing support and services to over 9,300 individuals in 2011. It has day centres in Dublin and Wexford, a training centre in Dublin, and 8 regional centres supporting a network of community resource workers in every county in Ireland.

There would appear to be little or no gap between this language and the language of the high-level ‘vision’ statements in the recent Department of Health policy and strategy documents. One of the key statements in the Introduction to the July 2012 Value for Money and Policy Review of Disability Services in Ireland, describes the characteristics of the HSE’s proposed new model of service delivery in this way:

(d) A fourth pattern, of widespread but not comprehensive geographical coverage, characterises the Central Remedial Clinic, which is also distinguished from the other participating organisations by its core provision of clinical and therapeutic services for children and adults with physical disabilities. It has a dual role, both as a specialised national information and referral resource and as the primary provider of a range of specialised interventions and services (such as gait analysis) for a regional catchment area of Dublin and surrounding counties, where it also provides adult day services and vocational training programmes and runs two schools. It also has a children’s clinic in Waterford, and a Limerick clinic, providing services to people in the mid-West.

Over time, all of these organisations have built up extensive banks of contacts and working relationships in the many localities where they are based, alongside an intimate knowledge of these areas. Their relationships with each other, with statutory services (by no means exclusively the health services) and with the many different community-based or voluntary bodies are a vital resource for supporting people with disabilities as equal citizens in their communities.

This ‘connectedness’ of the voluntary disability organisations is explored further in Chapter 7.

3.4 Supports and services provided

Client numbers

(d) A fourth pattern, of widespread but not comprehensive geographical coverage, characterises the Central Remedial Clinic, which is also distinguished from the other participating organisations by its core provision of clinical and therapeutic services for children and adults with physical disabilities. It has a dual role, both as a specialised national information and referral resource and as the primary provider of a range of specialised interventions and services (such as gait analysis) for a regional catchment area of Dublin and surrounding counties, where it also provides adult day services and vocational training programmes and runs two schools. It also has a children’s clinic in Waterford, and a Limerick clinic, providing services to people in the mid-West.

Over time, all of these organisations have built up extensive banks of contacts and working relationships in the many localities where they are based, alongside an intimate knowledge of these areas. Their relationships with each other, with statutory services (by no means exclusively the health services) and with the many different community-based or voluntary bodies are a vital resource for supporting people with disabilities as equal citizens in their communities. This ‘connectedness’ of the voluntary disability organisations is explored further in Chapter 7.

Assistant service of the West Limerick CIL provided several hours of support each week to 120 people in the County. At the other extreme, a national help-line might provide thousands of people with well-thought out and relevant information which helps them take the first step towards seeking help with managing a newly-diagnosed condition.

Types of disability addressed

The initial concern of several long-established disability organisations was with a specific condition – Enable Ireland originally focused on cerebral palsy, Rehab on tuberculosis – but they have since broadened out to include a much wider range, as the population of people with physical and neurological disabilities has changed, thanks to improved medical treatments or public health measures. The Centres for Independent Living were established to serve people across the whole range of disabilities (though this rarely included intellectual disability).

However, another important group of organisations in the voluntary disability sector has concentrated on advocating for better understanding of, and improved clinical treatment options for, a single condition such as cystic fibrosis, or muscular dystrophy.
What types of disabilities were the focus of each organisation's work at the time of this research? The following table shows the preponderance of physical, neurological and sensory disabilities, with more than half the organisations also catering for multiple disabilities.

Types of disability addressed

Type of disability	Number of organisations
Physical	14
Neurological	12
Sensory	9
Multiple disabilities	8
Mental health	4
Intellectual disability	4
Hidden disabilities	3

The Irish Wheelchair Association added: 'anyone with mobility problems', highlighting how their organisation and others such as Arthritis Ireland and the NCBI work with a range of different conditions, and support people who experience both very mild and very severe effects. They are also approached for information and advice by many who do not consider themselves ‘people with disability’, and who would not fall within official definitions of disability such as that in the Disability Act 2005[6].

In the interviews, several organisations underlined the relevance to their mode of service provision of the wide variety in types and duration of difficulties that can occur as a result of different conditions. Organisations may mainly work with individuals in relatively stable situations; others may support individuals with progressive conditions whose health and ability gradually deteriorates; and there are organisations which serve people whose need for support is unpredictable because of the episodic nature of their condition (for example, epilepsy).

Supports and services provided

The results of the pre-interview questionnaire underline the multi-faceted nature of many of these organisations, and the wide range of roles and profiles among the group as they respond to different aspects of disability. Their orientations include:

- providing clinical and therapeutic services.
- providing social, emotional and practical support to individuals and families.
- advocating for improved treatment by statutory health services of people with a particular condition, and fundraising for relevant clinical research.

In terms of the specific work they do:

- **Twelve or more of the fifteen organisations provided:** information, advice, family support, social programmes, transport, assistance with access to statutory services, and public awareness.
- **More than half (8 to 11 organisations)** were involved in individual advocacy, day services, a helpline, local support groups, aids and appliances, assistive technology, education/ training, employment-related services, planned respite care, assessment of need, referral to statutory services, lobbying/ campaigning, and training providers in statutory services, particularly health services personnel.
- **Six or seven services (just less than half) provided:** holidays and/or outings, community integration programmes, care in a person’s own home, rehabilitative training, psychological services, PA services, emergency respite care, occupational therapy, physiotherapy, and social work support.

[6] ‘A substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life.’

- **Smaller numbers (4 or 5)** listed supported employment, housing-related services, psychological assessment, specialist nursing, speech/ language therapy, and residential services. 3 provided clinical/ medical services and 3 provided group therapy. 1 organisation only provided a psychiatric service.

3.5 Funding

The variety in the level and type of State funding provided to these fifteen organisations for their service provision is striking.

Many (but not all) of the voluntary disability organisations were founded on the basis of philanthropy and public fundraising, and subsequently moved to a 'hybrid' situation where some activities and services began to be funded from State sources, notably the HSE.

Currently, the fifteen participating organisations cover a wide spectrum as far as the proportion of finance they receive from State sources is concerned. At one extreme, the HSE provides almost no funding to the Cystic Fibrosis Association, while at the other; four very different organisations with hugely varied budgets derive virtually all their income, from HSE sources: the West Limerick Centre for Independent Living, Muscular Dystrophy Ireland, Cheshire Ireland and RehabCare.

Eight organisations receive HSE-only funding for provision of specific services, but at varying levels. These organisations raise the remainder of their budget through their own efforts.

Table 3.2: HSE Funding to Organisations

Number of Organisations	HSE Funding
1	< 25%
1	26% - 50%
1	51% – 60%
1	61% – 70%
1	71% - 80%
3	81% - 90%

Source: Pre-Interview Questionnaires

Two very different organisations at opposite ends of the scale in terms of size and complexity, in addition to their HSE funding (61-70% in one case, 26-50% in the other), receive significant proportions of their income through FÁS.

Other State sources include Pobal, the Family Support Agency and Lottery funds, while several organisations compete for EU project funding.

It was interesting to hear in discussions how organisations which do not receive a majority of their funding from State sources value the independence this brings, as well as the associated strengthening of motivation and inter-personal links within an organisation which is substantially dependent on its fundraisers.

3.6 Personnel in the voluntary disability organisations

Paid staff

The size of the paid staff across this range of organisations is as varied as other aspects of their profiles. A high proportion of staff to clients will obviously be a feature of organisations providing 'hands-on' clinical or therapeutic services, one-to-one assistance with tasks of daily life, or intensively-supported training, while lower numbers will be employed in organisations focusing on information, advice, advocacy etc.

The following table includes the employee statistics that were provided for the study.

Organisation	Full time staff	Part time staff
Cheshire Ireland	650	0
NLN	298	371
RehabCare	340	720
Enable Ireland	449	672
NCBI	92	98
CRC	266	160
West Limerick CIL	11	110
MS Ireland	46	48
CFAI	8	5
Epilepsy Ireland	9	16
Headway	42	13
Arthritis Ireland	9	0
Co. Roscommon DSG	0	101
MDI	14	10
IWA	258	2,037*

* includes 230 core staff; 320 CE participants; 1,487 PAs

'Skill mix'

Against a background of encouragement by government to match staff skills and qualifications more closely to needs of service users, some voluntary disability organisations have made innovations, not to cut their own costs, but intended to ensure the appropriate provision of vital therapeutic services by statutory and voluntary services together. One example of this is the system of Physiotherapy Assistants recruited and managed by MS Ireland, who work in an integrated way with the community physiotherapists ('complementing their vision of what the service is'), to provide the level of intensity and duration of therapy which is essential to good outcomes.

Box 3.2: Skill Mix: Example of MS Ireland

MSI physiotherapy programme

Research carried out by UL for MS Ireland concluded that consistent physiotherapy and other physical activity had a positive effect in maintaining mobility and flexibility. Because statutory provision could not provide the necessary frequency, MS Ireland raised funds to recruit and train (to minimum FETAC level 5) Physiotherapy Assistants, who work under the supervision of a chartered physiotherapist and in the overall context of a jointly-devised physiotherapy and exercise programme, 'Getting the Balance Right'.

Modelling independent living: people with disabilities as staff and Board members

The original Independent Living Movement insisted that all its activities and services were to be decided, planned and managed by people with disabilities themselves. Although only two of the fifteen organisations followed this exact model, most began with a strong presence of people with disabilities (or, in the case of children with disabilities, their parents), who made alliances with relevant professionals and with those with influence and access to finance. However, the history of growth and professionalisation in the whole voluntary sector in Ireland (as elsewhere) has sometimes meant a shrinking space for those who are the organisations' purpose – whether older people, those from a minority ethnic background or those with disabilities.

At the time of this research, however, three of the fifteen participating organisations have appointed people with disabilities as CEOs or senior managerial staff and their presence sends a very powerful message, not only to their own organisations but to the whole sector.

Other data provided on this question was incomplete, and could only provide an indication of the level of involvement of people with disabilities on staffs and boards of management. It was pointed out that individuals do not necessarily 'disclose' a disability when seeking employment or standing for election to a Board, and that the nature of some conditions precludes all but the most exceptional individuals from taking on highly demanding full-time roles. The data suggested, however, that even where relatively few people with disabilities (or close family members) are in senior paid positions, they do have a substantial presence on most organisations' Boards, and can be influential beyond their numbers in that role. This was known to be the case in twelve of the fifteen participating organisations.

More analysis would be useful, but the presence of people with disabilities in leading positions in an organisation is clearly congruent with their fundamental ethos, and instils confidence and trust in those who seek its advice and support.

Volunteers and volunteering

From comments in the interviews, it would seem that a number of organisations are actively considering a wider range of roles for volunteers within their structures.

At present, volunteers feature in the work of the organisation mainly in the role of fundraising, although at local level this often encompasses informal awareness-raising, and also as Board members. Organisations like Enable Ireland and MS Ireland count such volunteers in their thousands, and in the context of involvement of people with disabilities themselves, it was noteworthy that Arthritis Ireland counted among its large number of volunteers 200 people with disabilities, and Epilepsy Ireland some 1,500.

Volunteers play a very important role as members of local branches (MS Ireland reported approximately 400, and CFAI 300). In addition to fundraising (often for local facilities and services), branch members may form and maintain local support groups, provide information and support to the newly-diagnosed, and assist with access to local services, and so are an integral part of their organisation's overall contribution.

Some organisations with residential or day services, such as Cheshire or RehabCare, have always welcomed the presence of volunteer 'befrienders' who link with individual clients to provide social interaction, and may accompany them to cultural or leisure activities of their own choice.

At present, it is rare to find people working on a voluntary basis in these organisations in roles equivalent or supplementary to paid front-line staff. However, several organisations are now giving serious consideration to internships and similar systems as a strategy for responding to financial constraints. They are acutely conscious, though, that great care and significant investment is required in the planning, initiating and management of such programmes, if the quality of service provision is to be maintained.

One example of an organisation already embarked on this path is Cheshire Ireland, which utilises an EU-wide volunteering scheme for recent graduates in appropriate disciplines; they gain valuable work experience while their skills and fresh knowledge contribute to the work for which core long-term staff are responsible.

Further insights into what it might mean to be a ‘voluntary’ organisation were provided by several of those interviewed, who identified ways in which paid staff were also, at times, volunteers themselves. Examples included: front-line staff putting in extra unpaid hours to keep a facility open in an evening or at a weekend, or assisting in their own time with essential fundraising for overheads; management-level staff sitting on Boards of relevant local community or county bodies, again in their own time.

Staff roles in relation to clinical and therapeutic services

Depending on the nature of the organisation and the work it does, a voluntary disability organisation may or may not itself employ clinical medical and therapeutic staff, and there are interesting variations across the fifteen participating organisations.

At one end of the spectrum is the Central Remedial Clinic which employs a range of clinical staff, including nurses, and therapeutic staff (including speech and language therapists) especially in Dublin and Waterford. Enable Ireland, also because of the nature of its services for children and adults, also employs a significant number of such staff. Most of the other thirteen do not directly employ clinical and/or therapeutic specialists, although many work extremely closely with them for specific purposes. This group includes the National Learning Network, West Limerick CIL, County Roscommon Disability Support Group Ltd, Arthritis Ireland, Cystic Fibrosis Association, Muscular Dystrophy Ireland, and the Irish Wheelchair Association.

There is one neuro-psychologist employed by Headway, while Epilepsy Ireland employs one specialist epilepsy nurse (the first such post to be established in Ireland). MS Ireland employs one physiotherapist based in the West overseeing the training of and services delivered by their physiotherapy assistants as well as a physiotherapist, occupational therapist and an MS Nurse Specialist at the MS Care Centre. NCBI employs a small number of family therapists, though this is not a major part of its services.

Nursing staff are employed by Cheshire Ireland in both residential and own-home settings but ‘to do those tasks only nurses can legally do’, and as supervisors and trainers of care staff. While the MS Care Centre also employs nurses, it primarily links closely with the local primary care teams, and consultants where appropriate.

The same is broadly true of staffing in the Resource Centres run by RehabCare around Ireland. Although, a few services have a physiotherapist and occupational therapist, all the others work on the basis of accessing specialised medical and related personnel in the locality, thus ‘building up the localised support system for the person’.

One very specific function of non-clinical staff employed by voluntary organisations is the way some of them have become an integral part of the healthcare provided by hospital consultants in their clinics, in a real 'continuum of care' which is explored further in Chapter 7.

3.7 Voluntary disability organisations in the recession

The participating organisations were asked in the interviews about the challenges they face in the current economic situation, in which those in receipt of HSE funding have suffered across-the-board cuts, which have been applied in several phases over the last few years.

The uniform way in which these have been applied is seen as inequitable by many, especially those with lower levels of HSE funding, and/or those who have already achieved efficiencies and had the same cut as those who have not. A further cut in Budget 2013 is anticipated[7]. In addition, no capital funding has been available for some time.

Many see themselves as nearing crisis point, despite the efforts they have made to review all their expenditures and become as efficient as possible. They pointed out a number of other factors, in addition to the funding cuts, which have brought them to this point.

For many, their own income from other sources has reduced too; in particular, national-level fundraising income has in most cases dropped in the last few years, as the recession has affected discretionary spending. Interestingly, one or two organisations whose local fundraisers contribute largely to local projects, reported only a small recent difference. Even where organisations might have buildings they no longer need, as a result of their move to more dispersed and community-based services and supports, boards of management consider it would be irresponsible to sell at current market prices.

One of the most significant changes in the overall environment is that 'alongside declining income, we are facing an increased demand for our services'. A number of elements in this difficult situation were outlined:

- The population of people with a particular condition is increasing; thanks to improved medical care, babies are surviving where previously they would not have lived, and people are living much longer with that condition, cystic fibrosis being an outstanding example.

- There are huge pressures on other health and social services, especially statutory health services, where posts remain unfilled and so vital medical care is often seriously delayed.

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[7] At the time of going to print, the cut in 2013 was yet to be finalised.

- Individuals, who might in better times have been willing to pay for necessary treatment or supports not provided by statutory health services, cannot now do so.

A number of supports and benefits for people with disabilities living at home have already been substantially affected by cutbacks, and there is now huge anxiety about the effects of any further reductions, particularly among parents fearing cuts in the domiciliary care allowance. Organisations are increasingly being contacted by people looking for reassurances they cannot give, and this inevitably has an impact on staff.

Although there was praise from several of those interviewed for the local HSE staff ‘on the ground’ whom they deal with on a daily basis, some noted the huge loss of ‘organisational intelligence’ and memory, especially in HSE local areas, because of early retirements, which can directly affect many of the services the organisations provide.

What has this changed funding environment meant for the organisations so far? There have been some positive outcomes in terms of innovations, discussed in Chapter 6, and the new situation has triggered some comprehensive and thoughtful organisational reviews, with beneficial effects. One organisation commissioned a review of services which demonstrated their efficiency and positive comparability with services offered by statutory and commercial providers, as well as their overall economic value in terms of positive quality of life outcomes for their clients.

But other outcomes for organisations are not so positive:

- There have been widespread staffing cuts, including cuts at senior management level, reductions in salaries, and ongoing review of staffing rosters. One CEO commented that, as large organisations with clinical/ nursing staff become ‘flatter’, the capacity for adequate supervision of staff can be threatened.

- Most organisations have made significant reduction across the whole range of non-pay items, which clearly affects services and supports.

- Withdrawal of capital funding has meant that more fundraising and other income-generating activity is necessary to cover costs of planned new facilities and essential developments in physical infrastructure.

A common view expressed by several of those interviewed was that, by now, they have achieved all the cost-savings possible, and are ‘down to the bone’ now. For one service, funded almost entirely by the HSE, the situation is especially difficult: ‘we’ve implemented all the efficiency measures we can since 2009…but we can’t go further’. Organisations graphically described the implications of all of this for the quality and availability of their services, some voicing the fear that if services are reduced beyond a certain level, the irony will be that people with disabilities now living in the community 'will be forced back to residential care'. As of now, one organisation reports that its staff in the regions 'can't get resources (from statutory health and social services) for people, who then end up in nursing homes'.

They also speculated on the possibility that other providers, operating with 'a medical model' and very different ethos – focusing on profits and the viability of the business rather than the dignity and independence of people with disabilities – will ultimately replace the person-centred voluntary service providers.
Some specific negative impacts on services and service generally of the current situation include:

- Staffing in one organisation was felt to be reaching dangerous levels: 'now safety is a consideration'.
- There are growing waiting lists for services and supports.
- Support staff such as community resource workers have less time to spend with each person, contradicting their basic principles of support for individuals and families.
- Less phone contact can be initiated, hindering effective preventative work.
- Home visits are being partially replaced by phone calls.
- Transport services are being curtailed.
- In one primarily PA service, 'people are only getting their basic needs met, not the other needs they have' (social contact, cultural and recreational activities etc.)
- A respite care centre, previously operating continuously, now closes every other weekend and the day following a Bank Holiday to save staff costs and overheads.
- For some organisations providing residential full-time care and support, there are concerns about the new HIQA standards, in the absence of State funding to support them to make changes in this context.

These are just some of the facts contributed and observations made during the course of the interviews, and they show a sector which has taken major measures in relation to its own costs and the efficiency of their operations. Their observations also show a deep frustration on the part of many organisations who feel they are facing new barriers to their effectiveness.

They also show voluntary disability organisations still determined to do their utmost to protect their ethos, the services founded on that ethos, and the people they support – as well as to take proper care of their staff in their increasingly demanding roles – yet which face the prospect of still more financial difficulties to come.

3.8 Key findings

- The data gathered in the interviews and through the questionnaire showed the enormous variety of organisations in the voluntary disability sector as exemplified by this sample. These organisations are serving a very wide range of people, conditions, and needs, and have developed extensive knowledge and built up important networks of contacts and working relationships, in many cases over decades. These are huge resources for the future development of the best possible services to people with disability.

- The organisations exhibit a strong, progressive, shared ethos, which focuses on rights and equality, the centrality of the individual, the promotion of independence, social inclusion, participation, and the opportunity to lead a life of one's own choosing.

- Their not-for-profit status means that any surplus is re-directed back to the services they provide and the individuals they support through those services.

- Most have wide geographical coverage, and all show strong integration at local, community level, which is also a crucial resource for future developments.

- Each organisation has been markedly affected by cutbacks in funding and other aspects of the current difficult economic times. This has necessitated reviews of costs and gains in efficiency, but has also forced them to make decisions which are viewed as detrimental to the quality of their services. All are concerned for the future, yet they are determined to continue prioritising their services to, and relationships with, people with disabilities and their families.

Part Two: Voluntary disability organisations as mainstream disability specialists

This part of the report presents four key themes that emerged from interviews with participating voluntary disability organisations and the documentary analysis. They concern core characteristics shared by these organisations, all of which highlight the important role they play in supporting people to live in the community:

- Being naturally person-centred.
- Having specialist knowledge and skills.
- Being adaptive to change, through innovative and flexible practices.
- Being connected.

These findings address a number of this study's objectives: exploring the range of supports and services provided by these organisations; investigating commonalities of approach; identifying the range of specialisms within the sector; and looking at the links which voluntary disability organisations forge both on local and national levels. Together, the findings illuminate how voluntary disability organisations act as mainstream disability specialists; work to support people with disabilities and their families live in the community; help people to keep healthy and live as independently as possible, out of residential care and in a position to take advantage of services and supports available in community settings.

4.1 Introduction

> Simply thinking that we are being person-centred does not make us person-centred. It is what we actually do in everyday exchanges with people that ultimately reveals our true priorities. (New Directions, 2012, p. 64)

This chapter explores the person-centred approach inherent in the ethos, evolution and practice of the fifteen organisations participating in this study. Here the focus is on the naturally person-centred approach to supporting people evident in both the ethos and the practice of all participating organisations.

Essentially, the concept of being person-centred was understood by interviewees as an approach that works towards addressing people's individual needs and aspirations. A key role was that of listening to the individual; one participant described this as 'the essential thing'. A closely related role was that of working with the individual to identify their aspirations and needs. It was at this critical point that an organisation's real contribution was seen to come into play – as one person placed it: 'at the interface between the staff member and the person with a disability'.

This understanding of a person-centred approach strongly reflects the definition of a person-centred approach provided in the NDA's guidelines on person-centred planning, which describes it as 'a way of discovering how a person wants to live their life and what is required to make that possible'.[8] It also clearly adheres to the definition provided in government policy:

> When services are person-centred, the service provider truly listens to and respects the choices that the individual makes and tailors services and supports around these choices. (New Directions, 2012)

4.2 Ethos

Being person-centred was a core aspect of the underlying ethos and approach of organisations. Some interviewees reflected that being person-centred was a core value of their organisation long before the term 'person-centred' was coined, and certainly before it became so commonly used in policy documents. And when they spoke of their organisation's mission and ethos, an important unifying factor was the centrality of the individual's wishes and needs:

> [It's about] allowing people to live life on their own terms.

[8] See: www.nda.ie/cntmgmtnew.nsf/0/12af395217ee3ac7802570c800430bb1/$file/05_whatispcp.html

> We have adopted the mantra, “Nothing about us without us.”
> The service is totally focused on the individual – it is one of our core values.

For many, being person-centred was strongly linked to the way in which the organisation had emerged and evolved. As outlined earlier, many of the participating organisations were founded by people with disabilities. Some were, and still remain, membership-based, with members impacting on the work of the organisation in different ways:

> The biggest single thing here is that we are member-focused. ... [The members] direct the organisation and we are very proud of that and are really keen to keep that ethos. Because it means that you’re actually delivering what people with disabilities want rather than me sitting here in my office saying, “This is what we should be doing”.

And user consultation is not limited to membership organisations; others described a range of consultation mechanisms with people who accessed their supports and services:

> I would be setting up our services in such a way that I train people and shape the service and develop the service. But it would be very much my role then to ensure that its people with [this condition] who are leading out that service in a lot of ways.

Across all these contexts came the view that this close ‘proximity’ to service users or clients has played an important role in their capacity to respond to people’s needs and a history of a naturally evolved person-centred approach. Managers of membership-based organisations who were not members shared a strong awareness of their responsibility in maintaining that crucial link between the work and focus of the organisation, and the views and insight from members. One person said that managing a membership-based organisation was like being a custodian of an ethos of placing the member at the centre of all decisions and developments.

A history of close user involvement also allowed organisations to play an important advocacy role, by providing a voice to those groups that would otherwise be marginalised. This in itself was another way in which being person-centred was reflected in organisations’ approach:

> One of the important functions of voluntary disability organisations like us is that we do become the voice for the people that we represent...It can be quite difficult for the member to have that ability and confidence themselves.

4.3 A person-centred ethos in action: planning and practice

Many organisations engaged in an in-depth and individualised person-centred planning process with clients/service users. A good example of this process is described in Enable Ireland's strategic plan, which describes person-centred planning as 'a system in which the service user is central to the direction of his or her own service. The process brings together key people in a person's life who support him or her in defining a vision for the future, setting goals and implementing realistic life plans'. In one example of this process, person-centred planning was broken down into the following elements:

- Identifying needs together with the service user and their family and devising an individual service plan to satisfy them.
- Ensuring that individuals are at the centre of all decisions that affect them.
- Supporting and empowering service users to advocate on the issues that matter to them

One very important feature of such plans is that the individual is at the centre. Interviewees described how important it was that this be reflected in the services and supports provided for each individual. One outcome of this approach could be that:

> what we could be dealing with one day is entirely different to another day.

Interviewees highlighted the importance of each individual having their 'circle of support' (family, carers, friends) identified and involved in this process, with their level of involvement depending on factors such as individual need and preference, the age of the individual (family members are more involved when the service user or client is a child). Some organisations like Headway, conduct three interviews at the initial stage: one with the client and the family, one with the family and one with the individual themselves. The aim here is to ensure the planning process reflects the needs and goals of the individual as well as involving the family.

Organisations described a holistic approach to the assessment and planning stage, with a wide range of issues and needs addressed:

> We take the person where they're at. [We ask] what are the barriers, what are the issues, what are the challenges, … [what is] preventing them becoming part of the community, being in the labour market if that's where they want to be, in higher education…having good relationships, being healthy, being able to plan a future…being able to do all the things we take for granted? What's preventing that? Let's identify [them] then let's identify the strengths, the competencies [the person's needs] and let's develop a plan with the person. The person is the main part of it, they decide all these things.

The importance of defining goals

An important part of this process was enabling people to identify their personal goals. Some described how they had adopted specific person-centred planning tools for this purpose. For example, the IWA have adapted a formal process, based on the 'Personal Outcome Measures' system[9], which identifies twelve quality of life indicators with an individual and works with them in identifying their goals and support needs regarding these indicators. MS Ireland use a 'solution-focused approach' which is 'all about putting the person, and their sense of what they need to live their life well, at the centre'. Through this process, which is led by the individual, barriers to achieving goals and means of addressing them are identified and planned out.

A large part of this work was about enabling people to gain (or regain) control of their lives; as one organisation described it, it was about trying to 'give people the tools to feel that they are meaningful people again'. Others spoke of how one goal, when set, might reveal many other (sometimes unanticipated) issues. For example, one participant shared the experience of a client who set a goal of getting her medication from her local pharmacy, rather than relying on her family to do this. Out of this goal, it emerged that she had up to then never owned a handbag, which in turn highlighted the extent to which her independence had been restricted up to that point:

> She didn't have a key, she didn't have a hairbrush, she didn't have any of those things that as women we would take completely for granted. ... But what did that say? It said that her family didn't see her as an independent person, they didn't see her as needing to have a purse with money in it, they didn't see her as needing to have a key to her door because there was always somebody to let her in, there was always somebody to go to the chemist, there was always somebody to hand over the money ... Her independence was hugely compromised by that.

This process of enabling someone to set personal goals, even apparently straightforward ones, clearly has the potential to lead to meaningful improvements in people's lives. In that regard, interviewees described that while goals might vary enormously on a surface level, each one is treated as equally important. So while one individual set the goal of sky-diving and another of being able to butter their

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[9] This was developed in the 1990s by the American-based organisation, the Council on Quality and Leadership, which works towards improving the quality of life for people with disabilities. Based on a series of focus groups with people with disabilities, personal outcome measures relate to factors that impact on people's quality of life and are applied and evaluated against the unique characteristics, needs and desires of each individual (www.thecouncil.org)

toast, or of making a phone call, none was seen as more or less significant than another. And meeting those goals was treated as a priority.

Often, helping someone to achieve a goal requires ongoing support, and a number of steps along the way:

> A major milestone for [one client] was to be able to get two buses to our service. That is major, for his wife, for him. And he is King of the Walk right now because he can do that. Now, two years ago, he wouldn't have had a chance of doing it. ... It's all the little building blocks we put in place.

Person-centred planning was sometimes cited as a very powerful way of measuring the achievements and efficacy of an organisation. This was particularly strong among organisations that engaged in a very formal person-centred planning process, because this process involved the setting of clear and specific targets.

Box 4.1: Person centred planning process: example of CRC

Clients of the Central Remedial Clinic on the person-centred planning process

'I have been successful in getting a college placement this year. This is a great achievement in my life, seeing as I had been previously told when I was a teenager that I would never achieve this. ... How wrong have I proved them.'

'For the first time in my life I have moved out of my home to an apartment. ... I am managing successfully to do everyday activities and live independently.'

'I now realise that mine and people's expectations of me were a lot lower. This I think was part of the problem of me not grasping my intellectual abilities and my real potential.'

'I hope to go to university and gain more experience in education. ... Eventually, I would like to gain full employment and this would mean that I do not have to rely on people for financial reasons.'

Source: CRC internal documents

This person-centred approach to setting and achieving goals was not limited to formal planning processes. Examples also emerged in less formal supports provided. For example, Headway runs support groups for people with an acquired brain injury. They described how members of one support group identified a need for an ID card stating that they had an acquired brain injury. This idea emerged after members of the support group shared negative experiences in public and social settings (examples included being asked to leave a pub because they were assumed to be drunk). The support group designed this ID card which Headway then produced.

Other examples include a person-centred approach being taken in planning activities at resource centres. In one of NCBI's resource centres, a group of men who shared carpentry skills decided they wanted to build a boat, and this was facilitated by the centre. In the IWA resource centres, those attending also choose their activities and programmes, as well as menu for their meals, on a weekly basis. RSG described how they invited service users to co-interview their personal assistant.

The MDI's new, purpose-built information and resource centre is another example of putting a person-centred ethos into practice. The building's design was largely informed by input from members of the organisation: DFI's Genio funded project, 'Listening and Changing' involved consulting members on the design of their new purpose built headquarters. The findings played a central role in its design. Opened in 2011, it has a wide range of facilities to enable people with neuromuscular conditions to access information and support services, including comprehensively equipped aids and appliances facilities, which members can try out. An information centre is open to members on a drop-in or organised basis, while a second floor consists of a self-contained, fully wheelchair accessible three bedroom apartment which is available for short breaks to MDI members as well as people with other disabilities.

4.4 Enabling independence requires a person-centred approach

Throughout the interviews, the two concepts of person-centredness and independence emerged as closely interlinked. This is evidenced, for example, in both concepts appearing in key sources such as mission statements and strategic plans. After all, being person-centred was largely seen as being about giving people choices, and about enabling them to take control of their own life.

For this reason, promoting independence was also a strong feature of the ethos of organisations, which was frequently discussed within the context of providing person-centred care. For example, Cheshire, traditionally a residential care provider, has in recent years been increasingly involved in supporting people to live in their own homes. Through their person-centred approach to working with clients, they have found that 'very very few people want to live in shared accommodation'. This interviewee described how these people, when moved from residential into independent living, 'could be transformed both in their own eyes and in their families'.

Box 4.2: Moving from residential to independent living

Barry's story of moving from Cheshire's residential accommodation to his own home

I moved into my new home in The Bungalows, Letterkenny on the 2nd of September 2008. Initially, there were some minor hiccups with the heating and some other things but nothing drastic and I have now settled in well.

The things that I have found to be different and much better in my life are:

- Having my own space and privacy.
- I can now come and go as I please.
- I can have long lie-ins in the morning when I am not working.
- Being able to do things when I want.
- Being able to cook.
- Having friends visit when you want them around.
- Being able to watch favourite programmes on television.
- Going shopping with P.A. (Personal Assistant) when I want, and going to the cinema.
- Being more independent and having the freedom to try new things and being able to build on certain interests, i.e. cooking.
- All of my family visit once a week.
- The enjoyment of going shopping for furniture and purchasing goods to make my house nice, bright and homely because it's where I will be staying for a long time.

I am very happy in my new home, and would recommend this for anyone who shares their home with someone else. I also know and am comfortable and aware that if I was stuck for anything, I would know who to contact whether it be my key worker, personal assistant or Manager in the Apartments.

Source: Cheshire Ireland Annual Report, 2008

Moreover, it emerged that enabling independence for people in the community required a person-centred approach: one that responded to the needs and goals of the individual, as articulated by them.

The life cycle approach and providing supports when needed

Working towards optimising people's independence in a person-centred way can necessitate intervening at different stages in a person's life. The NCBI described how they take a life cycle approach, linking in with people so as to enable them to continue living independently through different experiences.

For example, one of their clients lost his sight during second-level education. NCBI staff trained him in using assistive technology, a walking cane and in navigating his school campus. Four years later, the same individual went to Trinity College Dublin to study Law; the NCBI stepped in again to support him in his new environment. Years later, when he began working in the Law Library, he contacted the NCBI for further support. Over a total period of about 20 years, they provided him with 60 hours of support. Outside of these hours, the individual was living independently in the community, without needing to access care services.

As the above example clearly shows, this very person-centred approach is necessarily flexible and adaptable; different people require a different level of support, at different stages of their life. It can make it difficult for the organisation to price the support they provide. Here, being person-centred entails a certain level of unpredictability, as it is based on the individual's own support needs when they arise. As another interviewee described it:

> It's about sitting down with that individual ... wherever that individual is at, and trying to navigate the next step for them.…They may choose to do [one thing], and they're okay for a while, and then they come back to us because in six to twelve months' time they need to come here for respite, or you want a conversation about your engagement with your neurologist ... or if there's a vocational rehabilitation need. … It's very much led by the individual.

In this context, the importance of early intervention was highlighted:

> We're at the early stages of early intervention. We want to enable people before they get into a care regime. We don't offer home helps. ... [in order] to help people live independently. We try to keep people out of care. We're pre-care. And pre-care is prevention. And prevention is taking the loss of function and working with that to maximise people's ability.

Enabling independence through a person-centred approach was also highlighted in the way that some organisations allowed clients to use services in a non-linear way. Headway, for example, described how important it is that individuals are allowed to return to particular services or supports if they wish. In this regard their model of service delivery is informed by the 'slinky model' outlined in their report on best practice in rehabilitation following brain injury by the British Society of Rehabilitation Medicine (2003):

> The critical point of this model is that, although clients may need to access different services as they progress, their transition between services should be smoothed by communication and sharing of information between services, so that they progress in a seamless continuum of care through the different stages. They also acknowledge the fact that rehabilitation is not a linear process, and clients will often need to visit and revisit points on the continuum as their recovery progresses and new challenges emerge[10].

[10] Rehabilitation following Acquired Brain Injury - A Headway Review of Guidelines and Evidence. Available at http://www.headway.ie/download/pdf/rehabilitation_review.pdf

Box 4.3: Enabling independence through training

Individual plan

This course aims to provide people with sight loss the chance to build confidence, gain new skills and independence before moving on to further training or education. The NCBI have been providing it for more than ten years. It also gives people the opportunity to earn a FETAC accreditation. The course is one year full-time but is flexible depending on individual needs.

NCBI's rehabilitative training foundation course

NCBI staff meet with each individual to discuss their aims and help them set out short and long term goals for the course. Based on these goals, participants can choose the modules that interest them the most. A mentor is assigned to them, who provides advice and information and who reviews goals with the individual every three months.

Independence

The aim of the foundation course is to encourage independence. Mobility training helps to build confidence in using specific routes or public transport. Working with a mobility trainer, participants become familiar with routes from their house to places in their local area such as the bus stop, the shop or the bank.

The course content covers daily living and kitchen skills, which includes sewing on a button, ironing, using a washing machine and other kitchen equipment and everything from making a cup of tea to cooking a meal, with the opportunity to take further cookery classes.

Computer training and work seeking skills provide a base for further training and employment; participants can gain further advice on employment from NCBI's employment advisor.

The foundation course also provides people with an opportunity to take up new hobbies and meet new people. As well as access to a fully equipped gym, recreational activities include yoga, music, pottery and crafts.

Modules

Modules include: daily living skills; kitchen skills; job-seeking skills; computer training; recreational activities; Braille; handwriting; mobility training; telephony; literacy and numeracy; pottery; cultural studies; and personal effectiveness:

> If they didn't have [the training], they wouldn't learn. They would think it's an awful place of no return they're going into. ... In those ways we can increase people's independence.

Sources: Interview with NCBI; NCBI website.

Arthritis Ireland also provides training that aims to promote independent living. In 2006, they successfully applied for funding from the HSE to provide the training programme, Living Well with Arthritis, on a national basis. This is a very significant aspect of their work and strongly reflects the relationship between being person-centred and enabling independence. A programme of non-medical interventions, it is 'designed to complement the medical treatment of arthritis with simple but effective techniques'. It is an evidence-based programme that was originally developed in the Patient Education Research Centre in Stanford University (US). Like the training work of the NCBI, it is a self-management programme that aims to help people develop the skills they need for daily independent living with arthritis. So far, 65 people have been trained to deliver the programme, and thousands of people have received this training.

Box 4.4: Arthritis Ireland's Living Well with Arthritis self-management training programme

This programme of non-medical interventions is designed to complement the medical treatment of arthritis with simple but effective techniques. This six week course enables participants to manage and understand the various elements of arthritis more effectively. International evidence of this programme, which was developed by the Patient Education Research Centre at Stanford University, California, has shown that it is effective in reducing pain, reducing reliance on health professionals and medication and improving people's sense of wellbeing.

It covers the following subjects:

- Cognitive pain-management skills
- Coping with fatigue
- Planning setbacks and goal setting
- Healthy living and weight management in arthritis
- Dealing with negative emotions
- Exercise techniques for weak and damaged joints, developed by physiotherapists
- Understanding medication.

Most courses involve about 18 participants and trained leaders either have arthritis themselves or are health professionals. An evaluation of the programme found that it led to statistically significant:

- Decreases in fatigue and distress levels;
- Increases in knowledge, skills and confidence to manage the disease;
- Increases in people's use of cognitive techniques to manage symptoms;
- Decreases in visits to doctors, hospitals and emergency departments.

Some testimonials:

'Arthritis used to have a hold of me (but) now I truly believe that, while arthritis is unpredictable, I am in a better position to take control of it.' Laura, 25

'Their programmes are brilliant. People can learn in six weeks what it took me 20 years to discover.' Tim, 45

'I felt less crazy; I felt less alone, the isolation was removed. I knew that there was support out there and all of a sudden the world became a different place for me.' Maeve, 48

Sources: interview; Arthritis Ireland's website; Irish Medical News

The critical role of Assisted Living services

Assisted living services play a vital role in enabling many people to live independently in their own homes; without it, they would not be able to conduct activities of daily living. Organisations providing this service shared a strong sense of its value. As one person explained:

> You have to understand that a PA service is one-to-one so if 85% [of our budget] is spent on it, that's good. If 95% was pay that would even be better because you're spending on direct service delivery, rather than non-pay. That subtlety I can't seem to get across. You have to understand the nature of the service.

These providers emphasised how important it was that personal assistants understood their role as one of enabling and supporting.

Interviewees stressed the value of working within a social model of disability. Care provided by private companies was perceived by some as comprising fewer services and ultimately being more expensive. When the voluntary sector provided this service, its clients benefited from the absence of a profit-making objective, a mission and ethos that focused on the individual, as well as from a range of specialist expertise and supports that enabled people to live in the community, which were built up over decades. As one interviewee put it:

> This very fragile community and voluntary sector has grown organically. [It] has its issues but is generally a hugely positive element of our society. If you strangle it, you can't recreate it. I can't hand [private PA provider] my list of volunteers [for them to] pick up the ball and run. That's not the way it works because those volunteers are there for all sorts of reasons.

Cross boundary issues

A lack of flexibility across HSE regions arose as a potential barrier in relation to organisations' provision of supports and services. This theme emerged in many interviews, and is illuminated by the following example. A client of one organisation accessed a personal assistant service through them while staying in one of their transitional accommodation units, where he was staying to prepare for returning home. Through the organisation's support, he accessed funding to have adaptations made to his home. However, when it was time for him to return home to his family, he discovered that the personal assistant service was not transferable to the HSE region in which he lived. As a result, this individual was required to live away from his family, in the organisation's transitional housing unit, for longer than necessary.

Cuts in personal assistant hours

Another barrier was the growing reduction in the number of personal assistant hours granted, due to reductions in funding. In one case, an organisation saw that an individual required additional hours; the HSE's response was to split the same number of hours over the day:

> You can't come in and shower somebody and get them up and do everything in one hour, leave, come back another hour. ... You couldn't get somebody who would do that anyway. The two hours together gives them a better quality of life.

4.5 Diverse nature of supports and services provided

For participating organisations, being person-centred is deeply rooted in the social model of disability: the understanding that 'disability' is caused by physical, attitudinal and structural barriers within society. This means their work involves more than addressing the medical nature of a condition or impairment. All these organisations took a holistic approach to meeting clients' needs, addressing a wide range of barriers and associated needs, including housing, transport, social and personal issues:

> It's a person-centred approach so it's looking at the whole person in a very holistic way. ... It's not just about having this disease that's attacking your joints. It has much more effects on a person's life than just the physical manifestations of a disease.

> [The term] person-centred has become kind of a buzzword over the last few years ... but really, the association was person-centred from the start. Before it was ever heard of! ... It explains why we have our fingers in so many pies, whether it's housing, transport, access, you know, holidaying, or whatever.

For this reason, services and supports range across medical interventions, training and education, housing and psychological support, to name but a few. Examples can relate very specifically to particular conditions and needs. For example, the NCBI provides a large digital library serving 4,000 people. Some organisations employ family therapists to address specific emotional difficulties experienced by clients or their family members. MDI loans members accessible transport if the need arises. All play a very important role in supporting people to live in the community; this is highlighted in one case, shared by MDI, which shows the huge impact their transport loaning service could have on people's lives:

> We had to give a family a car for six weeks, and it made such a difference because the little fella had broken his leg, and they just couldn't get him to school in their van. We were able to give him a van for six or eight weeks. The parents had such gratitude. ... There was no way that they could have brought their child to school and back again, because they were completely isolated.

Providing seamless services and supports

Providing support that's needed can also involve providing an effective referral and advocacy service, so that clients can access relevant mainstream supports, services and entitlements. Epilepsy Ireland highlighted the importance of being able to advocate on behalf of a client in relation to housing, citing an example of a person with epilepsy living in a third floor apartment and wanting to relocate to a safer situation, because of the risk of falling. Others spoke of the importance of linking a person in with psychological support.

Often, organisations provided a combination of their own services alongside referral and advocacy support. The common factor was that of organisations working to identify and address all the barriers to an independent life faced by individuals who access them for support:

> When you have got a disability, it's so many things. It's housing. It's transport; if you can't drive yourself, have you access to public transport? Have you your other social welfare benefits in place? What kind of family supports have you got? Do you need personal assistance support? So there's a whole range of things that need to come together and require us to work with other people, like the HSE and like the county councils, whoever, to try to support that person to build an independent life.

For many, the need for an individualised approach was also important in meeting different levels of need and personal preferences. One interviewee described how one of their clients, whose clinical needs were increasing, experienced a great improvement in their quality of life when they successfully moved her to accommodation where her children could stay with her from time to time.

Taking an individualised approach can also mean reflecting an awareness of how different factors can influence experience in services and supports. For example, Epilepsy Ireland runs separate support groups for men and women because their needs can be different. They also work to address age-specific issues; older people, for example, are more likely to have experienced stigma surrounding epilepsy than younger people. In this regard this interviewee described how as 71 year old woman who had lived with epilepsy all her life, spoke about it for the first time when she attended a women's support group.

Box 4.5: A holistic approach in practice: a casework example from MS Ireland

Client: Female, aged 34, diagnosed at age 21

This client's first contact with an MS community worker was approximately 10 years ago. Their main issues at that time included 1) housing and 2) advice and support with her symptoms.

Over the next couple of years, the client continued to have problems getting appropriate housing. Money management was also an issue. She became pregnant with her first child and had concerns about how pregnancy would impact on her MS and how she would cope after the baby was born. Housing again became an issue. This client also suffered a relapse after having her baby and required home support services.

Finances continued to crop up as a problem and serious money management issues developed. Her partner was diagnosed with serious mental health issues. Contact has been maintained with this client over the course of the last 10 years, both in an ongoing supportive capacity; for example, home visits would take place if the community worker was in the area, and through phone calls. Contact is also initiated as and when various issues crop up.

Summary of interventions made by the community worker on behalf of the client:

- Negotiations with their local authority around appropriate housing (phone calls, letters and occasional meetings);
- Organising support services for client to be in place on her discharge from hospital to home with her baby. (These services took some convincing that this was a necessary service at that time, as they would normally respond to need as it arises rather than put in place as a preventative measure);
- Financial assistance sought from their local branch and community welfare officer.
- Contact and referral to MABS on client's behalf;
- Referral to physiotherapy and occupational therapy;
- Referral to home support agencies;
- Referral to MS counselling service;
- Contact with child protection social workers;
- Contact with client's mother;
- Liaising with hospital social worker following client's disclosure of being in an abusive relationship.

Source: MS Ireland document

4.6 Key findings

- Being person-centred emerged as an inherent characteristic of participating organisations, one that was rooted in their mission and practice. It was a core aspect of both their underlying ethos and their delivery of supports and services. Understood as an approach that involves listening to the individual and working towards meeting their expressed needs and aspirations, for many this was closely linked to the way in which they had emerged and evolved. Many organisations were and continue to be user-led for example, having been originally founded by people with disabilities. And even those organisations with a philanthropic or charitable provenance developed over the years strong mechanisms for user consultation. The service user or client is at the centre of organisations' development and delivery of supports and services.

- This meant that the person-centred nature of these organisations manifested itself in many ways. Not surprisingly, being person-centred was strongly reflected in the development of plans and setting of goals with service users; some described how outcomes of this process were used to measure an organisation's effectiveness.

- The goal of independence emerged as being strongly linked to the concept of being person-centred, and one which organisations displayed a strong commitment to meeting. Enabling independence was also grounded in organisations' philosophy and ethos and a common goal set in the person-centred planning processes. For some, this meant providing a high quality personal assistant service, or moving people from residential to independent accommodation. For others it meant early intervention: providing a 'pre-care' level of support, through training programmes for example. Importantly, this means providing the necessary supports, only when the individual needs them. It requires a high level of flexibility, whereby the organisation links in with people at important points during their life cycle, to provide the support and training needed to enable an individual to live in a new area, for example.

- This very person-centred approach is necessarily flexible and adaptable; different people require a different level of support, at different stages of their life. It can make it difficult for the organisation to price the support they provide. Here, being person-centred entails a certain level of unpredictability, as it is based on the individual's own support needs when they arise.

- A lack of flexibility across HSE regions was identified as a potential barrier in relation to organisations' provision of supports and services to enable people to live independently in the community.

- For participating organisations, being person-centred is deeply rooted in the social model of disability. They all took a holistic approach to meeting clients' needs, addressing a wide range of barriers and associated needs, including housing, environmental, transport, social and personal issues.

5.1 Introduction

Whether or not participating organisations had been founded by people with a disability, all had a mission that was either rooted in the social model of disability (recognising that disability is caused by physical, attitudinal and structural barriers within society), or which had evolved away from a medical model, and towards a more holistic approach to meeting people's needs. This chapter looks at how this broad understanding underpins both a specialist knowledge and skill-set that extend far beyond the medical nature of an impairment or condition, and relevant physical care and support needs. While such expertise is a very important aspect of the work of many organisations, it is also about expertise in enabling people with disabilities to live in their own home, with independence maximised and with real opportunities to engage in their community. As one interviewee put it, their real contribution lay in providing or enabling access to 'a whole range of supports to enable an individual person with a disability to live the life they want to lead'.

5.2 Access to appropriate clinical care and treatment

Direct provision of clinical care

Organisations providing clinical care (be it medical, rehabilitative or psychological) stressed the importance of this care being provided by specialists in particular fields. This was strongly related to the quality of care provided:

> If you were an orthopaedic surgeon in a hospital with a big busy clinic, seeing somebody coming in with cerebral palsy without the backup of experienced therapists and gait analysis, it's not very effective.
>
> It has to be a specialist. The person has to know what they are doing. ... All the people we have are either psychologists or come from a training background and are inducted here then into the brain injury and they have their peers.

This specialist clinical support was seen as playing a central role in people's quality of life and enabling them to live in the community. Interviewees described how without this support, people with disabilities would experience a decline in their health, their quality of life and their opportunities to live independently. In some cases, this led to organisations addressing gaps in clinical care. MS Ireland, for example, noted that often when they consult with people with MS and ask what service they most want, it is physiotherapy. In order to address this inadequate level of State support in this area, MS Ireland raised funds to train physiotherapy assistants, who work under the supervision of a HSE physiotherapist. The organisation receives no HSE funding for this very popular programme.

As another example, Epilepsy Ireland is one of a few organisations in the country with paramedical expertise in delivering emergency medication (buccal midazolam) for people with epilepsy, and is the only organisation providing training (to parents and health personnel) on this. They recruited the first specialist epilepsy nurse in Ireland in 2004, who now runs Epilepsy Ireland's helpline. (Under the new National Epilepsy Care Programme, there will now be one in each HSE region.)

Links to clinical care

While not all participating organisations were involved in providing clinical care, all did refer and link people to clinical care as needed and many worked to improve its availability and accessibility. For example, MDI worked closely with a neurologist, which led to the setting up of the only adult clinic for people with muscular dystrophy in Ireland. This has led to an improvement in the level of monitoring support for people with muscular dystrophy, which, as MDI stresses, plays an essential role in improving life expectancy. It also means that people can access specialist clinical support on MD in one location, rather than having to attend different clinicians (as MD has different biological effects):

> People would be travelling up and they might have to see the neurologist for five minutes and go home to whatever part of the country and then they would get another appointment to come up and see the respiratory person.

Supporting research

Others funded research, with the aim of improving clinical understanding of particular disabilities. The Cystic Fibrosis Association, for example, has a good track record of its funded research resulting in peer-reviewed articles in medical journals. It also supports people with CF through effective lobbying and advocacy for policy change. For example, they successfully lobbied for getting hospital-based isolation units; previously people with CF delayed going into hospital because of a real fear of infection. The CFAI are linked to the Medical and Scientific Council, which has two cystic fibrosis specialist consultants, thus enabling them to lobby both within and outside the health system. On a local level, a strong network of local branches made up of patients, and families enables CFAI to 'mobilise the troops'.

> For certain disabilities, enabling community living required outreach services. This is because some disabilities can make travel difficult. For example, many people with epilepsy cannot drive; a large part of Epilepsy Ireland's work is therefore providing outreach services.

Box 5.1: Health promotion and research programme: example of MS Ireland

Getting the Balance Right programme

Getting the Balance Right is a new nationwide exercise, health-promotion and research programme for people with MS which takes place in a variety of venues and settings. It is co-ordinated by the MS Society of Ireland in collaboration with the physiotherapy department of the University of Limerick. This project aims to offer a range of opportunities to people with MS to maintain and improve a full range of motions, which may have been impacted on as a result of the MS disease process. The programme is the first of its kind for MS Ireland, and is presented primarily as an opportunity for people with MS to participate in a monitored and guided physiotherapy programme, with greater frequency. It also represents an opportunity for MS Ireland to profile the physical needs of its members and learn more about the impact of a range of exercises and therapies on people with MS.

Participation is open to people who are:

- Independently mobile
- Mobile with an aid
- Using a wheelchair as a primary mode of mobility

It is designed to supplement/complement existing services provided by the HSE and other service providers. ‘Getting the Balance Right’ will enable people to engage in physical activity more frequently or at a higher intensity on an ongoing basis for the two years of the project. A network of chartered physiotherapists has been established to develop, inform and support the project.

The programme is being offered throughout the country on a pilot basis and will be co-ordinated by MS Ireland’s regional offices with an evaluation by a team of researchers from the physiotherapy department of the University of Limerick. The findings of the study will be shared with the HSE and other service providers so as to inform the development of services which are based on evidence and promote and develop general and specialised best practice in an MS population.

A case study

Anne-Marie was diagnosed with MS at 21. At the time she was a young mum working as a hairdresser. Her symptoms were aggressive. She quickly moved from tingling in her hands to being a full-time wheelchair user, incontinent and experience extreme fatigue and muscle spasms.

“I would get such spasms. One time it actually overturned my wheelchair and all Oisin could do was pick up the phone and ring my mother. He went and got a blanket, covered me with it and lay there rubbing and hair and saying ‘Mummy, it’s going to be okay.”

Anne-Marie began a one-to-one physiotherapy programme run by MS Ireland and has moved from being dependent to independent.

“Within three or four months of starting ‘Getting The Balance Right’ I was walking: from being in a wheelchair, back to full mobility.”

Anne-Marie has an action packed life now. She still uses a stick to get around but by continuing with her exercise and physiotherapy she’s an active fundraiser for her local voluntary branch, a spokesperson for MS Ireland and most importantly, a full-time mum to Oisin.’

Sources: Interview and MS Ireland’s website

Training health care providers

Another way in which organisations improve people's access to care is by providing specialist training to health care professionals and healthcare students. Some, such as Headway, provide training on non-clinical subjects such as dealing with challenging behaviour, while others, such as Arthritis Ireland and the CRC provide specialist clinical training. Those attending might include physiotherapists, occupational therapists, speech and language therapists, general practitioners, psychologists and social workers, among others, and there is a high demand for this training. Arthritis Ireland's work led to the identification of an absence of adequate training for health care professionals in relation to rheumatology. In response, they have established two academic chairs of rheumatology in two Irish universities.

Many described how their organisations often had a more specialised knowledge of particular conditions than did primary healthcare providers, such as GPs. This knowledge would extend beyond its medical nature, to include the social, emotional and practical issues related to living with the condition. One example is Epilepsy Ireland's training courses for parents and health professionals on delivering buccal midazolam. Another is MDI's information days, which are attended by people with MD, their family members and health professionals. In this example of reciprocity, people with MD learn from the health professionals, while the health professionals get a valuable insight into the non-clinical aspects of living with MD:

> We have information days. They're really useful for the members and the families that are coming up, because we usually have neurologists, genetic counsellors, researchers and [others] talking about particular conditions, and they would get to ask questions and get a bit more time with them than they might in a clinic setting. It's good for the clinicians as well, that they hear a bit more about how it's affecting their whole life and their family and everything. It gives them more of an insight into what people are dealing with.

5.3 Assessment

Living independently in the community is highly dependent on the accurate assessment of an individual's support needs. This was a strong feature of the work and focus of organisations participating here. West Limerick CIL, for example, explain that while people are referred to them by the HSE, the Centre carries out the assessment, in partnership with the person with a disability. This is done by a personal support service coordinator, whose recommendations are fed back to the HSE. Priorities of this assessment process are practical and focus on activities of daily living, such as getting up in the morning; the aim is to identify what supports are needed to enable the individual in question to live safely at home. On this basis, a number of personal assistance hours are requested for the individual. This can be a very important aspect of the assessment process, one that largely relies on the organisation's expertise, developed over years of providing support to people with a particular disability.

Fluctuating nature of need

Assessing support needs is not always a once-off, formal process. For some, it is also about knowing that support needs can vary from person to person, and across time. This can mean providing different supports at different stages, and as required. The point of diagnosis serves as one example:

> Sometimes people want to get the pack and have a read of it first and think about it before they want to talk to the family support worker. And then sometimes they want to talk to the family support worker right away and see what they can do. Everybody is a bit different in the way they deal with it.

For some people, needs can change over the life cycle. This requires organisations to assess need at different stages in a person's life. These points vary from person to person. It is a particular issue for people with a progressive condition, such as vision loss or multiple sclerosis:

> People are coming to us looking for supports. Maybe up to now they were able to manage themselves but as the condition progresses ... life gets harder, and you need more support. And people are coming and knocking on our door seeing what we can do to help them.

Organisations' understanding of this has led to many taking proactive steps to ensure people can always easily contact them and access their services.
Help lines are one good example of this as are information packs, which many provide.

5.4 Providing support in the home

Most organisations included in this research supported people in their own homes. Those who were funded by the HSE to employ personal assistants understood the specific needs relating to particular disabilities and groups of people. This influenced the way in which they provided this service and ensured that needs were being addressed. For example, West Limerick CIL spoke of how older people might be less likely to actively seek support; so the organisation's coordinators called out to visit people, and to discreetly identify and address any issues that may arise:

> Our coordinators work with individuals, they call out to see them, they're in regular contact with them…to ensure everything's going

> OK. People mightn't contact you, especially older age-groups who might say they're happy enough. We work with [older people] to make sure any concerns they do have are addressed, in a manner which doesn't make a huge song and dance about it.

The issue of being discreet was also discussed by other personal assistance providers, such as the IWA and RSG. RSG highlighted how this can be even more of an issue for people living in a rural context:

> They want their privacy respected and we are very big on confidentiality, it's a need-to-know basis. Some people might be comfortable if they know the person already that's going to be working with them, and that would work out fine, but some people don't necessarily want that, they would rather someone completely independent.

Despite being 'very much rooted' in the community, with services and support being provided either in people's homes or through community-based resource centres, organisations reported that there was a low level of awareness among the public regarding the existence of these services, which was partly related to their sense of the importance of protecting confidentiality.

Supports in the home can be adapted in other subtle ways to enhance its community-based nature. For example, RSG explained how personal assistants traditionally wore uniforms. However, some people found this 'too hospitalised looking' in their home, so in such cases, and where possible, uniforms were not worn.

'Pre-care'

Other organisations came to people's homes, but not to provide care. In these cases the emphasis was on early intervention; what one person referred to as 'pre-care'. For example, the NCBI's independent living training can include a mobility trainer working with a person within their home, so as to enable them to use appliances safely and to use a mobility aid, if required. Others, like the IWA, provide independent living apartments, as well as more transitional accommodation, for people moving away from their family or who are recovering post-injury and need support to adapt to living with their disability and with living independently.

5.5 Assistive technology

Assistive and communication technology formed a strong, and growing, feature of the support provided by some organisations. Work here focused on helping people access alternative communication devices, alternative means of computer access, environmental control systems, alternative access to technology and specialised software systems. The nature of this support included information on assistive technologies, assessing need, giving people the opportunity to try out certain tools and training on the use of assistive technologies.

Some variation emerged in terms of how organisations provided this support. For the NCBI, assistive technology has become increasingly important in terms of enabling people to live independently, allowing them to ‘create contact points in terms of printed word, using telephones and technologies to bridge communication, [and] to show people how to get around safely’. The NCBI provide information and support for accessing and using a range of assistive technologies. These include the use of CCTV to magnify images on a screen, scanners that can read text, and a range of assistive software that enables people with vision loss to use computers and the internet (e.g. screen magnification software, screen readers and Braille printers). This support can also relate to the use of generic technology, such as smart phones. In 2005, the NCBI set up the Centre for Inclusive Technology (CFIT), with the aim of ensuring that ICT-based products and services in Ireland are designed to be accessible to the widest audience.

MDI use their purpose-built headquarters as a place where people with MD can try out assistive technologies and witness their benefits. They found that by seeing these products in action, rather than reading or being told about them, made it much easier for people to see how certain products might significantly improve their mobility and independence:

> There are products that might make life that little bit easier, like the automatic doors. ... I think it’s very important that people see them practically. ... When you come and actually feel them and try them out [you can see how they might help.] We have products all around the building that people can try out. ... The whole idea behind the building itself is that it’s a one stop shop, so in between the time you come in the door and go out the back door, you would have all the information that you would require.

Enable Ireland runs a range of national assistive technology training courses, aimed at people with disabilities, their family and carers as well as therapists, employers and educators. The CRC’s assistive technology department provides an assessment service to people with physical disabilities to help people identify the most appropriate assistive technology tools for their needs. Typical areas of concern for which this multidisciplinary team works towards finding solutions, include accessing education, communication, problems associated with moving independently, reading or writing, and with controlling the environment.

For these organisations, this ‘gateway service’ was seen to play a very important part in enabling people to live in their own homes while maximising their independence and mobility:

> If our assistive technology department wasn't there, it probably would mean that people would have very limited access to assistive technology. Assistive Technology allows people to live at home, open the doors, open the curtains, use their computer, call emergency services etc. It allows people to be independent.

Box 5.2: Assistive technology supports provided by voluntary organisations

The Central Remedial Clinic's Client Technical Services (CTS) Department

The CTS department in the Central Remedial Clinic provides an assessment service to people with physical disabilities in the area of assistive technology. It aims to offer people alternatives and options to facilitate their personal independence in everyday living. Areas of concern for people who contact the service include issues in accessing the educational curriculum or in communication, problems with reading or writing or moving about independently and difficulties in controlling the environment either at home or in school or at work.

The department aims to find solutions through the use of alternative communication devices, alternative means of computer access, environmental control systems such as opening doors using remote control devices, personal alarms systems etc., alternative access to technology through for example, the use of switches, and specialised software or voice recognition systems.

A multidisciplinary team of assistive technology advisors include the following areas of expertise: engineering, occupational therapy, speech and language therapy, ICT and education. They operate both a centre based and national outreach service.

In order to avail of this service, an appointment is made for an assessment. Self-referrals are accepted.

Enable Ireland's Certified AT Training Course

This nine day AT course is certified by Dublin Institute of Technology under their Continuing Professional Development programme. It runs at least once a year. The course includes additional online learning components and post-course project work, all of which must be completed successfully by course participants to merit graduation.

The course objectives are:

- To provide participants with the AT knowledge and skills that they require to meet their own needs and for the needs of a diverse range of AT users.
- To ensure that AT users and potential users are central to the AT decision-making process.
- To increase course participants' confidence in their own AT skills.
- To provide course participants with an understanding of the processes, the resources and tools that are required to support AT users in a wide range of environments.
- To de-mystify technology.
- To promote best practice and encourage the development of ongoing discussion groups post-course.

It is aimed at AT advisors, therapists, teachers, AT users and potential users, personal assistants, special needs assistants, parents/carers, trainers, AT technicians and any other interested parties.

Enable Ireland also runs customized AT workshops to meet the needs of specific training groups, as well as one national annual AT seminar, employer AT seminars and employee training.

NCBI's Centre for Inclusive Technology

The NCBI Centre for Inclusive Technology (CFIT) was established in January 2005. Its stated role is to help work towards an information society that is accessible to all. CFIT's objective is to ensure that ICT-based products and services in Ireland are designed to be accessible to the widest audience, including older people and people with disabilities.

CFIT's work involves:
Promotion: promoting ICT accessibility and the correct use of appropriate technologies; campaigning on behalf of people with disabilities to ensure the accessibility of specific products or services; and adopting appropriate standards through legislation and public policy.

Education: educating technology designers, developers, managers and students in the fundamentals of accessibility and how to achieve it; providing awareness raising to a wide audience on access issues and the benefits of inclusive design; providing a resource for NCBI staff, NCBI service users and their representatives.

Assistance: providing practical help to organisations wishing to develop or implement accessible solutions, which takes the form of accessibility auditing, user testing and technical support; providing expertise and services to anyone in the private or public sector on an equal footing.

Research: CFIT takes part in many Irish and European research and standardisation initiatives.

5.6 Linking people to mainstream services

Specialist knowledge and expertise was also reflected in the important role organisations played in providing information, advice and, sometimes, advocacy services. As one example, Epilepsy Ireland described themselves as a bridge between the work of clinical specialists and the person living in the community, with ten community resource workers working in all HSE regions throughout the country. In this sense, they provide an important gap-filling role, providing personal advocacy support and linking people with public services such as housing. A one-year training course in Sligo IT grew out of their first training course for school leavers in Griffith College; 'Training for Success, which recently received an Aontas Star award, is offered to young people with epilepsy who are on disability benefit. It is an integrated programme including epilepsy awareness and personal development as well as career-oriented learning:

> It's always taken up…and it works. We have follow-up to show that. It gives them time to reflect and see how has the epilepsy impacted on their lives to now, and what they can do themselves to help that… It's unique in Europe…other countries are looking at the model, hoping to replicate it.

Some organisations focus on helping people access their rights and entitlements, in their provision of information and advice. For example, the CFAI provides information and advice to people with CF, particularly in relation to their rights and entitlements. They employ two patient advocates, both Galway-based, though they are hoping to recruit one in Dublin and one in Cork soon. Their role is to work on difficult or complex cases, especially in relation to refusals of disability allowance and domiciliary care allowance.

Organisations supporting people with rare conditions described this aspect of their work as very important. This was related to the fact that in some such cases, general healthcare professionals may not be able to provide an adequate level of information or advice. For example, information is one of the top three services provided by MDI. The rarity of the condition is exacerbated by the fact that there are many types of MD, some of them very rare; often this means that GPs and other 'mainstream' practitioners cannot always provide a sufficient level of information. MDI addresses these issues by providing an open access information centre, and by providing information packs to people who call the helpline. They stressed the value, to the individual with muscular dystrophy, of being able to access this specialised understanding of the condition:

I think it's very important, if there is an issue, to come to someone that can understand it. Because if people are looking for support, you can understand why they need it, instead of just pushing them under the carpet. It's very important that people would get that acknowledgement rather than just, "Oh we don't know what they are talking about." ...Even when they ring, [they might say] "You've heard of my condition? Nobody has heard of this before!"

Enable Ireland's Certified AT Training Course

One way in which some organisations provide both practical and emotional support on an ongoing basis is through dedicated phone lines. Some, like Epilepsy Ireland, have a helpline run by a clinical nurse specialist in epilepsy. Others, like Arthritis Ireland, run a helpline manned by volunteers who have undergone training and can provide an easily accessed source of practical and emotional help. Through them, people throughout the country can get information and advice specific to their disability. They can also receive emotional support from someone who understands their condition, and in some cases has the same disability (such as the Arthritis Ireland helpline). Some people use helplines to help them to deal with a diagnosis, or to accept the limitations it might bring to their lives:

The fact that the helpline volunteers have arthritis makes a huge difference. People open up easily.... Our volunteers come in and for the three hours that they are there, they dedicate their entire time to taking the calls so the calls are not rushed. If a person needs to talk for an extended period of time, they are not rushed through a call.

This service can also mean that health care professionals can share the role of helping people with non-medical issues; Arthritis Ireland promotes their helpline with primary care teams, rheumatology clinics and hospitals.

5.7 Addressing the needs of carers

Interviewees shared a strong understanding of the importance of carers of people with disabilities in terms of providing support. This was reflected in their inclusion of carers and family members during information sharing, assessment processes and, if appropriate, in setting goals and making plans:

> Family related problems might arise. Relations might be difficult for the seeing part of the relationship. They might take on more of the provider position in the household. The person is learning independence but they don't get back their role in the relationship. (NCBI)

Help lines are available to carers as well as people with disabilities, and some organisations provide information and support resources that specifically target carers. For example, MS Ireland describes taking a 'whole family' approach. Their support programmes are open to both carers and families and they provide a 'newly diagnosed' service to the person with MS and their family, 'so if Mary's husband has been recently diagnosed, she can come to us as well'.

Headway provides family education workshops, which provide information and strategies regarding the emotional and behavioural problems associated with having an acquired brain injury, issues associated with caring for someone with an ABI, and the importance of self-care and addressing the risk of stress and social isolation.

Support for carers: emergency and planned respite and other services

The needs of carers are also addressed by the range of both emergency and planned respite services provided by organisations. The nature of these supports can vary, depending on the particular disability and arising needs. MS Ireland, for example, provides respite support to teenage children of people with MS. This is mainly activity-based, such as mountain climbing. However, this support also aims to give children the opportunity to talk about any issues they might be going through that relate to having a parent with multiple sclerosis.

In some cases, this service involves respite workers providing support within people's homes: MDI has fourteen respite workers who provide emergency respite support to ten families around the country. This can be particularly valuable during gaps in the delivery of statutory supports for example:

> We had a young boy down in the North-East and he needed nursing support. So for three Wednesdays in a row, we sent a nurse in just to help out with the family. That was because the community nurse that was there who was doing it had gone off on indefinite leave and they hadn't replaced her. The family weren't even aware of this, so on a Wednesday they were waiting for the nurse to turn up.

Finally, services including day centres support from youth workers and holiday camps for people with disabilities have a dual role in that they provide a break for carers while also providing the individual with a disability with valuable opportunities for meeting other people:

> If the bus comes and takes the person away for the day, you know they're safe, you know they're comfortable, and you know they're happy because they are doing what they want. They have got friends, they have gotten to socialise, so you can get a break to do other things – it might be as basic as doing the shopping, because you can't leave the person otherwise. ... It serves a very important function because if that carer ... is without respite at any stage during the week, how long can they keep going?'

Box 5.3: Headway's Family Education Workshops

The ABI Family Education Workshop at Headway consists of five sessions that run weekly.

The first session provides an overview of the common difficulties of an ABI. The second session focuses on the emotional and behavioural consequences of ABI; for example, problems with impulsivity, anger, frustration and perseveration. Families are provided with information and strategies on how to cope with these issues.

The third session looks at the cognitive difficulties experienced by individuals with an ABI, with a particular emphasis on memory, attention, communication, and executive functioning. Families/carers are given guidance on how to support the individual with the ABI.

The fourth session emphasises the impact of ABI on the family; looking at the stages of coping, and acknowledging the different types of pressure families/carers face on a day to day basis.

The final workshop emphasises the need for self-care, and to educate families/carers on managing stress, guilt, and social isolation. Families/carers are reminded that their lives have changed, in addition to the individual with the ABI, and as a result attendees are encouraged to look after their wellbeing.

Sources: Interview and Headway newsletter

5.8 Promoting social and community integration

While organisations place a strong emphasis on promoting independence, some interviewees described how certain impairments (or levels of impairment) can reduce people's opportunities for social engagement. Again, interviewees shared an awareness of particular groups that might be more vulnerable to social isolation than others. Cited examples include a young person who cannot participate in certain school activities, such as school tours, young adults who are prevented from attending third level education, and older people whose vision loss can make some social situations difficult. For such groups, social isolation emerged as a major issue:

> You can read ... about people being independent. But a lot of the time, they've nowhere to go. They're in lonely flats and lonely houses. And there's no reason to go out. Our biggest problem is with older people. They have huge loneliness and they're not very active because they're not able to get out.

This understanding meant that many organisations tackled barriers to social and community integration. We have already seen the work of some organisations in setting up online support tools, such as networks and support groups. A range of other measures emerged, many reflecting the specific needs of an organisation's clientele. For example, County Roscommon Disability Support Group Ltd, whose clients live in a very rural county, aimed to address social isolation by providing a very popular transport service to their resource centre.

Good practice also emerged in terms of bridging clients to mainstream educational and employment opportunities. Headway, for example, described how one of their rehabilitative training centres is based within a VEC college, so participants socialised with other VEC students, which plays an important role in helping them to live normal lives in the community. RehabCare and the Central Remedial Clinic also encourage clients to avail of courses in local education or training services, or to get local part-time work or supported employment. The National Learning Network described their supported training services as 'pre-mainline' – a stepping stone that helped people access and sustain 'mainline' opportunities, be they in education or employment.

Supports for children

Organisations also addressed community integration in their work with children. MDI described how it can be potentially isolating if a young person with MD attends a youth club that involves a lot of physical activities, or is excluded from a school tour because of their disability. It responds through youth workers who provide the support that enables young people to take part in such activities. Epilepsy Ireland provides information packs to schools, and if a child in a school has epilepsy, they talk to pupils of that school, as well as parents, the principal and resource teachers. Over 2,000 teachers and students attended Epilepsy Awareness presentations in 2011.

Enable Ireland staff take practical steps, such as implementing therapy programmes with a child during their PE class, working with a teacher to develop strategies around handwriting or offering advice regarding enhancements to the facilities in the school. They also run an integrated playschool (Little Pals), where half of the children attend Enable Ireland services and half come from the wider community:

> You're managing what they need, bearing in mind that the children in mainstream school don't always need a highly specialised service. The physical barriers have to be broken down. Children are getting a more integrated service ... starting with the integrated playschool.

Some interviewees stressed that it is the quality of social interaction that matters and which should be considered in support planning, rather than its quantity, or simply whether or not it takes place. A distinction was made between bringing a group of people in and out of a community setting and enabling people to be meaningfully integrated in their community:

> People could be living in the community, but completely isolated because they have a disability and they can't access services or do normal things.

However, that is not to say that no place was found for peer support. Headway runs very popular support groups for people with an acquired brain injury. They noted:

> It is so important for them to realise that there other people that have the same problems. Together that gives them strength in some ways.

Many organisations run resource centres, at which people can take part in courses and activities and access information and support as required. RehabCare, for instance, has resource centres throughout the country which in 2011 served a total of 1,400 people. Those attending develop their own support programmes, which are very individualised and flexible. The IWA has 57 resource centres throughout the country, which were described as 'gateway services':

> They literally are resource centres, so people can get information there, they can hook into other services, whether it's holidays, whether it's learning to drive, whether it's sports, whether it's assisted living services. I would see them very much as a gateway resource.

One important feature of these and resource centres run by other organisations, was that people attending them had a say in relation to services and activities on offer there.

Some organisations also run holiday camps for people with disabilities. All shared very positive feedback on these camps. They provide people with opportunities to socialise, thus playing an important role in addressing social isolation, while also providing needed respite for carers. For some, they also enabled greater independence, albeit for a limited period of time. These organisations felt strongly that these camps are an essential support that enables people to continue living in the community. This is highlighted in an example of a woman who attended a holiday camp with MDI. Prior to developing muscular dystrophy she had been a primary school teacher, but over recent years, her reliance on a personal assistant had seriously reduced her independence:

> She said that it had been the first time in maybe three years that she had been up past nine o'clock because her PA came every evening from eight to nine and she had to go to bed. The PA wouldn't work past those hours. ... [She said] "the camp was brilliant, I felt I was an individual".

Feedback from parents also highlighted the value of these camps:

> Many parents say, "If MDI ever has to get rid of something, don't get rid of the camps". It's the biggest impact, it's huge, it gives both the parents, the carers, siblings, that break. And the individual member then, they will go off and do their own thing with independence.

Finally, organisations' specialist knowledge and expertise was also used in improving the accessibility of the local community and environment. In this regard, NCBI advocated and worked with town planners to 'advocate a barrier-free environment'. This might involve lobbying against obstacles on pavements, or campaigns about not parking on pavements or street furniture outside restaurants. It would also relate to announcements on trains and buses, audio pedestrian crossings, and markings on pavements to tell people where the crossings are:

> So behind the scenes, we'd be trying to make sure that when people came out, the environment was safe, that what people were moving around in was safe and had a certain logic.

They also work to improve awareness of low vision among service providers and people in the community generally.

5.9 Are voluntary organisations mainstream or specialist?

The findings presented in this chapter highlight the diversity of ways in which voluntary disability organisations provide specialist support to people with disabilities, which plays a central role in enabling many to live in the community, where they can avail of mainstream supports and services. A question that arises here, which was explored in some interviews, is how the organisations see themselves, and how they situate themselves in relation to ongoing initiatives and debates on 'mainstreaming'. It arises in the context of the opening definition in the recent Value for Money and Policy Review of Disability Services in Ireland (2012) which describes a voluntary disability organisation as ‘a **specialist** non-profit provider of disability services or supports’ (p.xiii). The government’s ‘mainstreaming agenda’ of recent years, which entails public services of all kinds becoming ‘universal’, equally open and available to everyone in society, comprises a substantial element in this overall policy framework.

In the context of disability services provided by the State itself or by voluntary organisations on its behalf, the Department of Health has stated its commitment to move as many people with disabilities away from ‘segregated’ services and into ‘community’ settings. These are different but related frameworks, and as several of those interviewed pointed out, much more applicable to the intellectual disability sector with its traditional providers and large-scale institutions, than to the organisations working with people with disabilities, who are already ‘in the community’ even where the organisation provides accommodation.

Not all of the fifteen participating organisations find the terminology and these discussions helpful, or see the relevance of these frameworks to their work. However, the majority are concerned and willing to engage with them, and to challenge the thinking of the Department and the HSE about voluntary disability organisations, thinking which they suggest may be based on several significant misunderstandings.

One person suggested that the decision-makers have never fully understood the physical/neurological and sensory disability sector ‘because they see them through the lens of intellectual disability’ and some models of institutional care (‘We’ve got to think of person-centred other than as person-centred care!’, as one person noted). Others pointed to what they saw as a confusion, in some official thinking, between the application of the two terms ‘specialist’ and ‘segregated’ to disability service:

> The whole discussion’s got very confused – the view grew up that if you are an organisation providing supports and services to people with disability, you must be in some way ‘specialist’ or segregated.
>
> The HSE tends to see mainstream as an alternative to specialist…as something in a building…a wrap-around service, from cradle to grave. We see our services as specialist in a different sense, in that we have a set of skills or set of competencies to give to people.

A large number of the participating organisations described one of their central roles as the provision of a bridge between the person with a disability and the other services they require. They argue that it is a special bridge, and necessary because principles still lag behind practice (incomplete primary care networks, for example). They are also clear that in some forms and levels of disability, the ideal of 'mainstreaming' or universal access to all public services on an equal basis, may never be fully realisable:

> It's not always feasible or meaningfully inclusive to use mainstream supports for people with [this condition].

It is important to acknowledge that quite a number of the participating organisations want to identify themselves as being both specialist (sometimes, but not always, in a clinical or therapeutic sense) and mainstream, and definitely consider themselves an integral part of the whole infrastructure of services which enables people with disabilities to live as well and as independently as possible in their families and communities. This was summed up by one contributor as:

> **Our services are specialist but our people live in the mainstream!**

Putting this into more specific terms, one organisation explained:

> We provide supports to people with autism, but if we provide [supported housing] to an adult with autism, it's in a typical house in the local community.

Clearly, as illustrated above, the term 'specialism' can be used simply to specific clinical or therapeutic expertise and services, which are features of some voluntary organisations. It also can and should be used to refer to the highly-developed and disability-specific knowledge and skills of referral and liaison which are a defining characteristic of the voluntary organisations and their support of people with disabilities and their families.

> As part of the [review] process we discussed and analysed deeply what is the value our organisation provides: we decided that it's at that interface between the person with the disability and our staff member, both the support being given and the manner in which it is being given. When we thought about what was valuable and important, that was it and we knew we couldn't touch it. It's what we have to protect! That helped us to decide what we could do without and where we should make cost savings.

5.10 Key findings

- Specialist knowledge of specific conditions and impairments emerged as an important aspect of the support provided by voluntary disability organisations. Some organisations responded to gaps in mainstream health services by either providing or facilitating access to specialised clinical interventions. Some provided a dedicated support worker to help people with disabilities access to the medical support they needed. Others trained mainstream healthcare providers in relation to specific conditions. All of them provided much needed specialist information and advice to the individual with a specific condition or impairment, as well as on relevant benefits and entitlements.

- The mission of these organisations is either explicitly grounded in the social model of disability, or has evolved away from a medical model and towards a more holistic approach. For this reason, their specialist knowledge and expertise also extends far beyond the medical nature of specific impairments and conditions and associated clinical support needs, and ranges across many fields. Organisations displayed a high level of understanding and expertise, built up over decades, in relation to the non-medical needs of people with a disability living in the community, and this was reflected in many supports and services. For example, many provided both planned and emergency respite support, reflecting a strong understanding of the needs of families and carers. Some provided personal assistant services. Understanding the needs of families was also reflected in one organisation providing holidays for children of people with a particular condition. Many shared a high level of expertise in assistive technology, which was used to provide training on using assistive technology, to help people to identify assistive technology that would best suit their needs and to help people access that technology.

- Participants shared insights on the increased risk of social isolation faced by many people with disabilities. This has led many to provide a wide range of social supports and opportunities for social interaction. They all spoke of the importance of such supports in enabling meaningful participation in the community, and many are also working to improve the accessibility of the local community and environment.

- At the same time, it was felt that there was an important place for dedicated but community-based social opportunities for people with disabilities, such as those provided by resource centres at which participants are facilitated to determine their activities (one memorable example is that of men in a Wexford-based NCBI resource centre building a boat). Other examples are peer support groups and the very popular holiday camps run by some organisations, which play an essential role in addressing social isolation, while also providing respite support for carers.

- Participating voluntary disability organisations receiving State funding to provide supports and services saw themselves as being *both* specialist *and* mainstream, and very definitely an integral part of the whole infrastructure of services that enables people with disabilities to live as well and as independently as possible in their families and communities

6.1 Introduction

A strong culture of change, review, and innovation was found among many of the participating organisations. Various examples of innovative measures were described, all of which aimed to identify emerging or newly identified needs, improve existing services or simply ensure that clients' needs are met. This drive to innovate within a changing environment – to develop and implement new, better and more efficient ways of meeting people's needs – reflects the shared underlying motivation of putting the client's needs before the organisation's.

In relation to the disability sector, the Department of Health Sectoral Plan 2006 states, 'The integral role of the non-statutory, voluntary and community groups is of particular relevance in this sector. … It is acknowledged that …many of these agencies were to the forefront in identifying needs in the community and developing responses to them' (p. 26-27).

The value of innovation within the sector is also cited by the Comptroller & Auditor General (2005) in highlighting 'the multiple roles performed by nonprofit organisations including mainstream delivery, innovative and flexible responses to new and emerging needs, interacting with and supporting policy development or service design' (p. 36). This chapter explores the many ways in which organisations have adapted to the changing environment in innovative ways, both in relation to improving supports and services, and in minimising the impact of five years of funding cuts.

6.2 Flexible supports and services

On the whole, participating organisations take a holistic approach in providing support, an approach that is grounded in the social model of disability (a theme explored in greater depth in Chapter 5). One outcome of this is that organisations provide an adaptable service, one which responds to the particular needs of each presenting individual:

> The outcome is almost, if you like, undulating for the individual because there's a different scenario each time.

Flexibility emerged as an intrinsic aspect of organisations' commitment to individual development. For the National Learning Network, this can mean keeping a place open for people who are temporarily obliged to stop attending, despite the funding difficulties this can raise, as funding is provided on the basis of utilisation. However, as this interviewee noted, 'we can't use funding as a reason not to allow them deal with their health issues.'

Flexibility was a feature of collaborating with other services and organisations, and of referring clients on to them. As one participant noted, ‘we collaborate with anybody who is willing to collaborate!’ As people’s disability-related needs vary by individual and across the life cycle (as explored in Chapter 5), so must organisations’ approach to collaboration and referral be flexible and fluid.

Flexibility also could mean something as straightforward as enabling people to have some control over when they access their personal assistance support:

> The whole discussion’s got very confused – the view grew up that if you are an organisation providing supports and services to people with disability, you must be in some way ‘specialist’ or segregated.
>
> The HSE tends to see mainstream as an alternative to specialist…as something in a building…a wrap-around service, from cradle to grave. We see our services as specialist in a different sense, in that we have a set of skills or set of competencies to give to people.

Some participating organisations support clients in accessing clinical care. Again, the level and nature of support required here varies by individual, and the role therefore can be very varied, and require a high level of flexibility. For example, MDI’s support worker might escort people needing blood tests done. She can help by checking or confirming appointments. Sometimes, presenting needs are unanticipated. In one situation, the support worker provided essential support to a person who did not speak English, and who therefore did not understand what was required of him for his assessment. Without this support, his assessment might have been delayed by months, which could have had a significantly negative impact on his health.

Developing supplementary services

Organisations that provide personal assistance shared strong feedback that people accessing this support often need more hours of personal assistance support than are allocated to them. In response to this, County Roscommon Disability Support Group Ltd set up a private personal assistant service called ‘24/7 Care’. While acknowledging that this was only available to those who could afford it, the service is provided at the lowest cost possible and was described as ‘just breaking even’. In this sense, it did not aim to address funding shortfalls; only to help to fill the gap between service and need.

Box 6.1: County Roscommon Disability Support Group Ltd's 24/7 Care service

24/7 Care, a private personal assistance service, was set up in 2010 by RSG, in order to meet a local demand for extra personal assistance hours, which was not being met by State-funded support. It is provided at as low a cost as possible, with RSG using fees to cover costs involved. It is usually accessed for covering short respite for carers, such as a weekend:

> 'It's used by a lot of families to get a break from caring for someone. It can be a big help if someone is going away for an event, maybe a wedding, and they just need extra hours'.

The service is available 24 hours a day and seven days a week and covers home care, personal care, domestic duties, support in the workplace, social events, training, overnight care and education. It includes transport arrangements, such as accessible bus transport to, for example hospital/medical appointments or for shopping, as required. Those who avail of the service can also access the RSG resource centre. Providers are the same personal assistants that work for RSG in providing State-funded support. It is advertised in local newspapers, freely, by announcing it in press releases rather than paid advertisements, as well as in Mass newsletters and on the RSG website.

An innovative attitude

Finally, innovation was found in the attitudes and approaches of workers, which was often rooted in a very personalised approach to meeting the needs of an individual with a disability. This could lead to people 'going the extra mile' or 'thinking outside the box' in responding to support needs. Participants described staff 'not taking no for an answer'. Despite a noted increase in the number of people approaching them for support, at least one participant described how their organisation would always respond to an emergency situation. In relation to this point, another participant emphasised the importance of investing in staff, and how experienced and motivated staff can make a big difference to the quality of their supports and services.

6.3 Adaptive services

There was evidence amongst participating organisations of adapting and changing their services in response to recent best practice policy guidelines. Evidence of organisations using the findings of key policy documents was demonstrated by a number of organisations. For example, the Central Remedial Clinic changed a sheltered workshop for adults into a series of vocational training programmes.

This change was a dramatic one and involved a lot of work. It has been running now for three years with good outcomes, and is considered to be much more person-centred than the previous model. Another example is Headway who regularly use the 12 guiding principles set out in 'New Directions' in gaining feedback from their service users. Cheshire's move away from congregated settings and towards supported independent living is another example of organisations adapting their services to policy.

Using online tools

Another example of how services are being reconfigured is in the increasing use of online tools. Some organisations have begun using the internet in meeting the needs of at least some people seeking support from them. For example, both Epilepsy Ireland and Arthritis Ireland have used social media tools such as Facebook to help younger people, many of whom felt 'too young' to benefit from existing services such as support groups. Online tools also enable people with disabilities and their carers to maintain contact; this is particularly valuable for less common conditions.

As the participant from Arthritis Ireland explained, young people with arthritis might feel that many of the organisation's services are aimed towards an older age group. In response to this, they set up the Young Arthritis Network, which uses Facebook to help people connect and arrange social outings. Only last year, Epilepsy Ireland set up online support groups which aim to help people access peer-based confidential, non-judgemental emotional and practical supports from other people with epilepsy. Meetings take place weekly and last 90 minutes; this free service is facilitated by a staff member.

Box 6.2: Arthritis Ireland's Networks

The Young Arthritis Network

The Young Arthritis Network is a resource for people aged between 18 and 45 years. Its main aim is to provide young people with arthritis with the opportunity to meet other young people with the condition. According to its Facebook page, it meets once a month for social nights out, once a week for a walking club. Both take place in Dublin; however, local branches of Arthritis Ireland also run local networks. Monthly informal meetings are also held; again the focus is on meeting other young people with arthritis.

This network was set up in response to feedback from young people with arthritis.

It was through anecdotal feedback where younger people were saying, 'Well, you know, the organisation isn't really for me, I don't want to come to an information talk in the evening and sit next to people who are the same age as my grandparents, I want to meet other young people but I never see any young people at this.' So our focus then was to establish a network for young people specifically.'

Parent 2 Parent Network

Arthritis Ireland's 'Parent 2 Parent network' aims to put parents of children with arthritis in touch with each other. A lot of the contact happens through a Facebook page, as well as through 'hubs' located throughout the country. The Facebook page, alongside posting information on upcoming social events, also posts links to relevant online articles and information sources. Regular coffee mornings often include a guest speaker with expertise in juvenile arthritis. A website dedicated to arthritis among young people (www.juvenilearthritis.ie) provides information for children and their parents as well as contact.

Fizz Friends

This Facebook page aims to provide a forum for teenagers with arthritis to chat about all aspects of their lives. It also provides links to articles, information on upcoming events and an opportunity to send a question to 'JA mentors'.

6.4 Increased efficiency and effectiveness

Organisations have demonstrated their flexibility and adaptability over the past five years through improved efficiency and effectiveness within their operations. In order to safeguard services, organisations have taken many steps to reduce expenditure in all areas. Interestingly, the recommendations that came from the Value for Money and Policy Review of Disability Services were cited by many organisations as already having been implemented, long before the Review was published.

> It's [the recession] making us look at doing things differently. We do assessment on people calling by phone to the various centres around the country. We're looking at [setting up] a national contact centre so we can screen at one central level. The people working on it don't have to be social workers. They could be bright people trained to understand what we do. That then releases our workforce to do the practical things. It's the only way of managing.

One organisation described how its employees travelled less and made greater use of video systems to liaise with external organisations. Another asked their local branches to subsidise some of the courses they provide; and some were able to do so. Some organisations were exploring the idea of using more volunteers (although not without awareness of issues this might raise).

In an effort to consider ways of maintaining services while addressing possible future funding deficits, a number of organisations are currently considering formal strategic partnership arrangements, for service provision purposes, with other organisations which have similar profiles, or which work in a particular geographical area with people with similar conditions and support needs. However, they were careful to point out that successful amalgamations require strong capacity at management level, which might not be currently available because of financial pressures.

Another example of organisations becoming more efficient related to training provided to their own staff or to external bodies. For example, RSG is a FETAC accredited training provider. Training internal staff cuts down on costs associated with bringing in and paying training providers. It also gives RSG the opportunity to adapt existing courses to meet local needs. For example, they have found that many FETAC courses related to providing care are ‘very hospitalised’, so their courses adapt material to make it relevant to caring for people in their own homes and within the community. They also intend to extend their training courses to cover other areas such as palliative care. These courses are also priced competitively, and staff coordinating the programmes are doing so as part of a FÁS community employment scheme, which reduces staff costs.

Other examples of steps taken to reduce costs include sharing premises with other voluntary organisations, negotiating cheaper rents with landlords, switching telephone provider, reducing stationery usage and cutting salaries, reduction in headcount, and review of rotas.

Co-funding

The issue of co-funding is also relevant here. Many participating organisations have traditionally received funding from a range of statutory and philanthropic sources; this has become for some a more significant part of their work and budgeting. As outlined in Chapter 3, participating organisations received varying levels of financial support from the HSE, with five receiving less than 60% (some significantly less). Organisations raised the rest of their budget through a range of means which are very labour-intensive, such as the preparation of complex and detailed grant applications and tenders. Some described how their paid staff were doing voluntary fundraising work outside their working hours, as this was seen as essential to the organisation’s survival:

> If we didn’t have fundraising, we wouldn’t be able to turn on the light here. We do church gate collections. ... There’s a lot of effort in it for the money we get out of it. ... Staff’s role [in fundraising] is huge. Most of us recognise that if you don’t volunteer, the light doesn’t go on, your computer doesn’t work.

Some organisations have developed innovative ways of involving young graduates temporarily out of work. For example, Enable Ireland has begun a programme for graduates, through which they assist with developing programmes, thereby benefiting from professional experience (one of these volunteers has since moved into paid employment with Enable). Similarly, Arthritis Ireland involved young people with arthritis who are not able to work in running the helpline they provide. This reciprocal arrangement had positive outcomes for both the volunteer and the organisation, exemplified by one young helpline volunteer for Arthritis Ireland who is now training to become a counsellor.

Long waiting lists for supports and services were a common feature among organisations, as discussed further below. This could act as a driver for continued innovation. For example, in the past it led to the NCBI switching from visiting people in their homes in order to provide support, to a more centre-based approach. The organisation invested in building regional centres and in developing a number of county-based satellite points. While home visits are still provided on an as-needed basis (for example, to help someone learn to use kitchen appliances with vision loss), community resource workers now spend less time travelling and more time providing support.

One strong commonality among interviewees, in the context of reduced funding, was the importance of protecting core services and supports at all costs. One participant described how their organisation applied their 'own version of Maslow's hierarchy of needs' in identifying which supports to protect at all costs; these supports are always those for activities of daily living. While core services were protected, for many this meant being 'down to the bone' in terms of management and administrative functions, and there were real fears in relation to any further reductions in funding. (see Chapter 3 for a more in-depth exploration of the impact of the recession on participating organisations).

Connections and collaborations

The level of connections and collaboration across the sector could also be considered an innovative aspect of the way the participating organisations work. As this emerged as one of the key inherent characteristics of the participating organisations, the next chapter outlines the extent and nature of linkages evident. It is noted here as an innovation.

6.5 Key findings

- Organisations demonstrated their flexibility and adaptability in the face of an ever- changing social and economic environment. Many examples of innovative measures emerged, in efforts to identify emerging or newly identified needs, improve existing services or simply to ensure that clients' needs are met. They highlight an underlying emphasis on putting the client's needs before the organisation. One example is the recent use of social media tools to facilitate online support groups and resources for people with disabilities and their families. Another is setting up a private, low-cost care service, to meet a local need for additional personal assistance hours. One organisation used the 12 guiding principles of the Department of Health's report, New Directions in gaining feedback from their service users.

- Innovation and flexibility were not only reflected in new models and initiatives. They were also a key and necessary aspect of the way in which services were provided. This relates to being person-centred, and the way in which some organisations provide support only when an individual needs it to achieve their goals. As one participant put it, ‘there’s a different scenario each time’.

- One area in which on-going review, responsiveness, and flexibility has recently acquired importance is in improved efficiency and effectiveness. In order to safeguard services, organisations have taken many steps to reduce costs. Examples include sharing premises with other voluntary organisations, negotiating cheaper rents with landlords, switching telephone provider, reducing stationery usage and cutting salaries, reduction in headcount, review of rotas, etc. Furthermore, a number of organisations are currently considering formal strategic partnership arrangements for service provision purposes, with other organisations with similar profiles, or working in the same geographical area with people with similar conditions and support needs.

- Through co-funding, many organisations supported their work from a wide range of sources other than HSE funding. Some organisations increased their fundraising efforts; in some cases even paid staff became involved. Many different approaches to improving efficiency were also shared. However, there was a strong feeling that opportunities for cost-cutting had by this stage been exhausted and the broad consensus was that further cuts would inevitably impact negatively on core services and supports.

7.1 Introduction

Across the fifteen organisations who participated in the research, there was an astonishing range and variety of connections with other disability organisations; with many statutory and voluntary agencies; community groups; local authorities; professionals especially in health and education; and with government departments. A key relationship for those receiving substantial HSE funding is of course with the local Disability Service Managers and their staff.

7.2 Building supports for individuals

One aspect of the complex interconnectedness that all the participating organisations saw as a central aspect of their work is the day-to-day collaboration on an operational level, of an organisation's key worker or caseworker with those local people and agencies who can assist and support an individual person with a disability ('All the local services they require'; 'It's anything that can benefit your life').

This may be for the purposes of resolving a specific difficulty (such as advocating with and working alongside the local Housing Department to secure, and if need be adapt, more appropriate accommodation for someone with a progressive disability) or it can be part of what some organisations see as a core responsibility toward the person: building up a long-term support network – involving people and points of contact in health and social services, the person's 'circle of support' of family and friends, community groups, the education system and so on.

One organisation, which provides a time-limited service to individuals, commented - in relation to building up a sustainable 'natural support plan around a person', - this has to be done expertly and with great care:

> Unless a person has a support plan that is natural, that fits their life and what's available in their community, their time with us is wasted!

The strong links between certain hospital consultants and staff in some voluntary organisations were mentioned earlier. The same staff may also maintain a more general relationship with a particular hospital or hospitals likely to be working with the clients to whom the organisation provides social and emotional supports.

Links such as these inevitably require thoughtful maintenance if the person-centred approach is to be effective.

7.3 Collaboration among disability organisations

A number of examples were provided of disability organisations collaborating with each other to provide different elements of care and support for individuals. For instance, West Limerick CIL transport services are used to take people from their rural homes into Limerick city to attend Enable Ireland day service. Epilepsy Ireland makes links for its clients with Headway and Acquired Brain Injury Ireland.

Muscular Dystrophy Ireland outlined how one of its family support workers would link on behalf of a new client with a public health nurse and the HSE Disability Area Manager in order to identify available services. If the client needed a personal assistant service, they would also link in with the local provider of that service. If the need is urgent but the HSE-funded personal assistant service is not immediately available, MDI would find a bridging arrangement for the interim. Children referred with muscular dystrophy will have support from the organisation in addition to the service they receive from Enable Ireland or the Central Remedial Clinic. Organisations stressed that they do not 'think of our clients as "ours"', and in very many instances it can certainly be said that:

> there's no-one in our service who's receiving their total support from us!

Another strand of connectedness has evolved out of the possible pathways a condition may take. Epilepsy Ireland links closely with Aware, as epilepsy can trigger depression, and Arthritis Ireland links with organisations such as the Diabetes Federation or the Irish Heart Foundation, which respond to conditions their clients may have or develop. Meanwhile, the Cystic Fibrosis Association collaborated with the Irish Hospice Foundation in a publication on end-of-life care for those with this condition.

7.4 Integrated working

and a respiratory consultant) on the same date, for those who have to travel long distances to attend.

The physical location of this type of co-working can also be within the disability organisation itself. The Central Remedial Clinic brings in 'a cohort of consultants', some part-contracted by the HSE to the organisation, including:

> four orthopaedic surgeons, a paediatric neurologist…a part-time psychiatrist… four paediatricians [who] all come in here'. This saves families having to access busy out-patient departments and has the added benefit of the whole team being available for the client.

This is another striking example of important links and collaborative relationships – and two-way trust – built up over time as a result of the efforts of the relevant voluntary sector organisations.

7.5 Working together at national and international level

One of the crucial strengths of a number of participating organisations is their networking with, and membership of, national and international bodies where expertise, experience and examples of good practice can be shared, and in some cases collective pressure generated for much needed change.

One example at national level is the Neurological Alliance of Ireland, which counts among its 30 non-profit members Epilepsy Ireland, Cheshire Ireland, Enable Ireland, Headway, Muscular Dystrophy Ireland, MS Ireland and the RehabCare Group.
The Care Alliance brings together non-profit organisations supporting 'family carers' including Cheshire Ireland, the Cystic Fibrosis Association, Headway, Muscular Dystrophy Ireland and MS Ireland, all of which focus on whole-family support.
Another national-level alliance mentioned was the Irish Lung Health Association. The CEO of CFAI chairs the Irish Donor Network, working on changes to legislation required for a more effective system of organ donation.

There were many international links mentioned, among them Headway's membership of a European grouping of organisations working with brain injury, and MS Ireland's participation in the European MS Platform.

7.6 High level collaboration with the Department of Health and the HSE

A further set of linkages and collaboration involves the crucial role played by some of the organisations in relation to Department of Health and HSE initiatives.

Among a number of examples, RehabCare made substantial input into the New Directions study and recommendations, based on its experience in the UK. Arthritis Ireland was part of a HSE task force looking at self-management of chronic conditions, and Cheshire Ireland was involved in developing the new HIQA standards applicable to the care of people with disability. Cystic Fibrosis Ireland is part of the National Steering Group for new-born screening.

7.7 Local level collaboration

A number of other significant relationships were mentioned, including the involvement of voluntary disability organisations on local/regional disability platforms, often connecting to County Boards and similar local authority planning and decision-making bodies.

7.8 Research links

A number of strong connections with specific researchers and research institutions were mentioned in the course of the interviews, including CFAI's links with the Heath Research Board; MS Ireland's research connection with University of Limerick (UL); Enable Ireland's research links with UCC and UL, as well as with Dublin Institute of Technology for research into assistive technology.

Several of the participating organisations are members of the Irish Medical Research Charities Group, which brings medical researchers and patient support charities together, believing that 'today's medical research is tomorrow's healthcare'.

6.4 Increased efficiency and effectiveness

Government departments & agencies	Education and research
Department of Education and Skills Department of Jobs, Enterprise and Innovation Department of Social Protection Health Service Executive (HSE) National Disability Authority Enterprise Ireland Pobal and Area Partnership Co.	UCD * All Institutes of Technology Blanchardstown IT ** Irish Vocational Education Association Work Research Centre VECs AHEAD*** RehabCare
Training and employment services	Associations and partnerships
Solas**** FÁS Supported Employment service Chartered Institute of Training & Development Skillnets Training Service Sureskills Training Local Employment and Training Boards Blanchardstown / Tolka Area Partnerships	Not for Profit Business Association (NFPBA) European Platform for Rehabilitation Pluryn (Netherlands)***** Irish Business and Employers Confederation (IBEC) Irish Small and Medium Enterprises

* Staff training programme
** Specific student support programme and other on-campus projects
*** Association for Higher Education Access and Disability
**** New national further education and training authority, replacing FÁS
***** Working together on integrated training/employment project in Romania

7.9 Key findings

- Across the fifteen organisations, there was a huge range and variety of connections: with other disability organisations; with statutory and voluntary agencies; community groups; local authorities; professionals especially in health and education; and Government departments. The day-to-day collaboration of an organisation's key worker or caseworker with those local people and agencies that can assist and support an individual with a disability is a central aspect of the work of participating organisations. This might be to resolve a specific difficulty or to build an individual's long-term support network, a task seen by many as a core responsibility.

- A number of examples were provided of disability organisations collaborating with each other to provide different elements of care and support for an individual. So in many instances it can certainly be said that, 'there's no-one in our service who's receiving their total support from us'. Sometimes this grew out of the possible pathways an illness or condition may take. For example, Epilepsy Ireland has linked with Aware, as epilepsy can trigger depression.

- A crucial strength of many participating organisations is their networking with, and membership of, national and international bodies where expertise, experience and examples of good practice can be shared, and in some cases collective pressure generated for change. For example, several of the participating organisations are members of the Irish Medical Research Charities Group. In addition there are fruitful connections in several instances with specific researchers and research institutions.

8. Voluntary disability organisations and value

8.1 Introduction

One of the main aims of the research was to investigate the concepts of value and 'value for money' in relation to the supports and services provided by voluntary organisations. This chapter explores questions of accountability, the measurement of outcomes, consultation processes, quality assurance and value for money itself.

At the start of the Department of Health's 'Value for Money and Policy Review of Disability Services in Ireland' is a clear statement of intent:

> The Review proposes a fundamental change in….the Disability Services Programme, with the migration from an approach predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports.
>
> The recommended model should be underpinned by a more effective method of assessing need, allocating resources and monitoring resource use… (p.xvii)

High on the list of Priority Recommendations (section 9.2.1) at the end of the report are the following two recommendations:

> Agencies that receive funding from the State for the delivery of services and supports to people with disabilities are accountable for that funding, and protocols should be put in place to ensure full accountability and transparency on a standardised basis.
>
> The achievement of measurable outcomes and quality for service users at the most economically viable cost underpins the recommendations.

In this framework, the report also devotes considerable space to both the 'efficiency' and the 'effectiveness' of disability services.

The final section of this report looks at these key requirements of the proposed new form of service provision from the perspective of the voluntary disability organisations participating in this study, and shows the extent to which they are committed to these principles and already operating in accordance with these requirements

8.2 Accountability

As outlined earlier (Chapter 3) the participating organisations have markedly differing levels of funding from State (mainly HSE) sources, so there is a wider context of accountability for many of them.

Accountability to members and supporters

Those which raise a substantial proportion of their income themselves have a very strong sense of accountability to all those individuals who support the organisation's work, and this is part of their core values. As one CEO said:

> The biggest thing is…that we are member-focused…they direct the organisation, and we are proud of that… it means you are delivering what people with disabilities want.

As shown in Chapter 3, the majority of the organisations have Board members who are themselves people with disabilities and/or their family members. Of the eleven organisations for which this information was available, seven have Boards that include both individuals with disabilities and their family members and four include one or other category.

The organisations consulted for this study are at different stages in relation to developing appropriate and systematic consultation and dialogue mechanisms with their members and clients, but all accept this as a vital part of their accountability to stakeholders, just as they accept the need to benchmark their contributions against currently-accepted 'best practice'. Some details are provided below (sections 8.3 and 8.4).

Legal accountability

In terms of legal status, most voluntary disability organisations are structured as a 'company limited by guarantee, and not having a share capital'. This positions them more strongly to attract funding from all sources, including corporate donors and philanthropic foundations, as they must now abide by an extensive set of legal requirements, and their Boards are responsible for overseeing all aspects of their financial and operational management. Where an organisation has an individual membership base, its Board is elected by and directly answerable to those members.

Accountability relationships with the HSE: measurements and issues

For organisations receiving HSE funding for the services they provide, a Service Level Agreement (SLA) is in place, which specifies certain concrete aspects of service delivery or 'outputs' ('what we have to deliver, how, when, where and so-on') but generally does not require defined 'outcomes' to be attained for clients.

A further dimension of accountability in the context of the SLAs is a growing list of legal obligations and service-related standards which organisations receiving funding are required to meet. Most will have adopted these because of their own legal status (see above).

There were a range of views on the subject of the effectiveness of current arrangements. For some organisations, requirements for specific quantifiable outputs can make for transparency and accountability, and they felt comfortable with the clarity of their current arrangements:

> We would have worked with the HSE in building up the reporting systems…so they know what the individual gets…it's the responsibility of any organisation receiving tax-payers' money to report back on what they are doing…

However, others regretted what they saw as a simplistic, 'one size fits all', approach, and organisations highlighted the disparity between their organisation's way of thinking about its effectiveness, and these forms of measurement, implying that they are already aligned to the new way of thinking embedded in the Value For Money and Policy Review of Disability Services:

> At this point in time I don't think they [HSE] want to know if people are doing well or not, they just want to know what it costs, how many people are employed.
> It's just not person-centred at all!

A particular issue for several HSE-funded organisations is the ever-growing administrative burden imposed by SLA reporting requirements. Because of HSE administrative structures themselves, some face the complex demands of negotiating and operating a large number of different SLAs across many different geographical areas. As mentioned earlier, sometimes such contractual arrangements work to the detriment of someone with a disability because, the flexibility of voluntary organisations is not matched by corresponding flexibility from HSE Local Health Offices which operate in 'funding silos'. The needs of the person may be caught between the two systems.

In cases where the organisation itself contributes some of its own resources to services, it was felt that the SLA exercise needed to be both more sophisticated (to capture this aspect) as well as simpler to operate – perhaps more aligned with the organisation's own developing ways of measuring their effectiveness. Indeed, another negative aspect of the current arrangements was highlighted in an expression of frustration about the lack of common understandings between themselves and the HSE, when it comes to considering outputs and outcomes:

> It's not that we're not measuring, but it's trying to fit that [our condition-appropriate way of doing it] in…it's about what the HSE is asking versus what you're giving, and having a common language to engage with – otherwise it's a box-ticking exercise.

Finally, SLA documents also refer to quality frameworks, such as the new HIQA standards for residential disability services, which are not yet mandatory. Although the participating organisations vary in relation to their level of engagement with such standards, they are all committed to measuring their own performance in appropriate ways, whether or not they are primarily HSE-funded.

Those which raise a substantial proportion of their income themselves have a very strong sense of accountability to all those individuals who support the organisation's work, and this is part of their core values. As one CEO said:

Data gathering and record-keeping

The voluntary disability sector is itself fully committed to high standards and good practice (as promoted and supported by umbrella bodies such as the Disability Federation of Ireland and Not for Profit Business Association) in this as in other areas of operation. Some participating organisations acknowledged the need for further improvement in their data-gathering and record-keeping systems, and are committed to achieving this. For other organisations, data-gathering – formal and informal, quantitative and qualitative – for evaluation purposes has long been embedded in the organisation's day-to-day work:

> We're constantly on the road talking to members, gathering useful national data… all that inputs into our service planning.

> Service users are consulted on exiting the service on every aspect of our service delivery.

8.3 Measuring outcomes

As services which are avowedly person-centred, all the participating organisations agreed on the importance of identifying and evaluating outcomes for the individuals they serve, as well as on the challenges of measuring and recording them (as elaborated in the international literature). It was noted that, as yet, no outcome-based reporting models have been put forward by the Department of Health or HSE for general adoption by the voluntary disability sector. However, a number of organisations are actively working to devise new systems which can capture a range of outcomes and indicate the quality of the service they provide.

Many of the organisations work in ways which already incorporate detailed monitoring and evaluation of outcomes, though these may not be easily quantifiable. Where organisations employ 'key workers' or 'case workers' to provide individual support, the agreed plan, with goals and time-frames put in place for each person, is the basis for outcome evaluation. In situations where a time-limited service is provided (as in specialised training), or where contact only lasts until current issues are resolved (as with the community-based resource staff employed by some organisations), desired outcomes can be specified at the outset and progress measured over that time.

In situations of much longer-term support of clients, person-centred planning approaches are in place, and joint assessment (by the individual, their immediate family or 'circle of support' and relevant staff) often takes place at set intervals to review how far agreed goals have been attained.

Several organisations provided examples of tangible outcomes which can be and are being measured and recorded, including:

- Rates of progression – to employment, to continuing education or training – of NLN students and those on the Epilepsy Ireland founded ‘Training for Success’ course in Sligo Institute of Technology.
- Self-assessment of how participation in a physiotherapy programme lessens the physical and psychological impact of MS on individuals.
- ‘Before’ and ‘after’ assessments carried out with participants on ‘Living Well with Arthritis’ programmes.
- In a short-term respite care scenario, monitoring of the individual plan of care put in place at the start, and recording its health-related outcomes.
- FETAC qualifications gained by Headway’s training centre clients.

Clearly, most of these are objectively verifiable, while others are based primarily on self-assessed change and improvement. It is generally agreed that, ideally, both perspectives should be included.

There were a number of reservations expressed, however, about developing over-standardised ‘grids’ or systems for measuring personal outcomes, and it will be important for policy-makers to take these reservations into account as they consider a more outcome-based mode of evaluating effectiveness.

- One was that the very concept of a personal goal-oriented plan which is agreed with a service provider and monitored at regular intervals sets up a dynamic which can run counter to a commitment to the individual’s autonomy (and freedom to change his/her mind!).
- Another was that most available outcome measurement systems are simplistic in relation to most ‘complex scenarios’ of disability, particularly those of individuals with progressive conditions.
- There’s an intermittent need for services and ‘outcomes can be “undulating” for the individual, because there’s a different scenario each time…With the whole family approach, there’s a myriad of issues going on, so if you measure outcomes on the basis of issues presented…it’s extremely difficult’.

- It was pointed out that there can be a huge difference between short-term and long-term impact and outcomes. Taking this line of argument further, one representative asked how outcomes could be meaningfully categorised and measured for people whose health conditions are progressive and deteriorating. For these clients, ‘it’s just about maintaining the best standard of health and independence over time’. As another said, ‘it would be a big personal goal for some people, the maintenance goal, maintaining a certain quality of life despite a progressive condition’.

- In these circumstances, a ‘poor’ outcome for an individual need not be a reflection of a poor service, as a number of participants pointed out. It was also suggested that, where an individual experiences severe ill-health linked to their disability, any form of ‘outcome measurement’ could be considered inappropriate and intrusive.

As the academic research literature indicates, there is general agreement on the need to find ways to understand and measure ‘quality of life outcomes’, and considerable work has been done recently towards this end, both in Ireland and elsewhere. The challenges to devising appropriate systems, however, are significant.

One organisation among the participating group, which supports people with a wide range of disabilities through their specialised training services, outlined their own substantial progress in this regard. In partnership with peers in seventeen different organisations across Europe, they are in a process of developing a ‘Quality of Life measurement system’, which they have discussed with the HSE and which may well inform national practice in the future:

> It’s perception measurement, the person’s perception, and …it looks across a whole range of areas, interpersonal relations, self-determination, personal development, employability, citizenship rights, social inclusion, emotional and physical well-being…then [gives] your total score. At the moment it’s an end-of-service measure but [we are considering] measuring three times during the life of a programme so we can develop relative data…that will inform our ‘social return on investment’ measurements.

A second organisation, working with people with a wide range of disabilities in both residential and independent living settings said they had been researching the most appropriate ‘evidence-based way’ to demonstrate outcomes, and had now reached the point of piloting in a modified form a highly innovative web-based personal planning system already in use in the UK. Its key feature is a personal on-line account which is ‘managed by the person themselves’:

> All the person-centred planning is recorded and structured on their own account. They have access to it at all times, they can individualise it, put their own information in, track their progress…the data entry is managed by staff, but they are doing it together, and so can their "circles of support"…and we can look at outcomes across all our clients.

A different and potentially fruitful perspective on measuring outcomes and benefits was presented by one organisation which has been thinking hard about ways to demonstrate the 'social return on investment', an approach currently used in the UK to measure 'soft' outcomes (see Chapter 2 above).

It looks at including in measurement the many transforming impacts of participation in a particular programme by an individual with a disability:

> [There is] the broader reduction in medication, the reduction in hospital stays and GP visits – but how do you put a value on the fact that a person is now confident enough to go out to the cinema…do their own shopping… leave the house on their own for the first time in five years…and so a family member who has given up work…can now go back to employment…[at present] that's not counted!

Across the board there is a clear consensus on the principle of evaluating personal outcomes, and it is also agreed that finding ways to 'count' such things appropriately and sensitively is the key immediate challenge – one, perhaps, where the voluntary sector is in a position to offer experience and leadership.

8.4 Consultation processes

User involvement has been emphasised at a policy level for some time, and widespread consultation, formal and informal, is a strong feature of the practice of all the participating organisations. It is itself an important dimension of accountability, as well as a means of keeping the focus on outcomes and monitoring the impact of an organisation's work. It is considered a crucial form of dialogue between the organisation and those it exists to serve: 'there has to be dialogue when we're supporting so many people… there's continuous consultation'. Of course often this continuous consultation takes place informally, in order to identify at an early stage issues which need resolving for clients (one example is the regular monthly 'phone around' to clients of a PA service by their service coordinator).

More formal and structured consultation is carried out in many different ways. In this context, a number of organisations referred to the importance of adequate and responsive complaints systems ('we'd be worried if we didn't get any complaints!').

In some instances, organisations serving a large membership or extensive client group have set up formal representative structures which bring issues and questions from the individual member or client level up to the Board and senior management. RehabCare, for example, has set up regional Advocacy Committees, which meet regularly with its Regional Service Managers. These committees elect members to the National Advocacy Committee, which itself has representation on the Board.
Such a structure provides the organisation with feedback on the impact of new policies and practices. It also fulfils another important role by giving individuals the opportunity to have their voices heard and to participate in decisions that concern them: 'it's part of a person's self-actualisation to be able to represent themselves…'

Other forms of consultation, designed to improve the quality of supports and services, include evaluation exercises when organisations run events such as an information and experience-sharing meeting for people with a particular condition, or provide specialist training to health professionals. When individuals leave the MS Ireland Care Centre they are invited to a 'departure meeting' to 'discuss their experience of the week and any suggestions they have for improvement'.

8.5 Quality assurance

Benchmarking their own practice against external standards is a feature, to a greater or lesser extent, of all the organisations interviewed for this study, and is touched on here because it can validate both how organisations run themselves, and the quality of their support and care practices. So it is a central component of value in a broad sense.

Many small organisations have undertaken accreditation through PQASSO (Practical Quality Assurance System for Small Organisations). DFI has promoted this as a relevant form of external validation, and provided support and training to organisations[11]. DFI has also encouraged its member organisations to subscribe to the recently-published Governance Code for Community, Voluntary and Charitable Organisations, which was itself developed by the community and voluntary sector.

Some of the organisations interviewed are members of the European Platform for Rehabilitation, applying its quality standards to different resource or training centres, and gaining accreditation – both for the organisation as a whole, and for its local centres – under EQUASS (European Quality Assurance in Social Services), which operates a system for benchmarking services with a person-centred approach.

Some of the large and more business-oriented voluntary organisations have also obtained recognition under the European Framework for Quality Management (EFQM), which is a business management framework.

[11] 28 organisations have participated on the PQASSO quality system, and 38 member organisations have participated on the "Organisation HealthCheck" since 2008.

There are also Irish-based National Quality and Excellence awards for companies – RehabCare was the first health and social care organisation to achieve this award. It was pointed out that the larger organisations which manage residential care services are not only in the process of adopting HIQA's recent but not yet mandatory Quality Standards: Residential Services for People with Disabilities, but were themselves involved in developing these standards.

A further example of benchmarking against well-respected standards is the accreditation of the MS Care Centre in Dublin by the UK-based CHKS[12], a standards body for clinical care settings.

Finally, some programmes operated by participating organisations have themselves been considered by their European peers as examples of best practice, which others are encouraged to replicate. Two such programmes are the Epilepsy Ireland founded course in Sligo IT, Training for Success, and the specialised supported training models developed by the National Learning Network.

A cautionary note was sounded by one or two organisations that reported their achievements in this regard, but pointed out the resource costs involved in meeting these standards, and expressed their fears for maintaining them in a period of shrinking State financial support.

8.6 Value for money

Voluntary disability organisations, while welcoming many positive aspects of the new approach signalled in the 'Value For Money and Policy Review of Disability Services in Ireland' have also expressed concern that the review does not adequately show the practical and operational matters in the sector, such as organisation's recent track record of making significant efficiency savings:

> The cutbacks…have meant very careful scrutiny of all aspects of the service, so we can protect the core service.
>
> We have done all the things they appear to think we have not done! Reviewed all our costs, cut non-pay items to bare essentials, reviewed and changed our staff rosters.

When asked whether they considered that their services gave 'value for money' a number of organisations who receive little or no State funding were quick to respond by asking 'Whose money?' Organisations referred to the close involvement of members in the planning of services as well as in fundraising activities. This guarantees a close match between overall expenditure decisions and the wishes of people with disabilities and their families. They pointed out that this element of user-driven choice which is a key feature of the new policy approach is firmly part of their practice.

[12] Originally Caspe Healthcare Knowledge Systems

The value of prevention and early intervention

The value for money debate in relation to the voluntary disability sector is primarily about the best (most efficient and effective) use of limited State resources by these organisations acting, with direct State support, to provide supports and services to people with disability.

A great deal of evidence was provided about the ways in which they save money for the State – though it was usefully pointed out that there may sometimes be a need for short-term investment (for example in the provision of supported training) if longer-term cost savings are to be achieved.

The person-centred, practical support services these organisations provide can reduce overall costs in many obvious ways, the most obvious being preventing or delaying hospital or nursing home admissions. The same process of reducing or avoiding health-related costs occurs in subtler ways, for example Epilepsy Ireland community resource staff work to help people reduce their stress levels, as stress is a major factor in epileptic seizures. PA services or rehabilitative training can enable an individual to go back to work, or free a carer to take up employment, or find more balance in outside activities.

Box 8.1 Economic impact of services: an example from the National Learning Network

NLN explained how it set out to put an economic value on the impact of their training services, and commissioned a firm of international economic consultants for this purpose. They made calculations based on the progression of around 1,600 NLN students into ‘open market’ employment over a 3-year period:
Assuming they retained their employment for between 2-5 years, their potential earnings were estimated at between €99 million and €275 million.

The State not only benefited from the tax paid by these individuals, it would have saved between €18 million and €37.6 million in reduced Disability Allowance over that period of employment, and both these benefits would continue alongside continued employment.

Meanwhile, costs of training compared very favourably with training through Community Employment schemes, though less favourably with State-sponsored traineeship initiatives. The difference, however is more than adequately accounted for by the much greater need of NLN’s clientele for personal supports integrated with training.

Source: Indecon, 2011. Assessment of Economic Impact of NLN Vocational and Rehabilitative Training in Ireland. Dublin: Indecon International Economic Consultants

Adding value

Many aspects of the voluntary disability organisations' ways of operating, when delivering services using State funding, generate situations in which, they are not only efficient and cost-effective, but frequently bring 'added value' to those services. Equally, organisations not in receipt of State funding still contribute directly to the overall quality of general health services through specific aspects of their work.

These indirect contributions are rarely recognised, and may even be taken for granted by the organisations themselves, but merit exploration and wider acknowledgement. Examples provided include the following:

- Co-funding, referring to the ability of voluntary organisations to attract additional funding from a variety of sources can greatly enhance services funded at a more basic level from State sources.

- Voluntary organisation staff, employed with State funding to provide specific services, frequently work additional unpaid and anti-social hours and generally 'go the extra mile' in order to fulfil obligations to their clients or provide much needed support to an individual.

- The voluntary ethos of contributing to society as a whole is demonstrated by the way organisations may use fundraised income to enable senior staff to undertake relevant outside duties, such as contributing on County Boards and community organisations or as part of local disability platforms.

- The specialist and detailed knowledge built up in some voluntary disability organisations enhances the quality of Ireland's statutory health services at many levels through the awareness-raising, information provision, and direct training of health professionals.

- Several organisations working with specific conditions, such as cystic fibrosis or muscular dystrophy, can, through their international links, bring into Ireland specialised expertise and the latest thinking about clinical and therapeutic practice, which produces benefits for the health services as a whole.

- Some organisations fund clinical research of the highest quality, which is a major contribution to improving national medical services overall.

- Several voluntary organisations own valuable buildings, sometimes as a result of bequests, and these are frequently made available rent-free as bases for HSE-funded services.

- Fundraising by a disability-specific organisation may provide new buildings for health facilities serving a wider population than that represented by the organisation itself.

- The careful use of volunteers in service delivery is beginning to be a new feature of the voluntary disability organisations, which have previously involved volunteers primarily as Board members or local fundraisers or organisers. Inputs such as the graduate volunteer scheme utilised by Cheshire Ireland, or the traditional ‘befrienders’ in other services, complement the work of the staff and by enhancing the service in this way they add to the quality of life of people with disabilities.

8.7 Key findings

- In relation to ‘value for money’, participating organisations have worked to achieve maximum efficiency, though they are deeply concerned about the potential impact on services of any further reductions in their income.

- In addition to efficiency in relation to the costs of services, they can provide demonstrable examples of how the supports and services they provide to people with disabilities save substantial amounts of money for the State.

- Voluntary sector organisations (in contrast to private, commercial provision) bring added value to the services they provide on behalf of the State in many ways, such as their co-funding of services, their links to international expertise, the involvement of volunteers, the flexibility of their staff, sharing of their buildings and generosity in contributing their knowledge and expertise.

- There are strong structures for accountability to all stakeholders in place across these organisations, based first and foremost on their uniform legal structure and the oversight role of their Boards, important elements of good governance.

- All organisations interviewed are committed to, and moving towards, demonstrating effectiveness by measuring outcomes for their clients. Service Level Agreements with the HSE do not at present go beyond quantifiable outputs but voluntary organisations are actively thinking ahead, in line with the need for appropriate outcome measures signalled in the recent Value for Money and Policy Review of Disability Services report.

- The sector can offer valuable experience and leadership in this field. Tangible personal outcomes are carefully documented in many instances, and innovative approaches to outcomes measures (social return on investment, quality of life outcomes) are being piloted in others. Equally organisations have recognised the challenges in relation to a comprehensive model which is sufficiently responsive to differences in services and in people with disabilities themselves.

- Reservations were expressed about the practicality and appropriateness of an ‘over-quantified’ approach to measuring outcomes – particularly in relation to progressive conditions and serious illness accompanying disability.

- In terms of good governance, there are strong and well-developed consultation structures and systems in place in most organisations.

- Voluntary organisations’ practice in the disability sector is characterised by a clear focus on quality assurance and on benchmarking against accepted good practice. Many are accredited within recognised European and Irish frameworks.

9. Conclusions and recommendations

9.1 Conclusions

These findings clearly show the vital role that voluntary disability organisations play in supporting people with disabilities to live in the community. They also suggest how much these organisations have to offer at this particular time, as national strategies for disability service provision move towards a new, person-centred vision for the future. The enormous variety of organisations in the sector is exemplified by the sample. Between them these organisations serve a wide range of people, conditions, and needs, and have built up extensive knowledge and contacts at all levels. Their experience and knowledge are huge resources for the future development of the best possible services for people with disabilities. And, despite their wide diversity, there is a strong level of commonality in relation to their overall voluntary ethos, which distinguishes them as service providers from others with a different orientation.

The research found strong evidence for four key characteristics of the voluntary disability sector which, in combination with their solid community basis and inter-connectedness at all levels, help to define them as mainstream disability specialists. These findings are not presented in isolation, but are closely supported by those from the review of literature from other jurisdictions which was undertaken as part of the research. It should also be noted that the evidence presented in this report is only a selection from the volume of rich data contributed by the participating organisations, and much more could be adduced to further strengthen the findings.

The first key characteristic explored is that of person-centredness. The findings show that voluntary disability organisations' person-centred approach and ethos are amply demonstrated in their provision of individualised services and supports. Secondly, they have a high level of specialist knowledge and skills, which relate not only to the medical aspects of particular impairments or conditions, but to the effects of disability on the person in all areas of life. This is evidenced by a holistic approach to support, which frequently includes the whole family, and which addresses issues in health, education, employment, housing and transport among others, as well as crucial personal and social issues.

Thirdly, organisations are innovative in the way they identify and address new and emerging needs, and in their commitment to continuous improvement of services. Finally, their strong links at community, regional, national and international levels, often built up over decades enable effective collaborations. These collaborations support individuals to access a range of public services, including health services, while their national and international networking contributes to clinical knowledge and brings new expertise into the Irish health services.

Valuable as these characteristics are, it is equally apparent that these essential qualities of the voluntary disability sector are both potentially fragile and could be irreplaceable. In this respect the research literature outlined in this report offers valuable insights to policy-makers and practitioners, since it examines developments elsewhere similar to the new agenda for disability services reform in Ireland. It shows the pit-falls: how over-complex, output-driven levels of regulation and inappropriate forms of accountability can compromise voluntary organisations' independence and undermine the trust they have traditionally enjoyed from their clients and society at large. Funding restrictions can significantly reduce disability organisations' capacity to provide clearly-needed services and supports, while rigidities in relation to State funding can limit organisations' capacity for innovation and flexibility.

Concepts of value, and the measurement of value in relation to voluntary disability organisations and their services, arose at many points in the discussions. Organisations are all feeling the effects of two forms of pressure. Firstly, income (particularly HSE funding) has been reduced when demands on organisations have increased. Secondly there is a new stringency in the requirement to demonstrate efficiency, effectiveness and 'value for money' as recipients of statutory funding.

Each organisation in its own way has been made to review costs and become as efficient as possible in its use of resources, and this has had some positive effects, although the consensus is that there is little more to be achieved in this respect, and a danger point may well be approaching if there are further funding cutbacks.

Some of the ways in which significant value for money is regularly achieved are not currently registered in health service accounting systems. There were many examples of how the services and supports they provide have saved significant amounts of taxpayers' money while benefiting their clients. People have been supported to live independently in their own homes rather than having to resort to nursing home or hospital care at a much higher cost to the State.

Participating organisations create value for money because they add value in a variety of ways to the services and supports provided on the basis of statutory income. Some of their work is for the common good, such as the clinical research they fund, and the expertise and knowledge they bring into the health service at national level as well as the contribution they make to county-level or community-level bodies.

Important forms of added, but largely unmeasured, value include the widespread use of co-funding of specific initiatives; the significant contributions of volunteers; the dedication and flexibility of staff; and the making available of buildings and facilities which are owned by voluntary organisations, and in which State-funded services are provided.

Accountability and quality were considered to be closely related to value, and perceived as a means to validate and underpin their overall value for money. Participating organisations are not lacking in this regard, and benchmarking against accepted good practice has become part of organisational culture for many organisations. They have appropriate legal frameworks, their contractual arrangements with the HSE (and with FÁS in some instances) include agreements on outputs, and most have or soon will have undertaken accreditation in relation to their governance and/or services. For smaller organisations this has meant the PQASSO framework, while some larger organisations have achieved European accreditation status (EQUASS) for their services as well as national excellence awards (EFQM).

The question of outcomes and outcome measurement is a key component of governmental thinking about disability services. Participating organisations accept that measuring the impact of supports and services is an important responsibility, while being acutely aware of the challenges involved and of the difficulty of going beyond one-dimensional measurements to fully capture the value of the multi-faceted contribution of the voluntary disability sector. Several, however, are actively considering forms of outcome measurement – such as quality of life measures or the Social Return on Investment approach – which, if adapted appropriately and put in place through a collaborative process with the Department of Health and HSE, could be greatly beneficial to the organisations themselves and to their clients, as well as to their funders.

9.2 Recommendations

As this report has documented, each participating organisation has been severely affected by governmental cutbacks in spending and other aspects of the current difficult economic times, and all are concerned for the future. Yet they are determined to continue maintaining their ethos, prioritising their supports to people with disabilities and their families, and providing high quality services which are both cost-efficient and effective.

It is important to recognise that the voluntary disability sector was not fully taken into account, or adequately valued, in the recent charting by policy-makers of new directions for disability policy and practice, particularly in the Value for Money and Policy Review of Disability Services. The sector has an enormous amount to contribute based on its long-established work in the community with people with disabilities, and it is open to bringing its knowledge and experience into new ways of working and new forms of relationship with statutory funders.

- Policy makers should recognise the important contribution of the voluntary disability sector in developments relating to the agenda for reform in the HSE's Disability Services Programme.

- The strategy for implementing reform should take full account of the role of voluntary organisations, and should propose ways in which they can be adequately supported to provide and extend the community-based services which are at the heart of current disability policy.

- DFI and the disability organisations themselves should continue to press the Government to articulate a full and clear vision of the future of disability services in Ireland, and the role of voluntary provision. As the voice of people with disabilities in Irish society, the voluntary organisations should take every opportunity to contribute to that vision.

- The voluntary sector as a whole – perhaps through DFI and NFPBA – should be proactive in identifying and analysing existing and emerging good practice models, the evaluation of outcomes and the measurement of the social value of the supports and services they provide. Once an appropriate model is identified, information should be disseminated and training provided so that organisations can apply it as effectively as possible in their own work.

- Linked to this, all organisations should adopt a policy of continuous improvement in relation to data-gathering and record-keeping. There is great potential for sharing information and learning between more experienced and less experienced organisations.

- This research study focused solely on the perspectives of the voluntary disability organisations themselves. Its findings would be strengthened by further research to explore the effectiveness of the sector from the point of view of the people with disabilities and their families who are their clients and service users.

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Appendix (A) DFI and NFPBA Members

Disability Federation of Ireland: members and associates

- Ability West (formerly Galway County Association for Mentally Handicapped Children)
- Acquired Brain Injury Ireland (formerly The Peter Bradley Foundation)
- Action for Mobility
- ACTS
- AHEAD - Association for Higher Education Access and Disability
- Alzheimer Society of Ireland
- Anne Sullivan Centre
- Arklow Disability Action Group
- Arthritis Ireland
- Asperger Syndrome Association of Ireland
- Aware
- Bluestack Special Needs Foundation Ltd
- Bodywhys
- Epilepsy Ireland
- Brí - The Acquired Brain Injury Advocacy Association
- Camphill Communities of Ireland
- Care Alliance Ireland
- Carmichael Centre for Voluntary Groups
- CASA Caring & Sharing Association
- Catholic Institute for Deaf People (CIDP)
- Central Remedial Clinic

- Centre for Independent Living
- Centre for Independent Living Kilkenny
- Centre for Independent Living Mayo
- Centre for Independent Living Tipperary
- Centre for Independent Living Blanchardstown
- Centre for Independent Living Carlow
- Centre for Independent Living Cork
- Centre for Independent Living Donegal
- Centre for Independent Living Greater Dublin
- Centre for Independent Living Galway
- Centre for Independent Living Gorey
- Centre for Independent Living Longford Ltd
- Centre for Independent Living Offaly
- Centre for Independent Living Sligo
- Centre for Independent Living Waterford
- Centre for Independent Living Wexford
- Cheeverstown House Ltd.
- Cheshire Ireland
- Children in Hospital Ireland
- Childvision
- CoAction West Cork Ltd
- Cope Foundation
- Cork Accessible Transport

- County Roscommon Disability Support Group Ltd
- Crosscare Cedar Programme
- Cystic Fibrosis Association of Ireland
- DeafHear.ie (formerly National Association for Deaf People)
- DEBRA Ireland
- Diabetes Federation of Ireland Southern Regional Office
- Disabled Drivers Association
- Disabled People of Clare
- Doorway to Life Ltd.
- Down Syndrome Ireland
- Dyspraxia Association of Ireland
- Dyslexia Association of Ireland|
- Enable Ireland
- Express Yourself Ltd.
- Extra Care
- Féach
- Fibromyalgia Support Group (Midlands)
- FICTA (Federation of Irish Complementary Therapy Associations)
- Fighting Blindness
- Friedreich's Ataxia Society of Ireland
- Genetic and Rare Disorders Organisation
- Grow
- Hail Housing Association for Integrated Living

- Headway Ireland
- Health Action Overseas
- Heart Children Ireland
- Huntington's Disease Association of Ireland
- iCare
- Ilikecake Ltd
- Institute for Disability & Senior Citizens Ltd
- Irish Deaf Society
- Irish Electromagnetic Radiation Victims Network
- Irish Guide Dogs for The Blind
- Irish Hard of Hearing Association|
- Irish Haemophilia Society
- Irish Kidney Association
- Irish Motor Neurone Disease Association
- Irish Raynaud's and Scleroderma Society
- Irish Society for Autism
- Irish Wheelchair Association
- Jack and Jill Children's Foundation
- KARE
- Leitrim Association of People With Disabilities
- Livability
- Lucan Disability Action Group
- Mid WestSpina Bifida & Hydrocephalus Association

- Migraine Association of Ireland
- Multiple Sclerosis Society of Ireland
- Muscular Dystrophy Ireland
- National Council for The Blind of Ireland
- National Federation of Arch Clubs
- Neurofibromatosis Association of Ireland
- Neurological Alliance of Ireland
- North West MS Therapy Centre
- North West Parents and Friends Association
- North West Stroke Group
- Noinin Support for Autism
- ONET
- Out and About Association
- Parkinson’s Association of Ireland
- Peacehaven Trust
- Post Polio Support Group
- Rathmines Community Partnership
- Reach Ireland
- Rehab Group
- Royal Hospital Donnybrook
- SonasaPc Ltd
- Sophia Housing Association Ltd
- Special Olympics Ireland

- Spina Bifida Hydrocephalus Ireland
- Spinal Injuries Ireland
- St. Catherine's Association
- St. Gabriel's School and Centre
- St Hilda's Services
- St Joseph's Centre for the Visually Impaired
- St. Mary's Centre (Telford) Ltd.
- St. Michael's House
- S.T.E.E.R.
- The Carers Association
- Vantastic
- Vergemount Housing Fellowship
- Voluntary Service International
- Walkinstown Association
- West Limerick Independent Living

Not for Profit Business Association (NFPBA) 2012

Central Remedial Clinic
Cheshire Ireland
Deafhear
Enable Ireland
Irish Wheelchair Association
National Learning Network
NCBI
Rehabcare

Appendix (B)

A note on research methods

Preparation and planning

After a detailed initial briefing and discussion with the Steering Group, the researchers undertook a review of the relevant policy documents at national level, and a search of the academic literature on the role of the voluntary sector in supporting people with disabilities living in the community, as well as the issue of measuring the value of this contribution.

Consideration of all of these contributed to the framing of a short pre-interview questionnaire covering factual matters, and a 'topic guide' for a series of semi-structured interviews, ranging over the most important research topics and questions. Two researchers worked closely together throughout, sharing all the research tasks, so it was possible to undertake a good deal of work in a relatively short period, which met the requirements of the bodies commissioning the study.

At the start, two meetings were held to give the representatives of all the participating organisations the opportunity to come together as a group with the researchers and with senior staff of DFI and NFPBA, in order to discuss the project and its purpose, and provide their feedback on draft versions of the planned questionnaire and topic guide.

Pre-interview questionnaire

The finalised questionnaire was forwarded to the nominated organisational representatives in the form of an on-line survey. All but one were completed and returned, providing a solid body of factual information in advance of the interviews. For the purpose of gathering the most useful statistical information on such matters as numbers of staff and 'service users', and levels of funding from different sources etc., it was decided to request figures for 2011.

At the subsequent interviews, many organisations also provided further information in the form of Annual Reports, information leaflets, current service user statistics, case histories, some specialised research reports, and other relevant documentation. In addition, two organisations provided all or part of their current Service Level Agreement (SLA) for reference. All of these added to the researchers' understanding of the voluntary disability sector at this time.

The data derived from the questionnaires proved to be useful beyond its original purpose of familiarising the researchers with each organisation and its work in advance of the interview. An analysis of the whole data-set produced a valuable overview of the fifteen organisations as a group, as well as yielding comparative information which illuminated important dimensions of the voluntary disability sector as a whole. Findings from this stage of the process are mainly incorporated into Chapter 3.

Interviews

Qualitative interviews were at the heart of the research process, and each researcher carried out a number of these with senior staff in the participating organisations. In most cases, the discussion involved one representative only, but in some instances two or three staff contributed from their different perspectives. The interviews, lasting from one to two hours, were audio-recorded with the participants' agreement. They were free-flowing, but aimed to cover in as much depth as possible the main questions and issues listed in the topic guide, which had been circulated in advance. This qualitative approach led to a flexible and open-ended exploration of the research topics.

A high level of commitment was shown by all those who participated in these interviews. It was demonstrated in their careful preparation, generous provision of information, engagement with the issues, and willingness to make time to consider the wider purposes of the research. A number of individuals found the process itself valuable: as one participant said, 'If you hadn't been coming here, I wouldn't have stopped to reflect on all of this'.

Analysis

Given the richness, detail and sheer quantity of the interview data, the researchers decided to transcribe each interview as fully as possible, prior to analysis. A process of thematic analysis was then undertaken, first for each organisation separately, then for the whole group of fifteen, using a template based on the original list of interview topics and questions. This process entailed much sifting and comparing of material, and ultimately facilitated both the clustering of closely-related and mutually-supportive contributions on key topics, and the recognition of unexpected and sometimes 'outlying' information.

Finally, as thematic outlines began to take shape, decisions were made on the forms of selection and presentation which would best correspond to the requirements of the commissioning bodies, and would in particular reflect the main concerns of the recent national-level reviews of disability policy and practice. The findings which are the outcomes of this process of analysis form Chapters 4 to 8 of this report.

Conclusion

Finally, in consultation with the Steering Group, the researchers outlined their conclusions from the whole research process, as these related to the original purpose and context of the study, and made a number of recommendations on the basis of their overall findings.

Appendix (C)

Research tools

(1) Themes for discussion in semi-structured interviews

The nature and scale of services and supports provided

- A brief overview, including any developments / improvements over the years

The organisation's general ethos

- Including any changes since it was founded

Challenges in the current economic climate

- Current and possible future implications for your organisation

Contribution of your organisation

- Gaps filled, approach to meeting needs, specialisms and expert knowledge, linking and referring people to other services and supports, geographic remit

Person-centred care

- How your organisation works with and for individuals (and families/ carers)

'In the community'

- What this phrase means in practice to you and your organisation

'Mainstream' and 'specialist' services

- How do these terms apply to your organisation?

Measuring value

- How your organisation defines success, what outcomes can/ should be measured, monitoring outcomes, challenges involved
- The role of service user/client consultation in this process
- Achieving 'value for money' services

Accountability to funders

- Experience of any accountability conditions from funders,
- Potential implications of (existing or future) accountability requirements

Links, collaboration and networking

- With other voluntary organisations, statutory services of all kinds

The questionnaire

- Checking through the questionnaire for any final points for clarification

Research and other literature

- E.g. annual reports, SLAs, other relevant formal documentation, research projects, evaluations etc

Appendix (C)

Research tools

(2) Topic outline for pre-interview questionnaire

BACKGROUND INFORMATION

1. Name of organisation and person completing the questionnaire
2. Legal status of organisation
3. Membership (if applicable)
4. Date it was established
5. Type of disability/ disabilities it responds to
6. Geographical level (national, regional, county, local)

SERVICES AND CLIENTS/USERS

7. Who founded it? (people with disability, families, professionals etc.)
8. Who uses the organisation's services and supports? (2011 information)
9. Age range/s of clients/ service users
10. Specific services provided
11. Three most frequently used services
12. How do people access services? (e.g. self-referral, health professionals etc)
13. Eligibility requirements (if any)

STAFF, BOARD AND VOLUNTEERS

14. Numbers in 2011 of: paid staff (full-and part-time); volunteer workers. Approximate number of hours contributed by volunteers, if known.
15. Numbers in 2011 of people with disabilities who were: paid staff; volunteers; Board members
16. Numbers in 2011 of carers/ family members of people with disabilities who were: paid staff; volunteers; Board members.

SOURCES OF FUNDING

17. Types of funding source (e.g. HSE, private donations, corporate funding)

19. What proportion of total income came from HSE in 2011?

RESEARCH EVALUATION AND CONSULTATION

20. Titles and dates of research/ review/ evaluations from last 10 years
21. Consultation with clients/ service users

Any other comments?

Arthritis Ireland
Little Things make a Big Difference

Cystic Fibrosis Ireland

Central Remedial Clinic

CHESHIRE IRELAND learning through listening

Action on Disability
Enable Ireland

WEST LIMERICK INDEPENDENT LIVING LTD.

epilepsy Ireland

Appendix (D)
Participating Organisations

HEADWAY
Brain Injury Services & Support

National Learning Network
Investing in People, Changing Perspectives

Irish Wheelchair Association

NCBI
Working for People with Sight Loss

MDI
MUSCULAR DYSTROPHY IRELAND

CELEBRATING 40 YEARS 1972 - 2012

Q Mark for Accessibility
ABLE

RehabCare
Investing in People, Changing Perspectives

MSIreland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

R.S.G
County Roscommon Disability Support Group Ltd

The **Not for Profit Business Association (NFPBA)** was formed in 1998 and consists of the 8 leading voluntary/charitable organisations supplying services, principally to people with physical disabilities and with sensory disabilities. The members of the association are Central Remedial Clinic; Cheshire Ireland; DeafHear; Enable Ireland; Irish Wheelchair Association; NCBI; National Learning Network; and RehabCare.

The services provided through NFPBA members are, in the main, personal, social services. Services include supported accommodation, residential care, housing, respite care, personal assistant, care attendant, home help services, education, independent living, transport, support with assistive technologies, sensory mitigating interventions, assessment, therapeutic services, day activation services, vocational training, sheltered occupational services, supported employment and information and advice services. These services are mainly based in communities, in mainstream settings, promote social inclusion and community participation and are very successful in ensuring mainstream individual quality of life outcomes for individuals.

The association represents the business interests of its members as service providers, particularly in view of the need to combine the care ethos of the past with a commercial ethos to deal with current and emerging market forces. Through the association, a platform of combined effort and commitment is provided to manage the change.

Not for Profit Business Association,
Unit G9, Calmount Park, Ballymount, Dublin 12
Tel: +353 (0)1 4293600   Fax: +353 (0)1 4600919
E-mail: info@notforprofit.ie   Web: www.notforprofit.ie

The **Disability Federation of Ireland (DFI)** represents the interests and the expectations of people with disabilities to be fully included in Irish society. It comprises organisations that represent and support people with disabilities and disabling conditions.

The vision of DFI is that Irish society is fully inclusive of people with disabilities and disabling conditions so that they can exercise their full civil, economic, social, and human rights and are enabled to reach their full potential in life. DFI's mission is to act as an advocate for the full and equal inclusion of people with disabilities and disabling conditions in all aspects of their lives.

There are over 126 organisations within membership, or as associates, of DFI. DFI also works with a growing number of organisations and groups around the country that have a significant disability interest, mainly from the statutory and voluntary sectors. DFI provides information, training and support, networking, advocacy and representation, research and policy development / implementation, and organisation and management development.

DFI works on the basis that disability is a societal issue and so works with Government, and across the social and economic strands and interests of society.

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