Living in your own home with a disability
- the experiences of people with disabilities of support from their community

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"I feel better about myself ...making my own decisions ...when to get up, what to eat, what to wear ...what to listen to on the radio, what doctor to attend ...that kind of thing." (54)

"I do as much as I can [for myself] ...As soon as you let someone in it's a slippery slope ...I miss out on a lot of things [because of impairment] ... but at least that's my decision [not to do them]." (6)

"Help with practical stuff is great ...It's really appreciated...when it's done well,...when the person doesn't belittle you or make you feel stupid or small." (52)

Executive summary

What the research was about

Recent NDA research shows that living in the community is a necessary condition for enjoying independent living, but that on its own it is not enough. Living independently in the community can also be an isolating experience.

There is little research on this topic, in Ireland or elsewhere, so in 2011 the NDA commissioned researchers to conduct semi-structured interviews with people with disabilities who access minimal or no support from specialist disability service providers. The research aimed to find out what makes independent living easier or harder for people with disabilities. In particular, it focused on how people with disabilities living independently in the community access "natural community supports". These are people who are not disability service providers, but who provide assistance, contact or companionship which enables people with disabilities to participate in their local communities.

Who took part, and how

The research report contains information gathered from interviews with 54 people with physical, sensory, intellectual and cognitive impairments aged between 19 and mid-60s living in six different parts of Ireland. Half were aged 19-34, and the rest were in the older age group. There were roughly equal numbers of men and women. Some lived on their own, and others with their families.

All interviewees had impairments which conformed to the definition used in the Disability Act 2005. Just over half had lifelong disabilities, with the rest acquiring their impairments at various stages in their lives. In line with the research requirements, all interviewees with cognitive impairments had acquired disabilities, and people with dementia were not included. While the researchers tried to ensure that interviewees came from a range of different backgrounds, they did not look for a representative sample.

The researchers asked a wide range of organisations for help in finding prospective interviewees. They did not look for assistance from specialist disability service providers, as the interviewees had to be people who access minimal or no support from these organisations. Community-based informal disability networks and word-of-mouth recommendation turned out to be the best recruiting methods.

The interviewees were held in neutral places, like community centres. They took a "narrative with prompts" approach, in line with the exploratory nature of the study. As far as possible the interviews were participant-led, with participants determining the range and depth of topics covered.

What the research revealed
Using natural community supports

> "Help with practical stuff is great ... It's really appreciated ... when it's done well, ... when the person doesn't belittle you or make you feel stupid or small." (52)

The interviewees came from all walks of life and described a wide breadth of life experiences. They shared some characteristics, which influenced how they used natural community supports to enhance their experience of independent living:

- Participants were self-directed and self-reliant. They valued independent living because it gave them more privacy, personal choice and control, and enabled them to exercise self-determination. They saw it as offering more opportunities to engage with other people and to develop personal and intimate relationships. They wanted to avoid residential care.
- Participants were reflective, showed high levels of perseverance and a strong commitment to problem-solving.

Interviewees said that they had the same needs as everyone else, albeit sometimes with an added specific dimension. They generally did not see their relations with others as being about any kind of particular support, still less "natural community support". They saw their main relationships as reciprocal. They saw themselves as part of the general web of everyday life; a particular part, with some specific needs, but not something separate.

Participants saw their use of natural community supports as part of the process of independent living, but not as its determinant; as a tool in the making of an independent life, but not the first or most important factor. Instead, they saw the use of natural community supports, and personal effort to maintain independence, as very closely linked. Their independence of spirit enabled them to judge how and when to access natural community supports. Without this spirit, or the necessary skills, independent living became harder.

This influenced the way in which interviewees used natural community supports:

- With family, friends and neighbours they thought hard about when to ask for help, so that they did not appear to be needy. They valued reciprocity: exchanging support and favours with other people, so that they did not feel like they were a burden to others. They wanted to do as much as possible for themselves, and sometimes preferred to pay for a service (such as house-cleaning), rather than to ask for help.
- With service providers in the community, participants particularly valued assistance in the form of unobtrusive, helpful, friendly staff delivering thoughtful customer service, such as showing patience, calling a taxi, filling a shopping bag or offering news or information.

Barriers to the use of natural community supports to enhance independent living

Some of the factors that made it hard for interviewees to use natural community supports included:

- being shy; lacking confidence; insecurity
- not having enough friends or local knowledge
- poor quality or absence of personal or intimate relationships
- not knowing who to ask
- ill-health; having low energy
- financial constraints; poor nutrition
- not having enough social outlets or enough to do
- inaccessibility of environments and services; lack of transport
- poorly trained staff in everyday services.

Facilitators of the use of natural community supports to enhance independent living

Some of the factors that made it easier for interviewees to use natural community supports included:

- family support and encouragement
- a secure home, adapted to their needs, in a place where they are recognised and known
- enough money to live on, and being able to manage it well
- positive mental attitude; living in the present; not dwelling on problems; developing good coping strategies; modest expectations
- avoiding potentially problematic situations
- finding enough social outlets
- being able to find out information
- being involved in productive activity, such as work, study or advocacy
- having hobbies and interests
- having good friends and good quality relationships in general: for some, this was particularly valued in the form of community-based informal disability networks
- companionship of pets
- using computers and other mainstream technology
- good quality accessibility and customer service in the community.

Participants did not discuss the following: most activities of disability service providers; religion, the clergy and the activities of faith-based groups; teachers, politicians etc. Few spoke about participation in sport, or about TV, radio, books or music. No-one mentioned being refused help.

Future directions

Some considerations for overcoming the barriers to participation, and for future directions, emerged from the interviews. These include:

- ring-fencing financial supports for independent living and funding for informal disability networks
- configuring a range of specific support services in ways which make them attractive to people with disabilities living independently
- promoting realistic role-models
- providing disability equality training to the staff of mainstream services.

Acknowledgements

The authors would like to thank the interviewees who so generously shared accounts of their lives with great openness, candour and dignity. Without their co-operation and informed contributions, this research study would not have been possible.

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Go raibh míle maith agaibh. Thank you.

The views expressed in this report are those of the authors and the research participants and do not necessarily reflect the views or policies of the NDA.

Preface

"Living a self-determined life" is the report of research undertaken in 2011 to explore what makes independent living easier or harder for people with disabilities who practise independent living and who access minimal or no supports from specialist disability service providers. In particular, the research focused on how people with disabilities living independently in the community access "natural community supports". These are people who are not disability service providers, but who provide assistance, contact or companionship which enable people with disabilities to participate in their local communities.

"Living a self-determined life" contains information gathered from interviews with 54 people with physical, sensory, intellectual and cognitive impairments aged between 19 and mid-60s living in six different parts of Ireland. The first chapter explains the background to the study, and the following chapter describes how the research was conducted. The next five chapters are mostly in the interviewees' own words, as they describe the barriers and facilitating factors that they encounter in their everyday lives. A summary chapter draws out the themes which emerged from the research, and the report concludes with a chapter which offers some suggestions for what should happen next, based on the research outcomes.

TABLE OF CONTENTS   Page Number

List of Tables and Charts

Living a Self-Determined Life

Appendices

1. Background

The National Disability Authority recently undertook research on the configuration of specialist disability services in certain jurisdictions, with a specific focus on outcomes (A Review of International Outcomes Measures in Disability Service Provision, www.nda.ie). This found that living in the community is a necessary, but not sufficient, condition for ensuring that people with disabilities can enjoy independent living. It also showed that some people with disabilities may feel isolated and disempowered in their local communities.

In order to understand the barriers to, and facilitators of, independent living for people with disabilities in the community, the NDA commissioned OCS Consulting to conduct a series of semi-structured interviews with people with disabilities who access minimal or no support from specialist disability service providers. The NDA asked the research team to explore how people with disabilities are mobilising natural supports in the community to achieve meaningful participation in their communities. The report takes a narrative approach, with minimal comparative material. It presents the results of the research process and is intended to complement two other NDA studies in the area (1. A Review of Literature on Natural Community Supports and 2. Exploring the Use of Natural Community Supports in Promoting Independent Living among Adults with Disabilities in Ireland: a survey of service providers, www.nda.ie)

Context

Throughout the world disability policy emphasises independent living as the optimum situation for people with disabilities, as it is widely believed to enhance their quality of life, as well as potentially incurring savings to the State. Inclusion, participation and equality are the emerging values which support the move to independent living, but practical actions are also required to ensure its success.

The NDA recently commissioned and published "A Review of Literature on Natural Community Supports" (www.nda.ie, 2011) which provides the specific context for the current study. The review interrogated available research evidence from around the world to answer the question: "What is the role of natural [community] supports in facilitating independent living on the part of people with disabilities?"

While aiming to include research relating to people with physical, sensory, intellectual and cognitive impairments, in practice the review focussed primarily on people with intellectual impairments, particularly those in contact with disability service providers, as this is the group of people with disabilities most frequently covered in the research literature. The current study was therefore conceived as a small scale qualitative exploration of the role of natural community supports in facilitating independent living for people with a wider range of impairments, living in Ireland.

Selection criteria

The NDA asked the researchers to conduct about 50 face-to-face in-depth interviews with adults with disabilities. The organisation specified disability types, age groups, the need for geographical spread and the requirement that interviewees should be "people with disabilities who either by choice or circumstance receive no or minimal support (e.g. sporadic respite) from disability service providers". In consultation with the NDA, the researchers refined and developed these criteria. The following is a list of the main criteria agreed between the NDA and the researchers:

- Disability type: The interviewees were adults (over 18 years) with physical, sensory, intellectual and cognitive disabilities[1]. Interviewees who had cognitive disabilities all had acquired their impairments as adults, in accordance with the definition of "cognitive impairment" which the NDA uses. Other interviewees had either lifelong or acquired impairments. The NDA excluded from the target group, people whose primary impairment is dementia .

- Age group: Half of the interviewees were aged 18-34 years, with the rest aged 35 and above.

- Geographical spread: The NDA asked for an equal number of interviewees from each of six regions. The interviewees were drawn from the following regions:

    o Dublin city
    o County Galway (later extended to include County Mayo)
    o County Kerry (later extended to include County Cork)
    o County Kildare
    o Counties Kilkenny and Waterford
    o County Laois.

  During the research process the researchers asked for the extensions of two of six regions, in order to make it easier to find interviewees

- Level of support from disability service providers: The researchers took "disability service providers" to be organisations funded through the Department of Health and Children's disability funding stream. "Minimal use" of disability-specific services included such usage as application for disabled parking permits, occasional consultation of a specialist assistive technology centre, occasional (as opposed to regular) use of respite services, and so on. People who use the services of personal assistants (PAs) were not eligible for interview. There was no restriction for people

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[1] 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.

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

who use mainstream services, such as public health nursing or community occupational therapy.

In consultation with the NDA, the researchers refined and developed other criteria essential for the work. The following is a list of the most important of these:

- Level of impairment: The researchers took the definition used in the Disability Act 2005 as their starting point. According to the Act a disability is a "substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment". (NB people with mental health difficulties were not part of the target group for this research project.) The researchers interviewed people who themselves considered:

  - that their impairment gives rise to a substantial restriction in their capacity to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State;

  - that this impairment is of an enduring, rather than a temporary, nature: this definition included people with episodic conditions, such as epilepsy, and people with conditions with a varying attack-and-remit pattern, such as multiple sclerosis.

- Substantial restriction: In working from the perspective of the social model of disability, the researchers took the view that, outside personal issues, such as the experience of pain, most restrictions to participation in life in the State can be eliminated through the provision of appropriate reasonable accommodations. They understood the term "substantial restriction in capacity" (see above) to include the need for the provision of reasonable accommodations. This made it possible to include, for example, people who are deaf, deafened or hard of hearing, people whose quality of independent living is compromised by the inaccessibility of information and/or the built environment, and so on.

  Many people have multiple impairments at various levels of severity which, when taken together, lead to significant levels of exclusion. People interviewed for this research had at least one impairment which met the description of "substantial restriction" as defined above.

- Independent living: The study understood interviewees to be "living independently" if they lived with their families (for example, siblings and/or parents) and either by choice or circumstance received no or minimal support from disability service providers, as defined above.

- Double disadvantage: The researchers tried to ensure a gender balance and that interviewees came from a range of ages, social classes and ethnic backgrounds (see pages 15-17). The results are not skewed by disproportionate representation of social inclusion or exclusion criteria related to other dimensions of marginalisation.

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

13

In reality, however, no normative group exists, since everyone has multiple identities, and no disabled person experiences differential treatment solely on the grounds of their impairment. For example, a Deaf middle-class man will face different challenges in social interaction and independent living than a Deaf working-class man or a Deaf middle-class woman.

The researchers strove to achieve a reasonable balance in relation to all the selection criteria listed above. However, it is important to state that the interviewees were not chosen as a representative sample (see pages 15-17).

2. Methodology

Ethical approval

With the approval of the NDA the researchers set up an ethical oversight group, comprising three professionals with extensive experience of either commissioning or conducting qualitative research with socially excluded groups (Appendix 6, pages 77-78). The ethical oversight group approved the study tools (Appendices 2-4, pages 67-73). They agreed to make themselves available to advise on any ethical issues which might arise during the research. In the event there was no need to call on this facility. The ethical oversight group also commented on this report.

Recruitment

The researchers produced a gatekeepers' guide (Appendix 5, pages 74-76) and asked a wide range of organisations for assistance in gaining introductions to potential interviewees. The terms of reference for the research stressed that interviewees were to be people with disabilities who, through choice or circumstance, received minimal or no service from disability service providers. The researchers therefore did not approach any such organisations for assistance in locating potential participants.

Recruitment was slow, which delayed the research schedule somewhat. Some community-based informal disability networks arranged for multiple interviews. In the event, the most productive recruitment strategy was word of mouth, with participants recommending to friends and contacts that they present themselves for interview.

All gatekeepers and prospective interviewees received information about the selection criteria. It was they who decided whether or not they fitted these criteria. The researchers did not conduct any objective test or ask any questions designed to measure how closely interviewees fitted the criteria.

Interviews

The vast majority of interviews were carried out in fully accessible neutral places, such as community centres. Where unavoidable (for example, in very rural places) the researchers interviewed participants in their own homes. Reasonable accommodations, such as sign language interpretation, were provided as needed. All interviewees were offered a €20 One For All gift token as a small appreciation.

The information and consent form for interviewees (Appendix 3, pages 69-71) made it clear to participants that they did not have to reveal any specific information or answer any fixed questions:

> "You do not have to participate in the research. If you decide to take part, you can withdraw at any time. You don't have to answer any question that you feel is too personal, or makes you uncomfortable.

> There are no "right" or "wrong" answers. The researchers just want to hear about your personal experiences and your ideas."

The researchers adopted a narrative approach, in line with the exploratory nature of the study, as defined with the NDA. As far as possible, the interview style was participant-led, with interviewees determining the range and depth of topics. This was not unfocussed ("tell me about your life") but rather evolved into "a narrative with prompts". The prompts were listed in the interview guide (Appendix 4, pages 72-73), developed in partnership with the NDA and the ethical oversight group.

Interviewees

As shown in Table 1 below the final analysis drew on interviews conducted with 54 adults from a wide variety of backgrounds.

The original agreement made with the NDA was to conduct a minimum of 48 interviews. This was to include a total of 12 interviews with people with sensory impairments (both hearing and vision impaired). The research team sought and obtained NDA approval to expand this number to 18 (nine of each impairment type) in order to introduce greater balance to the overall sample. This brought the total number of included interviews to 54.

Table 1: Total number of interviews

	Impairment type					
	Mobility	Cognitive	Sensory: vision	Sensory: hearing	Intellectual	Total
Targeted number of interviews	12	12	9	9	12	54
Total number of interviews completed, including "duplicates" (see page 14)	16	14	12	14	9	65
Total number of interviews included in the final analysis, as per agreed research specification	12	12	11	12	7	54

The research team did not secure the targeted quota of interviews with people with intellectual impairments, as it proved most difficult to trace potential interviewees who fitted the agreed research criteria. Seven interviews were completed from a target of 12. Potential referral sources suggested that many

people with intellectual impairments who live independently, and fit the agreed research criteria, are in the so-called "borderline to mild" range. They very often do not want to be identified as having an intellectual disability. Inclusion in such a study is *de facto* an acceptance of intellectual impairment and also of an explicit label of intellectual disability. The research team did invest, unsuccessfully, a significant amount of additional time in trying to secure further interviews in this category. At a certain point the researchers decided not to delay the report any longer and advised the NDA of this development.

By contrast, as shown in Table 1 the researchers conducted an excess of interviews in most categories. The decision to eliminate duplicates from the final analysis was based, primarily, on the achievement of gender balance in all categories. Following this process, preference was given to avoiding over-reliance on the work of any one of the three interviewers.

Table 2 shows the range of included interviews by region and age cohort. The youngest interviewee was 19 years old, and the oldest was in their mid-60s. As previously mentioned, during the study the researchers sought and gained NDA approval to expand the chosen regions, in order to facilitate more rapid identification of potential interviewees.

Table 2: Included interviews, by region and age cohort

	Region											
	Dublin City		Counties Galway and Mayo		Counties Kerry and Cork		County Kildare		Counties Kilkenny and Waterford		County Laois	
Age	18-34	35+	18-34	35+	18-34	35+	18-34	35+	18-34	35+	18-34	35+
Mobility	1	1	1	1	1	1	1	1	1	1	1	1
Cognitive	1	1	1	1	1	1	1	1	1	1	1	1
Sensory – Vision	1	1	1	1	1	1	1	1	1	0	1	1
Sensory – Hearing	1	1	1	1	1	1	1	1	1	1	1	1
Intellectual	1	1	1	0	1	1	0	1	0	0	0	1
Total	5	5	5	4	5	5	4	5	4	3	4	5

The interviews included in the data analysis corresponded to a broad gender balance (male 46%, female 54%).

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

Table 3: Included interviews, by impairment type and gender

	Impairment type					
	Mobility	Cognitive	Sensory: vision	Sensory: hearing	Intellectual	Total
Male	6	5	5	5	4	25
Female	6	7	6	7	3	29

As Table 4 shows, around 57% of interviewees included in the data analysis had lifelong disabilities, with the rest acquiring their impairments at various stages in the life cycle.

Table 4: Included interviews, by impairment type and onset of impairment

	Impairment type					
	Mobility	Cognitive	Sensory: vision	Sensory: hearing	Intellectual	Total
Lifelong impairment	9	0	7	8	7	31
Acquired impairment	3	12	4	4	0	23

Data analysis and report

The interview guide (Appendix 4, pages 72-73) and subsequent interview facilitation, were designed to ensure the generation of a series of themes. With the interviewees' consent (Appendix 3, pages 69-71) all interviews were recorded, and then transcribed in full.

On completion of the interviews the research team examined the data thoroughly and systematically, grouping all commentary that had relevance to the research question into an extensive series of themes for further analysis. The researchers then compared, contrasted and examined the text for content and meaning by reading, re-reading, interpreting and comparing similar texts. This involved assessing both dominant patterns of behaviour and divergences from those patterns. This process helped to ensure that the patterns reported actually existed throughout the data, rather than only in favourable examples. Quotations used in this report represent typical or common responses, balanced by variations or divergences where appropriate. The report indicates

patterns when they are discernible; frequently, they were not, as ideas often transcended categories, or reflected individual concerns.

The structure of the report of this study reflects categories of analysis and recurring themes in respect of the participants' experience, attitudes and needs. The reporting of the data does not include numbers and percentages, as this could convey the impression that the results could be projected to a population. This, as agreed with the NDA, is not in the capabilities of the qualitative research procedure that underpinned this study. In addition, given the small sample size, the spread of attitudes and responses, and the individual and specific nature of participants' circumstances, disaggregation has been applied in a limited way in order to protect confidentiality. Key messages and learning from the study have been collated into main findings and conclusions.

20

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

3. Why live independently?

As reported by participants, the primary motivation for choosing independent living is to maximise autonomy and keep the use of all human support, including natural community supports, to an absolute minimum. The involvement of others in their everyday lives was seen as threatening to their autonomy, unless they themselves were able to exercise significant levels of control over the situation.

Understanding why people with disabilities choose independent living offers an important indicator of how they will configure and use natural community supports. The factors in this choice detailed below are only those which relate directly to the use of natural community supports; others, including the opportunity to develop intimate relationships, the chance to access a broader range of activities and people, and many more, also play a part.

Choice and control

Having choice and control was the most important aspect of independent living for interviewees of both genders, all ages and with all disability types, wherever in Ireland they lived. Those who lived alone were most likely to emphasise this point, valuing the opportunity to choose where to live, how (see chapter 5, pages 28-43) and with whom. Accepting support was identified with losing or handing over control. Typical responses included:

> "I wanted to live on my own because I wanted to be in charge ...My parents were great ...They made huge sacrifices for me ...but I didn't want them to be butting into everything [making my decisions for me]... or for me to feel that I should do things certain ways because that's how I think my parents would like things to be done." (23)

> "I have been told I could have a carer if I want one but I want to feel at home in my own house for as long as possible. I want to be in charge [of decision making]." (60)

> "I wanted to live on my own..I didn't want to have a carer ...I didn't want to live in a home [residential setting] ... I don't want to feel indebted to people or having people doing things for me all the time ...I am stubborn but that [stubborness] has served me well." (22)

> "There are certain things I want to be able to do on my own for myself ... It's very personal ... I am sure different people [with disabilities] have different expectations ... but, for me, I want to be able to get up in the morning, use the bathroom, wash myself, get dressed, make myself a cup of tea, have breakfast ... I like things a certain way and I don't want somebody else telling me how I should do things ...I can come and go

as I please ...Living alone and not being answerable to someone or having someone telling you what to do is really important [to me]." (6)

Greater sense of personal identity

Several interviewees suggested that living independently had helped them to develop their own sense of personal identity. Their identity was viewed as vulnerable to outside influence:

"They [parents] encouraged me to be independent throughout my life... doing as much stuff as I could when growing up, so it was only natural that I would look to develop a life and an identity of my own ... To do that I had to move out [of the family home]." (9)

"I had always wanted to be independent ... to have my own place ... to look after myself ... to come and go as I please and not have to check in with my parents about every little thing ...like where I am going, when I will be back home, that kind of thing." (7)

"I don't want any assistance on how to plan things out." (65)

"I feel better about myself ... . making my own decisions ... when to get up, what to eat, what to wear ... what to listen to on the radio, what doctor to attend ... that kind of thing." (54)

"I am a person with a disability ... but first of all I'm a person [with my own identity] ... I should be able to decide on how I lead my life." (43)

"It's OK for a child to be told what to do ... the 'you're living in my house' rule, but when you are grown up and living in your own place you need to be able to make your own decisions." (53)

One interviewee suggested that her motivation to live independently had been prompted by a desire to prove her ability to live successfully on her own:
"I want to do it [live independently in the community] because I want to show [the health authorities] that I can do it ... I don't want them deciding where I should live." (62)

Interviewees valued independent living as a way to introduce a greater degree of control in respect of how they both structure and involve others in their day-to-day lives:

"I like making my own decisions ... doing things at times that suit me... staying in when I want to stay in and being on my own when I want to be on my own... I don't want to be forced into doing something that I don't want to do when it doesn't suit me or when I mightn't be in the mood." (43)

"I think I live quite an independent life but there are times that I would look to others for help... My sister is great for getting me involved in social stuff... it brings me out of my shell when I might have spent a lot of time on my own." (39)

This balancing of independence and seeking help on their own terms characterised most of the participants in the study. In this context the use of natural community supports is configured as a device for furthering and maintaining independence.

Desire to avoid a move to institutional care

Alongside the desire to avoid institutional living, safety and security (see page 24) were also motivations for choosing independent living:

"You heard so much about the schools and the homes. You'd always feel safer living on your own [not at risk]." (50)

"I never wanted to go to an institution like...You heard such bad things." (57)

In this context, participants saw the use of natural community supports as less threatening than the risks posed by institutional living.

Influential role of parents

Parents were also thought to play an important role in promoting independent living by fostering independent living skills and by encouraging and supporting the move:

"My parents always encouraged me to give things a go. Mum and Dad would always say 'you can do anything'...My parents pushed me ...not in an aggressive way ...to get involved in things... sports....clubs, my studies ...I was one of the first [names impairment] students to go on to third level. I have my parents to thank for giving me the confidence and determination to do that." (7)

Some were actively encouraged to move out of the family home:

"I have a life to lead as well ... My parents didn't want me hanging around at home and us all growing old together." (49)

Some interviewees had made a very conscious effort to create distance between themselves and their immediate families in order to develop a stronger sense of independence:

"We were driving each other mad at home ...Living with family is difficult... especially when they want to be involved in so many things...trying to make your decisions for you. We were going to drive each other crazy if we stayed living together." (47)

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting,
2012

Personal space and privacy

Interviewees, many (but not all) deaf, also spoke of the satisfaction that they take from having their own personal space and the opportunity that this provides for privacy (see also page 45):

> "I'd lived with my parents and all my brothers and sisters all my life... I wanted my own space ... I need time on my own ...just to calm down from all the stress and the ringing in my head [brought about through Deafness]." (13)

> "Even though I am lonely I do still value the privacy I have ...If I've had a bad day I can close the door behind me and just do as I please ... I need to have quiet time alone ... just to unwind and clear my head." (29)

> "It's strange sometimes ... No [it's strange] a lot of the time ...I am lonely ... but I do like having my own space." (4)

A few felt calmer living alone:

> "I don't get on well with people ... I'm no good with them ... especially since I gave up the drink." (57)

The desire for privacy and calm follows through into the way respondents access and use natural community supports.

Influence of direct payments

Direct payment of social welfare and other income supports enabled many interviewees to pursue independent living:

> "When I was living at home I always handed over my social welfare every week to my Mum ... I never felt like I had anything for myself... I can decide what to spend my money on ...It's different to living at home." (52)

> "It's my money [social welfare] ...I can decide what to do with it and how to live my life ...where to live." (6)

> "It's [social welfare] in my name ...I get rent allowance as well so that means I am more independent ...At least they [State] don't tell you where to live ...You get an allowance and you can choose [the living arrangement] what suits you best." (27)

25

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

Summary

Interviewees valued independent living because it offered them greater choice and control in their lives. It also contributed to a greater sense of personal identity and gave them precious personal space and privacy. Parental support for independent living was critical for some, while others, particularly those with intellectual impairments, were keen to avoid a move to institutional care. Interviewees also saw independent living as offering greater opportunities for engaging with non-disabled people and for developing personal and intimate relationships. Social welfare and income supports play a key role in facilitating independent living.

Taken together, these factors also influence the way in which respondents use natural community supports. For most participants, the maintenance of choice and control (both financial and personal), personal space and privacy are paramount issues. For them, the use of natural community supports is conditional on the extent to which these crucial values are upheld or enhanced.

4. Where to live

Respondents' choice of location for independent living aims to maximise the sense and practice of independence and to minimise the need for the use of natural community supports.

Safety and security

Interviewees saw security as a critical factor in succeeding in living independently. It was important to be confident:

> "If I was nervous about it I don't think it would have worked ... I would have wanted to go home." (49)

> "I live with my mum and dad ...[The family home] is where I feel safe for the moment." (8)

Whether living in an urban or a rural setting, feeling safe and secure in their home was very important to interviewees of both genders, all ages and with all disability types, especially those who lived alone. Typical responses included:

> "You want to feel safe when you close the door behind you... especially when you are on your own." (33)

> "This new place is so much safer ... .I never felt happy [safe or secure] in the other place." (14)

> "I spend so much time [at home] ... I don't want to be feeling nervous all the time." (60)

One interviewee described moving back to the family home because of feeling insecure in her accommodation:

> "I lived in one place and I just didn't like it ... There was always something going on in the block [of apartments] ... That's why I moved home again ...It was another year or so before I went again [to live independently]" (12)

Technology can assist in creating a sense of security and thus allow people to minimise their reliance on or vulnerability to other people:

> "I have an intercom with a picture so I see who it is [at the door] ...so I don't have to let in anyone I don't know or aren't sure about." (47)

"I have the panic button around my neck and that's a comfort ... but I haven't had to use it yet... I don't know what I will feel like if I do have to ...I hope I wouldn't be put off from using it if I really needed to." (35)

Alongside their other reasons for choosing independent living (chapter 3, pages 19-23), several intellectually impaired interviewees saw it as a safer option than institutional care, with its enforced intimacy with others:

"You heard so much about the schools and the homes ... You'd always feel safer living on your own ... I like it here in the town ... .with my dog ... I didn't want to be sent to a home or anything like that." (50)

"I never wanted to go to an institution ... You heard such bad things." (57)

Familiarity

Familiarity was a factor which influenced the use of natural community supports for most interviewees, irrespective of gender, age or impairment type. Many said that being known in the locality made independent living easier, by offering a range of trusted natural community supports, to be accessed when and as required by the person with a disability. Typical comments from people who live in small towns are:

"I know lots of people round the place... That's what's good about a small town... Everyone knows me...I've been here long enough [laughs], never lived anywhere else...so if I need a lift or anything up the town one of my neighbours will give me a run up." (23)

"I have lived here all my life ...Everyone knows me around town ...I stop in for a chat in the community centre and the post office." (10)

Local knowledge also enhanced independence in a city, thus (in this case) lessening the need for assistance:

"If I am organised then I can work out how to get there on my own, what route to take, what to wear, what to bring with me ....That makes me feel in more control." (51)

Familiarity linked closely to the sense of choice and control that characterised interviewees' preference for independent living. One interviewee linked these concepts explicitly, inferring that in a familiar environment the need for support is greatly reduced:

"Living on a farm is very different ... I can control this environment...I am master of my own destiny ...I know the place so well ...I can do anything. Once I leave the environment of the farm I am like a fish out of water." (3)

Quality of accommodation

Especially for people with mobility impairments, appropriate accommodation, and its suitabililty for them, was important for maintaining independence and thus lessening the need to use natural community supports. For example:

> "Moving from the bedsit to this accessible apartment scheme has changed my life ...I had no room in the bedsit for all my stuff or even for me to move around ...Everything is the right height and in the right place ...It means you are happy to be on your own. It also means that you are less worried about the future ...the apartment layout will let me stay here as long as possible." (6)

Adaptations allowed another interviewee to maintain her independence when she became disabled:

> "I had to get the house re-done ...countertops, turning space, doors, electric blinds, the shower, security ...At least then I could do a lot of stuff on my own...I could be in the house on my own without worrying ...I don't have to have eveything done for me." (59)

Maintaining independence in this way means that the use of natural community supports can be reserved for more unusual or important events (see also page 31). One interviewee saw it also in terms of investment:

> "People want to feel confident about where they live ...Why don't the Government support people [with disabilities] to buy their own places? ...That way people will be in it for the long haul... They will feel an investment in their own home... and they will be more likely to invest and get involved in their local communities." (4)

Choosing a living arrangement

The majority of interviewees lived at home, with a partner or on their own. Few lived with friends or peers. Typical reasons for living alone include:

> "I wanted to live on my own...I didn't want to have [co-tenants] feeling obliged to help all the time." (49)

> "I didn't want other people to think I was sponging off [co-tenants] that I was living with ...I wanted to see if I could make it on my own." (29)

Views such as these also reveal participants' expectations of people, such as friends and co-tenants, who might be considered as "natural community supports". Many respondents wanted to avoid any suggestion that they needed the regular support of others in their daily lives, wanting friendship and other relationships to be free of such pressures (see also pages 32 and 33). They were prepared to put up with inconvenience (see pages 19 and 20)

and loneliness (see page 22) in order to minimise their use of natural community supports.

While some interviewees chose to live away from home as a way of putting some distance between themselves and their families (see also pages 21 and 22), one cited the closeness of the family as the reason for not moving away from home:

> "We are very close as a family ... We all still live in the [family] house together ... I haven't ever wanted to move out. I'd miss it too much." (8)

Many also spoke about the satisfaction of having their own space (see, for example page 22; other examples occur throughout the report).

Summary

For interviewees, a sense of safety and security at home was essential for successful independent living. Appropriate housing maintained independence, lessening the need to use natural community supports. Being known locally enhanced independent living, offering greater control over the use of natural community supports. Interviewees differed in their approach to privacy, but it was notable that even when living alone was a lonely experience, some people preferred it to living with others, due to the greater feeling of control offered by choosing this way of life.

5. How to live

In this section interviewees describe the use of natural community supports in important parts of their daily lives:

- Everyday tasks, such as shopping, cooking and cleaning

- Asking for help

- Managing money

- Finding out information

- Connecting with other people (including family, friends, disability networks, professionals and service providers unrelated to disability issues)

- Work and other productive activity.

How to deal with everyday practicalities

Shopping

Shopping was an everyday activity for which many interviewees called on natural community supports:

> "My Mam taught me to ask for help if I need it ...not to be embarassed ...so I do. If I need bread or milk and I can't get out ...or if I need something in the chemist's I'll ask one of the neighbours ...ah, they don't mind."(27)

> "I don't like going to the shops on my own but my Mam calls in on her way to the shops and we go down together." (50)

Trust and intimacy were live issues for many respondents when deciding whether or not to use natural community supports to assist with shopping. Many preferred not to call on natural community supports for assistance when shopping for "something kind of private ... like my Lotto numbers, my cigarettes or my sanitary towels" (12). Others asked for help only in the purchase of more expensive items:

> "I like to go with someone to the shops if I'm buying something big... like a new coat or a new pair of shoes ...just in case.'' (57)

One interviewee felt pressured when non-disabled people accompanied her, and preferred peer support:

> "I don't want to be forced into buying things at the shop that I don't want, or to feel embarrased for buying things that I do want ...That's why I like to go shopping on my own or online ...Or else I sometimes go

with [a friend with a disability] ...I wouldn't feel embarassed in front of her.'' (23)

Many interviewees preferred to shop in familiar places, where they were known, and where they knew the layout, thus increasing independence and control and lessening the need to use natural community supports. One interviewee described the situations in which he was happy to shop alone, and when he preferred to have company:

> "My short term memory is very poor ...I can write a list ... and that works for most things, but I do like to have my wife with me when we are doing the groceries ...or especially if we have to pick up one of the kids ...I don't want to be late or forget." (35)

Preparing food

Many interviewees experienced difficulty in ensuring good nutrition. Men were more likely than women, and interviewees with impaired vision were more likely than others, to seek assistance from natural community supports in the preparation of meals:

> "I can do the basics ... tea and toast, heat some soup ...that kind of thing... I've got the voice-assisted stuff to help me with these ...but for everything else my wife does it ... I don't want to burn the house down [laughs]." (10)

> ''My sister comes in every second day and leaves out plates [of food] for me to heat in the microwave ...That's a big help." (25)

> "I don't like ... just cooking for one ...I would get a few hot plates dropped in by my brother's wife during the week.'' (36)

One interviewee enlisted the assistance of a friend with specialist knowledge:

> "I'm trying to put on weight, so I have a friend who is into nutrition and she comes over and makes me shakes, and every now and then would make a casserole which would do for a couple of days.'' (6)

When natural community supports were unavailable or inadequate, some chose convenience options:

> ''I get Meals on Wheels two afternoons a week and then the rest of the time I would just eat cereal and sandwiches." (9)

> "I go around to my sister's house for the day on a Sunday, so that's lunch and dinner [catered for]. She would send me home with sandwiches in tinfoil and some cold meat, and that would be Monday and Tuesday [catered for] ...I get a meal dropped in on a Wednesday and Friday, and I would buy sandwiches the other days. It's just easier." (15)

"Apart from going to my girlfriend's house on a Sunday for dinner I would usually eat chips and bread ... during the week." (34)

Housework

While interviewees with mobility impairments were more likely than others to discuss their need for assistance with housework, others also looked for help in this area. Many asked family members to assist:

> "The apartment is small ... It's easy to keep clean but it's still difficult for me to [clean] the bathroom, so I would usually ask my daughter to give that a run over when she visits." (36)

> "I flooded the flat with the washing machine a couple of times ... so my sister puts on a load when she calls over." (63)

Interviewees who were aware of the gap between their standards and their ability to meet them were likely to seek help from natural community supports:

> "I keep the house clean ...I hate when it's messy ... but I do need a bit of help with that... somebody comes in... to do the floors and the bathroom." (23)

> "The place does get messy ... I'm no good at [housekeeping] ... so my girlfriend comes in every now and again to give it a clean." (34)

Even with trusted natural community supports, such as family members, reciprocity led to a greater sense of control:

> "Cleaning the house is just a little too much for me, so my sister would give it a once-over every week, and then I would bring her out for a sandwich and a cup of tea." (31)

Others preferred to pay a professional rather than face the stress of using natural community supports:

> "The hardest thing [about living independently] is keeping the place clean ...I copped on pretty early that I needed help there ...My mum used do it but I didn't want that ...she was too old and I didn't want my mum round every few days, so now I have a cleaner." (27)

A few interviewees saw doing as much of their housework themselves as a way of maintaining their independence and proving that they could get by without accessing natural community supports:

> "I got the washing machine set up on a height so I could pull up in front of it and so I don't have to be bending down ...I wouldn't want to have people doing my laundry." (51)

> "I do as much as I can ... As soon as you let someone in it's a slippery slope ... I do get someone in once a week to give the place a hoover and clean the bathroom." (6)

For others, maintaining privacy and avoiding embarrassment were more important than getting the help of natural community supports:

> "I don't want anyone else doing my smalls." (4)

> "When I was drinking I would sometimes dirty the sheets ...so I'd be embarrassed ... I used clean them in the bath." (34)

How to ask for help

Asking for help from natural community supports isn't easy: "you want to prove you are as good as anybody else", as one interviewee put it (18). How others, including those termed "natural community supports" might see the disabled person was a factor in deciding whether or not to seek assistance:

> "You think [other people] will get bored of you or start to think of you as the person who is always going to be asking for help.'' (42)

For one interviewee, doing as much as possible for himself made it alright to ask others:

> "If I can do as much as I can on my own then I don't feel bad calling my friends or neighbours if it's an emergency.'' (51)

Most interviewees planned ahead about when to ask for help, often "saving" requests for events that really mattered.They were keen not to "waste" the request on something that was unimportant:

> "You know that you are going to have to ask for help every now and again ... If you were sick, if you needed to go to the doctor or if something happened around the house ... Like you fell, then you would have to call someone ... But you can't be doing that all the time...So there probably are lots of times that you could do with some help or even just some company but you just wouldn't ask." (59)

The act of asking for help from natural community supports is itself stressful and difficult:

> "I hate asking for help ... You feel weak ... I recognise it's something I'll have to get over but it's difficult ... especially as I was so independent all my life ... I did everything for myself ...I am getting better at it ....I can see [other people] just want to be asked.'' (27)

> "[Sometimes] you just wouldn't be able to summon up the energy to ask somebody." (4)

36

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

Asking for help from natural community supports is more difficult if you are not in the right mood:

> "Asking for help is ... sometimes difficult ... sometimes when I am angry I cannot ask for help.''(65)

> "I am very outgoing, I think ....but you don't want to feel like you are a burden ...If you aren't feeling good about yourself on a given day you just get a bit withdrawn [and don't ask for help].'' (60)

Imagining how natural community supports might view the person seeking assistance is a significant part of this reluctance:

> "I don't want them to think, 'Oh no, here comes [name] ... what will he want this time?'" (6)

> "I didn't ask anybody for help. It was stupid pride. I am non-national ... and I thought if I ask anyone then I would be highlighting [my disability] ...That's why I didn't want to ask... but then I realised if I don't ask I won't get anything ...I had to change ...I have to approach people for help but my pride won't always allow me to do that." (17)

One common way of dealing with this is reciprocity:

> "I always like to do as much for [neighbours] as I can ... like taking in packages for them, minding their post and their cats when they are away ...then I won't feel too awkward asking them for help when I need it ...I do like to have a favour or two in hand... then I won't feel that I can't call on [neighbours] when I need help.'' (6)

Using general community services

Interviewees viewed some general community services as acceptable sources of support which respected and enhanced their independence, lessening the need for other forms of natural community support. In this context they stressed the importance of having good access to information:

> "Some people are great at digging out information ... they know everything ...Others, though, need a bit of help ...Information is power ...It's so important ... and it has to be accessible ...You know, different formats, easy to read ... that kind of thing." (10)

Interviewees praised the public library service as a friendly source of information, and saw them as an acceptable form of often proactive natural community support:

> "The library is great ... You hear about everything that's going on down there ... The staff are lovely and would come over to you and tell you 'did you hear about this ...did you hear about that' [events in the local community]." (51)
>
> "[The staff] are lovely down at the library ... They are so patient and down to earth ... My memory has been affected and so I am sure I pester them about the same things every week. But I never feel embarassed ...They would spend any amount of time trying to help you." (5)

Many interviewees mentioned the importance of knowing about entitlements. They used a range of services in the community:

> "The [Citizens] Information Centres are very good ... .the staff there are very nice ...If you aren't sure about something, or think that you are missing out on something, they will go through it all with you.'' (51)

> ''You deserve to get everything [that you are entitled to] ...The girl at the credit union said I should be getting an extra allowance...I wouldn't have known [without her prompt].'' (50)

Interviewees used a wide range of other community-based services, both state-funded and not-for-profit, every day. As well as providing services, these were sources of support, especially for people with intellectual impairments, but also for others:

> "I don't mind going to get the social at the post office ...I like it actually ...The staff know me well ...They are very friendly ...They look out for me ...When I was sick and couldn't get there [to collect payment] they told my mother and she came over to check on me.'' (57)

> "There are a few places that I would call into every week…mostly for a chat…the community centre, the post office ...They all know me.'' (50)

Interviewees appreciated the support offered at community centres:

> "It's nice to drop in to the [community] centre ... catch up with people... see what's going on ... have a look at the papers... and then if you have any problems you can see somebody and get advice ...You are made to feel very welcome.'' (35)

The staff of shops and pubs also functioned as natural community supports:

> ''I put a bag on the back of the wheelchair and the girls pack it for me... They are great." (18)

> "I was going to [name of pub] for the best part of 20 years ...After [my injury] I was afraid to leave the house...The staff in the bar sent me a card in hospital and then they visited me when I got home...After a few

months they persuaded me to come down to the pub...I go down every Wednesday or Thursday now for an hour or so...It's quieter then...One of the young lads [from the bar] would call up for me at about 8 and then the owner would drop me home by 10." (35)

"I always go to [name of supermarket] ... They all know me on the checkouts ... and make sure I am looked after and get my bags packed and get the right change." (34)

"When I go in with my book to the credit union [name of staff member] would always come out to see am I OK…The security [staff in the shopping centre] would always call me a taxi when I've finished my shopping ... They make sure I get home safe."(50)

"The credit union... seems to be... clued in ... They know how to act, which puts you at ease." (23)

"I always buy the same few things...the manager would even come around [the store] with me." (33)

Lack of support, combined with lack of confidence, prevented one interviewee from using a local community centre:

"I wouldn't know anyone [at the community centre)... It does sound nice but I wouldn't go in there on my own now." (62)

Others had stopped using community services unrelated to disability issues when their friends were no longer there to support their participation:

"I used to be involved in the snooker club but that closed down and then it was hard to get into other [community activities] because my group of friends all moved away for work." (14)

''I used to go [to the community centre) but then a couple of my friends who used to go stopped going so then I stopped." (62)

Computers and technology

Interviewees of all ages and most disability types used computers and other technology to access information. Using IT "takes the effort out of doing some things" (4), makes it easier to live independently and, crucially, lessens the need to rely on natural community supports. Even those who were less familiar with computers could see the benefits:

"I'm a bit scared of [computers] really...but I see how much [friends attending a computer club for people with disabilities] get out of them.'' (12)

Interviewees used computers in many aspects of their lives:

> "I spend a lot of time on the computer ...If I'm looking for information on anything really ...like an address, directions, job ads, my course notes, talking to people...I do so much of it on the computer." (5)

Mainstream technology made life much easier for those interviewees who used it:

> "I do all my banking over the internet ...I can't remember the last time I was at the bank." (18)

> "The mobile phone is the best thing that has happened Deaf people. Hearing people don't realise that. Texting became popular 10 or 12 years ago. It opened so many doors ...to communicate ...Even the mobile phone companies don't realise how much it helps deaf people ... .the confidence it gives deaf people. Email as well. Without your mobile phone or internet you would be locked up at home." (16)

Using IT enhanced interviewees' sense of freedom, privacy and control, lessening the need for the use of natural community supports:

> "I do all the bank stuff online. I order my shopping online. Once I got it set up it was brilliant. It's important to be able to do these things for yourself ...You don't want to be asking people all the time ...feeling obliged and having people know how much you have in your bank account or what you want to buy in the shop." (6)

> "Simple things, like having the Dictaphone and a notebook with me to write important things down, are important ...My short term memory can be very poor ...I can forget things so easily ....I might meet you in another hour or two and you would have to remind me who you were... that we had spoken ...I like having the mobile phone with me as well with the preset speed dials ...that means if I get panicky or don't know where I am meant to be that I can call my wife or my daughter... I wouldn't go out on my own without those few things.'' (35)

Computers and other technology also helped people to stay in touch with what's going on:

> "I am on the computer every day ... That's where I get to hear about everything that's going on [in the local community]. Between that and the telephone I kind of keep up to speed.'' (10)

> "I would be a big fan of IT ...It really helps you to stay in touch ...I'd say it would be very important for someone who's blind ...There is some very easy-to-instal software that could make life so much easier for you." (49)

"I use email ... to communicate with people ... to solve the problem. If it's an interview situation I would use an interpreter." (16)

Ironically, though, some interviewees reported that technologies which make life easier and lessen dependency on others also increased their sense of isolation:

> "I do all my banking online which is good in a way but
> it cuts down on the opportunity for me to meet people, to talk to people
> ...which is a shame." (23)

Assistive technology

Interviewees valued assistive technology as a tool for successful independent living which, like IT, lessened the need to depend on natural community supports:

> "The power chair has made a big difference ...I still have to be realistic about what I can do each day but the power chair makes [living independently] a lot easier ...I'm not physically exhausted." (6)

> "Getting set up with all the various technologies was really important ... the kettle, the doorbell, the telephone, all the voice recognition software, text to speech ...that stuff really makes a difference...Otherwise someone would have to be with you most of the time ...You wouldn't feel as confident being on your own…Having the house set up in the right way means that I can do stuff most people take for granted ...making a cup of tea ...a bowl of soup, that kind of thing ...even the little bits of cleaning around the house." (10)

Computer adaptations enhanced one interviewee's confidence:

> "The text to speech is great. I get to read all the papers every morning ...It allows me to keep in touch…That was something I really worried about when I lost my sight ... that I would become totally detached from everything ... Stuff like [text to speech] gives you confidence." (10)

Connecting with other people

Most interviewees placed a high value on contact and companionship with other people. Alongside family members (in most but not all cases), friends were seen as the most important and acceptable form of natural community support. Emotional support was prized above practical assistance:

> "Life's tough enough [living with a disability]... It's important you have friends and people that you can to talk to ....It's very easy to go into a shell [otherwise]." (8)

> "I'm not rich but I have a few very good friends ...Money seems to be all important [in today's society] but you have to have friends." (56)

Interviewees who enjoyed good contact with other people felt that this compensated for certain lacks in their lives:

> ''There's things I'd love to have you know... a job ...more money ...but I think of myself as lucky ...because I have good friends." (9)

Others, who had less contact and companionship in their lives, felt their absence:

> Unfortunately everything is based on the fact that I am on my own and [companionship] is a big part of what I miss."(19)

Those who were in long-term relationships valued them enormously:

> "Marrying me was a brave thing to do... It was a one-way ticket [due to deteriorating impairment]... but we pioneered and persevered ...It was important that [name] was the right wife ...who could come on board and accept everything overnight ...It says it all." (3)

> "My wife is a saint ...she was so patient with me ...I know I was horrible to live with [when I became disabled] ...so cranky, bad mooded all the time ...I had a huge chip on my shoulder for a wee while ....thank God she didn't leave me." (10)

The avoidance of the use of natural community supports can also have negative aspects. Interviewees cited contact and companionship with others as making the difference between existing and having a good life:

> ''I have been on my own a lot [isolated] in the past ...It's not a good place to be ...You have to force yourself out of it ...get moving ...It's important to keep in touch with people...Otherwise things get in on you pretty quick.'' (36)

> "It's not healthy to be on your own all the time ...Even if you don't need help with anything specific, like... You still have to have a bit of chat.....know what's going on in the world and your own home town... Otherwise you're just serving time." (53)

Several interviewees explained how friendship made it easier to access natural community support when needed:

> "If I didn't have [the computer club] and the [disability] network and my old workmates it would be just me, the wife and the boy [long pause]...It's important you have friends who you can rely on ...who you don't mind asking for help ...a lift or something simple like that.'' (10)

> "I've had good friends all through my life ...but it's not just about them helping me ...I'm there for them when something goes wrong ... I've listened to them when they've lost a boyfriend ...or they've had a bad day.'' (7)

Interviewees were adamant that everyone disabled or not, uses "natural community supports" as a normal part of life:

> "Everyone needs help from time to time ...We all need to help each other [and it's no different for people with disabilities].'' (51)

An interviewee summed up participants' general attitude to contact with others:

> "Life...whatever way you are living it ...no matter who you are ...is about people....the people you mix with every day...the people you think of as your friends.'' (52)

Having a social life

While some interviewees said that they spent too much time alone (see pages 44-45), experienced barriers to socialising (pages 46-48), or found socialising too tiring or challenging (pages 48-49), others, people with sensory impairments in particular, described a rich and varied range of social activities, including chess, dancing, hill-walking, fishing and watching sports matches with "the lads". Some expressly linked social activities with friendship and support:

> "I really like the computer club ... The craic is mighty...We take no prisoners and slag each other off...You wouldn't want to be too sensitive ...although no-one crosses the line [offends others]." (10)

> "I love chess ...It's a real mental challenge ...It's a great game for me ... I just get totally absorbed in it ...and I have found it's a great way for making new friends...The first thing I did when I moved [to a new location] was to join a new chess club ...That put me in touch with people.'' (5)

Relating to the family of origin

Many interviewees valued their connections to their families:

> "I came from a strongly bonded family ... We don't live in each other's pockets ...but we are supportive of each other. I would love to see everyone have that level of family back-up...It seems to be becoming increasingly rare." (3)

"My parents were very good to me ...I lived with them until they both passed on. I miss them. We were so close ...They were so important to me.'' (14)

Many interviewees of all ages and disability types credited their parents with instilling them with an independent spirit (see page 21):

"I was treated just the same as my sisters really ... .I didn't feel any different [from them] and, just like when my sisters moved out [of the family home], my parents were very supportive when I moved out." (7)

"I had to do the washing and the cooking just like my two sisters... I knew how to look after myself." (27)

Remaining in close contact with family members was a key support for some interviewees:

"I wanted to move out and try it [living] on my own but I wanted to stay close [nearby and in regular contact] at the same time." (9)

''I call in home ... every few days ...I like staying in touch.'' (63)

"I'm on the phone [to family] every day ... sometimes a couple of times a day ...I didn't want to lose touch.'' (46)

"We are always in and out of each other's places ...Me more so than them ...They're probably sick of me ...I'm there all the time [laughs].'' (20)

Family closeness was not universal, however:

"I have... one brother, two sisters...They are all hearing ...I am always left out. It's not their fault. Maybe they think I am fine about it, [but] sometimes I feel left out. They don't visit me." (16)

For some, family support is protective and influential. For example, one person said, "If [mother] didn't think something was a good idea I probably wouldn't do it" (14). For others it was burdensome:

"I had always wanted to be independent ...to have my own place ...to look after myself…to come and go as I please and not have to check in with my parents about every little thing... like where I am going, when I will be back home, that kind of thing." (7)

Even where family relationships provided valued natural community supports, reciprocity was important to interviewees:

"We do a lot for each other ... my Mam and I... We go shopping together ...I would help with the washing up and the little bit of cooking ...making bread and that type of thing. We walk the dog together." (56)

Protecting children

Interviewees who were parents themselves were anxious not to use them as natural community supports:

> "It's really important that they don't have to grow up too fast ... that they don't feel obliged to be around all the time looking after you ... They are kids after all... they should be out having fun... not feeling responsible for their parents." (36)

> "I am anxious that they wouldn't fall into a caring role for their own father ...That just wouldn't be right ....That's why you have to think ahead all the time... Getting the house re-modelled means I can do mostly everything on my own." (10)

One interviewee realised from talking to her non-disabled friends that difficulties with her child were not disability-related:

> "I was afraid that she was embarrassed about me ...That did really worry me ...but as some of my other friends told me ... all teenagers are embarrassed about their mothers and fathers." (36).

Relating to other people with disabilities

For some interviewees, peer support from other people with disabilities was **the** "natural community support":

> "It's much easier asking my friends [with disabilities] for help ...They know what it's like ...they understand." (52)

> "Only a person with a disability really understands what life is like for you. That's why I am most comfortable being in the company of other people with disabilities…You don't feel you have to explain yourself all the time ...They just understand you ...I think you would share experiences [and]…feelings more readily with another person who has a disability." (36)

> "I don't have to put on a show or be explaining myself or feel that I have to make a special effort...or even feel that I have to make other people feel good about my disability ...I can be myself." (10)

A smaller group of interviewees made a conscious effort to keep their distance from other people with disabilities. For example:

> "I like to get involved in mainstream things ...I think being independent means being able to get on with ... all different kinds of people ...That's

why I have kind of shied away from getting involved solely in a lot of disability groups and clubs." (7)

For those who chose to be members, formal and informal disability-related networks provided opportunities for mutual support and friendship, as well as a sense of purpose and belonging. Importantly, the advocacy and empowering role of disability networks enhanced independence and self-confidence:

> "It's important that people with disabilities speak out ...that it isn't just some suits in Dublin deciding what should happen." (35)

> "Without [the disability network] people with disabilities wouldn't be heard." (10)

> "I learned a lot [through involvement with network] ...how the system works ...how to influence change…I learned how to speak in public...at a meeting ...I wouldn't have done that before." (36)

For many members they were also sources of emotional support and enhanced self-worth:

> "You don't have to put on a show [at the network] ...You can be yourself ...feel totally normal...It's a great way of meeting people...and it doesn't cost you anything…Nobody is treading on eggshells ...We all take the piss out of each other ...You aren't afraid to... It's very normal…I look forward to [names day of week] mornings so much... even though it might take me half an hour to get here [to meeting]...I would do it a few times a week if it was on ...It's just nice hanging around with people who get you...We mightn't talk about [disability] at all but you would come away from it in good spirits...My wife and family always tell me I am in much better form after it. If [funding] was taken away people's lives would be ruined...It's the only real outlet I have."(10)

Relating to professionals

Few interviewees discussed their relationships with professionals. A few spoke about the value of professionals linking them to disability networks:

> "My doctor told me that I could come [to the disability network] ... He said I would be better off learning about all the equipment [assistive technology] from people who use it everyday." (10)

> "The people in [names place] told me about [disability network] ...I was happy to try it out ...I was keen to talk to other people and to find out they had coped [with impairment]." (35)

"The therapist thought I might like it and she got somebody [from the disability network] to call into me to tell me about it ...That's how I started going." (34)

Work and productive activity

Consideration of this important aspect of the lives of people with disabilities lies outside the scope of this study. Suffice to say that work and other productive activity was highly valued as a source of income, status and meaning. For those engaged in it, disability advocacy was an opportunity to act as a natural community support to other people:

"If [people with disabilities] are silent we will lose everything we fought so hard for ...You have to speak out…I've a responsibility to do it ...I feel better for it having played some small part in it......to help others [with disabilities] who are trying to live independently." (6)

"Everything I'm involved in has something to with disability....teaching computers ....attending conferences...speaking out ....It's important to me. I want to help others [with disabilities] who are trying to make it on their own [live independently]." (49)

Summary

In this section interviewees described their daily lives, and the role that natural community supports play in them. Most accessed some supports as a seamless part of their routine – for example, accepting cooked meals from family or friends. Interviewees were inclined to do as much as possible for themselves: "you want to prove you are as good as anybody else", as one interviewee put it (18). Many interviewees were reluctant to ask for help, being concerned about how this might reflect on them and create an image of neediness or lack of capability. Most planned ahead about when to ask for help, being keen not to "waste" a request on something that was unimportant. Several spoke of preferring to pay for a service – cleaning, for example – rather than to accept help from family, in particular. Interviewees stressed reciprocity as an essential ingredient of all relationships with family, friends and peers. Underlying much of what many participants said was a fear of being seen as a burden, or of becoming dependent on others. What others might think of them if they were seen to accepting support was also a factor in minimising its use.

The ability to access natural community supports – on their own terms – was critical in enabling many interviewees to live independently. Participant after participant described the advantages of being known in the area in which they lived. Throughout Ireland people who work in shops, libraries, information centres and many other everyday mainstream services are looking out for and supporting the independence of people with disabilities in simple, natural ways. Interviewees appreciated and valued their unobtrusive assistance on all levels, from calling taxis to invitations to join in community activities.

It was notable that interviewees tended either to live with their family (either family of origin or a partner and children) or on their own. None appeared to live with friends. Concern about appearing needy was one reason given for this, while deaf people cited the need for quietness. Those who lived with family stressed close ties and the urge to protect their children from any possible adverse effects of having a parent with a disability.

While a few interviewees preferred not to be in close contact with other disabled people, those participants who belonged to informal disability networks valued them greatly. For these interviewees support from peers was the best type possible. At the same time, those interviewees who used computers and other technology, including assistive devices, credited them with simplifying and easing their daily lives, and lessening the need to access natural community supports.

When discussing "how to live" interviewees stressed the importance of productive activity, whether paid or unpaid. Advocacy on behalf of other disabled people was important to some.

In this section, as in others, the use of natural community supports, and personal effort to maintain independence, regardless of living situation, were almost inextricably linked. Accessing natural community supports appears to require independence of spirit; an independent spirit enabled people to judge how and when to access natural community supports. Without this spirit, or the requisite skills, successful independent living was compromised.

Overall, interviewees cited contact and companionship with others – family, friends, people in the wider community – as making the difference between existing and having a good life. A participant summed it up: "Life ...whatever way you are living it ...no matter who you are...is about people." (52)

6. How to deal with adversity

Everyone experience difficulties in their lives, but many people with disabilities who live independently in the community face additional challenges. Dealing with adversity required interviewees to practise a high level of personal insight, reflection and planning. For many interviewees this related also to their use of natural community supports.

Loneliness and lack of intimacy

Adversity was particularly apparent in the area of interviewees' personal relationships. Loneliness and lack of intimacy were difficult topics for many participants, while others commented on the negative effects of loneliness, which could lead them to neglect their health or to behave in a self-destructive way, for example, by drinking to excess:

> "I've been off the drink for nearly four years now ...Even though I know I'm better off I do miss it...It's hard when you spend so much time on your own." (34)

Interviewees were aware that their disability often prevented them from forming the relationships which provide natural community supports for other people:

> "Since I split up with a girl a few years ago it has been very difficult...People are very slow to take you on.....as a partner." (19)

> "I do date like everyone else, but it's more difficult. I am very confident ...but it can be difficult to push yourself ...to stay confident all the time. You do get knocked back. Like most other people you want to be in a relationship...have someone to care for you...to love you ...to love them back...It's just more difficult for someone with a disability." (7)

> "I would to love to have that closeness...that couples have ...even that single people have when they meet someone they like." (47)

A small number of people in the older age group, mainly, but not only, women, voiced disappointment at not having children:

> "I'm happy with my life ...but I do look back and think ...a family would have been nice."(4)

> "I would have [been] a brilliant mother ...I have so much love to give." (12)

> "A family of my own is probably the only big thing that I've missed out on." (6)

Living alone also created practical difficulties for some interviewees:

> "Even in the house I have fallen once or twice and I would like somebody there to help me ...I am on my own and [companionship] is a big part of what I miss." (19)

Natural community supports helped to ease this situation for some:

> "I get on very well with my neighbours...next door ...They look after my home when I go on holidays." (16)

Others spoke warmly of the physical and emotional support they received from family, friends, pets and people they met in their daily lives whose understanding and practical help made their lives easier and more enjoyable (see pages 36-41, pages 55-57 and throughout this report).

Maintaining privacy

Loneliness notwithstanding, maintaining privacy (including financial privacy,) was a priority for almost all interviewees. The use of natural community supports in some situations was very nuanced:

> "Doing stuff around the house ...particularly personal stuff...dressing, washing ...I want to do that all myself ...Other stuff can also be very private ...like the bank or the doctor...and you might need someone to go with you but it's important that you can trust that person [to respect your privacy]." (52)

Privacy mattered to interviewees in many situations:

> "My doctor is very nice, and I have been going to him for years, but I still like to have a bit of moral support ...They [companion] wouldn't come in to the doctor's room with me now...They'd just wait with me." (51)

Dealing with bureaucracy

Although many mainstream services (unrelated to disability) were experienced as supportive and helpful (see pages 33-34), dealing with bureaucracy made most interviewees feel frustrated and disempowered on many levels:

> "Day-to-day life should be so much easier [for people with disabilities] ...Going to the bank, the post office, the social welfare office...Everyday places you just have to go to can be really difficult ...I just don't go the bank anymore ...The counters are too high up ...The staff don't know

what to do...The same with the social welfare ...[Staff] can come across as feeling really awkward which makes you feel awkward." (23)

Interviewees used technology (pages 34-35) or natural community supports to deal with this:

"I used get stressed out going to the bank ....It's impossible to hear them behind those screens and I don't want to be shouting out my business across the floor..That's what made me learn how to use the computer ... I can do it all [banking] from home." (4)

"If there are [administrative] forms to be filled out I like to have my Mam or my brother with me." (12)

"I don't like being in the flat on my own when there's somebody else here [on official business] that I don't know I would always ask can I have someone with me." (63)

However, some interviewees reported that technologies which make life easier can also increase their sense of isolation (see page 36). Similarly, the use of natural community supports in this context does not always work out as intended:

"Sometimes I would use my daughter as an interpreter ...One time the credit card statement wasn't right and she kept talking on the phone but didn't communicate with me...she closes the conversation before I am finished. It's very difficult. My daughter doesn't really understand. If [she] was in my shoes she would understand my frustration." (16)

Barriers to socialising

While some interviewees described a rich and varied social life (see page 38), many, of all ages and with all forms of impairment, said that this aspect of their lives was limited by inaccessible locations, lack of transport and lack of natural community support:

"There are times you feel ... ' I would love to do that'....but then you think 'Oh, I would need somebody to bring me' ... ...and that would put you off." (46)

"Transport is a huge thing ...I have applied for a disability pension ...I don't like the term 'disability' or 'pension'...but ...the transport ticket would make a huge difference ...It costs me a fortune to go anywhere ...even getting to the station requires a taxi." (19)

"Most of my friends are nurses, so they...understand, ...but if I am with people I don't know as well I would always make sure that I would meet them somewhere that is accessible...I don't want to be dependent."(18)

"Buildings have improved but pubs and clubs still tend to be really poorly laid out ...lots of steps, uneven surfaces, dark corners, and so it doesn't really suit [me] there ...People do still socialise a lot [in pubs and nightclubs], especially young people, so it does rule things out for you." (52)

"Football matches ... I haven't gone to any this year ....This is a great year for Dublin ...[but] I can't go....Getting to the seats is difficult."(19)

Some interviewees found social events very difficult, regardless of the availability of natural community supports:

"I just wouldn't have the same social life [as my sister]. I just find it too hard to cope in pubs or in noisy places. My head gets so sore ...If I turn the hearing aids up I get this loud ringing and if I turn them down I can't hear a thing ...I just wouldn't be able to go to certain types of places ... and then you don't want to have the whole evening planned around you." (4)

"I used go to pubs and nightclubs but I haven't since I had the accident ... It's just too much hassle ...Asking to use the lift ... needing the doormen to lift the chair up the steps...It's not so much people looking at you all the time...I have got over that ... but it's the feeling that I need so many things to be changed around to suit me." (52)

Some interviewees' perception of other people's response to their disability was a constraint on their social lives:

"I'm sure [I avoid socialising] because I have been thinking about my disability and thinking what do others think?" (32)

"As much as you try not to be, you would be self-conscious [about impairment] ...That's why I don't go out a lot ...only when I am really up for it. You would have to be in good form ... Otherwise something might upset you." (13)

"You just sense that some people aren't comfortable [with impairment] ...That makes me feel uncomfortable." (33)

Some responded by limiting their social lives to other people with disabilities:

"I just socialise with other people with disabilities ... people who I know through the disability network ...They know the score ...We understand each other much better ...I just don't go outside that circle much." (14)

Many lacked confidence:

"You want to feel confident and if it's a new place ...new people ...that can make me feel quite scared." (22)

For others, the physical and psychological effort required to socialise led them to avoid social events. Self-care trumped the use of natural community supports in these circumstances:

> "Unless it's one of your best friends or somebody else with a disability who understands then you kind of ...have to 'get yourself up for it'...If you aren't in the mood or are feeling in anyway low then you don't." (20)

> "I don't want to get myself into a situation that is too stressful ...I have to look after myself and my health." (61)

> "I have learned how to cope better, how to look after myself more. I know what I am able for and what I'm not. If I think I won't get on with the people, or if the place that they are meeting won't suit me, I won't go." (46)

> "I do spend a lot of time thinking ...Will that suit me? Will I like it? How will I get there? How will I get home again? Who'll be there? What are they like? Do I like them? If I'm unsure I probably wouldn't go." (31)

> "My energy levels aren't what they used be. If I feel this would wear me out I just wouldn't go ...where I probably would have in the past ...As I get older and as my body is becoming more frail I need to look after myself more ...I am saying 'no' much more than I used to." (6)

Interviewees' relationships with natural community supports were sometimes fragile, easily damaged, or difficult to maintain:

> "One friend is good, two friends is too many and three is a crowd. I prefer to have one true friend than having too many. There were always problems when I had too many friends." (16)

> "We were best friends ...and then she took up with her boyfriend and I was left on my own." (62)

> "We fell out over something stupid ...her dog and my dog were always fighting ...I did have [another] very good friend but sometimes she goes away and I mightn't see her for ages." (12)

> "[My friend and I] fight something terrible ...When we're fighting we don't talk but then if it goes more than a few weeks we would nearly always make up." (30)

Managing to survive

Similarly, the use of natural community supports was of limited assistance in dealing with economic adversity. Interviewees living on benefits budgeted carefully in order to live within their means, but this was not always sufficient:

> "During the winter I take to the bed a lot ...When it snowed last year...It was so cold I could have been in bed for days at a time." (34)

> "When you pay rent, do your shopping, buy clothes, pay bills, you have nothing left ... that's always been the way ... I've always had to mind my money very carefully and do without things ...but now I find I'm doing without [even] more essentials ...I heat the house less ... [I] go to the library whenever I can so that I wouldn't have to heat it." (51)

> "I have ...lost a lot of weight with different infections. My doctor told me that I need to build myself up again ...but good food is expensive, so I have to think carefully about what I cook." (4)

Interviewees with physical impairments anticipated difficulties in the future availability of carers' allowances, with implications for long-term sustained independent living, the invasion of privacy and lack of choice:

> "I might need a live-in carer in the future ...I don't know what kind of [financial] assistance I would get with that ...I might well need one, though, if I am to continue living on my own." (6)

> "As I get older I am able to do less and less... Small things are taking a lot longer than they used ...getting dressed, washing myself ...I don't want to give up the apartment but I probably will need [a carer] in a few years' time ...I don't know what the future holds for me but [living independently] is getting more difficult." (36)

Thinking about future finances was stressful for many interviewees, and they preferred not to dwell on it (see also pages 50-51):

> "I just don't think about the future. It's too much of a battle getting through each week ...minding myself ...my health ...making sure I have enough money to get through the week." (61)

Planning to survive

As previously discussed (page 31), interviewees generally found it difficult to ask for help. To offset this, participants invested a great deal of time and thought into managing situations in order to maintain their independence and self-respect. Planning ahead enabled respondents to survive and to keep their use of natural community supports to a minimum. This frequently took considerable personal effort, time and energy:

"I feel that I need to be very organised ...to know well in advance what I am going to be doing ...if there are any trips coming up ...like to the doctor or the specialist in the hospital ... ...If I am organised then I can work out how to get there on my own, what route to take, what to wear, what to bring with me ....That makes me feel in more control. If I can do as much as I can on my own then I don't feel bad calling my friends or neighbours if it's an emergency." (51)

"I am lucky but I work hard at it. I have to protect myself ...manage myself all the time ...I have to think ahead about my day, my week, what needs to be done, who I need to meet with, what places I need to go to. I have to plan that out carefully and even that planning takes a lot of time and energy ...and a lot out of me ...I do everything I can to mind myself because I get worn down so easily and quickly because of all the stress involved in looking after myself." (4)

Strategies for dealing with adversity

Many interviewees reported that they deal with difficulties by "putting them out of their minds", by developing routines that meant they did not spend too much time alone at home, or by living in the present. For example:

"If I'm not working I would often go a couple of days at a time without meeting someone. You fall out of the habit and feel you don't need [human interaction] but...of course, you are lonely. It's best not to think about it." (5)

"I am strong and I do have ...very good friends....but it's not the same ... You would feel alone ...but I have taught myself to put that to the back of my mind." (27)

"I live in the flat on my own. I do like my own company and being on my own for long stretches at a time, but you do get lonely. I just try to avoid thinking of that ...That's how I cope. If I do think about it I would get very down...There's nothing I can do about [the future] so I don't really think about it." (4)

"My mother isn't going to be around for ever ...but I don't dwell on it ...I want to have enough supports in place that I am not a burden on my sisters." (18)

Others coped by finding positives in their situations:

"[Without my impairment] I would never have gone to college ...I have decided to go to college because I always had a sneaking interest in history ...so I have done my degree and a diploma ...a higher diploma in Irish history ... and am now doing a masters in European history in [names university] ... I love it." (19)

"My advice would be don't stop believing ...There is a mountain in the way, but don't stop [trying to progress]." (17)

"As I've got older I've probably got stronger mentally." (36)

"When I went to a third world country I see people much worse than me ...when I came back to Ireland I thought I should be happier [here]. Other countries opened that up to me that I should be happier...when they have nothing." (16)

"You get knocked back again and again but you have to pick yourself up and go again ... If you don't have the right attitude it [independent living] will be hard." (61)

Summary

All people experience difficulties in their lives, but people with disabilities living independently face additional challenges. Those described in this study varied depending on people's circumstances. Common concerns related to the inaccessibility of buildings, lack of transport, poor nutrition and financial constraints. Loneliness and lack of relationships troubled many participants, as did issues relating to self-confidence and social ease. The use of natural community supports was thought to be of little assistance in relation to those issues that were seen to be particularly taxing.

Interviewees generally faced and reflected on the challenges in their lives and dealt with them with determination, flexibility, adaptability and the use of natural supports where deemed appropriate and unthreatening to independence. Like many other people living in Ireland, they were anxious about the future. They harnessed many strategies for dealing with adversity: recognising their problems, planning ahead, taking control, finding solutions, adopting a positive mental attitude, avoiding potentially problematical situations and living in the present. Key issues were maintaining control, exercising choice, maintaining self-respect and defending their privacy.

7. How to succeed at independent living

Ireland in the 21st century

While barriers to full participation undoubtedly still exist (see, for example, chapter 6, pages 44-52), many interviewees thought that attitudes to people with disabilities had improved (thus making the provision of natural supports in the community easier). At the same time they found that the availability of suitable, secure housing made independent living possible and that technology had made life easier (see, for example, chapter 5, pages 28-43). Participants reported that they accessed some excellent services, where they are treated with courtesy, understanding and friendliness (see, for example, chapter 5, pages 28-43). Services that received favourable mention included post offices, libraries, shops, Citizens' Information Centres and credit unions.

Despite their experiences of adversity (see chapter 6, pages 44-53), many interviewees spoke about very positive things in their lives. For some, this related to their belief that life is becoming easier for people with disabilities, not least due to the contribution and self-reliance of disabled people themselves:

> "If you look back over 20 or 30 years a lot of good things [positive improvement for people with disabilities] have happened ... That's down mostly to the people [with disabilities] themselves and their families ...They fought for everything they got ...Nothing was handed to them ...The big thing now will be trying to hold onto it [in a period of cutbacks]." (36)

> "I do think about the future ...for my country ...for other people with disabilities ...and I try to bring about improvements for others [the next generation] coming up behind us." (6)

> "There was an awful lot of pejorative thinking [in Ireland about disability] which is disappearing ...It's great to see people standing up and demanding their rights." (3)

Interviewees born outside Ireland compared attitudes to people with disabilities in this country favourably with those in their home countries, and recognised that this simplified the use of natural community supports:

> "Fortunately in Ireland I don't have to hide my disability. I am very thankful for the people [in Ireland] who work for disability ...In Ireland it [disability] is natural,...thank God, but in [names country] it's not! People [in Ireland] accept people with disability." (17)

> "It's interesting ...In [names country] my biggest problem was my disability ...but here in Ireland it is my nationality...It is more difficult to

be non-Irish here in Ireland than it is to have a disability. In [names country] there are many restrictions for people [with disabilities]... People's attitude [to people with disabilities] in [names country] is terrible ...[By contrast] Irish people are so friendly and when you are in a wheelchair ...they don't say 'you can't do this'." (65)

Looking to the future, interviewees anticipated greater understanding about impairment and disability, resulting in better lives for people with disabilities and, with that change, easier access to natural community supports:

"Twenty, thirty, forty years ago people with disabilities were hidden away in homes but now they are living very successfully in the community...We want to be independent ...I want to be treated the same as everyone else but people need to be more aware ...Very young kids, I think, are actually the best...They ask questions...often very direct...but that breaks the ice, gets people talking, normalises the whole thing." (7)

Getting the basics right

Interviewees cited suitable housing as a critical element in successful independent living (see chapter 4, pages 24-27), enhancing self-reliance and lessening the need to ask for assistance:

"If you get the house set up with the various bits and pieces that makes it [living independently] much more practical ... much easier to get around ... [Housing adaptation is] vital really if you are on your own." (59)

"[Living independently] does take effort ... but getting the house sorted was a huge step ...I wouldn't have been able to do anything [living independently] without the adaptations." (10)

Many interviewees cited community-based services as helping them to thrive (see, for example, pages 33-34). For example, participants from all over the country mentioned public libraries as a service which enhances their lives (see page 32), along with Citizens' Information Centres (page 33):

"The people in the [Citizens Information] Centre are very good ... It's easy going in there ... They treat you nice". (36)

Being known to staff in shops, and being able to access services predictably, are also important elements in making participants' lives easier, more independent and more enjoyable. For example:

"We go to the same place every week ...I know where everything is [layout of shop] and the staff would all know me." (50)

This sense of belonging creates a sense of security, especially for interviewees with intellectual impairments:

> "When I go in with my book to the credit union [names staff member] would always come out to see am I OK ... The security [staff at the shopping centre] would always call me a taxi when I've finished my shopping ... They make sure I get home safe." (50)

> "Everybody knows in me the town ...They all keep an eye out for me." (12)

Participants emphasised the value of information in ensuring that they receive the services to which they are entitled, to enable them to live independent lives and to feel connected to their community (see, for example, page 33). The internet has transformed the lives of many participants (page 35):

> "Everyone [with a disability] should be encouraged to learn how to use a computer ...[Computer skills] really help [independent living]." (7)

> "[Online shopping and banking] saves me so much time every week." (6)

> "Learning to use the computer and the internet has given me a new lease on life ...I loved reading the newspaper every morning...Now I can do that on the computer." (10)

Participants valued the control they had over their lives (see page 19) and the people and services which facilitated this and supported them. Personal relationships with close friends and family (pages 36-39), and simple interactions with people doing their jobs with consideration and courtesy, were greatly valued (pages 33-34). This was natural community support in its purest state:

> "Help with practical stuff is great ... It's really appreciated ... when it's done well, ... when the person doesn't belittle you or make you feel stupid or small." (52)

Living a self-determined life

Interviewees demonstrated great insight into their own situations. They expressed satisfaction with the choices they are able to make concerning what to do and when to access natural community supports, even when these proved difficult:

> "I miss out on a lot of things [because of impairment] ...but at least that's my decision [not to do them]." (6)

> "I don't want any assistance on how to plan things out. I have accepted that there are things I can't do [physically]." (65)

"I feel better about myself ... making my own decisions ...when to get up, what to eat, what to wear ... what to listen to on the radio, what doctor to attend ...that kind of thing." (54)

"I am into doing different things each week ...the network meetings, the camera club, tai chi ...my classes and my work ...but I can decide: if I don't want to go ...I won't go." (53)

Those who owned their own homes took great satisfaction from the freedom this conferred. Interviewees also took satisfaction from being able to spend their income however they pleased:

"It's my money ...I can decide what to do with it and how to live my life ... where to live." (6)

"I can decide what to spend my money on ...It's different to living at home." (52)

"It's in my name [social welfare] ...I get rent allowance as well so that means I am more independent." (27)

Several interviewees developed absorbing interests (for example, study, chess), which brought joy and fulfilment (see, for example, page 38). One participant valued the benefits that had come from his impairment, remarking that it had made him more adaptable, bringing out qualities that might have remained dormant. He asserted, "I wouldn't have it any other way" (3).The same interviewee valued the urge to creativity that impairment necessitates:

"Not driving [in a rural area] creates certain [very significant] limitations ...I was living by myself as a bachelor, so how to survive, [how to get] food, groceries?" (3)
Note: This individual found another form of independent personal transport he could manage so that he could get to the shop.

Although not universal (see page 21), frequently interviewees mentioned their gratitude to their parents for instilling them with confidence and an independent spirit (see page 21). For example:

"I am very confident ... That's how my parents brought me up. My parents encouraged me to be as independent as I could be ...to push myself as much as I could and to be proud of who I am...That's stayed with me throughout my life ...Mum and Dad would always say 'you can do anything'." (7)

"I had never any difficulty ...psychologically ...in dealing with [my impairment] because I was well prepared for it by my parents ...so I could work out ways to deal with things ...I was expecting it to happen

and it happened ... When [faculty] was taken away I could accept it." (3)

"I had to do the washing and the cooking just like my two sisters...I knew how to look after myself." (27)

Very many of the interviewees valued the self-esteem and fulfilment brought by participation in productive activity, whether this was paid employment, voluntary work or study (see page 42):

"Saying that I am a nurse is such a big thing ... [for my self-esteem] ...If I didn't have a role ...I probably would find it very difficult." (18)

"I always knew I was going to work..it was never in question." (7)

"I've been studying for years ...first to get my Leaving Cert ...then I did a certificate in computers ...It took me two years to do the [follow-on] diploma but I got it ...and now I'm heading for my degree ...I hope it'll lead to something [employment-related opportunity] ...I've loved it but it's been very hard work.....very hard work." (5)

Above all, warm personal relationships allowed people to thrive and have good, rather than average, lives (see chapter 5):

"Life....whatever way you are living it...no matter who you are... is about people....the people you mix with every day...the people you think of as your friends." (52)

"I am a family man ...I came from a strongly bonded family ...We don't live in each other's pockets ...but we are supportive of each other. I would love to see everyone have that level of family back-up." (3)

In terms of natural community supports, many participants spoke of female relatives: wives, sisters, mothers. As well as practical help, such as cooking, laundry and cleaning, they gave emotional support:

"I was in a very dark place ...and not just because I'm blind [laughs] ... but my wife put up with a lot ...I was really depressed. Without the counselling I don't know how [wife] would have stuck me... and then without her ... [voice trails off]." (10)

"My sister is great for getting me involved in social stuff... It brings me out of my shell when I might have spent a lot of time on my own." (39)

"Me and my mum and my sister are best friends ...I still see them every day." (20)

"Sometimes I would use my daughter as an interpreter." (16)

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

63

"If I get panicky or don't know where I am meant to be I can call my wife or my daughter." (35)

This type of support from close relatives appeared to be gender-related. Husbands or boyfriends were not mentioned as sources of support, and brothers were only mentioned twice. Women, whether wives, sisters, daughters, mothers or girlfriends, played the key supportive roles in participants' lives. Practical support from outside the family also involved women:

"The place isn't as clean as it should be ...The [Society of St Vincent de Paul] call around most weeks, and now and again the [female VdeP visitor] would give it a clean-up." (63)

Many interviewees discussed the importance of maintaining positive mental health (see, for example, pages 50 and 51). Participants spoke of the value of counselling in enabling independent living:

"Counselling made a big difference for me ...It built up my confidence ...I had a lot of insecurities ...all related to my disability ...I don't think I would ever have been able to move out [of family home] on my own without it ...It sort of helped me get my head around [the move] ...like what's the worst that could happen ...If it didn't work out I could always move back home." (52)

For those who chose to be members, disability networks provided meaning and belonging (see pages 40-41). For others pets provided great companionship and comfort, providing companionship as well as a kind of reciprocal support:

"I suppose my biggest disappointment of all [due to onset of impairment] was not being able to work with my sheepdog ...my best friend of all ...There is something very special about the relationship between man and dog ...He was the best dog ever ...He would do anything ...He was so well-controlled ... and he and I bonded and we loved each other." (3)

"I love him ... I would be lost without the cat." (13)

"I just love to pet him [dog] ...We are great friends ...He would sit up beside me when we are watching TV and he sleeps in the same bedroom as me as well." (50)

"The dog and I ...we are great company for each other." (15)

"The place just doesn't seem as lonely as it would if you were on your own. Even his [dog's] breathing [consoles me]." (14)

"I couldn't imagine life without the dog. It's a huge part of me." (58)

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

64

Summary

Interviewees cited a range of elements that made the difference between surviving and living a meaningful life in their communities. Positive attitudes mattered, including recognising the changes that have happened in Ireland in recent years. Other key factors included participating in productive activity, living in a secure place, enjoying the company of pets, being known and supported in the local environment and harnessing helpful technology.

For almost everyone who participated in the study, though, the most significant determinant of how to thrive concerns the quality of their relationships with other people. Female relatives and friends provide practical and emotional support, staff of shops and community services look out for them, information providers are proactively helpful, other disabled people offer information, support and fun. Mobilising natural community supports is not always easy (see pages 31-32) but the rewards, in terms of living a self-determined life, are invaluable. It is people who determine the quality of an independent life.

65

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

8. Summary and conclusion

The participants in this study were adults with various impairments, living in several parts of Ireland, whose lifestyle could be described as "independent living" and who were not major clients of disability service providers. They came from all walks of life, ranged in age from 19 to mid-60s, and described a wide breadth of life experiences. This broad diversity is reflected in the fact that there were few discernible patterns in their answers.

There were, however, similarities in the approaches that participants took to harnessing natural community supports and making a success of independent living. Self-direction and self-reliance were determining themes that emerged strongly from the individual interviews. Participants demonstrated high levels of perseverance, and a strong commitment to problem-solving and to finding solutions for the common issues of everyday survival which confront everyone in their daily lives.

The use of natural community supports was part of this process, but not its determinant. Similarly, the use of natural community supports was a tool in the making of an independent life, but not its prerequisite. Instead, the use of natural community supports, and personal effort to maintain independence, regardless of living situation, were almost inextricably linked. Accessing natural community supports appeared to require independence of spirit; an independent spirit enabled people to judge how and when to access natural community supports. Without this spirit, or the requisite skills, successful independent living was compromised.

Personal choice and control, and the right to exercise self-determination, were paramount for study participants. They were notably reflective, thinking hard about when, how and in what circumstances to seek assistance. The assistance of natural community supports was often sought, and generally welcomed, but with conditions. A participant summed these up: "Help with practical stuff is great...It's really appreciated...when it's done well,....when the person doesn't belittle you or make you feel stupid or small" (52).

Time and again interviewees asserted their insistence that they should be in charge, whether of their finances or their choice of washing powder. Assistance was particularly valued when it came in the form of clued-in, helpful, friendly staff working in regular community services, whose everyday and unobtrusive human kindnesses – patience, calling a taxi, filling a shopping bag, offering news or information – translated as thoughtful customer service.

Interviewees asserted time and again that they had the same needs as everyone else, albeit sometimes with an added specific dimension. They generally did not conceive of their relations with others as any kind of particular support, still less "natural community support". Instead they saw

themselves as part of the general web of everyday life; a particular part, with some specific needs, but not something separate. Successful independent living reinforced this feeling, whether through reciprocal cat-minding with neighbours, clearing overgrown verges or working on a CE scheme.

The following section offers observations based on the data, with the focus of the study in mind, and with the lived evidence of interviewees' lives to the forefront.

Themes and priorities

In line with the above comments, the following overarching themes emerged from the study:

- Privacy, choice and control are the primary drivers of the decision to live an independent life; participants with intellectual impairments, in particular, were anxious to avoid institutional care, while those with degenerative conditions wanted to maintain independence for as long as possible.

- An independent spirit, frequently, but not always, instilled by the family of origin, is a key success factor for independent living.

- Interviewees lived alone, with a partner or with family, but not with peers or friends.

- The use of natural community supports is not unconditional; valued and acceptable natural community supports respect disabled people's dignity and autonomy.

- A sense of belonging, meaning and positive identity, delivered through work, friends, family or other means, bridges the difference between existing and living a good life.

- By contrast, poor quality or absence of personal or intimate relationships was an indicator of less fulfilling independent living.

- Reciprocity places the relationship with many natural community supports – for example, with family, friends and neighbours – in an acceptable framework which preserves dignity and self-esteem, and prevents interviewees from feeling like they are a burden on others.

Participants receive support and also offer it, through exchange of favours, listening to others' woes, helping their mothers to bake bread or a hundred other daily transactions.

- Unobtrusive natural community supports delivered by mainstream services unrelated to disability issues are particularly valued as a way of living an independent life as a known and accepted part of a local community.

- Interviewees were characterised by their empathy for other people with disabilities.

- Participants had developed a range of effective coping strategies and skills.

- Loneliness, or being too much and too often alone, was an issue for those who lived without companions; this was mitigated by activities, contact with family and friends, and the company of pets.

- Many interviewees functioned in small, close-knit geographical communities or communities of interest, such as informal disability networks; these, along with appropriate accommodation, provided much-valued safety and security.

- Outside of service provision unrelated to disability issues, both practical and emotional support was overwhelmingly delivered by women.

- Managing on benefits was difficult, and getting harder; the struggle to ensure good nutrition was an issue for many participants.

- In common with many people living in Ireland today, interviewees were worried about the future, especially about the impact of cuts in benefits and services. To deal with this, participants used a range of coping strategies, of which living in the present and not dwelling too much on

the future was most dominant, along with adopting a positive mental attitude wherever possible.

- Ironically, participants generally planned ahead, whether for activities or to garner natural community supports; little was left to chance; finances, social lives and other elements of everyday life were managed closely.

- Substandard or unsafe accommodation, uneven delivery of benefits and allowances, poorly trained staff in mainstream services and other shortcomings made daily life difficult for those who encountered them.

- Interviewees' expectations were often modest, and their lives sometimes appeared circumscribed, but as a participant said, "I miss out on a lot of things [because of impairment]...but at least that's my decision [not to do them]" (6).

As well as the topics and themes which emerged from the interviews, some were conspicuous by their absence. These included:

- Most of the activities of disability service providers

- Religion, clergy and the activities of faith-based groups

- Teachers, politicians and other traditional gatekeepers

- Little or no mention of TV, radio, books or music

- With a few exceptions, little discussion of sport or other physical activity

- No mention of a refusal to help.

For almost everyone who participated in the study the most significant determinant of how to thrive (as opposed to merely getting by) concerns the quality of their relationships with other people. Female relatives and friends provide practical and emotional support, staff of shops and community services look out for them, information providers are proactively helpful, other disabled people offer information, support and fun. Mobilising natural community supports is not always easy but the rewards, in terms of living a self-determined life, are invaluable. It is people – those people with disabilities who live in the community, and those who interact with them as natural community supports – who determine the quality of an independent life.

9. Future directions

A small and exploratory qualitative study does not lend itself easily to the discernment of specific recommendations. However, some considerations for overcoming barriers to participation and for future directions emerge from the data:

- Specific support services: To be acceptable to the kinds of people who participated in this study, any future services specifically targeted at supporting their independent living would need to:

    o be configured in the context of general, as opposed to disability-specific, services, and offered through general service providers, rather than through disability service providers (as defined by the NDA)

    o be very clearly a choice, rather than a requirement

    o preserve service users' dignity, and scrupulously avoid any explicit or implicit suggestion that acceptance or usage of the service denoted dependency or neediness.

- Finance: Successful independent living is reliant on a reasonable level of income. It is essential that disability allowances and benefits, rent allowance and other supports to independent living are ring-fenced and are not cut further. The maintenance of mainstream community-level support services such as home helps and homemakers is also vital for the continued independence of disabled people.

- Managing money: Linked to the above, the more proactive availability of MABS (now more closely linked to the Citizens' Information Service) through easily-accessible community-based services (e.g. libraries, community centres) would be helpful for people with disabilities living independently on benefits and low or uncertain incomes.

- Disability equality training (DET) for mainstream service providers: It is evident that the quality of service provision to people with disabilities has improved in those services which have invested in DET. It should be made more widely available, particularly to those services about which interviewees complained (for example, banks, social welfare offices). The provision of DET for volunteer-using groups (for example, the Society of St Vincent de Paul, Tidy Towns committees) would also be useful and, in addition, could result in the acceptance by these groups of a higher level of volunteering from disabled people.

- Positive mental health: In the current climate life, already challenging for everyone, including people with disabilities living independently in the community, is becoming ever more uncertain and unsettling. People with disabilities would benefit greatly if strategies to promote positive mental health were to be promoted, and delivered through local community-based services. With the provision of appropriate DET, community-level counselling services, currently available through some community centres, have the potential to play a vital role in maintaining and strengthening the mental health of people with disabilities who live independently.

- Ageing: Several older participants expressed concern about their changing support requirements as they age. There is a need to examine how older people's services relate to people with pre-existing impairments living in the community, and how best to ensure that older people with disabilities can continue to live independently in the community.

- Role-models: Interviewees expressed fears that the next generation of people with disabilities might be discouraged from trying to live independently. It would be useful if ways could be found to promote realistic role-models (for example, "how I cope") to ensure that the momentum towards independent living is not lost.

- Accessibility: Interviewees reported, as others have for years, on the inaccessibility of premises and transport and the inadequacies of infrastructure. This aspect of everyday life cannot be allowed to fall victim to recessionary cuts.

- Funding for informal disability networks: The study provides ample evidence of the vital role that informal disability networks play in the lives of their members. It is crucial that ways are found to continue to support and promote the provision of informal disability networks that are independent of disability service providers, as defined by the NDA.

- Capacity building: People with disabilities living independently in the community would benefit from the provision of services which enable them to develop and hone social and coping skills, including the negotiation, harnessing and appropriate use of natural community supports.

- Computers and other technologies: The study provides ample evidence of the facilitative and positive effects of using computer-based and other technologies for people with disabilities. Support to develop and hone computer skills can improve the quality of life of many more people with disabilities living in the community.

- Home visits: Many participants in this study spoke of loneliness and isolation. Few community-level organisations offer a home visiting service; those that do often use a charitable model which many respondents in this study indicated would be unacceptable. A new model of home visiting could enhance social solidarity and help to alleviate the loneliness and isolation experienced by many people with disabilities who live on their own.

- Further research: Exploratory studies such as this one often conclude by recommending the instigation of more research. In this instance there are several avenues which could be explored, including:

    o comparison with the lives of non-disabled equivalents

    o exploration of the ambitions for independent living of those people with disabilities who are not at present living independently, especially those who receive substantial support from disability service providers

    o exploration of the attitudes and motivations of those people who provide natural community supports

    o seeking innovative ways of accessing the views of people with intellectual impairments living independently in the community.

Appendix 1

Glossary of Specialist Terms

Disability: A substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.

Disability service providers: Organisations funded through the Department of Health and Children's disability funding stream.

Independent living: People living alone or with their families (e.g. partners, siblings and/or parents) if they either by choice or circumstance receive no or minimal support from disability service providers.

Natural Supports: People who are not disability service providers but who provide assistance, contact or companionship to enable people with disabilities to participate independently, or partially independently, in integrated community settings.

Appendix 2

Natural supports semi-structured interviews: selection criteria for interviewees

The tender documents for the NDA's qualitative research on the use of natural supports describe the target group as "people with disabilities [who] are mobilising natural supports in the community to achieve independent living". They go on to specify disability types, age groups, the need for geographical spread and the requirement that interviewees should be "people with disabilities who either by choice or circumstance receive no or minimal support (e.g. sporadic respite) from disability service providers".

This short document details the clarification and elaboration of selection criteria agreed with Christine Linehan and Mary van Lieshout.

Degree of impairment
The researchers have adopted a commonsense approach which takes the definition used in the Disability Act 2005 as its starting point. According to the Act a disability is a "substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment". (NB people with mental health difficulties are not part of the target group for this research project.)

OCS Consulting is working with interviewees who themselves consider:
- that their impairment gives rise to a substantial restriction in their capacity to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State
- that this impairment is of an enduring, rather than a temporary, nature: this definition includes people with episodic conditions, such as epilepsy, and conditions with a varying attack-and-remit pattern, such as multiple sclerosis.

Substantial restriction
In working from the perspective of the social model of disability OCS Consulting takes the view that, outside personal issues, such as the experience of pain, most restrictions in participation in life in the State can be eliminated through the provision of appropriate reasonable accommodations. For this research OCS Consulting interprets "substantial restriction in capacity" to include the need for the provision of reasonable accommodations. In this way it will be possible to include, for example, people who are Deaf, deafened or hard of hearing, people whose independent living is compromised by the inaccessibility of information and/or the built environment, and so on.

Impairment type
Many people, especially older people, have multiple impairments at various levels of severity. Taken together, these may cumulate into significant levels of

exclusion. For the purposes of this research, when selecting people with multiple impairments OCS Consulting is ensuring that the definition of "substantial restriction", as discussed above, applies to at least one of the impairments that interviewees experience. OCS Consulting will ascribe people who have more than one impairment to the disability category relating to their main impairment type, while also documenting the presence of more than one impairment.

Disability service providers
"Disability service providers" are understood to be organisations funded through the Department of Health and Children's disability funding stream. "Minimal use" is taken to include application for disabled parking permits, occasional consultation of a specialist assistive technology centre, occasional (as opposed to regular) use of respite services, and so on. People who use the services of PAs will not be interviewed. Receipt of mainstream services, such as public health nursing or community occupational therapy, will not render a person with an impairment ineligible for interview.

Lifelong and acquired impairments
The researchers hope to achieve a reasonable balance between interviewees with lifelong impairments and those who may have acquired their impairments at a later stage. The exception to this is the category of "cognitive impairment", since the definition given in the NDA tender documents limits this category to people who acquire their impairment at the age of 18 years or older. NDA has excluded people whose primary impairment is dementia from the target group for the research.

Independent living
People living with their families (for example, siblings and/or parents) are considered to be living independently if they either by choice or circumstance receive no or minimal support from disability service providers.

Double disadvantage
The researchers are aiming for a range of ages, social classes and ethnic background among interviewees, as well as achieving a reasonable gender balance. OCS Consulting will ensure that the results are not skewed by disproportionate representation of social inclusion or exclusion criteria related to other dimensions of marginalisation.

In reality, however, no normative group exists, since everyone has multiple identities, and no disabled person experiences differential treatment solely on the grounds of their impairment. For example, a Deaf male Traveller will face different challenges in social interaction and independent living than a Deaf settled man or a Deaf Traveller woman. In order to assist with the interpretation of themes in the data, OCS Consulting will indicate in its report (within the confines of strict confidentiality and only where relevant) interviewees' apparent social class, ethnic background and/or other dimensions of identity.

Maureen Gilbert
Bríd McGrath

Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

75

Hugh O'Connor

OCS Consulting

Appendix 3

Information and consent form

The National Disability Authority (NDA) is the independent state body providing advice on disability policy and practice to the Irish Government. It has asked an independent research company, OCS Consulting, to carry out a study about how people with disabilities live in the community. The researchers (Maureen Gilbert, Bríd McGrath and Hugh O'Connor) are trying to find out what kinds of support people with disabilities have, and how these supports help them in their daily lives. Maureen, Bríd and Hugh have been running studies like this for many years, and have lots of experience of working with people with disabilities.

What is the research about?

The researchers hope to find out about:

- the experiences of people with disabilities living in the community

- the support and practical assistance you may use to live your life in the community.

The results of our research will appear in a report which will explain to the NDA and other policymakers how people with disabilities get the support they need to live their lives. The information may be useful also to other people with disabilities living in the community.

What will happen in the research?

We hope that about 60 adults from different parts of the country will take part in this research. Taking part in the research means meeting one of the three researchers for about 60 minutes for an interview that would be just like a conversation – answering some easy questions about:

- your everyday experience of living independently (on your own, or with a partner, family or friends)

- what parts are easy for you, and what parts are more difficult

- the kinds of support you have

- how these supports help you to live independently and enjoy your life.

How can I take part?

If you decide to take part, we will agree a time and place for the interview that suits you. Interviews will be in private but it is OK if you would like a friend or family member to be with you during the interview.

Your conversation with Maureen, Bríd or Hugh will be kept strictly confidential. No one from the NDA, or anyone else, will know what you have said. In the research report, all the information that you and other interviewees give will be grouped together so that no one person can be identified. If we quote something that you say we will make sure that you cannot be identified. We will not include any personal information that might allow someone to guess who you are.

You do not have to participate in the research. If you decide to take part, you can withdraw at any time. You don't have to answer any question that you feel is too personal, or makes you uncomfortable. There are no "right" or "wrong" answers. The researchers just want to hear about your personal experiences and your ideas.

We would like to tape the interview to ensure that we have an accurate record of what people tell us. If you let us record the interview you may stop the recording and the interview at any time. All the recordings will be stored in a secure place. We will delete them six months after the research study is completed.

What about costs?

The researchers will provide appropriate reasonable accommodations, such as sign language interpretation, for all interviewees who need them. The interviews will be carried out in fully accessible neutral places, such as community centres.

Although we cannot pay you for your time in talking to us, we will give each research participant a €20 One For All gift token as a small "thank you". Unfortunately, we are unable to pay any transport costs involved in attending the interview.

If you have any questions or concerns about this study at any time please contact:

Hugh O'Connor at OCS Consulting, 26/27 Upper Pembroke Street, Dublin 2

Tel: 01 637 3928

Email: hugh@ocsconsulting.ie

Text/SMS: 087 978 6232

or

Shane Hogan at the National Disability Authority, 25 Clyde Road, Dublin 2

Tel: 01 608 0400

Email: STHogan@nda.ie

Text/SMS:

Your consent

Please sign below to give your consent to participate in the research

I have received an explanation of the research. I understand that my participation in this research is completely voluntary. I also understand that I may withdraw from the study at any time.

I have been given an opportunity to ask questions about the research. I understand that any questions I answer will be anonymous, and that my identity will not be disclosed at any point.

I am 18 years old or over, and am legally able to provide consent.

Name _____

Date _____

Please sign two copies of this form. Please keep one for your records and return one to the researcher.

Many thanks for your assistance with this important research.

80

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- the experiences of people with disabilities of support from their community. OCS Consulting, 2012

Appendix 4

Interview Discussion Guide – Natural Community Supports

- Brief outline 'reminder' of NDA/OCS research process

  o Assurances of confidentiality/anonymity, how data will be recorded, process for discussion

- Warm up; Can you tell me a little bit about yourself? (<u>V. brief</u> to 'warm up' discussion)

  o Background; age, family, outline recent / current living arrangements, hobbies etc, etc.

- Could we talk for a while about your day to day life 'at home'/ 'household activity' / everyday 'life';

  o Are you living alone or with a partner, friends or other family members? (Describe)

  o Do you have friends, relatives, 'good neighbours' living nearby or within easy reach? Are you in regular contact (frequency of contact)? How would you describe these 'relationships' in terms of 'contact', 'companionship' and 'assistance'?

  o Do you have a regular daily and weekly routine? Probe:

    - daily events, tasks, and activities (some prompts here if necessary - washing, dressing, preparing food, cleaning, shopping for groceries etc)

    - social activities,

    - hobbies

    Probe for involvement of others in this (e.g. I go to the supermarket with my mother; I carry the bags home for her)

  o Are there day to day tasks and activities' (e.g. shopping, going to the bank, etc) that you are comfortable in doing on your own? (Describe)

  o Are there other tasks and activities that can be more 'challenging' or 'frustrating'? (Describe)

  o What things do you do on your own? What things do you do with other people? Are there occasions when you would like to have help or assistance? *Whom* would you ask for help or assistance? *How* do you ask for help? How easy (or difficult) is it for you to ask for help?

  o Could we talk for a while about these 'relationships' that you have built up over time? What are the things that you like to get a bit of help with? Who are the people who you support or help out?

  o Are there circumstances in which you would *not* ask for help? (Describe)

- o Outside these '*every day'* events are there tasks and activities that can be 'challenging' or 'frustrating'? (Prompts: e.g. buying clothes, going to the doctor, going to a football match, local social event etc) (Describe)

  o Have you ever received services (prompt) from a disability service provider (prompt)? What/when? Why did it stop? Would you like to use the services more often/less often?, Would you like to use other services? If you haven't ever received services from a disability service provider, why do you think that is? Would you like to?

  o What makes it difficult to ask for help / is there anything they could do to make it easier for you to ask them for help?

- 'Community activity';
  o What do you really enjoy 'doing' or 'being a part of'? What's the 'best thing' about your life? (Some prompts here…. activities, paid/unpaid roles, family/community involvement, hobbies etc)

  o What and/or How do you think you contribute to your household / local neighbourhood and community / social circle or peer group? (Describe)

  o Is it 'easy' to become involved in these activities and/or networks? Do 'others' provide help or assistance that make it easier or more attractive for you to get involved? Who? (Describe) What would make it easier for you to get involved in these activities?

  o What aspects of living here (within this 'community') do you dislike most or would like to see changed?

  o Have you ever been 'put off' or discouraged from getting involved in certain activities, networks or social circles? (Describe). What would have helped you to get involved?

  o What are your hopes for the future? What 'supports' (assistance, contact, companionship) at a community level would make the biggest difference in your life?

  o Anything else you would like to say? Any advice you would like to offer?

  o If you met another person with disabilities, what advice would you give them about living in the community?

Appendix 5

Information for Gate Keepers

Natural supports semi-structured interviews: selection criteria for interviewees
The National Disability Authority has commissioned OCS Consulting to conduct approximately 60 face-to-face interviews with people with disabilities, in order to explore the use of natural community supports in promoting independent living among adults with disabilities in Ireland. The NDA defines "natural supports" as people who are not disability service providers but who provide assistance, contact or companionship to enable people with disabilities to participate independently, or partially independently, in integrated community settings. Interviewees are to be adults (over 18 years) with physical, sensory, intellectual and cognitive disabilities who, either by choice or circumstance, receive no or minimal support (e.g. sporadic respite) from disability service providers.

The interviewees are to be drawn from six distinct parts of the country:
- Dublin city
- County Galway (including Gaeltacht)
- County Kerry (including Gaeltacht)
- County Kildare
- Counties Kilkenny and Waterford
- County Laois.

There are to be equal numbers of interviewees in two age groups:
- 18-34
- 35 and over.

NDA regards this study as innovative and ground-breaking. The number and spread of interviewees mean that the project report will take a narrative approach, discussing results under domains (to be determined once all data are collected), with minimal comparative material. The final report has to be signed off in November 2011.

In collaboration with the NDA, OCS Consulting has refined the inclusion criteria for prospective interviewees as follows:

Degree of impairment
The researchers have adopted a commonsense approach which takes the definition used in the Disability Act 2005 as its starting point. According to the Act a disability is a "substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment". (NB people with mental health difficulties are not part of the target group for this research project.)

OCS Consulting is working with interviewees who themselves consider:

- that their impairment gives rise to a substantial restriction in their capacity to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State
- that this impairment is of an enduring, rather than a temporary, nature: this definition includes people with episodic conditions, such as epilepsy, and conditions with a varying attack-and-remit pattern, such as multiple sclerosis.

The impairment categories for this study are:
- mobility impairment
- vision impairment
- hearing impairment
- intellectual impairment
- cognitive impairment (defined by the NDA broadly as acquired brain injury of whatever type, excluding dementias).

Substantial restriction
In working from the perspective of the social model of disability, OCS Consulting takes the view that, apart from personal issues, such as the experience of pain, most restrictions in participation in life in the State can be eliminated through the provision of appropriate, reasonable accommodations. For this research OCS Consulting interprets "substantial restriction in capacity" (see above) to include the need for the provision of reasonable accommodations. In this way it will be possible to include, for example, people who are Deaf, deafened or hard of hearing, people whose independent living is compromised by the inaccessibility of information and/or the built environment, and so on.
Impairment type
Many people, especially older people, have multiple impairments with various levels of severity, which, taken together, may cumulate into significant levels of exclusion. For the purposes of this research, when selecting people with multiple impairments, OCS Consulting will ensure that the definition of "substantial restriction", described above, applies to at least one of the impairments which interviewees experience. In the data analysis, OCS Consulting will ascribe people who have more than one impairment to the disability category relating their main impairment type, while also documenting the presence of additional impairments.
Disability service providers
"Disability service providers" are understood to be organisations fully or partially funded through the Department of Health's disability funding stream. "Minimal use" is taken to include application for disabled parking permits, occasional consultation with a specialist assistive technology centre, occasional (as opposed to regular) use of respite services, and so on. People who use the services of PAs (Personal Assistants) will not be interviewed. Receipt of mainstream services, such as public health nursing or community occupational therapy, will not render a person with an impairment ineligible for interview.

Lifelong and acquired impairments
The researchers hope to achieve a reasonable balance between interviewees with lifelong impairments and those who may have acquired their impairments at

a later stage. The exception to this is the category of "cognitive impairment", since the definition given in the NDA tender documents limits this category to people who acquire their impairment at the age of 18 years or older. NDA has excluded people whose primary impairment is dementia from the target group for the research.

Independent living

People living with their families (for example, parents and/or siblings) are considered to be living independently if they either by choice or circumstance receive no or minimal support from disability service providers, as defined above.

Double disadvantage

The researchers are aiming for a range of ages, social classes and ethnic background among interviewees, as well as achieving a reasonable gender balance. OCS Consulting will ensure that the results are not skewed by disproportionate representation of social inclusion or exclusion criteria related to other dimensions of marginalisation.

In reality, however, no normative group exists, since everyone has multiple identities, and no disabled person experiences differential treatment solely on the grounds of his or her impairment. For example, a Deaf male Traveller will face different challenges in social interaction and independent living than a Deaf settled man or a Deaf Traveller woman. In order to assist with the interpretation of themes in the data, OCS Consulting will indicate in its report (only where relevant, and within the confines of strict confidentiality) interviewees' apparent social class, ethnic background and/or other dimensions of identity.

General issues

All data will be anonymised, and all raw data will be destroyed six months after the acceptance of the final report.

The interviews will be carried out in fully accessible neutral places, such as community centres. With the consent of interviewees, interviews will be recorded. Reasonable accommodations (e.g. sign interpretation) will be provided. Although OCS Consulting cannot undertake to pay transport costs incurred in attending the interview, and cannot pay an attendance fee, all interviewees will receive a €20 One For All gift token, as a small appreciation.

Maureen Gilbert
Bríd McGrath
Hugh O'Connor

OCS Consulting

Appendix 6

Ethical Oversight Group

Members: Sharon Foley, Prof. Séamus O Cinnéide, Dr. Margaret Rogers

Invitation for the Ethical Oversight Group

June 7, 2011

Dear,

Maureen Gilbert, Dr. Bríd McGrath (a Research Associate in the School of Social Work and Social Policy in Trinity College Dublin) and I have been awarded a contract (under the OCS Consulting banner) by the National Disability Authority to conduct approximately 60 face-to-face interviews with people with disabilities, in order to explore the use of natural community supports in promoting independent living among adults with disabilities in Ireland. The NDA defines "natural supports" as people who are not disability service providers but who provide assistance, contact or companionship to enable people with disabilities to participate independently, or partially independently, in integrated community settings. Interviewees are to be adults (over 18 years) with physical, sensory, intellectual and cognitive disabilities who either by choice or circumstance receive no or minimal support (e.g. sporadic respite) from disability service providers. The resulting report will take a narrative, rather than analytical, approach to documenting the views of the interviewees. NDA regards this as innovative, ground-breaking work. The work is to be completed by November 2011.

As you might expect, we are anxious to ensure that our work on this project is conducted in an exemplary and ethical manner and therefore wish to establish an 'Ethical Oversight Group' to help us with this. We envisage 3 members, to include:

- at least one senior academic with expertise in qualitative research on sensitive issues
- at least one senior regular commissioner of qualitative research on sensitive issues.

We intend that this group will provide us with support and advice at critical stages of the study

- ethical oversight of the interview protocol, recruitment process, research tools etc
- ethical oversight of the interview process, as a reference point in the event of any sensitive issues or disclosures

We do not propose that this should be unduly onerous for those on the Oversight Group. We envisage 2 or possibly 3 meetings, and some e-mail contact, particularly around a small number of 'milestones' in the project, and will, of course, endeavour to fit it around members' other commitments. We are looking for oversight and advice, rather than approval, and will, of course, indemnify the members against any adverse results arising from the conduct or outcomes of the study. As you 'tick all of the above boxes', we would very much like you to be a member of this Ethical Oversight Group and wonder would you consider this request on our behalf?

Many thanks for your kind help in this matter and for considering this request. I will look forward to hearing from you.

Yours sincerely

Hugh O'Connor

87

 Living in your own home with a disability
- the experiences of people with disabilities of support from their community. OCS Consulting,
2012