

**Exploring the Use of Natural Community Supports  
in Promoting Independent Living among Adults  
with Disabilities in Ireland**

**Survey of Service Providers**

**Volume I**

**The Research Findings**

By

John A. Weafer

Anne Marie Weafer

2012

## Table of Contents

### VOLUME I

<b>Table of Contents .....</b>	<b>2</b>
<b>Executive Summary .....</b>	<b>3</b>
<b>Acknowledgements .....</b>	<b>7</b>
<b>Chapter One .....</b>	<b>8</b>
<b>Chapter Two .....</b>	<b>18</b>
<b>Chapter Three .....</b>	<b>42</b>

### VOLUME II

Profile of Selected Programmes and Initiatives.

#### Appendices

- A. Letters from National Disability Authority to Service Providers.
- B. Questionnaires.
- C. Charted Summary.

While the research was commissioned and funded by the National Disability Authority, the report represents the views of the service providers and the researchers.

## Executive Summary

### 1.1 Background to the Research

This survey was commissioned by the National Disability Authority to explore how organisations in Ireland which provide supports to people with disabilities also provide programmes/initiatives which link people with disabilities to natural supports within their communities. The study was informed by a separate literature review, commissioned by the National Disability Authority, which identified previous international research on interventions to promote natural supports among people with disabilities (WRC, 2012). WRC placed such interventions into four main categories, which were:

1. Circles of Support and similar models (such as MicroBoards) which draw principally on existing natural supports such as family and friends, but involve these in a more formalised way in supporting the person with disability.
2. Peer-based approaches including peer advocacy groups and interventions using self-authored spaces.
3. Programmes which seek to promote social inclusion through developing social skills and social competence amongst people with disabilities and/or implement individual goal setting in relation to social participation.
4. Programmes which seek to develop social capital through implementing befriending strategies and strategies to build inclusive communities.

Service providers made the decision as to whether their programmes came within the remit of the study, based on criteria provided by the research team (Appendices I - 4). Volume II of this report gives details of the programmes included in the study.

Data was collected by means of a telephone and self-completion survey, which was administered to 500 service providers. These service providers were selected from the Health Research Board disability databases to reflect the range of intellectual, physical and sensory, and neurological disability agencies currently operating in Ireland. Some service providers did not respond, others provided only partial data. This suggests that the findings in this study should be taken as indicative rather than statistically representative of the programmes and structured initiatives relating to natural community supports which existed in Ireland over the time period covered (1986 – 2011). However, within these limitations the findings are considered to be robust and sufficiently credible to inform discussion.

## **The Research Findings: Summary**

Just over one in ten of the disability service providers contacted indicated they had a programme or initiative in place which fitted within one of the four categories used to guide the research. While most service providers did not have a relevant programme or initiative in place, due mainly to the person-centred focus of their service provision, most agencies acknowledged the value in providing natural supports. Most respondents said that if they had access to additional funds, they would consider introducing this type of initiative.

Some of the principal features of the programmes and initiatives included the following:

- The programmes/initiatives were relatively evenly spread around the country, with approximately one quarter of the total in each province.
- The 86 programmes/initiatives were relatively evenly spread across the four programme categories, with 'innovative social skills training' the most popular category. Almost 38% of all programmes/initiatives fell into this category. This was followed by befriending schemes (20%), peer advocacy programmes (17%), and programmes supporting family and friends (16%).
- More than nine in ten programmes, regardless of disability sector, had specific aims and objectives, the most frequently reported were social learning/life skills, the promotion of community integration, the promotion of independent living, and reducing isolation. This varied by disability sector. The Physical/Sensory disability agencies placed most emphasis on the development of social learning skills, followed by independent living and social inclusion. Intellectual disability agencies' programmes emphasised the development of social learning skills, community integration, and the development of practical skills. Neurological disability agency programmes emphasised independent living, support given to families/carers, and social inclusion.
- Most of the programmes were relatively recent, with 66% starting since 2005 and 11% starting before 2000. This pattern was consistent across the three disability sectors.
- The target groups for the different programmes and initiatives corresponded with the primary focus of the service provider's services and in the majority of cases focused on people with disabilities rather than members of the community more generally. Thus, for example, intellectual disability agencies had programmes or initiatives that benefitted adults with an intellectual disability. On average, 16 people have benefitted from each programme during the past year or so. This figure was consistent across the three disability sectors, with neurological disability programmes somewhat higher.

- Approximately half (47%) of the 86 programmes/initiatives were local, with the remainder described as national (32%) or regional (19%).
- Statutory funding was very important for many of the programmes, with 44% of all programmes depending on statutory funding as the sole means of funding and another 22% availing of statutory sources for part of their funding requirements. Funds provided by service providers and fundraising were also significant sources of support for these programmes.
- When asked what resources were made available to the programmes/initiatives, most respondents mentioned staff, followed by office/space, administrative support, funding, and volunteers. Most of the programmes/initiatives were resourced by a person/s who provided assistance as part of the programme/initiative. The support provided was usually general, on-going support, such as a programme organiser or someone who provided practical support to people to access the programme (48%). The next most common type of support was specialist support, such as that provided by educational or medical professionals (29%) and individualised support (11%).
- The majority of programmes had either been evaluated already (51%) or there were plans in place to conduct an evaluation later in 2011 (37%).
- When asked to indicate what indicators, if any, would determine if the programme had been successful, the majority of respondents said that if 'the programme outcomes had been achieved' (66%) or they received 'positive feedback from participants' (57%), then this would indicate the programme had been a success. Other indicators of success mentioned by a number of service providers included client progression, good attendance by clients, the achievement of personal outcomes, positive feedback from family/carers/staff, and positive feedback from funders.
- The respondents identified a number of aspects of the programmes which they felt had worked well including: the support given to service users by peers and by staff/family; the progression that resulted from the achievement of targeted outcomes; the development of service users' social skills; increased community integration; the perceived empowerment of service users; the value of a flexible approach and a focus on inclusiveness. Conversely, they also identified a number of issues that had not worked so well including: the limited resources available to the programme, such as funding; the failure of some participants to participate as fully as others; difficulties associated with attracting additional participants, and a variety of administrative issues.
- Some of the main 'learnings' from the programmes included the value of support in helping people with disabilities to become more independent, especially through peer support; the importance of taking a practical

approach, and the value of adopting a flexible approach which does not assume that 'one size fits all'.

- Most (90%) of the programmes had been changed to some extent since they had commenced and most service providers said that these changes were relatively organic and had taken place in response to issues that had arisen during the delivery of the programme. Just over 72% of the programmes/initiatives expected to encounter some problem with the programme in the coming year, with most of these mentioning funding/resources (69%) as the likely source of the problem.
- Most (78%) of the respondents indicated they were very satisfied with the progress of the programme/initiative. The remainder were generally satisfied.

## **Acknowledgements**

We would like to thank the service providers who responded to our request for information in a generous and professional manner, particularly at a time when many of them are experiencing cutbacks and resource issues. We would also like to thank the staff of the National Disability Authority for their support and guidance during the project, particularly Christine Linehan, Mary van Lieshout, and Jacinta Byrne. Finally, we would like to thank the members of the Steering Group for reading an earlier draft of this report and their helpful comments.

# Chapter One

## Introduction and Background

### 1.1 Background

The National Disability Authority is the national independent statutory body, which advises the Government on policy and practice relating to people with disabilities.

The National Disability Authority published in 2010 – 2011 findings of a programme of research exploring international developments in disability service provision. A commonality across these diverse jurisdictions is the process of systems change in the delivery of services and supports for people with disabilities. These jurisdictions have achieved, in full or in part, the transition to independent living options for people with disabilities within the local community. Notwithstanding this progress, there is considerable evidence that people with disabilities may feel isolated and disempowered within their local communities.

The National Disability Authority is aware of innovative practices nationwide that provide quality outcomes for people with disabilities through the promotion of natural community supports. In 2011 the NDA decided to commission a nationwide survey of service providers which provide supports to people with disabilities, regarding their experiences of mobilising natural supports to enhance independent living for people with disabilities in their local communities. The aim of the survey was to ‘explore how organisations in Ireland that provide supports to people with disabilities are attempting to provide innovative initiatives that link people with disabilities to natural supports within their communities’. The survey team reported in early 2012.

### 1.2 Working Definitions of Key Concepts

Three core definitions were proposed by the National Disability Authority to guide the research as follows:

**People with disabilities:** Were defined as adults (over 18 years) with physical, intellectual, neurological or cognitive disabilities.<sup>1</sup>

---

<sup>1</sup> According to the US President’s Committee for People with Intellectual Disabilities, ‘Cognitive disabilities is often used by physicians, neurologists, psychologists and other professionals to include adults sustaining head injuries with brain trauma after the age 18, adults with infectious diseases or affected by toxic substances leading to organic brain syndromes and cognitive deficits after the age 18, and with older adults with Alzheimer diseases or other forms of dementias as well as other populations that do not meet the strict definition of intellectual disability’.



**Natural Supports:** Natural supports were defined as assistance, feedback, contact or companionship from people who are not service providers to enable people with disabilities to participate independently, or partially independently, in integrated employment settings or other community settings ... individuals providing natural supports may receive assistance and consultative support from disability service providers and provide natural supports with no compensation or nominal compensation.<sup>2</sup>

**Innovative Programmes and Initiatives:** Were defined as those offered by organisations which provide supports to people with disabilities (in conjunction with mainstream organisations where applicable) having as a primary aim the bridging of people with disabilities to natural supports within the community. The projects and programmes should be person centred, cost effective and have a commitment to research and evaluation. The interventions may include but are not limited to: befriending projects, host family arrangements, innovative supported employment services, time banking, circles of support, engagement by people with disabilities in volunteering, sporting and civic activities etc. The commonality across these initiatives is that they provide opportunities for people with disabilities to engage in sustainable and meaningful activities in the community (whether recreational or task focused) by harnessing existing natural supports within local communities. These initiatives were to be restricted to programmes and projects and exclude individual case studies.

From the outset it was acknowledged that the concept of natural support was relatively complex which would be difficult to 'operationalise' in a questionnaire in such a way that would be readily understood by the service providers. The discussion on definitions was informed by a literature review commissioned by the National Disability Authority on natural community supports in the context of independent living. The literature review found that very little had been written on the terms 'natural supports' or 'natural community supports' in the past twenty years outside the domain of employment. Consequently, the literature review recommended the adoption of a broader approach to the study, which would incorporate the notions of social networks, social supports and community participation. The study identified a number of interventions to promote natural supports among people with disabilities, as follows:

- Circles of Support and similar models (such as MicroBoards) which draw principally on existing natural supports such as family and friends, but involve these in a more formalised way in supporting the person with disability.

---

<sup>2</sup> Adapted from Storey, K. and Certo, N.J. (1996) – Natural Supports for increasing integration in the workplace for people with disabilities: A review of the literature and guidelines for implementation. *Rehabilitation Counselling Bulletin*, 40 (1) 62-76.

- Peer-based approaches including peer advocacy groups and interventions using self-authored spaces.
- Programmes which seek to promote social inclusion through developing social skills and social competence amongst people with disabilities and/or implement individual goal setting in relation to social participation.
- Programmes which seek to develop social capital through implementing befriending strategies and strategies to build inclusive communities.

These four relatively wide-ranging and inclusive interventions were used as a framework for defining the scope of natural supports in the survey of service providers. The service providers would make the decision as to whether or not they provided programmes relevant to the remit of the study.

Self-selection is always a difficulty within research. Accordingly, it was decided to publish details of most of the individual programmes which formed the sample, in volume II of this report to provide readers with additional insights into the basis of the present research findings.<sup>3</sup>

The scope of the survey was explained to service providers at several stages. First, each of the 500 service providers selected for the research was sent a letter by the National Disability Authority explaining the aims of the research and inviting them to take part. Second, the service providers were subsequently contacted by telephone, email or post with a short recruitment questionnaire to determine if they had any salient programmes in place. Third, each service provider that said they had a relevant programme was asked to provide details of the programme. The scope of the research was reiterated to respondents on each of these occasions.

### **1.3 The Survey of Service Providers**

The survey of service providers comprised a number of stages, including informing service providers of the survey, selecting a sample of service providers, designing questionnaires, and conducting the research. Details of these stages are outlined below.

Firstly, a letter was sent by the National Disability Authority to the Chief Executive Officers of the larger disability organisations informing them of the research and requesting their assistance. A copy of this letter is appended to the report (Appendix A). Secondly, a sample of 500 service providers was randomly selected from the National Intellectual Disability Database (NIDD) and the National Physical and Sensory Database (NPSDD) administered by the Health

---

<sup>3</sup> Some organisations did not wish their programme details to be published separately.

Research Board.<sup>4</sup> The National Intellectual Disability Database contains information that outlines specialised health services used or needed by people with an intellectual disability. The National Physical and Sensory Disability Database outlines specialised health services used or needed by people with physical/ sensory disability. Excluding agencies located outside the State, the databases have a combined total of approximately 3,400 agencies. A breakdown of the distribution of agencies by HSE area is outlined in Table I.

**Table I Distribution of Disability Agencies by HSE Area**

<b>National Physical and Sensory Disability Database Agencies (NPSDD)</b>	<b>Total</b>
<b>Eastern Regional</b>	471
<b>Midland</b>	135
<b>North Eastern</b>	145
<b>Mid Western</b>	173
<b>North Western</b>	149
<b>South Eastern</b>	297
<b>Southern</b>	150
<b>Western</b>	125
<b>Total NPSDD</b>	1,645
<b>National Intellectual Disability Database Agencies (NIDD)</b>	
<b>Mid-Western</b>	364
<b>North Western</b>	364
<b>Midland</b>	179
<b>North East</b>	238
<b>West</b>	101
<b>South</b>	57
<b>South West</b>	123
<b>Northern</b>	71
<b>South East</b>	190
<b>East Coast</b>	82
<b>Total NIDD</b>	1,769

Source: Health Research Board

Following a preliminary review of the databases the NDA decided to exclude a number of agency categories from the study: elderly/nursing homes, young people's facilities, FÁS training centres, hospitals and other medical facilities. This resulted in the exclusion of just over 1,200 agencies, Other service providers

<sup>4</sup> <http://www.hrb.ie/publications/disability>

were excluded from the study when the nature of their service was subsequently established (Table 2).

**Table 2 Distribution of Agencies by HSE Area (with Exclusions)**

<b>Physical and Sensory</b>	<b>Total</b>	<b>Exclusions</b>	<b>Sample</b>
<b>Eastern Regional</b>	471	279	192
<b>Midland</b>	135	62	73
<b>North Eastern</b>	145	86	59
<b>Mid Western</b>	173	85	88
<b>North Western</b>	149	80	69
<b>South Eastern</b>	297	134	163
<b>Southern</b>	150	63	87
<b>Western</b>	125	64	61
<b>Total NPSDD</b>	1,645	853	792
<b>Intellectual</b>	<b>Total</b>	<b>Exclusions</b>	<b>Sample</b>
<b>Mid-Western</b>	364	44	320
<b>North Western</b>	364	115	249
<b>Midland</b>	179	42	137
<b>North East</b>	238	26	212
<b>West</b>	101	21	80
<b>South</b>	57	10	47
<b>South West</b>	123	37	86
<b>Northern</b>	71	33	38
<b>South East</b>	190	30	160
<b>East Coast</b>	82	14	68
<b>Total NIDD</b>	1,769	372	1,397

Thirdly, two questionnaires were designed in consultation with the NDA (Appendix B). The first screening questionnaire was designed to establish if the service provider qualified for the main part of the study i.e., if they had a programme or initiative that corresponded with the survey criteria. It also contained a number of supplementary questions, including their views of barriers to independent living for people with a disability. The second questionnaire requested service providers to summarise some of the main features of their programmes or initiatives that supported independent living in their services.

Fourthly, a letter was sent to 500 service providers, randomly selected to reflect the spread of service providers around the country, with approximately 250

service providers chosen from each of the two databases.<sup>5</sup> The NDA also requested that a third category of service providers, corresponding to cognitive or neurological services, should be included in the study. While these agencies are not identified separately in the Health Research Board databases, it was decided to construct a third 'neurological' database. Accordingly, the NDA agreed that a modified list of Neurological Alliance of Ireland (NAI) member organisations would comprise the neurological database, as follows: Acquired Brain Injury Ireland, Aware, Brí, Brainwave, Dystonia Ireland, Headway Ireland, Huntington's Disease Association of Ireland, Irish Motor Neurone Disease Association, Migraine Association of Ireland, Meningitis Research Foundation, Multiple Sclerosis Society of Ireland, Muscular Dystrophy Ireland, Neurofibromatosis Association of Ireland, North West MS Therapy Centre, Parkinson's Association of Ireland, Post-polio Support Group, Spina Bifida Hydrocephalus Ireland, Syringomyelia Self Help Group, and the Volunteer Stroke Scheme. There was a delay in making contact with some service providers due to a variety of factors.

Many service providers found the concept of natural support difficult to comprehend, with the result that some service providers who initially said they had a relevant programme or initiative in place subsequently changed their minds when sent the main profile questionnaire. Conversely, other service providers submitted details on programmes that some may argue lie outside the remit of the present study. However, in keeping with the agreed inclusive scope of the study, that the service provider should decide the relevance of their programmes, all programmes and initiatives deemed relevant by the service providers are included in this report. A selection of programme/initiative profiles is contained in volume II of this report to illustrate the range of programmes/initiatives that exist and also the similarity in the nature of programmes/initiatives across the three disability sectors.

Some service providers referred our request for information to their regional or national offices. Some of these organisations subsequently decided to reply by providing a national or regional response, while others chose not participate due to resource constraints. Thus, the information provided by some service providers is not fully representative of all programmes/initiatives in their service.

---

<sup>5</sup> The lists in the NIDD display all agency codes that were set up on the NIDD since it was established in 1995, by county and parent agency (where known). The agency data is not historically validated and the HRB acknowledge that some of the names may have changed or have incorrect data in the address. They also note that larger agencies sometimes set up an agency code to record small units. The NPSDD represents all agencies that have been assigned a code since the database was set up in 2002.

Accordingly, caution should be used in comparing the submissions made by different service providers.

Fieldwork began in June and finished in October 2011, during which time, approximately 500 service providers were contacted by letter, email or telephone (Table 3). In some cases, contact was made with a single location, such as a national or regional office, whereas in other instances, a number of the service locations or branches of an organisation received a letter and subsequent phone call. Just 48% of the service providers agreed to complete the screening questionnaire, while a similar proportion (44%) referred us to their regional or national offices, and 8% could not be contacted. At least three attempts were made to contact each service provider.

**Table 3 Sample of Service Providers**

<b>PHYSICAL AND SENSORY DISABILITY AGENCIES</b>
<b>Action for Mobility</b>
<b>Arthrogryposis Association of Ireland</b>
<b>Anne Sullivan Centre</b>
<b>APT – HSE</b>
<b>Arthritis Ireland</b>
<b>Asperger Syndrome Association Ireland</b>
<b>CASA</b>
<b>Centres for Independent Living</b>
<b>Central Remedial Clinic</b>
<b>Cheshire Ireland</b>
<b>Citizen Information Services*</b>
<b>Cuan Mhuire Rehabilitation Centre*</b>
<b>Cluid Housing Association*</b>
<b>Co. Roscommon Support Group for People with Disability</b>
<b>Cystic Fibrosis Association of Ireland</b>
<b>DeafHear (National Association for Deaf People)</b>
<b>Debra Ireland</b>
<b>Diabetes Federation of Ireland</b>
<b>Disabled Drivers Association of Ireland</b>
<b>Doorway to Life (Abode)</b>
<b>Dystonia Association Ireland</b>
<b>Enable Ireland Adult Services</b>
<b>Fighting Blindness</b>
<b>Irish Deaf Society</b>
<b>Irish Wheelchair Association</b>
<b>Irish Thalidomide Association</b>
<b>Leitrim Association of People with Disabilities</b>
<b>Livability</b>
<b>Lucan Disability Action Group</b>
<b>Merchants Quay*</b>
<b>Muscular Dystrophy Society of Ireland</b>
<b>National Council for the Blind of Ireland</b>
<b>Prosper Fingal</b>
<b>Simon Community Dublin</b>
<b>Sophia Housing Association Ltd*</b>
<b>St. Joseph's Centre for the Visually Impaired</b>

\*Service providers listed in the HRB databases where disability is not their core business.

**Table 3 Sample of Service Providers (continued)**

<b>INTELLECTUAL DISABILITY AGENCIES</b>
Brothers of Charity Services
Camphill
Cheeverstown House
COPE Foundation
Daughters of Charity
Down Syndrome Ireland
EVE
KARE
Muirioso (SCJM)
National Learning Network
Rehabcare
St John of God Services
St. Michael's House
Sunbeam House
Western Care Association
<b>NEUROLOGICAL DISABILITY AGENCIES</b>
Acquired Brain Injury/ The Peter Bradley Foundation
Brainwave – The Irish Epilepsy Association
Bri
Freidreich's Ataxia Society of Ireland
Headway Ireland
Huntington's Disease Association of Ireland
Irish Motor Neurone Disease Association
Multiple Sclerosis Society of Ireland
Parkinsons Association of Ireland
Post Polio Support Group
Spinal Injuries Ireland
Mid-West Spina Bifida and Hydrocephalus Association
North West Stroke Group
Irish Association for Spina Bifida and Hydrocephalus
Syringomyelia Support Group of Ireland

Details of 86 programmes and initiatives were provided by 25 agencies (Table 4).



**Table 4 Agencies with Programmes and Structured Initiatives in Place by Disability Sector**

<b>Disability Sector</b>	<b>Total Number of programmes and Initiatives in place</b>	<b>Service Providers Giving information on Programmes and Initiatives</b>
<b>Physical/ Sensory</b>	28	11
<b>Intellectual</b>	41	9
<b>Neurological</b>	17	5
<b>Total</b>	86	25

A relatively small number of agencies accounted for a disproportionate number of the programmes and initiatives that are in place around Ireland. Those agencies providing information on more than three programmes and initiatives included the following: Centres for Independent Living, the Irish Wheelchair Association, Enable Ireland, Headway, Multiple Sclerosis Society of Ireland, Brothers of Charity, RehabCare, and the National Learning Network.

#### **1.4 Structure of the Report**

The research findings from the survey of service providers are presented in chapter two, followed by a number of recommendations in chapter three. Copies of the National Disability Authority letters and the two questionnaires used in the research are appended, together with a chart summarising the main findings. Finally, a selection of programme/initiative profiles is contained in volume II of the report.

## Chapter Two

### The Research Findings

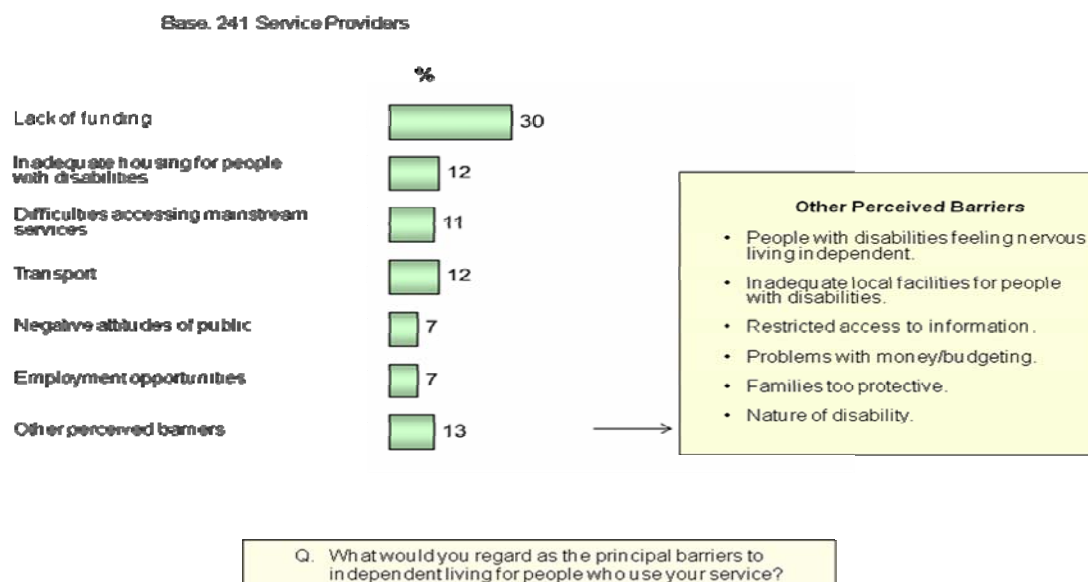
#### 2.1 Introduction

This chapter presents a summary of the 86 programmes and initiatives which are part of the services provided by 25 disability service providers across a range of disability sectors in Ireland.<sup>6</sup> The service providers' views of barriers to independent living are summarised first.

#### 2.2 Perceived Barriers to Independent Living

The service providers' views of barriers to independent living were determined by a three-part question.<sup>7</sup> First, they were asked an unprompted question on what they would regard as the principal barriers to independent living for people who access their service (Figure 1).

**Figure 1 Perceived Barriers to Independent Living (Unprompted)**

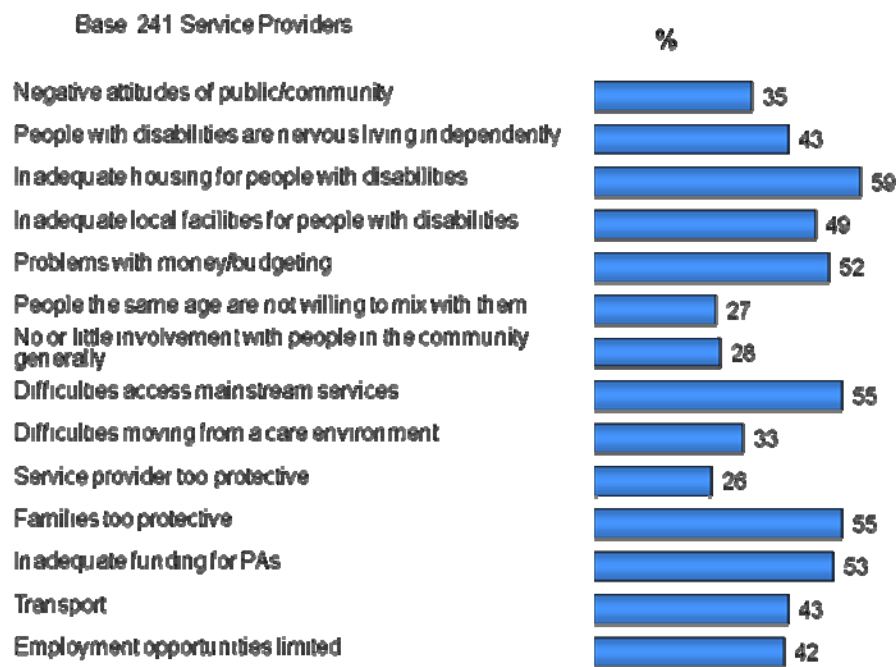


<sup>6</sup> In most instances, the database designation used by the HRB is used in this report. However, it should be kept in mind that a number of disability agencies opted to describe themselves as 'multi-sectoral' disability agencies, with service users coming from a variety of physical, sensory, intellectual and neurological sectors. Furthermore, some agencies were listed in both the NIDD and NPSDD.

<sup>7</sup> The sample for this part of the study comprised the 241 service providers who responded to this part of the screening questionnaire. Most of the remainder chose not to give any information and/or referred us to their regional or national offices. Twenty-five of these service providers subsequently gave information on 86 programmes (see Table 4).

Their unprompted responses indicated that perceived deficiencies in funding, housing, access to mainstream services and transport constituted the main barriers to independent living for people that used their services. Thus, for example, 30% of service providers who responded to the survey cited inadequate funding as a barrier to independent living. Just less than one in ten respondents were unable to suggest any barrier to independent living. The respondents were then read out a list of 14 possible barriers to independent living and asked to indicate which, if any, were of relevance to people who access their service (Figure 2).

**Figure 2 Perceived Barriers to Independent Living (Prompted)**

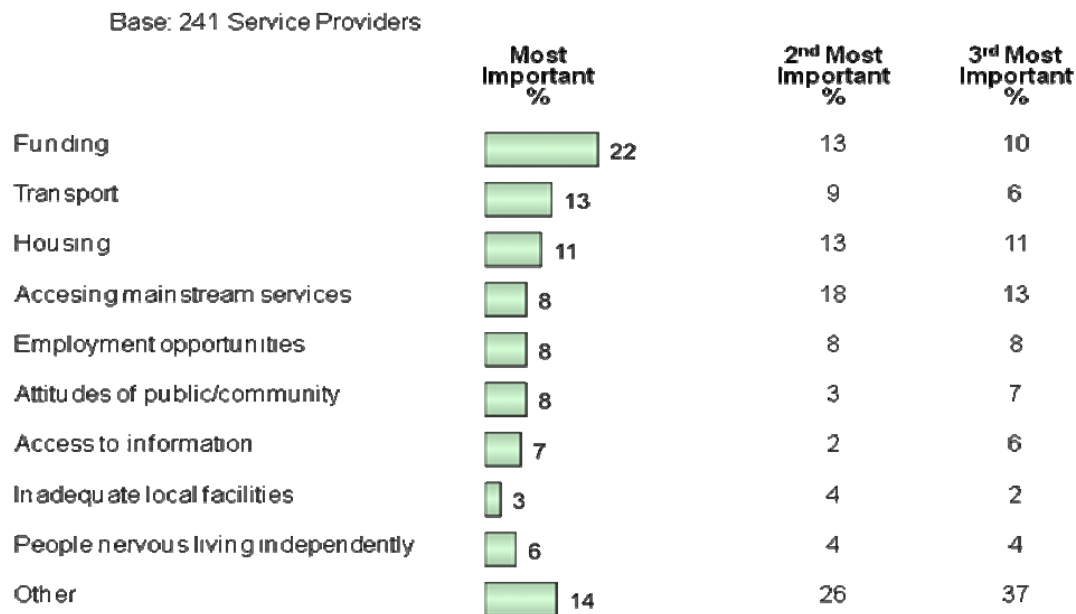


Q. I am now going to read out a list of some other possible barriers to independent living (excluding those already mentioned) and I would like you to tell me if you think they are relevant to people who access your service?

Their prompted responses confirmed their initial unprompted views by highlighting the perceived relevance of housing, access to mainstream services, transport, and funding to independent living. Their responses also clarified that issues cited around funding had two distinct elements, i.e. funding from the State for personal support, such as Personal Assistants, and also personal difficulties experienced by some people with budgeting. This question also identified the perception of families as being too protective and the impact of limited employment opportunities for independent living. Finally, respondents were

asked to consider all the different barriers mentioned up to that point and to select the three barriers to independent living they regarded as most important (Figure 3).

**Figure 3 Perceived Barriers to Independent Living  
- Priority Ranking**



Q. Now taking all of these barriers into account, which 3 barriers to independent living would you regard as most important?

The responses to this final question confirmed the perceived significance of funding, transport, housing, access to mainstream services, employment opportunities, the attitudes of the public, access to information, the perceived negative attitudes of the public, people feeling nervous living independently, and inadequate local facilities. Other perceived barriers mentioned by a relatively small number of respondents included:

- restricted access to information (including the Internet/ social networking environments).
- families and service providers being too protective.
- difficulties experienced by the individual moving from a care environment.
- issues associated with the nature of a person's disability.

- a fear of losing benefits if the individual works (even part-time) however, they need to work to live independently.
- if a person has multiple disabilities.
- health and safety concerns.
- unsupportive government policy.
- a need for cultural change.
- difficulties associated with an individual's transition from school to adult status.
- a lack of proper care plans.
- inadequate links with other service providers.
- isolation.
- a lack of flexibility with regard to support workers.
- insurance issues/ society is too risk conscious.
- reporting requirements.
- a lack of creative thinking.
- a poor understanding of what is involved in independent living.
- a lack of appropriate models of independent living to help build confidence.
- the cost of home help.
- gaps in peer support advocacy.
- the expense of installing technology in their homes for people who need technological support.

Some verbatim comments made by service providers illustrate some of their thoughts and concerns regarding independent living:<sup>8</sup>

What happens if a person with a disability lacks the skills to live independently?

Sometimes I think that society has become too risk adverse and that it can be a question of independence or health and safety.

---

<sup>8</sup> These and later verbatim comments are reported exactly the way they were written by respondents, including some grammatical errors.

A client's readiness for independent living is very important. It should be up to the individual to choose whether or not they wish to get involved with the community.

People with disabilities have something to give the community.

The HSE fits people into services that are already available rather than asking people with disabilities where they want to live or checking to see what sort of accommodation is suitable for them. You have to design accommodation around what a person wants. We are all individuals.

It could take a year to put unpaid support in place and Garda clearance can take a long time.

Independence can mean loneliness.

The programmes should be led by people with disabilities. They are more enthused and interested.

Many physical disabilities incur huge costs for equipment etc and this has an impact on opportunities for independent living.

Social networking and technology generally is very important for young people with disabilities.

Some people are living 'independently' at home.

It can be very difficult to jump from a home to a flat. It would be great to have a half-way house.

Many young people with ABI don't consider themselves to have a disability and they don't want to be associated with people with disabilities. It is a hidden disability.

## **2.2 Structured Initiatives and Innovative Programmes**

Approximately one in ten (n=25) of the agencies that completed a screening questionnaire (n=241) said they had relevant innovative programmes or structured initiatives in place within their organisation which corresponded with one of the four categories used to guide the research (see overleaf). Most of the remainder (85%) could see a value in providing natural supports and their main reason for not doing so was financial. If they had access to additional funds, most said that they would consider introducing natural supports. However, other services felt that more individually based programmes were more appropriate to

their clients. The main features of the 86 programmes and initiatives are summarised under the following headings:

- Location.
- Description.
- Aims and objectives.
- Year started.
- Target group served.
- Number of people who benefitted in 2011.
- Coverage.
- Funding.
- Resources.
- Evaluation.
- Indicators of success.
- What has worked well and what has not worked well?
- Main learning.
- Changes to programmes.
- Anticipated problems.
- Overall views of the programmes/ initiatives.

More complete details of the individual programmes and initiatives are contained in volume II of this report.

### **Location of Programme/ Initiative**

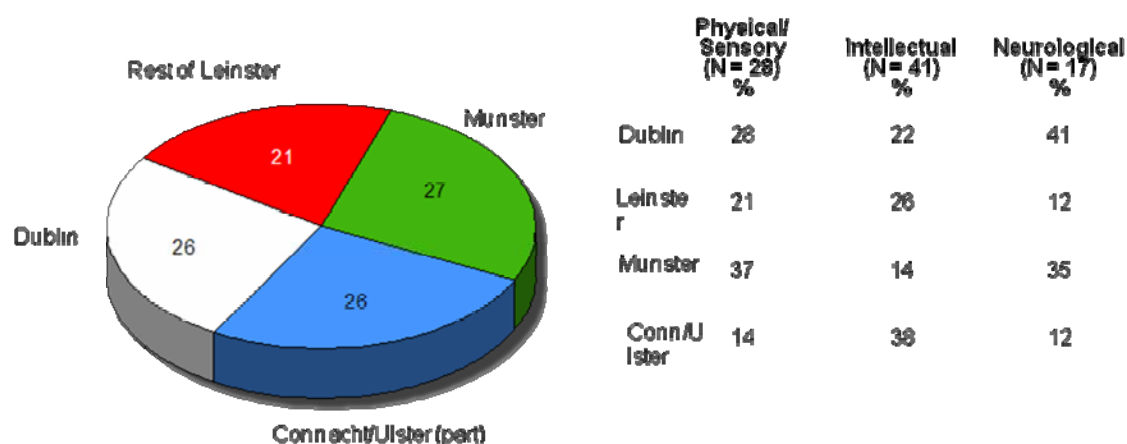
The programmes/initiatives are relatively evenly spread around the country, with approximately one quarter of the total in each province (figure 4).<sup>9</sup> Allowing for the limitations of the relatively small sample size, it would appear that the Physical/Sensory disability agencies are most likely to be based in Munster, while the Intellectual disability agencies are most likely to be based in Connacht/Ulster (part of) and the Neurological disability agencies in Dublin (Figure 4).

---

<sup>9</sup> When the service provider indicated a programme or initiative was regional or national, and indicated that the programme or initiative operated in a number of locations without giving details of these locations, the corresponding regional or national address was used.

**Figure 4 Location of Programmes and Initiatives**

Base: All Programmes/Initiatives, N = 86



Q. Where is the programme or initiative based?

## Description of Programme/ Initiative

The respondents were asked to select one or more of the agreed categories, which described the structured initiatives or innovative interventions provided by their service, either independently or in association with other individuals or groups:

- Programmes supporting family and friends to develop structures, such as circles of support, microboards or support clusters.
- Peer advocacy programmes supported through the provision of venues, administrative support, funding etc.
- Befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members.
- Innovative social skills training programmes aimed at establishing and maintaining the development of social relationships.

The respondents were reminded of the primary purpose of the research, which was to determine if service providers had structured initiatives or innovative programmes in place whose primary aim it is to enable people with disabilities to become more independent in the community. In order to assist them to decide if



they had relevant programmes or initiatives in place, they were also informed that a common theme underpinning many of these initiatives is that the provider organisation assists in the establishment of the programmes with a view to 'fading' support over time, thus enabling natural support to be maintained. Individual programmes relating to person-centred planning were not to be included.

The 86 programmes/initiatives were relatively evenly spread across the four categories, with 'innovative social skills training' the most popular category (Figure 5, overleaf). Almost one in four (38%) of all programmes/initiatives fell into this category.<sup>10</sup> This was followed by befriending schemes (20%), peer advocacy programmes (17%), and programmes supporting family and friends (16%). Allowing for the relatively small sample size (n=86), especially when divided across three disability sectors, and given the relatively high score given to innovative social skills training across the three disability sectors, the findings in Figure 5 suggest that physical/sensory service providers are most likely to have peer advocacy programmes; intellectual disability agencies are most likely to have befriending schemes; and neurological agencies are most likely to have family/friends support groups and peer advocacy programmes (figure 5).

---

<sup>10</sup> A number of respondents felt that their intervention could not be described by just one of the four categories, while others used an alternative description.

**Figure 5 Description of Programmes and Initiatives**

Base: All Programmes/Initiatives, N = 86

	%	Physical/ Sensory (N = 28) %	Intellectual (N = 41) %	Neurological (N = 17) %
Programmes supporting family and friends to develop structures such as circles of support, micro boards or support clusters	16	14	17	(18)
Peer advocacy programmes supported through the provision of venues, administrative support, funding etc.	17	(26)	13	18
Befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members	20	17	(22)	12
Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships	38	(43)	33	35
Other	9	*	10	(18)

Q. Please describe the programme or initiative using the following categories.

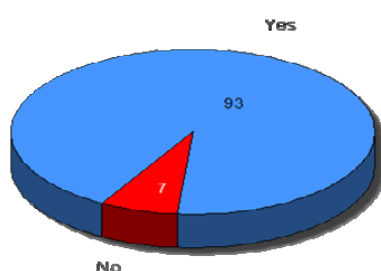
(\* less than 1%)

## Programme Aims and Objectives

More than nine in ten programmes, regardless of disability sector, have specific aims and objectives, the most popular of which include, social learning/life skills, the promotion of community integration, the promotion of independent living, and reducing isolation (Figure 6).

**Figure 6 Programme Aims and Objectives**

Base: All Programmes/Initiatives, N = 86



### Aims and Objectives

- Development of social living/life skills (N = 30)
- Promoting independent living (N = 21)
- Promoting community integration (N = 20)
- Practical skills for employment, further education, progression (N = 17)
- Reducing isolation/increasing social opportunities and social inclusion (N = 13)
- Encourage advocacy/employment (N = 7)
- Support for families/carers (N = 7)

(\*Same programme and initiatives had multiple aims and objectives)

Q. Does the programme or initiative have specific aims and objectives?

Other aims and objectives included the empowerment of clients, support for families and carers, maximising the potential of the individual, providing rehabilitative training, and promoting accessible tourism for people with a disability.<sup>11</sup> Analysis of the aims and objectives within the three disability sectors suggest that a different emphasis is given to the different aims and objectives (Table 6). The physical/sensory disability agencies placed most emphasis on the development of social learning skills, followed by the promotion of independent living and social inclusion; intellectual disability agencies' programmes emphasised the development of social learning skills, community integration, and the development of practical skills; and neurological disability agency programmes emphasised independent living, support given to families/carers, and social inclusion.

**Table 6 Aims and Objectives by Disability Sector**

<b>Aims and Objectives</b>	<b>Physical/ Sensory (N=28) %</b>	<b>Intellectual (N=41) %</b>	<b>Neurological (N=17) %</b>
<b>Development of social learning/life skills</b>	31	34	12
<b>Promoting independent living</b>	28	10	27
<b>Promoting community integration</b>	9	26	15
<b>Practical skills</b>	9	24	8
<b>Reducing isolation/ increasing social inclusion</b>	19	4	19
<b>Support for families and carers</b>	3	2	19

### **Year Programme or Initiative Started**

Many of the programmes are relatively recent, with two thirds (66%) starting since 2005 and approximately one in ten (11%) starting before 2000 (Figure 7). This pattern was consistent across the three disability sectors.

---

<sup>11</sup> Some programmes and initiatives had multiple aims and objectives.

### Figure 7 Year Programme or Initiative Started

Base: All programmes/initiatives N=86

Year	Total (n=86)%	Physical/Sensory (n=28)%	Intellectual (n=41)%	Neurological (n=17)%
Prior to 2002	11	11	12	11
2000 - 2004	23	25	25	16
2005 – 2009	34	29	38	37
2010 – 2011	32	35	25	36

Question: What year did the programme or initiative start?

### Target Group Served by the Programme or Initiative

The target groups for the different programmes and initiatives corresponded with the primary focus of the service provider' services. Thus, for example, intellectual disability agencies had programmes or initiatives that benefitted adults with an intellectual disability. A minority of programmes are targeted at adults with a disability, regardless of the nature of the disability. On average, 16 people have benefitted from each programme during the past year or so. This figure was consistent across the three disability sectors, with neurological disability programmes somewhat higher.

### Coverage of Programmes/Initiatives

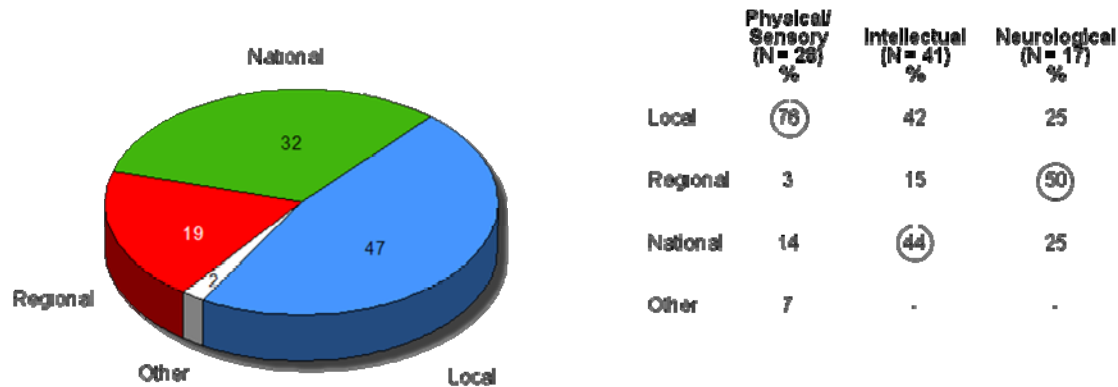
Approximately half (47%) of the 86 programmes/initiatives were described as local, with the remainder described as national (32%) or regional (19%).<sup>12</sup> The programmes and initiatives operated by physical/sensory disability agencies were most likely to be local, reflecting the number and diversity of agencies in this sector. Conversely, programmes operated by intellectual disability agencies are more likely to be national, and neurological agency programmes are more likely to be regional (Figure 8).

---

<sup>12</sup> Caution is required in the interpretation of this question. While most of the programmes and initiatives operate on a local basis, some are administered and promoted by regional or national level staff.

**Figure 8 Coverage of Programmes and Initiatives**

Base All Programmes/Initiatives, N = 86



Q. Is the programme a local initiative or part of a broader regional/national initiative?

## Funding

Statutory funding is very important for many of the programmes, with almost half (44%) of all programmes depending on statutory funding as the sole means of funding and another 22 per cent availing of statutory sources for part of its funding requirements. Funds provided by service providers and fundraising are also significant sources of support for these programmes. Intellectual disability agencies are most dependent on statutory funding, while physical/sensory agency programmes are most dependent on funding from statutory funds and service providers, and neurological agency programmes are most dependent on statutory funding and fundraising (Figure 9). The level of funding was not measured in this survey.

### Figure 9 How Programmes and Initiatives are Funded

Base: All programmes/initiatives N=86

<b>Funding</b>	<b>%</b>	<b>Physical/Sensory (N=28)%</b>	<b>Intellectual (N=41)%</b>	<b>Neurological (N=17)%</b>
Service Provider	18	24	17	5
Statutory Funding	44	31	54	40
Fundraising	3	3	5	
Service provider/statutory/fundraising	12	14	12	10
Statutory/fundraising	10	7	5	35
Other	13	21	7	10

Question: How is the programme/initiative funded?

### Resources Available to Programme/ Initiative

When asked what resources were available to the programmes/initiatives, 96% of respondents mentioned staff, followed by office/space, administrative support, funding, and volunteers (Figure 10). Allowing for the limitations of the relatively small sample size, programmes operated by neurological agencies provided most support for their programmes, particularly in relation to the provision of volunteers.

### Figure 10 Resources Available to Programmes and Initiatives

Base: All programmes/initiatives N=86

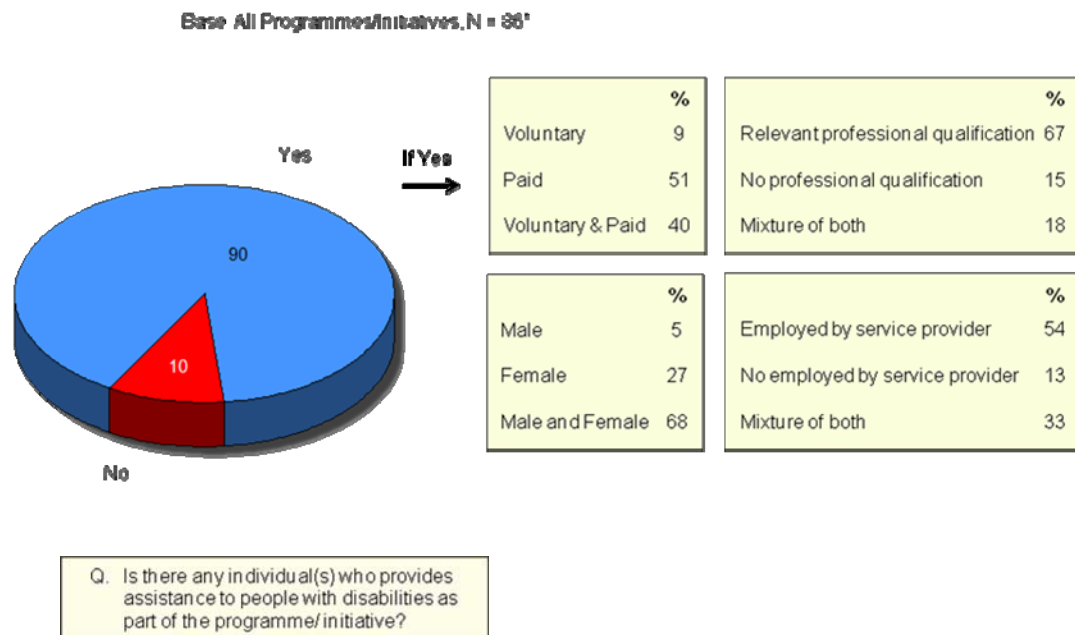
<b>Resource</b>	<b>%</b>	<b>Physical/Sensory (N=28)%</b>	<b>Intellectual (N=41)%</b>	<b>Neurological (N=17)%</b>
Staff	96	100	92	100
Volunteers	46	39	46	70
Office/space	69	75	61	100
Administrative Support	66	71	61	76
Funding	59	54	61	82

Question: What services are available to the programme?

Most of the programmes/initiatives are resourced by one or more persons who provide assistance as part of the programme/initiative. Most support provided is general, on-going support, such as by a programme organiser or someone who provides practical support to people to access the programme (48%). The next most common type of support is specialist support, such as that provided by educational or medical professionals (29%) and individualised support (11%).

Most of these individuals are employed by the service provider, and they are paid, have a relevant professional qualification, and are female. However, a substantial number of programmes had a range of different individuals supporting the programme as the following chart illustrates (Figure 11).

**Figure 11 Assistance to Programmes and Initiatives by Individual**



As previously noted, neurological agencies are most dependent on volunteers and Intellectual agencies employ most people with a relevant qualification. The service provider is an important source of employment for support staff (Table 7).

**Table 7 Personal Assistance to Programmes by Disability Sector**

Characteristics of Individuals	Total (N=86)	Physical/Sensory (N=28)	Intellectual (N=41)	Neurological (N=17)
<b>Paid or Voluntary?</b>	%	%	%	%
Voluntary	9	4	8	19
Paid	51	71	46	38
Mixture of paid and voluntary	40	25	46	43
<b>Employed by Service Provider?</b>				

<b>Yes</b>	54	64	43	63
<b>No</b>	13	11	16	13
<b>Mixture</b>	33	25	41	25
<b>Gender?</b>				
<b>Male</b>	5	11	3	27
<b>Female</b>	27	32	25	73
<b>Mixture</b>	68	57	72	-
<b>Relevant Qualification?</b>				
<b>Yes</b>	67	64	73	63
<b>No</b>	15	21	11	13
<b>Mixture</b>	18	14	16	25

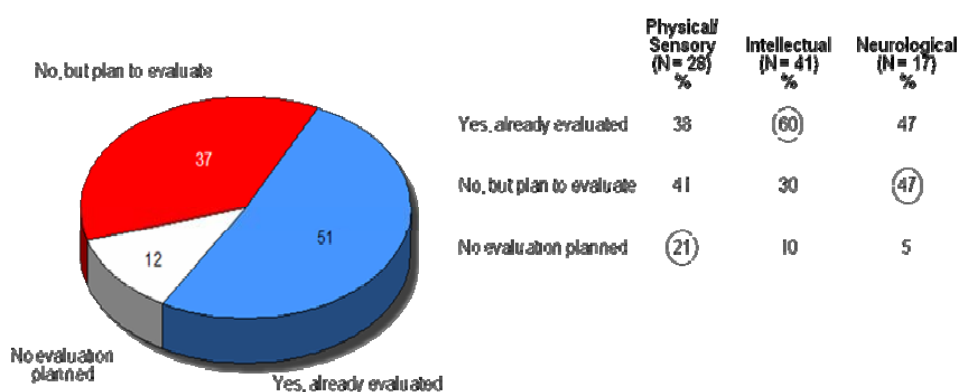
Note: The question did not specify any particular form of personal assistance consequently, the information in the table refers to a broad range of helpers

## Programme Evaluation

The majority of programmes had either been evaluated already (51%) or there were plans in place to conduct an evaluation later that year (37%). The scope of these evaluations was not explored. Intellectual agencies are most likely to have carried out an evaluation while physical/sensory agencies are least likely to have done so (Figure 12).

**Figure 12 Has the Programme or Initiative Been Evaluated?**

Base All Programmes/Initiatives, N = 86



Q. Has the programme been evaluated and/or do you plan to evaluate it this year?



## Indicators of Programme Success

When asked to indicate what indicators, if any, would determine if the programme had been successful, the majority of respondents said that if 'the programme outcomes had been achieved' (66%) or they received 'positive feedback from participants' (57%), then this would indicate the programme had been a success. Other indicators of success mentioned by a number of service providers included client progression, good attendance by clients, the achievement of personal outcomes, positive feedback from family/carers/staff, and positive feedback from funders. Small differences may also be noted in the responses of the three disability sectors (Figure 13).

**Figure 13 Indicators to Show Programme or Initiative Has Been Successful**

Base: All Programmes/Initiatives N=86

Question: What indicators would determine if the programme has been successful or not?

Indicator	%	Physical/Sensory (N=28) %	Intellectual (N=41) %	Neurological (N=17) %
Positive feedback from clients	57	50	61	46
Programme outcomes achieved	66	43	68	53
Client progression	29	21	32	18
Good attendance by clients	22	29	32	7
Personal outcomes achieved	12	14	12	-
Positive feedback from family/carers/staff	14	28	12	23

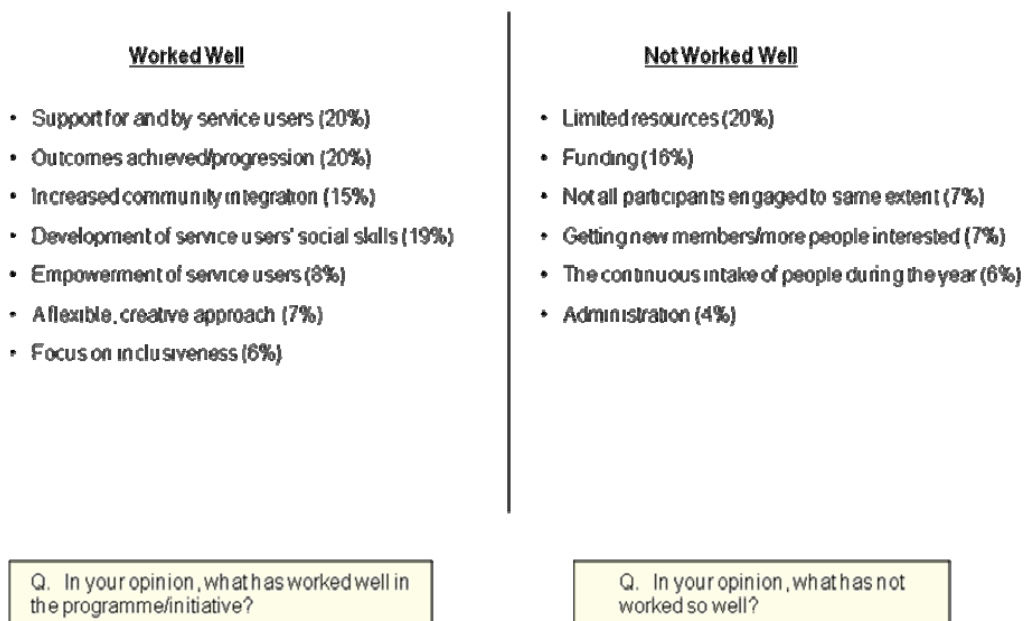
Other less frequently mentioned indicators included, access to funding, innovative and cost-effective use of resources, formal evaluations, good publicity in the local area, increased community inclusiveness, clients demonstrating skills learnt, personal insights, access to facilities, increased group activities, work placements, implementation of organisation's ethos, a diversity of clients, and the use of a multi-disciplinary approach.

## What Has Worked Well and Not Worked Well in the Programme/ Initiative?

The respondents identified aspects of the programmes which they felt had worked well in their programmes/initiatives including, the support given to service users by each other and also staff/family, the progression that resulted from the achievement of outcomes, the development of service users' social skills, increased community integration, the perceived empowerment of service users, the value of a flexible approach and a focus on inclusiveness (Figure 14).

**Figure 14 What Has Worked Well and What Has Not Worked Well with Programmes and Initiatives**

Base: All Programmes/Initiatives, N = 86



Conversely, they also identified a number of issues that had not worked so well including, the limited resources available to the programme including funding, the failure of some participants to participate as fully as others, difficulties associated with attracting more participants, and a variety of administrative issues.

## The Main 'Learnings' of the Programme/ Initiative

Some of the main 'learnings' from the programme were perceived to include the value of support in helping people with disabilities to become more independent, especially through peer support; the importance of taking a practical approach, and the value of adopting a flexible approach which does not assume that 'one size fits all' (Figure 15).

### Figure 15 Main 'Learnings' from Programmes and Initiatives

Base: All Programmes/Initiatives, N = 88

- The value of support generally in helping people with disabilities become more important (21%)
- The importance of practical skills (20%)
- The value of peer support (13%)
- One size does not fit all – flexible approach vital (12%)
- Group consensus and partnership works best (7%)
- The capacity of people with intellectual disabilities to make decisions for themselves (7%)
- The benefit of engaging with local communities (5%)

Q. What have been the main 'learnings' from the programme/ initiative to date?

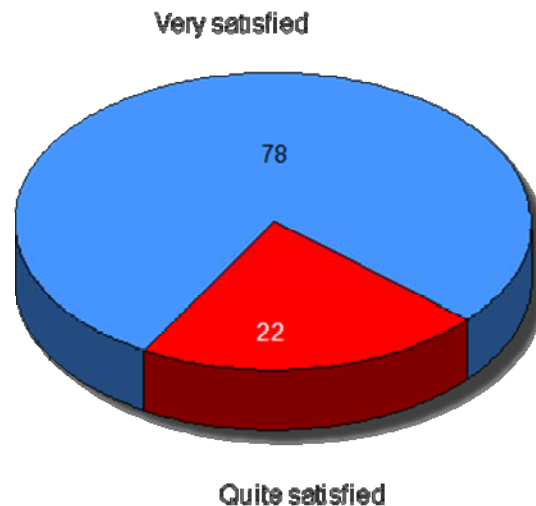
While most (90%) programmes had been changed to some extent since they had commenced, most service providers said that these changes were relatively minor and organic, and had taken place in response to issues that had arisen during the delivery of the programme. Just over 72% of the programmes/initiatives expected to encounter some problem with the programme in the coming year, with most of these mentioning funding/resources (69%) as the likely source of the problem.

### Overall Views of the Programme/Initiatives

Most (78%) of the respondents indicated they were very satisfied with the progress of the programme/initiative. The remainder were generally satisfied (Figure 16).

**Figure 16 Overall Satisfaction with the Programmes and Initiatives**

Base: All Programmes/Initiatives, N = 86



Q. Overall, how satisfied are you with the programme/initiative?

Some verbatim comments below illustrate the views of some service providers towards the innovative programmes and structured initiatives operated by their services. Further details are contained in volume II of the report.

### **Positive Comments**

People with disabilities feel empowered by taking control over their lives. It has truly been a positive experience. Small changes are made each year as we are constantly learning and evolving.

The programme has been a huge success by bringing a group together that is often neglected.

What has worked well is the opportunity it gives for learners to gain practical experience of skills, such as shopping, cooking, budgeting and living independently in a supported environment. However, very small groups can cause learning to be disjointed if, for example, someone is absent.

Regular consultation with the group has highlighted very positive outcomes for the participants on the programme. The young adults have been very successful in self-directing how they wish to socially participate in the community.

We are quite satisfied with the programme, given the limited resources available. We know that the service is important to participants, and that the partnership approach to providing the service is helping to develop social capital within the deaf community.

This is a programme that works very well for the current learner profile. It covers a niche that is not fulfilled by any other service or agency in the county and the outcomes and progression are very positive to date.

We were surprised at the interest in the programme and the demands for similar from other service users.

The programme has demonstrated that with the right kind of support adults with and without an intellectual disability can develop friendships, which are sustained over time. One of the key factors is the initial matching of people with similar interests and compatible personality traits.

There is very positive feedback from clients and their families. We are very satisfied with the programme and we believe that it has worked well to encourage clients to adopt critical thinking and coping skills related to their brain injury. To date, all monitoring and audits have been deemed successful by the HSE. The programme is supported by a highly successful and motivated staff

## **Difficulties**

Facilitating independent living is not easily achieved in an institutional setting when that setting has a different ethos and main purpose.

Finance is a continuing problem.

It is a slow process to construct the core model and to enable people to take more responsibility for their own lives.

We anticipate problems with funding. We are frequently receiving calls from people seeking to engage in social activities but who are

not in a position to pay a lot. We really need to secure additional funding for this programme to continue and be successful.

Due to a lack of resources, both financial and in terms of man-hours available, we are not in a position to cater for the demand from parents.

It takes 16 weeks from the time a potential volunteer completes their vetting form to us receiving their clearance; during this time the volunteer may find some other voluntary activity which does not require vetting and we lose them.

The staff member who successfully steered this programme through its first two years has left and replacing her will be difficult.

It requires a lot of commitment, willingness and rational thought for our clients to engage in self-management. This is often difficult where people may lack the ability to engage or be unwilling to engage due to their being preoccupied with their own distress and difficulties and not being able to take a rational look at solutions/options.

By and large we are well satisfied. However, moving these young people into programmes that cater for all ages and all disabilities can be daunting for them and us.

External factors can limit the effectiveness of the training. For example, the payment of a disability allowance can limit a learner's need/desire to work.

### **Additional Comments on the Programmes and Initiatives**

The programme facilitates the opportunity for adults to experience living independently in the community for the first time, while their place is held in our independent accommodation. This is particularly important for families who are extremely anxious about their relative losing their place. Additionally, we provide support to attend third level education and sports training and competition events. Unfortunately, we will not be able to offer all who would like the opportunity to live with a greater degree of independence a place on the programme.

All four individuals were phased into this project, allowing people in the community who had no knowledge of people with intellectual disability and their needs to slowly get to know the person.

The programme on personal relationships and sexuality is helping to break the taboo in this area and gives people 'permission' to discuss the issues openly and without judgement.

People accessing the programme have a range of different abilities and aspirations. By using a person-centred approach we have endeavoured to make the programme more relevant to the individual needs of the service user. While encouraging progression to further training or supported employment, we realise that this is not an option for many of our service users who will continue to remain within our service after completing their training. We have endeavoured to make the programme more relevant to these service users.

The programme is constantly evolving in response to the needs and aspirations of our service users. We have increased the range of modules and have developed greater links with mainstream colleges and other colleges in the local community in order to foster community integration. There is a great focus on independent living skills and the use of assistive technology.

Although the programme is in its early stages, we are aware there is a need to think outside the box in order to create more opportunities and choices for participants and thereby increase their participation in community-based activities.

We have learnt the importance of an on-going need to be innovative in targeting people to attend events; the need to have variety; the need to be aware of the ability of group members e.g., literacy, some members have no power in their arms or hands, mobility problems etc.; and to planning activities that are sensitive to all members' needs and capabilities. One size does not fit all.

We have learnt the need to be flexible in our approach and the need to build in regular reviews of progress and thus be able to proactively manage risk elements as they arise.

The community has been open and welcoming. People are enthused by the initiative. It is a great model for social inclusion and enterprise. It avoids the concept of charity and associated stereotypes. It is contributing in a real way – it changes minds and builds relationships.

Our learning has been the importance of listening to the person and supporting them to achieve real things in education or work.

The programme is reliant on staff initiatives, flexibility and community networking. Recruiting the right staff is key.

There is a need for more independent programmes to develop skills in the community. There is a lack of 'half-way' support to bridge residential and community living. The skill, expertise and knowledge of a multi-disciplinary team can help complex people move forward in their lives. We do a lot of individual support packages and these work well. As with all programmes, funding becomes stretched and the service is at capacity. This may lead to less people using the service. If there is no 'move on' then the service has a limit to the work that can be done.

We review our programme annually and this year we plan to conduct a service review to see how best we can meet the needs of our participant group as the demand on our service grows and the participants' needs change.

The programme is working well but there are ways in which it can be improved and streamlined. However, we are not allowed to work outside the RT remit, meaning many of the needs of our participants cannot be fully addressed. The programme could be expanded to involve participants in the community more and address the specific needs adults with AS face when trying to live active independent lives.

We can give people all the information regarding relationships, but what people really want and need is to be able to form and maintain real friendships and relationships and they need support to do this.

The Prospects programme places strong emphasis on social skills training. This is promoted and delivered using a person centred approach to ensure each individual understands each step of the process and can progress at their own pace in an environment conducive to social learning. The use of a multi-disciplinary approach ensures that a holistic and dynamic view is maintained in planning and delivery of training.

Increased interest in the course may mean that learners will have a waiting period before a place can be allocated on the course.



The practical modules, for example, IT, health and fitness and cooking skills were identified as strengths of the programme. The benefits to the participants in terms of increased self confidence and self-esteem were noted. We have placed greater emphasis on practical skills & activities and independent living skills & development of self-confidence and self-esteem and health & fitness in participants.

We learnt the willingness of the community to support natural inclusion of people with disabilities as this project idea was brought to us rather than we pursue inclusion with local community groups. The programme has made us look at service users needs in a different way and understand that some of these needs are also experienced within the local community.

## Chapter Three

### Concluding Comments and Recommendations

#### 3.1 Introduction

The findings from the survey of service providers are relatively straightforward, and it is hoped that the information on innovative programmes and structured initiatives will add to the small but growing body of evidence in this area. Further, it is hoped that the information will help the National Disability Authority better understand the extent and nature of the programmes and initiatives that link people with disabilities to natural supports within their communities in Ireland. The study had a specific remit and other interesting issues were inevitably omitted from the research. However, it is hoped that further research will address these gaps in the data, such as identifying best practice in promoting natural supports or exploring those factors, which help or hinder the development of effective natural supports.

The credibility of the data is a crucial aspect of any study and there are some grounds for questioning the reliability and generalisability of the current data. In the first instance, there are acknowledged problems with the lists of sample providers; not all of the service providers participated in the study or some did so only partially; and while some service providers chose to give information on local programmes, others did so on a regional or national basis, thereby making direct comparisons problematic. Second, the self-selection process, which allowed the service providers decide if one or more of their programmes qualified for the research raises the possibility of bias.

In response, it should be noted that sampling error, non-response and gaps in information are standard parts of all sample surveys. Various steps can be, and were, taken to minimise these problems, such as random sampling, utilising comprehensive lists and letters of introduction, and multiple contacts using different media. Accordingly, given the rigour of the methodology employed and the relatively large sample size, it is argued that the data, whilst not statistically representative, is nevertheless robust and indicative of the innovative programmes and structured initiatives that existed in Ireland in 2011. In this regard, it is reassuring that the findings confirmed the relative scarcity of programmes and initiatives, previously suggested by the literature review commissioned by the National Disability Authority.

Self-selection is always a difficulty within research, especially where the criteria for the selection is not known or controlled. However, most of the questions were straightforward and there is no obvious benefit for an organisation to exaggerate their satisfaction or otherwise with a project. Accordingly, it was

subsequently decided to publish details from most of the individual programmes in volume II of this report to provide readers with additional insights into the basis of the present research findings. The focus of the present study specifically excluded more detailed case studies, which would be expected to shed further, and possibly different, light on natural supports.

The study found that only one in ten of Irish service providers had relevant programmes and initiatives in place. However, the research suggests that this figure possibly underestimates the range of relevant services because some service providers gave only a partial response to the survey or none at all. Thus, for example, a service provider may have responded for some of its regions but not all, while indicating that additional programmes operated in the other regions. It was also the case that some service providers which had initially indicated the presence of relevant programmes or structured initiatives in their services did not respond to the survey within the timescale of the study, due in part to resource issues. The result is that the benchmark findings in this study should be taken as indicative rather than statistically representative of the number and range of innovative programmes and structured initiatives that existed in Ireland at the time of the research.

In this final chapter, a number of recommendations are made for consideration by the National Disability Authority. It is hoped that these recommendations will inform discussion and guide further research in this area.

### **3.2 Recommendations**

The programmes and initiatives described in this report are perceived by their organisers to fulfil a positive role across the disability services, as illustrated by the satisfaction expressed by the vast majority of service providers.

It is recommended that service providers be encouraged and facilitated to provide innovative programmes and structured programmes through the implementation of various measures, such as the development of appropriate guidelines and the dissemination of best practice models. The National Disability Authority could play an important role in both of these areas.

It is also recommended that more in-depth case-study research be conducted with service providers and service users to further explore the perceived and actual impact of these programmes and initiatives. Ideally, the results of this research should indicate some of the most effective ways to promote natural supports across the different disability sectors.

Some service providers would appear to have more developed programmes and initiatives in place than other services. Their experience suggests that programmes and initiatives perform most effectively when they incorporate a

number of key features including, the empowerment of individuals with disabilities, recognition of the value of support from all sections of the community, a focus on practical skills, flexibility, group consensus, and the benefits of engaging with the local community.

It is recommended that service providers be encouraged to share their experiences with other services seeking to promote innovative programmes that link people with disabilities to natural supports within their communities in Ireland. An independent body, such as the National Disability Authority, would be ideally positioned to facilitate this process.

Funding is critical to the continuity of these programmes and initiatives, with many services dependent on statutory funding.

Given the present economic climate, it is recommended that consideration be given to the increased use of resources that do not require direct funding, such as volunteers from the community. The research findings indicate that while most programmes and initiatives are supported by staff, substantially less service providers use volunteers than paid staff.

The move to independent living is a slow process and one that can be fraught for all concerned, including the people with disabilities, their families and friends, their service providers, and the local community. The potential difficulties are not always acknowledged, with the result that people can become unnecessarily disappointed and frustrated with the relatively slow progress.

It is recommended that this reality is acknowledged and that a wide range of appropriate resources are put in place to address the needs of people seeking to live independently, including measures such as half-way houses, appropriate technology, structured links with the wider community, and a minimum of basic living and social skills etc.

**Exploring the use of Natural Community Supports  
in Promoting Independent Living among Adults  
with Disabilities in Ireland**

**Survey of Service Providers**

**Volume II**

**Profile of Selected Programmes and Initiatives**

By

John A. Weafer

Anne Marie Weafer

7th November 2012

## **Section I**

### **Physical and Sensory Disability Services Programmes and Initiatives**

## Development Programme

How would you describe the programme?	Peer advocacy support programme. Innovative social-skills training programme aimed at establishing and maintaining the development of social relationships.
Does the programme have specific aims and objectives?	The aim of the programme is to provide an opportunity for people with a physical disability under the age of 65 who are inappropriately placed in an elderly care nursing home to: increase opportunity for social inclusion, develop confidence and social skills, and provide opportunities to maximise independence and self –direction.
What year did the programme start?	2006
What target group does your programme serve?	Adults with primary physical disability (50% have concomitant mental health problems, 60 % have some cognitive impairment) who are inappropriately placed in Elderly Care Nursing Home.
Programme coverage	Local
How is the programme funded?	Statutory funding, augmented by self-funding of consumables. Self-funding
What resources are available to the programme?	Direct PA Staff Office/space Administrative support Funding
Evaluation	Yes, already evaluated
What indicators would determine if the programme has been successful or not for you?	If service users experience a benefit. If service users direct their own service. If service users engage in other community based opportunities.
In your opinion, what has worked well in the programme?	The service users have stated that they enjoy the programme. The service users are engaged in new initiatives but they are not yet initiating new activities.

In your opinion, what has not worked well?	Service users are not yet initiating new activities. Two service users still dominate the choice and decision-making of the group. The relationship between the Programme Provider organisation and the nursing home is finely balanced. These are two agencies with different philosophies.
What have been the main learnings of the programme to date?	Facilitating independent living is not easily achieved in an institutional setting when that setting has a different ethos and main purpose.
Have you made any changes to the programme?	Yes - increase the variety of experiences for participants so that they can then make more informed decisions.
Envisage any problems?	Funding is on a 12-monthly basis only and fixed. The level of intervention is likely to reduce as cost of intervention increases (e.g., salary costs, transport, venue cost etc)
Overall views of the programme.	It will serve as a valuable pilot for future potential interventions in communal living settings.



## Contact Volunteers

How would you describe the programme?	Befriending scheme that aims to build connections between people with disabilities and local community members.
Does the programme have specific aims and objectives?	The aim of the programme is to reduce isolation of the person with the disability and empower them to participate in society.
What year did the programme start?	2011
What target group does your programme serve?	People with disabilities in the Dublin 15 area.
Programme coverage?	Local
How is the programme funded?	Service provider
What resources are available to the programme?	Staff Volunteers Administrative support
Evaluation	No, but plan to evaluate.
What indicators would determine if the programme has been successful or not for you?	Comments from people with disabilities.
In your opinion, what has worked well in the programme?	Contact between volunteers and people with disabilities.
What have been the main learnings of the programme to date?	Reducing isolation can help with the person's mental health and give them a positive outlook on life,
Have you made any changes to the programme?	Not yet.
Do you envisage any problems with the programme in the coming year?	The waiting time with Garda clearance.
Overall views of	The programme is in its early stages but it is going

programme now.	well.
----------------	-------

## Family and Friends Support Group

How would you describe the programme?	Programme supporting family and friends to develop support structures.
Does the programme have specific aims and objectives?	The aim of the programme is to support people with disabilities in their own homes and empower them to take control.
What year did the programme start?	2000
What target group does your programme serve?	People with disabilities in the Dublin 15 area.
Programme coverage	Local
How is the programme funded?	Statutory (FÁS CE)
What resources are available to the programme?	Staff Office/space Administrative support Funding
Is there any individual(s) who provides assistance to people with disabilities as part of the programme?	Yes – paid – male and female – no relevant professional qualification – employed by service provider They provide support for people with disabilities in their homes.
Evaluation	Yes, already evaluated.
What indicators would determine if the programme has been successful or not for you?	Comments from the service users. Feedback has been excellent and this has helped change the service over the years.
In your opinion, what has worked well in the programme?	Contact between people with a disability and staff on the maintenance team.
What have been the main learnings of the programme to date?	That people with disabilities feel empowered by taking control over their lives.
Have you made any changes to the	We moved from basic support to more home improvement.

programme	
Envisage any problems?	The length of time it takes to have people get Garda Clearance can cause some difficulties.
Overall views of programme now.	Very satisfied but always room for improvement.

## Independent Living Skills Development

How would you describe the programme?	Programme supporting family and friends to develop support structures. Life skills programme.
Does the programme have specific aims and objectives?	The aim of the programme within the next 12 months is to provide individuals with individualised person centred support and assisting them to fulfil an independent a life as possible in their own communities.
What year did the programme start?	Commencing later 2011/2012 (awaiting funding approval)
What target group does your programme serve?	Physical disability, intellectual disability and autism at present. However, we cover all areas of disability and clients that are living in unsuitable accommodation.
Programme coverage	Local
How is the programme funded?	Funding applied for via Genio. The programme will commence when funding is approved.
What resources are available to the programme?	Staff Volunteers Office/space Administrative support
Has the programme been evaluated and/or do you plan to evaluate it this year?	We plan to evaluate the programme in-house.

## Personal Relationships and Sexuality

How would you describe the programme?	Innovative social skills training aimed at establishing and maintaining the development of social relationships.
Does the programme have specific aims and objectives?	The aim of the programme is to explore relationships and sexuality.
What year did the programme start?	2001.
What target group does your programme serve?	Adults with physical and sensory disability.
Programme coverage	Local
How is the programme funded?	Service provider
What resources are available to the programme?	Staff Office/space
Evaluation	No evaluation planned.
What indicators would determine if the programme has been successful or not for you?	Feedback from participants.
In your opinion, what has worked well in the programme?	Breaking the taboo in this area and allowing people 'permission' to discuss the issues openly and without judgement.
In your opinion, what has not worked well?	Need to develop more group work.
What have been the main learnings of the programme to date?	Group work opportunities need to be developed alongside individualised work.
Have you made any changes to the programme	Trying to develop groups in conjunction with other services.
Envisage any problems?	Resources.
Overall views of programme now.	Very satisfied.

## Learning Skills

How would you describe the programme?	<p>Programme supporting family and friends to develop support structures.</p> <p>Peer advocacy support programmes.</p> <p>Befriending schemes that aim to build connections between people with disabilities and local community members.</p> <p>Innovative social skills training programme at establishing and maintaining the development of social relationships.</p>
Does the programme have specific aims and objectives?	<p>The overall aim of the programme is to offer people, whose primary disability is physical and/or related disabilities, the opportunity to develop a broad range of skills according to their different needs and ability. These skills include both practical work skills as well as the fostering of greater independence, personal effectiveness and self-advocacy. An effective Person Centred Planning process gives us the opportunity to design and modify our programmes based on individual need. The programme also aims to facilitate and encourage service users to become more involved and included in their local community. At the end of their programme, service users will have the opportunity to access supported employment as well as further education or training. It would be anticipated that they would have significantly increased their level of knowledge in reference to their local communities and the services available for them within a mainstream setting. Equally important to the overall aim of the programme is that levels of independence would be achieved in the areas of independent living i.e., transport, community access and self-advocacy.</p>
What year did the programme start?	1990
What target group does your programme serve?	The programme is aimed at a young adult whose primary disability is physical and/or a related disability, and who live in the catchment area for the specific centre applied for.

	<p>Who is interested in developing their skills through the Life Training Programme.</p> <p>Who may have attended service provider's children's services.</p> <p>Who may have participated in formal education to Junior Cert level, or a person who may not have participated in formal education.</p>
Programme coverage	Local
How is the programme funded?	HSE
What resources are available to the programme?	<p>Staff</p> <p>Office/space</p> <p>Administrative support</p> <p>Funding</p>
Evaluation	Yes, already evaluated
What indicators would determine if the programme has been successful or not for you?	<p>On completion of the programme we would expect participants to:</p> <ul style="list-style-type: none"> <li>• Exhibit a greater level of independence, self-confidence and personal effectiveness and personal development.</li> <li>• Demonstrate advocacy skills.</li> <li>• Demonstrate improved social skills, awareness of personal self-care and independent living skills.</li> <li>• Be more involved in their local community.</li> </ul>
In your opinion, what has worked well in the programme?	It gives school leavers a good basis for progression to further training, increases their independence and gets them more involved in their own communities.
In your opinion, what has not worked well?	<p>Progression to mainstream courses can be hindered by lack of access to PA support, transport and accessibility issues.</p> <p>There are very few employment opportunities at the moment.</p>
What have been the main learnings of the programme to date?	People accessing the programme have a range of different abilities and aspirations. By using a person-centred approach we have endeavoured to make the programme more relevant to the individual needs of the service user. While encouraging progression to further training or supported employment, we realise that this is not an option for many of our service users who will continue to remain within our service after completing their training. We have



	<p>endeavoured to make the programme more relevant to these service users.</p> <p>We have developed an evening social programme and also offer regular short holiday breaks to our service users, which provide opportunities for independent living training as well as being a social outlet.</p>
Have you made any changes to the programme?	<p>The programme is constantly evolving in response to the needs and aspirations of our service users. We have increased the range of modules and have developed greater links with mainstream colleges and other colleges in the local community in order to foster community integration. There is a great focus on independent living skills and the use of assistive technology.</p>
Envisage any problems?	<p>Hopefully funding for training will be maintained at the current level and as new people come into our service we will receive additional funding for individual PA support and/or transport if required.</p>
Overall views of programme now.	<p>This programme is frequently reviewed to respond to the needs of our service users.</p>

## Day Service

How would you describe the programme?	Innovative social skills training programme aimed at establishing and maintaining the development of social relationships.
Does the programme have specific aims and objectives?	The aim of the programme is to work in partnership with those who use our services to achieve maximum independence, choice and inclusion in their communities.
What year did the programme start?	2005
What target group does your programme serve?	Adults with physical disabilities.
Programme coverage	National
How is the programme funded?	HSE
What resources are available to the programme?	Staff Volunteers (in process) Office/space Administrative support Funding
Evaluation	Yes, already evaluated – yearly review – EFQM monitoring tool.
What indicators would determine if the programme has been successful or not for you?	Service user feedback and the number of people who participated in different activities.
In your opinion, what has worked well in the programme?	Person-centred approach. Service users accessing 3 <sup>rd</sup> level college with support. Independent living programme. Community based activities – horticulture, community radio.
In your opinion, what has not worked well?	Accessibility of some community areas/ spaces.
What have been the main learnings of the programme to date?	Planning/flexibility
Have you made any	Yearly review and changes put in place.

changes to the programme	
Envisage any problems?	Resources in current economic climate.
Overall views of programme now.	Very satisfied – service users are developing skills and meeting new opportunities.

## Community Outreach Service

Does the programme have specific aims and objectives?	The aim of the programme is to support individuals in the development of pathways to appropriate services and supports within their own community.
What year did the programme start?	2010
What target group does your programme serve?	Adults with physical disabilities (excluding Acquired Brain Injury) who reside in County Kerry.
Programme coverage	Local
How is the programme funded?	Statutory funding.
What resources are available to the programme?	Staff Administrative support
Evaluation	Yes, already evaluated.
What indicators would determine if the programme has been successful or not for you?	That the individuals availing of the service have achieved their goal or that a referral to the appropriate community pathway has been initiated.
In your opinion, what has worked well in the programme?	Person centred approach Networking with community services Advocating for/with individuals Supporting individual to establish pathways and supports within community
In your opinion, what has not worked well?	Red tape within statutory agencies. Sourcing information in entitlements. Regional/area differences in service provision.
What have been the main learnings of the programme to date?	A lack of knowledge by the individual on services available within his/ her community. A lack of confidence by the individual to challenge authority e.g., appeal decisions etc.
Have you made any changes to the programme?	Employed more staff Emphasis on local contacts and services the individual is already accessing Supporting the individual to gain knowledge of local/national services
Envisage any	No

problems?	
Overall views of programme now.	We are satisfied that the service is of value to individuals.

## Outreach Support Programme

How would you describe the programme?	The Out-Reach Support programme supports people in making the transition to live independently in the community. The pathway to independent tenancy is planned in partnership with each individual. Initially, people reside in independent accommodation where they utilise all service provider's services and local community supports to gain experience and new skills. When each individual is ready, the programme then moves onto the next stage of supporting them with the transition into a rented house or apartment in the community. Throughout this transition period the programme continues to provide support on an individual basis. This approach benefits the person by providing continuity of support, assistance in organising community services and on a very practical level support with settling into their neighbourhood. Additionally, the provision of individual support has proven successful in facilitating capacity building amongst the participants enabling them to peruse education, participation in sport and community events etc.
Aims and objectives	The main aim of the Out-Reach Support programme is to provide support that enables people to: <ul style="list-style-type: none"> <li>• Progress and make the transition to live independently in the community.</li> <li>• Attain personal milestones and goals.</li> </ul>
Year start	2010
What target group does your programme serve?	Adults with a physical or sensory disability.
Programme coverage	Local
How is the programme funded?	Statutory funding.
What resources are available to the programme?	Staff Administrative support Funding
Evaluation	Ongoing evaluation
What indicators would determine if the	The success of the programme has been determined against:-

programme has been successful or not for you?	<ul style="list-style-type: none"> <li>• The programme's aims and objectives being achieved</li> <li>• Individual outcomes for participants</li> <li>• Innovative and cost effective use of resources.</li> </ul>
In your opinion, what has worked well in the programme?	The programme facilitates an opportunity for adults to experience living independently in the community for the first time, while their place is held in service provider's independent accommodation. This is particularly important as the family are often anxious about their relative taking this step and losing the security of a place. Additionally, support is provided for people to engage in third level education, sports training and community events etc.
In your opinion, what has not worked well?	The lack of available alternative accommodation and funding for support packages means that opportunities to avail of independent living are limited.
Main learning?	The nature of the programme calls for planning in partnership with each individual and the co-operation of all interested parties in supporting the person through this transitional period.
Have you made any changes to the programme	Not to date, but we envisage enhancing the programme in response to recommendations from the planned evaluation in 2012.
Envisage any problems?	Unfortunately, we are not able to offer all candidates that applied a place on the programme and as a result the opportunity to live with a greater degree of independence.
Overall views of programme now.	We are pleased with progress to date. The mid year review session, held with the participants, showed that the programme has supported real outcomes for people.

## Supported Living Service

How would you describe the programme?	The primary focus of the service is to support residents to live an independent life, engage in personalised independent living training programmes and to participate in community activities in the local area. Based on their individual requirements and interests the resident identifies the programmes and community activities they wish to get involved in to increase their, social participation, skills, experience and knowledge.
Does the programme have specific aims and objectives?	The aim of the programme is to offer people with disabilities the opportunity and individualised supports that will enable them to live self-determined independent lives in the community.
What year did the programme start?	2006
What target group does your programme serve?	Adults with physical-sensory disabilities.
Programme coverage	Local
How is the programme funded?	Statutory funding.
What resources are available to the programme?	Staff Office/space
Evaluation	Ongoing annual evaluation through service provider's structured process.
What indicators would determine if the programme has been successful or not for you?	The success of the programme is measured against:- <ul style="list-style-type: none"> <li>• Aims and objectives of the service</li> <li>• Personal outcomes for participants</li> <li>• The impact of independent living training programmes</li> <li>• The cost effective use of resources.</li> </ul>
In your opinion, what has worked well in the programme?	Planning and reviewing in partnership with each individual person. The provision of targeted individualised supports. Coordinated approach with all services involved in supporting the person i.e. GP, OT, Physio, PHN,



	Speech and Language, as some residents have moved from a hospital setting. Implementation of an Independent Living Training programme.
In your opinion, what has not worked well?	While the programme works well, significant barriers still remain for people to live independently in the community. These barriers include the limited opportunities for people to move from IWA accommodation into housing in the wider community and access to funding for personal assistants.
What has been the main learning of the programme to date?	Learning from implementing the programme:- <ul style="list-style-type: none"> <li>• Sustainable outcomes are gained by working from the individual's perspective</li> <li>• A consistency of approach is required to support self-determination</li> <li>• Individual supports must be consistently reviewed in the early stages</li> <li>• Planning through a partnership approach supports expectations being met</li> <li>• Working in a partnership approach with families and community services is a vital success factor</li> </ul>
Have you made any changes to the programme?	The annual evaluation process has resulted in recommendation's being enacted to enhance the programme. For example consistent review was implemented so a person's supports could be increased or decreased according to their changing requirements. Additionally, the programme's content has also been adapted to support an individual's change in condition or circumstances.
Envisage any problems?	The uncertainty facing all frontline services in the current climate is one of funding.
Overall views of programme now. How satisfied are you with the programme?	We are very satisfied with the consistent good feedback we have received from people who have availed of the programme. The participant's have identified their growth in confidence and ability to take control over their lives as the most significant benefit of the programme. Family members and support staff have also highlighted how the programme increased each

	participant's self-esteem and general well being.
--	---

## Sports and Social Programme

How would you describe the programme?	<p>The programme is a self-directed programme that runs on a Tuesday evening and utilises community sport and social amenities. The programme operates under service provider's range of peer advocacy support programmes.</p> <p>This innovative social-skills training programme is aimed at establishing and maintaining the development of social relationships. This is achieved by building connections between people with disabilities and people in the local community through common interests.</p>
Does the programme have specific aims and objectives?	<p>The aim of the programme is to promote and support the social participation of young adults in the community through:-</p> <ul style="list-style-type: none"> <li>• Young adults self directing the programme and generating choices and opportunities</li> <li>• Increased skill in sports</li> <li>• Increased physical activity, confidence and the promotion of wellbeing</li> <li>• Sports enable interaction between diverse peer groups in the wider community</li> <li>• Increased social opportunities.</li> </ul>
What year did the programme start?	2009
What target group does your programme serve?	Adults with Physical and Sensory Disability.
Programme coverage	Local
How is the programme funded?	The programme is funded by the local service provider and the participants on the programme additionally self-fund.
What resources are available to the programme?	<p>Staff and volunteers</p> <p>Accessible transport</p>
Evaluation	The programme is consistently reviewed by the participants and annually evaluated through service

	provider's structured process.
What indicators would determine if the programme has been successful or not for you?	<p>Indicators of success have been measured by evaluating did the programme support :-</p> <ul style="list-style-type: none"> <li>• Increased opportunities for social gain</li> <li>• Increased individual social participation</li> <li>• Progression of skills, sport aptitude</li> <li>• Increased physical well being</li> <li>• Increased confidence and self-esteem.</li> </ul>
In your opinion, what has worked well in the programme?	<p>Regular consultation with the group has highlighted very positive individual outcomes for the participants on the programme. This group of young adults have been very successful in self-directing the programme by naming and organising how they wish to socially participate in the community.</p> <p>The programme generates two clear benefits;</p> <ul style="list-style-type: none"> <li>• Sport generates enjoyment, self achievement and fitness</li> <li>• The social side of sport generates friendships, a wider network, fun, and well-being.</li> </ul>
In your opinion, what has not worked well?	N/A
What have been the main learnings of the programme to date?	<p>Supporting people who don't necessarily require a traditional model of 'day service' requires innovative responses.</p> <p>The programme's approach must truly support self-determination / self direction in order for the young adults to benefit fully from the experience.</p>
Have you made any changes to the programme	The level of staff support has been gradually reduced in response to the participants taking more control over the programme.
Envisage any problems?	The programme is well established now and no immediate problems are foreseen.
Any other aspect of the programme you would like to mention?	The focus of the programme is to utilise community supports and amenities these included; Community Sports Partnership, utilising local sports clubs and gyms, coffee shops and restaurants. Additionally, playing in competitive games and creating links with transition year students have been success factors of the programme.

	Service provider's accessible transport has always been required to support this programme due to the lack of accessible public transport.
Overall views of programme now.	It has been satisfying to see the programme evolve from initially being quite heavily supported by staff to becoming a totally self-directed programme. This is a model that we will continue to implement and further develop into the future.

## Self-Advocacy Programme

How would you describe the programme?	The Self-Advocacy Programme aims to equip people with disabilities (service provider's members) with a range of self-advocacy skills necessary for many, work, social and life situations. The programme supported members to look at areas such as decision making, assertiveness and understanding of rights.
Does the programme have specific aims and objectives?	<p>The programme aims to:-</p> <ul style="list-style-type: none"> <li>• Equip participants with the skills that will support them in everyday living</li> <li>• Develop an understanding self-advocacy</li> <li>• Increase participants awareness of their rights</li> <li>• Give practical experience in exercising self-advocacy in the many, work, social and life situations i.e. skills utilised in making a complaint, exercising a right etc.</li> </ul>
What year did the programme start?	2010
What target group does your programme serve?	People with physical and or sensory disabilities.
Programme coverage	Local
How is the programme funded?	Statutory funding Back to Education Initiative
What resources are available to the programme?	Staff Office/space Administrative support Funding
Evaluation	The programme was evaluated through service provider's structured process in full consultation with the programme participants.
What indicators would determine if the programme has been successful or not for you?	A self-evaluation sheet was completed by each participant to establish the success of the programme. The tutor also filled in a tutor feedback form enabling the tutor to identify areas that worked well, together with areas for improvement. The informal and formal feedback from the participants indicated that they had a good experience and gained individually from the

	<p>programme. Many participants identified how they used their new skills and knowledge to self-advocate for changes in their lives. The group expressed a wish to continue learning in this area. Following a presentation of their project work, other members in our Resource and Outreach centre expressed an interest in the programme.</p>
In your opinion, what has worked well in the programme?	<p>The participants on the programme gained vital skills, which have assisted them in many areas of their lives. The participants demonstrated their learning by presenting their project work to both staff and service provider members in the centre. This event was a challenge for many, but the event showed how much confidence they had gained from the self-advocacy programme.</p> <p>A vital component of the programme was the utilisation of Staff resources to provide additional support outside of the programme. The one-to-one support enabled participants to continue to transfer their newly acquired skills and knowledge into every day life.</p>
In your opinion, what has not worked well?	The programme ran smoothly.
What have been the main learnings of the programme to date?	<p>From the group feedback certain themes came to the fore which will be utilise to further enhance the programme, these included:-</p> <ul style="list-style-type: none"> <li>• The importance of confidentiality</li> <li>• Gaining an understanding rights</li> <li>• Promoting respect for themselves and others</li> <li>• Building self-esteem, assertiveness and confidence.</li> </ul>
Have you made any changes to the programme?	We would have wished to extend the duration of programme hours as we felt participants would have gained additional benefits. However, this could not have been facilitated within the budget.
Envisage any problems?	<p>The programme is funded by the Back to Education Initiative. If this funding is cut we will not be in a position to make the programme available in the centre.</p> <p>Facilitating such a programme requires additional support being made available so people can gain practical experience in utilising the knowledge to</p>

	enhance their lives.
Any other aspect of the programme you would like to mention?	The programme has proved hugely popular amongst those who have participated. Their confidence grew, they showed initiative and changes became evident on a daily basis as participants took more control and made decisions for themselves.
Overall views of programme now. How satisfied are you with the programme?	<p>The programme has exceeded all expectations. The group involved organised:-</p> <ul style="list-style-type: none"> <li>• A formal meeting to request a follow up programme which showed initiative and increased confidence.</li> <li>• A presentation was given to all staff and members, which impressed everyone on the day.</li> <li>• People who struggled with literacy read out loud to the group about their learning from the course and others who had no experience in presenting showed their professionalism and organisational skills.</li> </ul> <p>Essentially, participation in the programme generated individual achievements and practical experience in managing everyday life situations.</p>



## Adventurer's Outreach Programme

How would you describe the programme?	The programme is a self-directed social programme that utilises service provider's community centre and local social amenities. The programme operates under service provider's range of peer advocacy support programmes.
Does the programme have specific aims and objectives?	<p>The programme is a self-directed programme that is aimed at increasing participants' independence and social participation in their local community. Participant's' utilise supports to:</p> <ul style="list-style-type: none"> <li>• Establish links within the community</li> <li>• Organise and implement opportunities</li> <li>• Increase participation in local community.</li> </ul>
What year did the programme start?	2011
What target group does your programme serve?	People with a physical disability aged between 18 and 35.
Programme coverage	Local
How is the programme funded?	Statutory funding.
What resources are available to the programme?	<p>Staff</p> <p>Volunteers</p> <p>Office/space</p> <p>Administrative support</p>
Evaluation	The programme is consistently reviewed by participants and will be evaluated at the end year, in consultation with all stakeholders, through service provider's structured process.
What indicators would determine if the programme has been successful or not for you?	<p>Success will be measured against the programmes aims and objectives and will determine if :-</p> <ul style="list-style-type: none"> <li>• Sustainable links were established within the community</li> <li>• Opportunities were created and implemented</li> <li>• Individuals increased their community participation.</li> </ul>
In your opinion, what has worked	One particular outcome has been the peer support generated by the group. Taking these steps together has

well in the programme?	led to participants becoming more socially active; going to the cinema or out for a meal etc.. Another part of the programme that has worked particularly well was when the group were asked to organise an event that would take them out of their comfort zone, they chose to go swimming. The participants did six sessions in the local swimming pool. During this particular part of the programme participants' confidence in their own ability substantially increased.
In your opinion, what has not worked well?	Although the programme is in an early stage of implementation we are aware that there is a need to think 'out side the box'. This approach is creating more opportunities and choices for participants and thereby increases their participation in community-based activities.
What have been the main learnings of the programme to date?	Regular consultation with participants ensures that the programme is meeting the requirements of each individual. Supporting the group to plan and review the programme has supported them in developing skills that they can bring to other areas in their lives.
Changes to programme	Once the annual evaluation has been completed any changes required will be made to enhance the programme and our approach in delivering supports.
Envisage any problems?	Not at present.
Any other aspect of the programme you would like to mention?	The programme has developed a strong peer support network between the participants. They share ideas, skills and personal experiences which has been a positive outcome.
Overall views of programme now. How satisfied are you with the programme?	The programme is relatively new, but 'thinking outside the box' has led the group to explore new options and create new opportunities to participate in the community. The group have taken on a leadership role within the programme, which has had a very positive impact on developing their self-esteem and confidence.

## **Section II**

### **Intellectual Disability Services Programmes And Initiatives**

## Bookshop

How would you describe the programme?	Befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members. Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships. Experiential learning opportunity in a real social enterprise that is inclusive, welcoming and which provides a valuable service locally.
Does the programme have specific aims and objectives?	The main aims of the programme are to: <ul style="list-style-type: none"> <li>• Help people to get to know each other – welcoming.</li> <li>• Develop skills, confidence and enjoyment.</li> <li>• Capacity building in the community.</li> <li>• Change mindsets and seize opportunities.</li> </ul>
What year did the programme start?	2009
What target group does your programme serve?	West Clare community. People with disabilities. Anyone interested in social enterprise/meitheal.
Programme coverage	Local
How is the programme funded?	Self-financing
What resources are available to the programme?	Small staff input. 15 volunteers. Stock donated by community in abundance. Artists use the facility and also volunteer.
Has the programme been evaluated?	No, but plan to evaluate.
What indicators would determine if the programme has been successful or not for you?	People working there enjoy it and look forward to going in. Volunteers' relationship building. People can work there semi-independently. It is self-financing and profits are used for further enterprises.
In your opinion, what has worked well in the programme?	Helping to change people's perceptions of disability. Raising people's expectations. Building self-esteem and confidence in people.

In your opinion, what has not worked well?	People need real pay for work. A decision is needed to decide how to distribute profits equitably. Perhaps it would be better if broader community group would steer it.
What have been the main learning's of the programme to date?	Community has been open and welcoming. People enthused by this initiative. Great model for social inclusion and enterprise. Avoid concept of charity – citizens providing service avoids stereotypes. Contributing in a real way – it changes minds and builds relationships.
Have you made any changes to the programme	No great changes to date. We have extended the shop. We need to decide what to do with money/profits.
Envisage any problems?	No
Overall views of programme now.	It is so positive for everyone. No one who enters would think it is anything other than an attractive, welcoming second hand shop. It has given the street, town and people we support a great lift. All credit to the volunteers, staff for their creativity.

## Access for All

How would you describe the programme?	Befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members. Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships.
Does the programme have specific aims and objectives?	The aims of the project are to: Promote accessible tourism as an attractive positive initiative in West Clare. Involve people we support to advocate for change. Access for everyone
What year did the programme start?	2009
What target group does your programme serve?	People with reduced mobility and wheelchair users. Decision makers.
Is the programme a local initiative or part of a broader regional/ national initiative?	Local, regional and national (lot of national coverage in press for beach wheelchairs).
How is the programme funded?	Service pays staff and fundraising bought a chair.
What resources are available to the programme?	Staff (half day per week) and 2 volunteers.
Evaluation	No, but plan to evaluate.
What indicators would determine if the programme has been successful or not for you?	Good publicity and feedback. Evidence of local pride in innovative project. Get invited to contribute on issues of accessibility.
In your opinion, what has worked well in the programme?	Initiative and networking. Local people who come forward to play their part. Capture imagination locally and nationally. Open doors and generate further projects. Valued role for people we support.
In your opinion, what has not worked well?	Some teething problems around the use of beach wheelchairs.
What have been the	Strand and seashore can be accessible for those with

main learning's of the programme to date?	mobility issues. Challenging mindsets. Working together and bring people on board.
Have you made any changes to the programme	Continual reflection on how we can make accessibility a popular topic, and overcome fear and be creative.
Envisage any problems?	Ongoing work to help people pull together and focus on the topic of accessibility we need.
Overall views of programme now.	A good start is great and augers well for future work. We need to build on it.

## Independent Skills Training

How would you describe the programme?	<p>Programmes supporting family and friends to develop structures such as circles of support, microboards or support clusters?</p> <p>Peer advocacy programmes supported through the provision of venues, administrative support, funding etc?</p> <p>Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships?</p> <p>Create inclusive opportunities in mainstream education and employment in partnership.</p>
Does the programme have specific aims and objectives?	The aim of the programme is to support the person to develop independent skills and to have an inclusive educational experience at third level. There is also a strong focus on 'on the job' training with the view to gain employment.
What year did the programme start?	2000
What target group does your programme serve?	Young adults with intellectual disabilities.
Programme coverage	Regional
How is the programme funded?	Statutory funding
What resources are available to the programme?	<p>Staff</p> <p>Volunteers</p> <p>Office/space</p> <p>Administrative support</p> <p>Funding</p>
Evaluation	Yes, already evaluated
What indicators would determine if the programme has been successful or not for you?	Successful placement in mainstream education or employment. The individual sets goals to achieve in line with the programme when they start.
In your opinion, what has worked well in the programme?	Being based in the adult education community in Ennis. Working on different partnerships/



In your opinion, what has not worked well?	Always work in progress on new ideas
What have been the main learning's of the programme to date?	The importance of listening to the person and supporting them to achieve real things in education or work. The successful delivery of inclusive classes with VEC students on community topics.
Have you made any changes to the programme?	We constantly review what we are doing. The nature of the programme brings new students to it every year. Each person wants different things so we change to meet the need.
Problem	Funding challenges
Overall views of programme now.	New partnerships are being developed with third level provider for inclusive mainstream educational experience. We are very satisfied but always reviewing and re-evaluating our effectiveness.

## Community Garden

How would you describe the programme?	Befriending scheme that aims to build connections between people with disabilities and local community leaders.
Does the programme have specific aims and objectives?	<p>The aims of the programme are:</p> <ul style="list-style-type: none"> <li>• To develop community cohesiveness and community participation.</li> <li>• To develop a garden area for picnics for flower and vegetable patches.</li> <li>• To raise money for other projects by selling the organic products.</li> </ul>
What year did the programme start?	2008
What target group does your programme serve?	Individuals with an intellectual disability and local Community.
Programme coverage	Local
How is the programme funded?	Statutory funding
What resources are available to the programme?	Volunteers
Is there any individual(s) who provides assistance to people with disabilities as part of the programme?	Yes – voluntary and paid – male and female – relevant professional qualifications – employed and not employed by service provider.
Evaluation	No, but plan to evaluate
What indicators would determine if the programme has been successful or not for you?	The individuals with an intellectual disability fully participating and learning in the project. Also, the fact they are missed if they do not attend.
In your opinion, what has worked well in the programme?	The inclusiveness of the project. The learning for the Community about the needs and challenges that people with an intellectual disability have.
In your opinion, what	The project worked well

has not worked well?	
What have been the main learning's of the programme to date?	All four individuals were phased into this project, allowing people in the community who had no knowledge of people with intellectual disability and their needs to slowly get to know the person.
Have you made any changes to the programme	No
Envisage any problems?	Funding is an issue to continue developing the garden and buy more plants and vegetables to increase the turnover.
Overall views of programme now.	Overall, very satisfied with the programme. The project is very good as it also teaches a skill that may be used in future employment.

## Supported Independent Living Programme

How would you describe the programme?	Supporting people to live independently.
Does the programme have specific aims and objectives?	<p>The aims of the project are:</p> <ul style="list-style-type: none"> <li>• To support people have more control over their lives.</li> <li>• To support people access services to enable them to have a full life.</li> </ul>
Year Start?	1990
What target group does your programme serve?	People with mild to moderate disability and who are unhappy living in a group home residential setting.
Programme coverage	Local
How is the programme funded?	Service provider
What resources are available to the programme?	<p>Staff</p> <p>Volunteers</p> <p>Office/space</p> <p>Administrative support</p> <p>Funding</p>
Evaluation	Yes, already evaluated
What indicators would determine if the programme has been successful or not for you?	<p>Personal outcome measures.</p> <p>Withdrawal of staff support as the individual gets more independent.</p> <p>Individual feedback.</p>
In your opinion, what has worked well in the programme?	<p>Accommodation: people have moved from sharing to living on their own, and each individual has made a home out of their accommodation.</p> <p>Use of community services such as retirement clubs, or the use of grants such as home care package, Centre for Independent Living, community catering etc.</p> <p>Assisted technology.</p> <p>Individualised support means that people have been getting the support they need – some people are receiving daily visits and others weekly visits.</p>
In your opinion, what	Loneliness and lack of genuine friendship.

has not worked well?	Lack of employment opportunities or meaningful activities. Transfer of training/ education into daily support, thereby maintaining learning.
What have been the main learning's of the programme to date?	Sharing accommodation does not work in the long-term for most people. Flexibility is key to providing individualised support. Most community programmes are welcoming. The balance between duty of care and dignity of risk is very important.
Have you made any changes to the programme?	There are ongoing changes in terms of individualised support especially as the people are ageing and their health is deteriorating.
Envisage any problems?	Maintaining independence and home while ageing. Financial restraints – cut backs within our service and outside our services. Loneliness and creating genuine friendship.
Overall views of programme now.	The programme is reliant on staff initiatives, flexibility and community networking. Recruiting the right staff is key. I am satisfied that each individual has shaped the support and service they receive. However, this programme is always developing as the needs and wishes of people are changing.

## Family and Friends Support Group

How would you describe the programme?	Programme supporting family and friends to develop support structures. A multi-disciplinary service with learning disability expertise. Promoting independence and inclusion.
Does the programme have specific aims and objectives	The aims of the programme are: To provide a service, which is person centred and service user led To support people to live safe and full lives within their own community. To enhance the quality of life and well-being of clients. To have goals and to help people to achieve their personal aims and goals. To provide a flexible and responsive service
What year did the programme start?	1986
What target group does your programme serve?	Adults with a mild learning disability within the community, living at home or independently.
Programme coverage	Regional
How is the programme funded?	Statutory funding
What resources are available to the programme?	Staff Volunteers Office/space Administrative support Funding
Has the programme been evaluated?	No evaluation planned
What indicators would determine if the programme has been successful or not for you?	We complete personal outcomes reviews and interviews. Our team and clients score very highly on outcomes through our team.
In your opinion, what has worked well in the programme?	Personal outcomes – community support and practical support and the multi-disciplinary team approach. One does not work without the other.
In your opinion, what has not worked well?	Need more independent programmes to develop skills in the community. There is a lack of 'half-way' support

	to bridge residential and community living.
What have been the main learning's of the programme to date?	The skill, expertise and knowledge of a multi-disciplinary team can help complex people move forward in their lives. We do a lot of individual support packages and these work well.
Have you made any changes to the programme?	Yes – over the last three years the team are more flexible due to having the support and expertise. This is supported by management and developments in individualised services.
Envisage any problems?	As with all programmes, funding becomes stretched and the service is at capacity. This may lead to less people using the service. If there is no 'move on' then the service has a limit to the work that can be done.
Overall views of programme now.	Satisfied but the service is working at its capacity at present.

## Gardening

How would you describe the programme?	Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships?
Does the programme have specific aims and objectives?	The main aim of the programme is to offer participants who have an interest in gardening the opportunity to interact with gardeners in an allotment setting. Also, to help develop the social and practical skills needed.
What year did the programme start?	2010
What target group does your programme serve?	People with moderate intellectual disability.
Programme coverage	Local
How is the programme funded?	Service providers
What resources are available to the programme?	Staff Volunteers Office/space Administrative support Minimum Funding
Evaluation	No, but plan to evaluate.
What indicators would determine if the programme has been successful or not for you?	Continuous interest in participation. There is a waiting list and we are already considering expansion to other allotment sites. Improved social skills and improved confidence.
In your opinion, what has worked well in the programme?	The group have bonded and work well together. There is an eagerness from people to remain on the programme. Learning outcomes are being achieved and modified.
In your opinion, what has not worked well?	Vandalism to the site. A site with access to public transport would facilitate more independence. There are limited opportunities to develop friendships with other gardeners.
What have been the main learning's of the programme to date?	We were surprised at the interest in the programme and the demands for similar from other service users. Also the lack of previous knowledge of where our food comes from by participants. The eagerness to spend



	time outdoors.
Have you made any changes to the programme	Yes – input is given on food production/growing. We have also introduced a Healthy Eating Programme. More changes are expected following an evaluation.
Envisage any problems?	The main problem is vandalism to our site. We also need to develop an indoor winter programme when growing season stops. We need transport.
Overall views of programme now.	Whilst our group are welcomed by many, few opportunities have arisen to extend social interaction away from the allotment with other like-minded people. Feedback from participants is very positive. Therefore we are very satisfied.

## Parent Link Programme

How would you describe the programme?	Programme supporting family and friends to develop support structures.
Does the programme have specific aims and objectives?	The aim of the programme is to put parents in touch with one another and provide them with the skills to assist each other.
What year did the programme start?	2005.
What target group does your programme serve?	Parents of people with disability.
Programme coverage	National. The programme is carried out on a local level but is organised at a national level.
How is the programme funded?	Fundraising.
What resources are available to the programme?	Staff Volunteers Office/space Administrative support Funding
Evaluation	No evaluation planned.
What indicators would determine if the programme has been successful or not for you?	Feedback from the participants and subsequent usage of the skills acquired.
In your opinion, what has not worked well?	Due to a lack of resources, both financial and in terms of man-hours available, we are not in a position to cater for the demand from parents.
What have been the main learnings of the programme to date?	Parents are appreciative of having the expertise to deal with other parents and provide the necessary and appropriate support to their contemporaries.
Have you made any changes to the programme	The programme has evolved over time in line with international developments as well as changes that take place at a national level in terms of the provision of services in any given local area.
Envisage any	A lack of resources is our biggest challenge.

problems?	
Overall views of programme now.	Delighted with the programme both in terms of content and delivery.

## Rehabilitative Training Programme

How would you describe the programme?	Innovative social skills training programme aimed at establishing and maintaining the development of social relationships.
Does the programme have specific aims and objectives?	Yes.
What year did the programme start?	1999.
What target group does your programme serve?	Service users.
Programme coverage	Local.
How is the programme funded?	Statutory funding.
What resources are available to the programme?	Staff. Funding.
Evaluation	No, but plan to evaluate.
What indicators would determine if the programme has been successful or not for you?	Participants' progression to further education and employment. Being able to mix in their local community and access mainstream social outlets and opportunities.
In your opinion, what has worked well in the programme?	The peer support and social programme.
In your opinion, what has not worked well?	Not being able to obtain funding to establish an outreach service.
What have been the main learnings of the programme to date?	People with AS have a desire to integrate and be social the same as everyone else. They feel isolated due to the inability to learn social cues and mores but with adequate supports they can live active independent lives to some extent.
Have you made any changes to the programme	We review our programme annually and this year we plan to conduct a service review to see how best we can meet the needs of our participant group as the demand on our service grows and the participants' needs change.

Envisage any problems?	Yes, participant/staff ratios are growing. In 2007 we operated on a ratio of 2.5:1, whereas now we are operating on a ratio of 6:1. There are growing numbers of people with AS looking for services and we can either change how we deliver our services or create long waiting lists which do not lend well to individuals who are looking to isolate away from the community.
Overall views of programme now.	The programme is working well but there are ways it can be improved and streamlined. However, we are not allowed to work outside the RT remit, meaning many of the needs of our participants cannot be fully addressed. The programme could be expanded to involve participants in the community more and address the specific needs adults with AS face when trying to live active independent lives. The proposed implementation of “New Directions’ by the HSE will allow this service more latitude to be more community based and in turn address more clients’ needs.

## **SECTION III**

### **NEUROLOGICAL DISABILITY AGENCIES PROGRAMMES AND INITIATIVES**

## Skills for Life

Does the programme have specific aims and objectives?	<p>The aims of this programme for people with MS are:</p> <ul style="list-style-type: none"> <li>• To develop insights into 'self' as a project.</li> <li>• To support people to gain the skills necessary to become effective in self-management which will enable them to better deal with symptoms.</li> <li>• To promote good health and well-being.</li> <li>• To use simple skills to take control of the way they think and feel about their health.</li> <li>• To assist them to manage everyday life and find new ways to live life to the full.</li> <li>• To encourage them to make decisions about lifestyle choices that are right for them.</li> <li>• To enable them to put into practice the professional advice and information they have received on self-management.</li> <li>• To make best use of available resources.</li> </ul>
What year did the programme start?	2011.
What target group does your programme serve?	People living with multiple sclerosis.
Programme coverage	Regional.
How is the programme funded?	Service provider. Statutory funding. Fundraising.
What resources are available to the programme?	Staff. Volunteers. Office/space. Administrative support. Funding.
Evaluation	Yes, already evaluated.
What indicators would determine if the programme has been successful or not for	What the participants say.

you?	
In your opinion, what has worked well in the programme?	<p>The great thing about the course is that it reminded people that they have their own skills that can be drawn on to manage a chronic illness. The course drew on some of the following principles:</p> <ul style="list-style-type: none"> <li>• Self-help philosophy – people speak for themselves.</li> <li>• Participation.</li> <li>• Focus on ability.</li> <li>• Solution focused approach.</li> <li>• Investment in skills for life and self-management tools.</li> <li>• Agree standards for programmes.</li> <li>• Respect data protection.</li> <li>• Develop monitoring/ measure success.</li> <li>• Encourage feedback/ evaluation opportunities.</li> <li>• Provide opportunities for PwMS to avail of quality service in line with Irish Standards.</li> <li>• Align resource to provide Direct Service to PwMS in keeping with SLA.</li> </ul>
In your opinion, what has not worked well?	<p>It requires a lot of commitment, willingness and rational thought for PwMS to engage in self-management. This is often difficult where people may lack the ability to engage or be unwilling to engage due to their being preoccupied with their own distress and difficulties and not being able to take a rational look at solutions/ options.</p>
What have been the main learnings of the programme to date?	<p>it is an investment in people.  It encourages independence.  It is value for money.  It builds capacity.  It is a sustainable model.  It is a win-win.</p>
Have you made any changes to the programme	<p>We believe that it is best for our own staff to deliver the programme as opposed to bringing in external facilitators. This will help us in our Solution Focused case-work.</p>
Envisage any	No.



problems?	
Overall views of programme now.	Both facilitators are very satisfied. The guest speakers are also very happy with how the programme went. As a team we are determined to roll it out as a core programme to PwMS in each of the five counties in the SE Region.

## Life Skills Programme

How would you describe the programme?	Innovative social-skills training programme aimed at establishing and maintaining the development of social relationships.
Does the programme have specific aims and objectives?	The aim of the programme is to promote independent living.
What year did the programme start?	2009.
What target group does your programme serve?	Teenagers and young adults.
Programme coverage	Local.
How is the programme funded?	Service provider and fundraising.
What resources are available to the programme?	Staff. Volunteers. Office/space. Funding.
Evaluation	No, but plan to evaluate.
What indicators would determine if the programme has been successful or not for you?	Participants gaining independent living status rather than parental support or dependence.
In your opinion, what has worked well in the programme?	It has had a moderate success.
In your opinion, what has not worked well?	Not enough participants and parental support is not great. Travel is a major issue, particularly in rural areas.
What have been the main learnings of the programme to date?	Ability to socialise. Ability to cook correct meals. Ability to generally cope with day-to-day challenges. When a problem occurs, they are able to solve it, be it personal, social etc.
Have you made any changes to the programme	No.

Envisage any problems?	Possibly people not attending the rural sessions.
Overall views of programme now.	From the general feedback it seems that the programme is quite effective.

## **Appendix A Letters from National Disability Authority to Service Providers**

Dear Colleague,

I am writing to inform you of an important piece of research, which we in the National Disability Authority, will be undertaking over the coming months in association with an independent research agency, *Weafer Research Associates*.

The National Disability Authority has completed an extensive body of research in the area of community and independent living. A key finding is that the physical presence of people with disabilities within the community is a necessary, but not a sufficient condition for independent living. Unfortunately, some people with disabilities feel isolated and disempowered within their local communities. To address this issue, the National Disability Authority is now undertaking a suite of research to examine the role of natural supports in promoting independent living for people with disabilities.

A primary objective of this research is to explore good practice by organisations such as your own, that provide structured initiatives or innovative programmes that aim to link people with disabilities to 'natural supports' within their communities. For the purposes of this research, the structured initiatives or innovative programmes may include, but are not limited to; programmes supporting family and friends to develop structures such as circles of support, microboards or support clusters; peer advocacy programmes supported through the provision of venues, administrative support, etc.; befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members; innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships. This list is not exhaustive but provides an overview of the kinds of programmes of interest. A common theme underpinning many of these initiatives is that the provider organisation assists in the establishment of the programmes with a view to 'fading' support over time, thus enabling natural support to be maintained. It is important to note that on this occasion we are not including individual programmes relating to person centred planning.

Our research partners, Weafer Research Associates, will be contacting 500 service providers, randomly selected from the HRB databases, over the coming months. If you are selected, we would be very grateful if you would co-operate

with them. If you have any questions on any aspect of the research, please contact John or Anne Marie Weafer on 01-6014092.

Yours Sincerely,



---

Mary Van Lieshout

Head of Research and Standards Development

Dear Colleague,

I am writing to inform you of an important piece of research, which we in the National Disability Authority, will be undertaking over the coming months in association with an independent research agency, *Weafer Research Associates*.

The National Disability Authority has completed an extensive body of research in the area of community and independent living. A key finding is that the physical presence of people with disabilities within the community is a necessary, but not a sufficient condition for independent living. Unfortunately, some people with disabilities feel isolated and disempowered within their local communities. To address this issue, the National Disability Authority is now undertaking a suite of research to examine the role of natural supports in promoting independent living for people with disabilities.

A primary objective of this research is to explore good practice by organisations such as your own, that provide structured initiatives or innovative programmes that aim to link people with disabilities to 'natural supports' within their communities. For the purposes of this research, the structured initiatives or innovative programmes may include, but are not limited to; programmes supporting family and friends to develop structures such as circles of support, microboards or support clusters; peer advocacy programmes supported through the provision of venues, administrative support, etc.; befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members; innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships. This list is not exhaustive but provides an overview of the kinds of programmes of interest. A common theme underpinning many of these initiatives is that the provider organisation assists in the establishment of the programmes with a view to 'fading' support over time, thus enabling natural support to be maintained. It is important to note that on this occasion we are not including individual programmes relating to person centred planning.

I am writing to you now to let you know that you or some of your services may be randomly contacted by *Weafer Research Associates* for information on this important topic. In the event that a representative from your organisation is not

selected to participate, and given the size and scope of your organisation, I would be very grateful if you could let me know of any initiatives, programmes or projects that may be hosted by your organisation that fit the definition above. I will then pass on the information to our research partners who will follow up to get further details of the initiatives.

If you have any questions on the research please contact Jacinta Byrne by email at [jgbyrne@nda.ie](mailto:jgbyrne@nda.ie).

Yours sincerely,

Mary Van Lieshout

Head of Research and Standards Development



## **Appendix B Questionnaires**

19<sup>th</sup> July 2011

**EXPLORING THE USE OF NATURAL COMMUNITY  
SUPPORTS IN PROMOTING INDEPENDENT LIVING  
AMONG ADULTS WITH DISABILITIES IN IRELAND**

**SURVEY OF SERVICE PROVIDERS**

**COMMISSIONED BY THE NDA**

**SURVEY BY WEAVER RESEARCH ASSOCIATES**

**2011**

**© Weaver and Associates Research: 19<sup>th</sup> July 2011**

**Please fill in the following details.**

19<sup>th</sup> July 2011

**NAME OF ORGANISATION:** \_\_\_\_\_

**NAME OF CONTACT FOR LETTER:** \_\_\_\_\_

**YOUR TITLE:** \_\_\_\_\_

**ADDRESS:** \_\_\_\_\_

\_\_\_\_\_

**QUESTIONNAIRE CODE: (Office use only)**

**TELEPHONE NUMBER:** \_\_\_\_\_

**EMAIL:** \_\_\_\_\_

Thank you for agreeing to complete the questionnaire. All the information relates to your local service. If you have any questions please contact John or Anne Marie Weafer at 01-6014092.

**THE PRIMARY PURPOSE OF THE RESEARCH IS TO EXPLORE IF LOCAL SERVICES SUCH AS YOURS HAVE STRUCTURED INITIATIVES OR INNOVATIVE PROGRAMMES IN PLACE, WHOSE PRIMARY AIM IT IS TO ENABLE PEOPLE WITH DISABILITIES TO BECOME MORE INDEPENDENT IN THE COMMUNITY.**

A common theme underpinning many of these initiatives is that the provider organisation assists in the establishment of the programmes with a view to 'fading' support over time, thus enabling natural support to be maintained. It is important to note that on this occasion we are not including individual programmes relating to person centred planning.

**You indicated in our earlier interview that you had initiatives in place that corresponded to at least one of the following programmes.**

**If so, please complete the form overleaf for EACH of the initiatives.**

<b>Q.10</b> Does your service provide any of the following initiatives or interventions for people with disabilities in your local area, either independently or in association with other individuals or groups? ( <b>READ OUT</b> ).	<b>YES</b>	<b>NO</b>
1. Programmes supporting family and friends to develop structures such as circles of support, microboards or support clusters?	1	2
2. Peer advocacy programmes supported through the provision of venues, administrative support, funding etc?	1	2
3. Befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members?	1	2
4. Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships?	1	2

**INITIATIVE/PROGRAMME No 1****PLEASE DESCRIBE THE INITIATIVE UNDER THE FOLLOWING HEADINGS**

Location of programme	
What is the title of the programme?  <b>Write in opposite</b>	
How would you describe the programme?  <b>Please circle number(s) opposite or place X beside number(s) to indicate your answer(s) and/or write in comment.</b>	Programme supporting family and friends to develop support structures..... 1  Peer advocacy support programmes.....2  Befriending schemes that aim to build connections between people with disabilities and local community members..... 3  Innovative social-skills training programme aimed at establishing And maintaining the development of social relationships.....4  Other (Please write in:
Does the programme have specific aims and objectives?  <b>Please circle number</b>	Yes ..... 1  No    2

<p>or place <b>X</b> beside number <b>AND</b> write in aims.</p>	<p>If yes, what is your programme's main aim(s)?</p>
<p>What year did the programme start?</p> <p><b>Please write in opposite</b></p>	
<p>What target group is served by your programme?</p> <p><b>Please write in opposite</b></p>	
<p>How many people with disabilities have benefitted from the programme this year/ in total?</p>	<p>This year:</p>
<p>Is the programme a local initiative or part of a broader regional/national initiative?</p> <p><b>Please circle number or write in X beside number and /or write in comment opposite</b></p>	<p>Local ..... 1</p> <p>Regional      2</p> <p>National      3</p> <p>Other (Write in.....)4</p>
<p>How is the programme funded?</p> <p><b>Please circle number(s) or write in X beside number(s)</b></p>	<p>Your Service ..... 1</p> <p>Statutory funding      2</p> <p>Fundraising      3</p>

<b>or write in comment opposite</b>	Other (Write in.....4
What resources are available to the programme?  <b>Please circle number(s) or write in X beside number(s) for all that apply or write in comment opposite</b>	Staff.....1 Volunteers 2 Office/space .....3 Administrative support .....4 Funding.....5  Other (Write in 6
Is there any individual(s) who provides assistance to people with disabilities as part of the programme? Please circle number or write in X beside number.  If yes, please describe their principal characteristics and their role in the programme.  <b>Please circle numbers or write in X FOR EACH CHARACTERISTIC</b>	Yes .....1 No 2  Voluntary.....1 Paid 2  Male .....1 Female 2  Relevant professional qualification .....1 No professional qualification 2  Employed by service provider .....1

	<p>Not employed by service provider      2</p> <p><b>DESCRIBE ROLE OF SUPPORT</b></p>
<p>Has the programme been evaluated and/or do you plan to evaluate it this year?</p> <p><b>Please circle number or write in X beside number.</b></p>	<p>Yes, already evaluated ..... 1</p> <p>No, but plan to evaluate      2</p> <p>No evaluation planned .....3</p>
<p>What indicators would determine if the programme has been successful or not for you?</p> <p><b>Please write in opposite</b></p>	
<p>In your opinion, what has worked well in the programme?</p> <p><b>Please write in opposite</b></p>	



<p>In your opinion, what has not worked well?</p> <p><b>Please write in opposite</b></p>	
<p>What have been the main learnings of the programme to date?</p> <p><b>Please write in opposite</b></p>	
<p>Have you made any changes to the programme in the light of your experience to date?</p> <p><b>Please write in opposite</b></p>	
<p>Do you envisage any problems with the programme in the coming year?</p>	

<p><b>Please write in opposite</b></p>	
<p>Any other aspect of the programme you would like to mention?</p> <p><b>Please write in opposite</b></p>	
<p>Overall views of programme now. How satisfied are you with the programme?</p> <p><b>Please write in opposite</b></p>	
<p><b>Contact Details</b> for further information on this programme (if necessary)</p>	

**INITIATIVE/PROGRAMME No 2****PLEASE DESCRIBE THE INITIATIVE UNDER THE FOLLOWING HEADINGS**

What is the title of the programme?  <b>Write in opposite</b>	
How would you describe the programme?  <b>Please circle number(s) opposite or place X beside number(s) to indicate your answer(s) and/or write in comment.</b>	Programme supporting family and friends to develop support structures..... 1  Peer advocacy support programmes.....2  Befriending schemes that aim to build connections between people with disabilities and local community members..... 3  Innovative social-skills training programme aimed at establishing and maintaining the development of social relationships.....4  Other (Please write in:
Does the programme have specific aims and objectives?  <b>Please circle number or place X beside number AND write</b>	Yes ..... 1  No    2  <b>If yes, what is your programme's main aim(s)?</b>

in aims.	
What year did the programme start?  <b>Please write in opposite</b>	
What target group is served by your programme?  <b>Please write in opposite</b>	
How many people with disabilities have benefitted from the programme this year/ in total?	This year:  Total (including this year).
Is the programme a local initiative or part of a broader regional/national initiative?  <b>Please circle number or write in X beside number and /or write in comment opposite</b>	Local ..... 1  Regional      2  National      3  Other (Write in.....4
How is the programme funded?  <b>Please circle number(s) or write in X beside number(s) or write in comment</b>	Your Service ..... 1  Statutory funding    2  Fundraising    3

<p><b>opposite</b></p>	<p>Other (Write in.....4</p>
<p>What resources are available to the programme?</p> <p><b>Please circle number(s) or write in X beside number(s) for all that apply or write in comment opposite</b></p>	<p>Staff.....1</p> <p>Volunteers 2</p> <p>Office/space .....3</p> <p>Administrative support .....4</p> <p>Funding.....5</p> <p>Other (Write in 6</p>
<p>Is there any individual(s) who provides assistance to people with disabilities as part of the programme? Please circle number or write in X beside number.</p> <p>If yes, please describe their principal characteristics and their role in the programme.</p> <p><b>Please circle numbers or write in</b></p>	<p>Yes .....1</p> <p>No 2</p> <p>Voluntary.....1</p> <p>Paid 2</p> <p>Male .....1</p> <p>Female 2</p>

<p><b>X FOR EACH CHARACTERISTIC</b></p>	<p>Relevant professional qualification ..... 1</p> <p>No professional qualification      2</p> <p>Employed by service provider ..... 1</p> <p>Not employed by service provider      2</p> <p><b>DESCRIBE ROLE OF SUPPORT</b></p>
<p>Has the programme been evaluated and/or do you plan to evaluate it this year?</p> <p><b>Please circle number or write in X beside number.</b></p>	<p>Yes, already evaluated ..... 1</p> <p>No, but plan to evaluate      2</p> <p>No evaluation planned ..... 3</p>
<p>What indicators would determine if the programme has been successful or not for you?</p> <p><b>Please write in opposite</b></p>	
<p>In your opinion, what has worked well in the</p>	

<p>programme?</p> <p><b>Please write in opposite</b></p>	
<p>In your opinion, what has not worked well?</p> <p><b>Please write in opposite</b></p>	
<p>What have been the main learnings of the programme to date?</p> <p><b>Please write in opposite</b></p>	
<p>Have you made any changes to the programme in the light of your experience to date?</p> <p><b>Please write in opposite</b></p>	
<p>Do you envisage any problems with the programme in the coming year?</p> <p><b>Please write in opposite</b></p>	

19<sup>th</sup> July 2011

Any other aspect of the programme you would like to mention?  <b>Please write in opposite</b>	
Overall views of programme now. How satisfied are you with the programme?  <b>Please write in opposite</b>	
<b>Contact Details</b> for further information on this programme (if necessary)	

**IF YOU HAVE MORE THAN 2 PROGRAMMES IN PLACE PLEASE COPY THIS QUESTIONNAIRE AND COMPLETE ACCORDINGLY FOR EACH PROGRAMME.**

**Thank you very much for your assistance. If you have any questions please contact John or Anne Marie Weafer at  
01-6014092**

**(Anne Marie Weafer, 54 River Forest View, Leixlip, Co.Kildare)**



<b>I. NDA SCREENING QUESTIONNAIRE</b>
---------------------------------------

**NAME OF ORGANISATION:** \_\_\_\_\_

**NAME OF CONTACT FOR LETTER:** \_\_\_\_\_

**TITLE:** \_\_\_\_\_

**ADDRESS:** \_\_\_\_\_

\_\_\_\_\_

**QUESTIONNAIRE CODE:** \_\_\_\_\_

**TELEPHONE NUMBER:** \_\_\_\_\_

**EMAIL:** \_\_\_\_\_

**DATE LETTER SENT:**

Q.1 LEVEL OF SERVICE

National..... 1  
Regional ..... 2  
Local..... 3  
Other..... 4  
Don't Know ..... 5

Q.2 REGION/ LOCATION

(Write in county: \_\_\_\_\_)

Dublin..... 1  
Leinster (ex Dublin) ..... 2  
Munster ..... 3  
Connaught ..... 4  
Ulster (part of) ..... 5

Q.3 DISABILITY DATABASE

Physical and Sensory ..... 1  
Intellectual..... 2  
Neurological..... x

### ASK TO SPEAK WITH CONTACT

Good morning/afternoon. My name is XXXXX from Weafer Research Associates and we are conducting research on behalf of the National Disability Authority (Refer to letter sent by the NDA or Weafer Associates). We have been commissioned to conduct research to explore the use of natural community supports in promoting independent living among adults with disabilities in Ireland.

Would you mind if I asked you a few questions.

**IF PERSON UNAVAILABLE TO ANSWER QUESTIONNAIRE AT THIS TIME,  
RECORD NAME AND GOOD TIME TO PHONE.**

**NAME:** \_\_\_\_\_ **DAY:** \_\_\_\_\_ **TIME:** \_\_\_\_\_

**FIRSTLY, I WOULD LIKE TO ASK YOU A FEW GENERAL QUESTIONS  
ABOUT YOUR ORGANISATION. ALL THE INFORMATION SHOULD  
RELATE TO THIS LOCAL ADDRESS WHERE YOU WORK (NOT THE  
NATIONAL OR REGIONAL ORGANISATION)**

**Q.4** Which disability sector does your service mainly serve? (READ OUT – Code One and mark others with an X if necessary).

Physical..... 1  
Sensory..... 2  
Intellectual..... 3  
Neurological/ Cognitive..... 4

More than one sector.....5

**Q.5** Approximately how many people with disabilities over the age of 18 years are served by your local service?

Write in Approximate Number: \_\_\_\_\_

Less than 50 ..... 1

51-75 2

76-100..... 3

More than 100..... 4

**Q.6** What kind of community is served by your local service/ Where people come from?  
(READ OUT)

Mainly urban..... 1

Mix of town and rural 2

Largely rural ..... 3

**Q.7** What would you regard as the principal barriers to independent living for people who access your service? (NO PROMPTING).

**Q.8** I am now going to read out a list of some other barriers to independent living. They are general because we are covering a range of disabilities. So can you tell me which of them are relevant to people who access your service?  
READ OUT ALL NOT MENTIONED IN Q7.

**Q.9** Now taking all of these account, which 3 barriers to independent living would you regard as most important? **RANK 1,2,3 DO NOT PROMPT**

	Q 7	Q 8	Q 9 RANK 1,2,3
Negative attitudes of public/ Community	1	1	
People with disabilities are nervous living independently	2	2	
Inadequate housing for people with disabilities	3	3	
Inadequate local facilities for people with disabilities	4	4	
Problems with money/budgeting	5	5	
People the same age are not willing to mix with them	6	6	
No or little involvement with people in the community generally	7	7	

21st July 2011

Difficulties accessing mainstream services	8	8	
Difficulties moving from a care environment	9	9	
Service providers too protective	10	10	
Families too protective	11	11	
Lack of personal supports e.g. PA	12	12	
Transport	13	13	
Employment Opportunities	14	14	
Other			
Other (write in			

**ONLY READ OUT IF RESPONDENT NEEDS CLARIFICATION ON LETTER**

**THE PRIMARY PURPOSE OF THE RESEARCH IS TO EXPLORE IF LOCAL SERVICES SUCH AS YOURS HAVE STRUCTURED INITIATIVES OR INNOVATIVE PROGRAMMES IN PLACE, WHOSE PRIMARY AIM IT IS TO ENABLE PEOPLE WITH DISABILITIES TO BECOME MORE INDEPENDENT IN THE COMMUNITY.**

A common theme underpinning many of these initiatives is that the provider organisation assists in the establishment of the programmes with a view to 'fading' support over time, thus enabling natural support to be maintained. It is important to note that on this occasion we are not including individual programmes relating to person centred planning.

<b>Q.10</b> Does your service provide any of the following initiatives or interventions for people with disabilities in your local area, either independently or in association with other individuals or groups? ( <b>READ OUT</b> ).	<b>YES</b>	<b>NO</b>
5. Programmes supporting family and friends to develop structures such as circles of support, microboards or support clusters?	1	2
6. Peer advocacy programmes supported through the provision of venues, administrative support, funding etc?	1	2
7. Befriending schemes that aim to build community inclusion and social capital between people with disabilities and local community members?	1	2
8. Innovative social-skills training programmes aimed at establishing and maintaining the development of social relationships?	1	2

**Q.11** Does your local service have any other initiative or programme in place that might be described in this way?

Yes..... 1

**(GO TO Q13)**

No 2

**IF NO TO ALL, ASK Q12 AND CLOSE. OTHERS (IF YES) GO TO QUESTION 13**

**Q.12a** Is there any reason(s) why you do **not** provide innovative natural community

Lack of finance..... 1

21st July 2011

supports? DO NOT PROMPT

Lack of staff 2

Never thought about it ..... 3

Other ..... 4

No particular reason 5

**Q.12b** Do you see a value in providing natural community supports? DO NOT PROMPT

Yes ..... 1

No 2

Don't Know ..... 3

**Q.12c** What resources would you need to provide natural community supports? DO NOT PROMPT

Money ..... 1

Staff 2

Volunteers ..... 3

Other:

**THANK AND CLOSE.**



21st July 2011

**IF YES**

We have a number of questions we would like to ask which are designed to explore the use of natural community supports in promoting independent living among adults with disabilities in Ireland. I can ask you them now or post you a questionnaire to complete over the coming week, whichever you prefer. The information provided will be totally confidential and individual organisations will not be identified.

**Q.13** NAME AND ADDRESS/ Email address if person would also like to receive a copy by email.

**Name:**

**Address:**

**Email:**

**Phone Number:**

**Good time/day to make contact:**

**Q14** How many initiatives has your service?

**IF NOT WILLING TO ANSWER QUESTIONNAIRE**

**Is there anyone else in the organisation who is qualified to answer the questionnaire?**

**Name:** \_\_\_\_\_

**THANK AND CHECK POSITION OF RESPONDENT IN ORGANISATION**