

A Review of Literature on Natural Community Supports

A Contemporary Developments in Disability Services Paper

This report was commissioned by the National Disability Authority (NDA) to present a review of literature on natural community supports in the context of independent living. It specifically set out to address the question: “what is the role of natural supports in facilitating independent living on the part of people with disabilities?” and sought to answer this on the basis of the research evidence available.

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Chapter 1

Introduction to the Study

1.0 Introduction and Context for the Study

This report was commissioned by the National Disability Authority (NDA) to present a review of literature on natural community supports in the context of independent living. It specifically set out to address the question: "what is the role of natural supports in facilitating independent living on the part of people with disabilities?" and sought to answer this on the basis of the research evidence available. Independent living was defined by the NDA as people with disabilities 'having choice and control over the support they need to go about their daily lives and any practical assistance being based on their own choices and aspirations' and at the behest of the NDA, literature relating to the domain of employment was not included in the review. Implicit in the definition above is that independent living is community-based, whether in a group home, other forms of supported accommodation, living with friends or living alone. Institutional settings such as nursing homes or long stay-hospitals were excluded. The focus of the review was on adults (over 18) with physical, sensory, intellectual and cognitive disabilities; in effect, however, the principal focus is on those with intellectual disabilities (and mainly those with intellectual disabilities who are in contact with service providers) as this is the category of disability most frequently covered in the relevant literature. One cannot assume that research findings for this group of people can be generalised to all those with an intellectual disability, far less to the wider population of people with other forms of disability. The research has value, however, in highlighting key areas of concern and debate in relation to this category of disability and a broader value in relation to the types of issues that need to be considered by policy makers in designing measures to promote the development of natural supports.

In Ireland, as in most other countries in the developed world, it is people with intellectual disability who are also most likely to reside in residential settings. There are approximately 300,000 people with disabilities in Ireland. Currently there are two sources of data on their living arrangements: the National Physical and Sensory Disability Database (NPSDD) which relates to people with a physical or sensory disability; and the National Intellectual Disability Database (NIDD) which relates to people with an intellectual disability. The annual analysis of these databases shows the extent of variation in the living circumstances across people

with these two types of disability. It should be noted, however, that only the circumstances of those registered with these databases are reflected in the figures.

As of December 2009 29,948 people with a physical disability were registered on the NPSDD, of whom 26,169 were aged less than 66. An analysis of this group showed that 85.6% lived with family members, 9.6% lived alone and just 2.9% were in residential services. Data from the 2009 Annual Report of the NIDD Committee shows that 26,066 people with intellectual disability were registered, and of these 31.7% were living in full-time residential services. That is almost ten times the proportion of those with physical disability. Those in residential services were mostly living in community group homes or residential centres with just 1% in psychiatric hospitals. Only 3.8% of those on the database were living independently or semi-independently while 64.2% lived in the family home with parents, relatives or foster parents. This report also revealed the correlation between age and residential living: 97.8% of those aged under 18 lived at home, compared to 49.3% of those over 18. The likelihood of living in full-time residential services was also related to level of intellectual disability: those with a mild intellectual disability were less likely to be in full-time residential services and, when they did so, were more likely than those with moderate, severe or profound intellectual disability to be in community group homes.

Internationally, the number of people with an intellectual disability who are living in institutional settings has been decreasing dramatically over the past three decades. In the USA the number of institutional beds decreased from 194,650 in 1967 to 48,496 in 1999. In England, institutional beds have decreased from over 51,000 in 1976 to less than 4,000 in 2002. Similar trends have been noted in Australia (Lemay, 2009). In addition, people with developmental disabilities are increasingly residing in smaller residences or group homes. In the USA, the number of individuals living in homes with fewer than four residents increased from 18,304 in 1996 to 195,450 in 2006 (Lemay, 2009) In other jurisdictions too, the trend is towards group home models catering for small numbers. In Ireland, a group home is defined as 'a standard domestic-style house in a residential neighbourhood where a small number of people with an intellectual disability live together with appropriate staff supervision' (NDA, 2009). However, the group home model has been criticised for replicating the routine and regimes of the larger institutions (National Health Committee, 2004) and, in some jurisdictions, has led to a move towards more flexible and individualised alternatives (NDA, 2009).

It is in this context of deinstitutionalisation and the move to community living, and the further shift to individualised supports, that the relevance of natural supports becomes particularly germane.

The current policy interest in natural supports is also linked to an overarching shift in disability policy globally. This policy emphasises independent living as the optimum situation for people with disabilities and is reflected in the move from institutionalisation to community living noted above. Independent living approaches and community-based services are widely considered to enhance the

quality of life of people with disabilities (Forrester Jones et al, 2006), as well as potentially incurring exchequer savings (Lemay, 2009). The key drivers of these approaches, therefore, are (1) an understanding of disability services which emphasises the principles of inclusion, participation and equality and (2) a concern with cost-effectiveness which anticipates potential benefits to the state of relocating disability supports to social and community settings.

These developments are evident also in a wider body of disability policies and measures such as person centred planning, individualisation and direct payments. Some of these enabling measures are in place in other jurisdictions but most are in their infancy in Ireland, and are frequently only at the stage of being explored. In many respects, therefore, this is a critical juncture in the development of disability services in Ireland, and it is entirely appropriate that the ongoing formulation of policy in this sector should be informed by international best practice and supporting research. This, then, is the objective of the current study: to provide a knowledge resource for policy makers by bringing together and critically reviewing available evidence on the role and potential of natural supports in enhancing the autonomy and independence of people with disability.

1.1 Literature on Natural Supports

At the outset, a key concern was to ensure the relevance and quality of research and evidence based material to be included in the review. To achieve this, the following parameters were established:

- The review was to be confined to material published after 1990 and more especially material published in the past ten years. This was to ensure that the review focused on the most recent relevant material available.
- The review was to be confined to two main bodies of work: (a) material published in the English language and relating to the jurisdictions of the Republic of Ireland, Northern Ireland, Great Britain, USA, Australia and Canada; (b) material published by international disability organisations or other relevant international bodies.
- Quality control mechanisms were to be used, such as, including only peer reviewed material, and studies with robust methodologies and generalisable results.

The initial literature search using the term 'Natural Supports' and 'Natural Community Supports', however, quickly revealed that very little material has been produced on these themes in the past twenty years outside the domain of employment. Consequently, there is very little research evidence of the role of natural supports per se, and even less on their role in supporting independent living. For this reason, the scope of the search was broadened and new search terms used with the term 'social networks / social support' being substituted for that of 'natural supports'. As Bigby (2008) notes, social networks provide a framework for the study of relationships, and can be seen as the vehicle through which informal support (i.e. natural supports) might be exchanged. Similarly,

Forrester-Jones et al, (2006) note, social networks are 'opportunity structures' for a range of relationships which may or may not provide a person with various types of social support.

The initial search using the term 'independent living and social support' produced a large body of literature, but the preliminary analysis of abstracts revealed that much of this was focused on young people, on those with mental health issues, on employment, or in some other way fell outside the concerns of this review. Consequently, the terms 'community participation and social inclusion' were substituted for 'independent living'. This produced a more relevant body of literature. It is generally recognised that independent living has three elements: (1) productive activity (i.e., employment and studying), (2) household activity (including domestic activities) and (3) community participation (sometimes referred to as leisure activity) (see Fox-Harker et al, 2002). As noted previously, employment related activity fell outside the scope of this review while domestic activity is, as Verdonschot et al, (2009) point out, a neglected arena of study and consequently there is almost no literature relating to this aspect of independent living (amongst 23 studies reviewed by Verdonschot et al, only one referred to domestic living). Consequently, the term 'community participation' was used as a proxy for independent living, as was the term 'social inclusion'. Thus, the literature search was refocused on literature that referred to social networks and / or social support and / or community participation / social inclusion. McVilly et al, (2006a), amongst others, have identified the link between social networks and community participation. These terms, therefore, have a basis in the literature as indicators of natural supports and independent living.

Broadening the search terms in this way produced a vast and varied body of literature relating to themes such as:

- the meaning and reality of community and social integration for people with disabilities,
- the scale and composition of social networks among people with disabilities,
- measures (such as befriending interventions) to facilitate the social integration of people with disabilities.

Yet, none of this material addressed the key question which this review sought to address: that is the role of natural supports in promoting independent living. In view of this, the focus of the study was broadened to examine the role and **potential** of natural supports in facilitating independent living. This modification, together with the very broad range of literature relating to the key themes of social networks and community participation, meant that it was necessary to amend the search criteria as follows:

- Given that the broadening of the search terms would potentially yield a huge volume of literature, some of which would be only tangentially relevant to the key concern of this review, it was necessary to narrow the search criteria to enable a more manageable body of literature to be reviewed within the time frame of the study. Thus, only literature published after 2000 is included, and in fact, most of the peer reviewed and other material referred were produced in the last five years. This allowed the review to focus on the most recent research evidence available.

- Criteria relating to jurisdiction were relaxed, and relevant material published in the English language is included regardless of jurisdiction (off-setting the narrowing of the time frame). Thus, this review includes research from Norway, Israel, the Netherlands and Hong Kong.
- Within the body of literature dealing with social networks, social support and community participation, a number of methodological considerations arise regarding the robustness of the methodologies used (Verdenschot et al, 2009) and the generalisability of the research findings (Bigby, 2008). The quality control mechanisms, therefore, outlined above had to be relaxed in order to include these studies.
- In addition to the peer reviewed material, some descriptive and prescriptive material that was considered particularly relevant is presented here as context, or as examples of relevant interventions.

The outcome of this modified search was a sample of very recent literature, drawn from a range of jurisdictions, and reflecting both peer reviewed studies and more descriptive material. It must be stressed that, in view of the broadening of the focus of the review and the necessary changes to the search criteria, this review does not claim to be fully comprehensive. It does, however, claim to be a focused assessment of the most recent material pertaining to the broader set of issues that can be seen as relevant to natural supports, and presents the most relevant and recent research data on this issue. The review, therefore, includes the most relevant references necessary to grasp the current state of research and debates on the broader issue of the role of social relationships in supporting community living. It has to be stressed again that very little of the literature reviewed here directly refers to natural supports or independent living. The main work of this review, therefore, was not to summarise the existing literature, but rather, to draw out from the reviewed studies any research evidence that could point to learning for policy and service development in relation to natural supports and independent living.

1.2 Methodology

The elements of the search-methodology were as follows:

1. Academic search engines

The principle search engines used in the initial trawl were ERIC, INFOMINE, OPENJGATE and DOAJ (Directory of Open Access Journals). Of these, ERIC proved most useful and was the most frequently used. The initial search terms used were 'Natural Supports' and 'Natural Community Supports'. But, as noted, these terms produced very little material. Subsequently, the search terms were broadened to include the related terms of 'social networks', 'social supports' and 'community participation' (see Table 1.1).

2. Journal searches

Following the initial searches on ERIC and other search engines, the online directories of those journals which featured most prominently in the results were then searched using the extended list of search terms. These journals were

- Disability and Rehabilitation
- Disability and Society
- International Journal of Rehabilitation Research
- Journal of Applied Research in Intellectual Disability
- Journal of Disability Policy Studies
- Journal of Learning Disabilities
- Journal of Social Work in Disability and Rehabilitation
- Journal of Vocational Rehabilitation
- Psychiatric Rehabilitation Journal

In addition, and to ensure comprehensiveness, the following Journals' on-line directories were also searched:

- British Journal of Sociology
- Social Policy
- Sociological Research On-line
- Sociology

The latter produced little or no relevant material highlighting the extent to which disability related issues, even in the context of community living, are largely confined to the specialist journals.

3. Bibliographical follow-up

Material listed in the bibliographies of relevant articles (and which had not been located through the above methods) were sourced as appropriate. Consequently, the data search was ongoing throughout the study.

4. Website searches

The final element of the methodology was searches of the websites of relevant organisations and agencies. These included organisations of people with disabilities, formal service providers, statutory agencies and policy making bodies. This element of the methodology was also ongoing throughout the study.

This methodology produce 31 peer reviewed articles dealing with social networks, social support and community participation. These form the basis of the literature review. In addition, a further 16 articles are also included here to provide context or relevant examples of interventions to promote natural supports.

Table 1.1: Overview of Search Terms and Outcomes.

Search Terms	Number of Articles	Number* reviewed	Number included as example or context
Natural supports	27	0	6
Social networks / support	110	24**	4
Social capital	32		
Independent living	363	20**	6
Social integration	447		
Community participation	246		
Total	Na	30	16

* Number meeting search criteria.

** A number of studies focus on both social networks / social capital and on independent living / social integration and community participation.

1.3 A note on the Reviewed Literature

The literature reviewed in this document can be grouped under the following headings:

- Literature which examines social networks amongst people with disabilities. This literature, much of which focuses on people with intellectual disabilities, explores the extent and scale of social networks amongst people with disabilities and, less frequently, the actual support provided by members of these networks. It may also explore their experiences and aspirations in relation to interactions with friends, neighbours and family members. The available literature on social networks, in general, does not directly engage with the issue of independent living.
- Literature broadly focused on community participation. The most contemporary examples of this literature explore the quality of life of people with disabilities living in the community. Issues explored include:
 - an ordinary life versus a good life,
 - the benefits of community living versus the risks (isolation, neglect, abuse),
 - participation versus belonging.
- The literature includes empirical research with people with disabilities, as well as discussions of the experience of community participation and social inclusion.
- Literature which is frequently developed by practitioners and/or researchers. This literature is typically concerned with how professionals and paid workers (i.e. the service delivery systems) can contribute to the development or reinforcement of social networks, social inclusion or community participation. Some of this literature acknowledges the tensions between professional modes of operating and those of the providers of natural supports, as well as the tensions between people with disabilities and those who provide support for them.

The above material, which forms the main content of the review, is amplified by material which focuses on interventions to build social capital or natural supports, including those spearheaded by family and friends, by people with disabilities themselves, and community-based interventions such as befriending

programmes. Some of this material is descriptive / biographical or prescriptive and written by people with disabilities or their representative organisations.

Overview of the report

The report structure is as follows:

- Chapter 2: Provides an overview of the contemporary international policy frameworks, as well as some examples of disability policies in various jurisdictions. The National Disability Strategy is also noted here.
- Chapter 3: Provides an overview of the research relating to social networks, social support and community participation. It highlights some of the shortcomings in the research, as well as noting contemporary debates on the issue of community living for people with disability. Definitions of natural community supports are also looked at in this chapter.
- Chapter 4: Presents the detailed review of the peer reviewed literature drawing out the evidence in relation to natural supports and their role in promoting community participation. The chapter examines the scale and composition of social networks amongst people with disability, the type of support members of these networks provide, the correlation between social networks, social support and community living and the extent to which social networks can facilitate community participation.
- Chapter 5: Picks up on the main themes emerging from Chapter 4 and looks at interventions to support the development of natural supports amongst people with disabilities. The interventions examined include:
- support circles,
 - peer based strategies,
 - individual capacity building,
 - befriending / community building approaches.
- Chapter 6: Factors that act as barriers to natural supports are discussed as are those that can facilitate their development. This chapter concludes with a discussion of the policy implications arising from the review.

Summary of Key Points

- The original research question which this review sought to address concerned the role of natural supports in promoting independent living. This question has relevance for both the development of policy and service delivery in Ireland. Greater usage of natural supports can potentially provide benefits for people with disabilities, in terms of their greater independence and for the State, in terms of more cost effective services.
- Preliminary searches indicated a lack of literature directly relating to natural supports, per se, as well as to their role in supporting independent living. As a result the search criteria were expanded and the term ‘social networks’ was used as a proxy for natural supports while the terms ‘community participation’ and ‘social inclusion’ were substituted for independent living. These revised terms produced a broader range of material than initially envisaged (including some non-peer reviewed literature) and in order to include an appropriate cross section of this material, the research question was modified to refer to the **potential** of natural supports in relation to independent living.
- This broadening of the search criteria resulted in a very substantial body of literature. Further refinement of the search criteria resulted in 30 recently published peer-reviewed articles, which form the substance of this review and a further 16 texts which are used here for context, elaboration and examples of interventions to promote natural supports.
- Given the modified search criteria, this review does not claim to be fully comprehensive. In addition, most of the studies reviewed here relate to people with intellectual disabilities. The generalisability of the findings of these studies to the broader population of people with disabilities, therefore, cannot be determined and certainly should not be assumed.
- However, the review does provide a focused assessment of the most recent material pertaining to the broader set of issues that are relevant to understanding the potential role of natural supports in supporting independent living. It also highlights the research evidence from these studies that point to learning for policy and service development in relation to natural supports and independent living.

Chapter 2

Developments and Trends in Disability Policy

2.0 Introduction

Since 1990, the main thrust of disability policy, globally as well as in Ireland, has been away from segregationist and institutionalised services towards supporting people with disabilities to live their lives independently in the community. Key to that development was a shift from a medical model of disability to a more social understanding. This understanding holds that the main barriers to full citizenship faced by people with disabilities are imposed by the economy, culture and society in which they live. As Johnson et al, (2010) comment when describing the recent period of policy development: "Normalisation, social role valorisation, deinstitutionalisation, person-centred planning, the social model, and more latterly, personalisation have informed the way in which service providers, policy developers and advocates have shaped the lives of people with intellectual disabilities" (Johnson et al, 2010).

Importantly, this was a policy shift that was demanded by people with disabilities themselves, who over the period increasingly argued for better services and better policies to facilitate independent living (Evans, 2004; Martinez et al, 2003). The wider community also frequently welcomed this new paradigm, in response to a growing public awareness of the abuses and neglect sometimes experienced in institutions. Finally, it was compatible with Government requirements to find more cost effective ways of meeting the needs of people with disabilities. Across a wide range of countries including the UK, Australia, Canada, the USA and Ireland, there have been changes at policy and service level commensurate with these global trends. Challenges remain to achieving full community living, however, and there is an ongoing search for more effective policies and practices to support people with disabilities to live independent lives (Kendrick, 2009; Dunn, 2002).

In general, policy objectives as they are articulated in national (or federal) strategies tend to be broadly stated, emphasising choice, control and citizenship / participation and sometimes drawing on rights based aspirations. They are less precise in describing the policy mechanisms necessary to underpin these aspirations or to reflect them in service delivery. In some jurisdictions, Disability Strategies and Independent Living Strategies help close this gap between the broad policy objectives and the means to achieve their stated aims, by identifying a range of measures to support community participation and independent living – such as direct payments. In jurisdictions, including Ireland, where Independent Living strategies have not been developed by Government, there are nonetheless services that can support independent living such as Personal Assistants. In this chapter, the broad global policy frameworks are summarised and key themes within them are amplified with reference to specific strategies and policies for disability and independent living in a number of jurisdictions.

2.1 International Policy Frameworks for Disability

What has been called a 'paradigmatic shift in policy for disability' emerged in 1993 with the UN adoption of the Standard Rules for the Equalization of Opportunity for People with Disabilities. The Standard Rules sought to articulate a new concept of disability. It established a relationship between the limitations experienced by people with disabilities and the design and structure of the environment, as well as the attitudes of the general population. Although they were not legally binding, the Standard Rules were hugely influential. Thirteen years later, the UN Convention on the Rights of Persons with Disabilities was adopted by the 8th General Assembly in December 2006 and came into force in May 2008. The purpose of the Convention is to:

"Promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."

The UN Convention builds on existing human rights treaties including the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social, and Cultural Rights and it operates alongside and in synergy with the Standard Rules. The Convention contains 50 Articles covering a range of areas pertaining to the human rights of people with disabilities and to States' responsibilities in regard to these. The Convention, as a whole, is an important driver of policy change in relation to disability but a number of the Articles are particularly relevant to the issue of independent living. These include Article 24 which covers education, Article 27 which relates to work and employment, Article 29 which deals with participation in public and political life and Article 30 which relates to participation in cultural life, recreation, leisure and sport.

Article 19 which specifically refers to living independently and being included in the community is particularly relevant to the concerns of this review. This Article states:

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The Convention firmly establishes a rights based approach to disability and is expected to be a major factor in the reform of disability policy and law throughout the world (Quinn, 2010). As of February 2011, a total of 82 countries have ratified the Convention including the UK, fifteen other member states of the EU, Australia, New Zealand and Canada. In December 2010, the Convention became the first UN human rights convention to be ratified by the EU itself. Ireland was one of the first countries to sign the UN Convention on the Rights of People with Disabilities but, at the time of writing, has yet to ratify it.

2.1.1 Some International Approaches to Disability Policy

Internationally, the themes of the UN Charter are reflected in disability policies in numerous jurisdictions.

- In the USA, the Americans with Disabilities Act (2004) embodies a rights based approach and has been called a milestone in the USA's commitment to the Charters of Freedom, the founding documents of the USA which comprise the Declaration of Independence, the Constitution and the Bill of Rights. The Americans with Disabilities Act extends Government backed rights to people with disabilities and, in particular, seeks to guarantee equal opportunity for all individuals with disabilities and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. Recent legislation in the USA (called the ABLE legislation) introduced in 2009 complements the Americans with Disabilities Act by enabling trust funds to be built up by people with disabilities, using targeted and cost-effective tax breaks that allow adults to purchase the services they need. The Americans with Disability Act also established a National Council on Disability within the Federal Government which is charged with "advising the President, Congress and other federal agencies regarding policies, programs, practices and procedures that affect people with disabilities". (www.ncd.gov/about) The National Council on Disability operates a policy of engagement with people with disabilities through conducting hearings to enable people with disabilities to be part of policy and budget debates; it convenes Policy Summits and regional forums on the key themes of living, learning and earning and seeks to develop ongoing policy on this basis; finally, it operates through a series of ad hoc working groups to help develop actionable policy recommendations and find ways to implement these recommendations.
- In Canada, as elsewhere, the demand for independent living emerged from grass roots organisations many of which delivered innovative services to people with disability. Throughout the 1990s and beyond, the Canadian government adapted policies to support independent living. This was reflected in moving people from institutions to community-based services, more coordination of services, development of single point entry,

decentralized services, individual planning and funding, and cross-disability supports. The main policy directions in Canada include housing adaptations, transportation services and personal supports. The new policy paradigm also emphasised consumer control, choice and flexibility so that consumers could control their own services. Thus, individualized funding programmes and microboards were established to allow individuals to direct their own personal supports (Dunn, 2002).

- In Australia, policy has also emphasised concepts such as inclusion, integration and participation and these are seen as central to the vision of disability policy (Bigby, 2008). In 2008, the Australian Government introduced a new disability framework which advocates greater economic independence for people with disabilities. These policy objectives are reflected in the Disability Strategies and Plans of the various states throughout Australia. One of the three goals of the Victorian State Disability Plan, for example, is to build inclusive communities, and one of the standards for disability services is to support the participation and integration of each client to be involved in the life of the community. An important delivery mechanism in Australia has been the development of new positions in local government, Community Liaison Workers, specifically to foster community relationships for people with disabilities. Community Liaison Workers work with people living in community settings, including those in supported accommodation, and seek to build natural supports within their local community (Clement and Bigby, 2009).
- New Zealand's disability policy follows the same lines as that of its neighbour and the New Zealand Disability Strategy has, as its main aim, a strategy of transformation from a disabling to a fully inclusive society, with progress benchmarked against the participatory presence of people with disability in mainstream activity. In addition to actions to promote independent living, the strategy also recognises the role of natural supports and the needs of those who provide them. It promotes a wide range of actions, including the provision of supports for the natural supporters of people with disabilities. It also promotes the inclusion of people with disabilities and those who provide support for them in policy and service development.

2.2 Disability Policy in Europe

The objectives and direction of the UN Convention are reflected in European policy on disability. Two key policy strategies are relevant here. The first of these is the Council of Europe Disability Action Plan (2006 – 2015). This document acknowledges the UN Convention on the Rights of Persons with Disabilities (subsequently ratified by the EU) and gives effect to the Malaga Ministerial Declaration on People with Disabilities (2003) which stressed 'progressing towards full participation as citizens'. The plan recognises the need for a broad spectrum of public policy to support the participation of people with disabilities. It comprises 15 Action Lines covering a range of areas of relevance to community living. These are as follows:

Action Line 1: Participation in political and public life
Action Line 2: Participation in cultural life
Action Line 3: Information and communication
Action Line 4: Education
Action Line 5: Employment, vocational guidance, training
Action Line 6: Built environment
Action Line 7: Transport
Action Line 8: Community living
Action Line 9: Healthcare
Action Line 10: Rehabilitation
Action Line 11: Social protection
Action Line 12: Legal protection
Action Line 13: Protection against violence and abuse
Action Line 14: Research and Development
Action Line 15: Awareness raising

The Council of Europe Disability Action Plan provides a framework to which policy makers in the member states can refer when designing, implementing and evaluating disability policies and strategies. Action Line 8 which refers to community living states: "This action line focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices on how and where they live". Referring to the need for appropriate policy to support this, it states: "Independent living policies are not just confined to living arrangements, but are also dependent on the accessibility of a broad range of services, including transport". Thus, the Plan identifies the actions that can be taken by member states as follows:

- To ensure a co-ordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life;
- To develop and promote housing policies which enable people with disabilities to live in suitable housing in their local community;
- To support formal and informal help, making it possible for people with disabilities to live at home;
- To recognise the status of carers by providing them with support and relevant training;
- To have the needs of families as providers of informal care thoroughly assessed, especially those with children with disabilities or caring for persons in need of a high level of support with a view to providing information, training and assistance including psychological support to enable life within the family, paying particular attention to the reconciliation of private and professional life and to gender equality;
- To ensure community-based quality service provision and alternative housing models, which enable a move from institution based care to community living;
- To ensure that individuals can make informed choices with the assistance, when appropriate, of a skilled advocacy service;
- To promote schemes which will allow people with disabilities to employ personal assistants of their choice;
- To provide complementary services and other facilities, for example, day centres, short-stay centres of self-expression groups, offering suitable forms

of therapy to give people with disabilities and their families periods of support and respite;

- To provide people with disabilities in particular those in need of a high level of support, with tailored support provision, including advocacy in order to reduce any risk of social exclusion.

The Council of Europe Disability Action Plan is paralleled by the Disability Action Plan of the European Commission which is focused on reinforcing the work of the Member States in relation to disability policy. The objective of the Commission's disability strategy since 2003 has been to make equal opportunities for people with disabilities a reality by ensuring that disability issues are integrated within all relevant EU policies. This approach, called "mainstreaming of disability issues" means that disability issues and interests should not be isolated and treated separately, but be taken further into the 'mainstream', into general provisions, legislation and society as a whole, so that it recognises the needs, as well as the contribution, of people with disabilities. According to the website of the European Commission, mainstreaming involves "analysing the relevant policy areas from the disability perspective, understanding the diverse needs of people with disabilities and taking them into account when developing policy".

2.2.1 Some European Approaches to Disability Policy

Independent living assumed a central role in the UK's policy on disability in 2008 when the **Independent Living Strategy** was published. The Strategy sets out actions aimed at improving the choice and control people with disabilities have over the services they need to live their daily lives. The aims of the strategy are that:

- people with disabilities (including older people with disabilities) who need support to go about their daily lives will have greater choice and control over how support is provided; and
- people with disabilities (including older people with disabilities) will have greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

In December 2009, the Scottish Government, the Confederation of Scottish Local Authorities (COSLA), and the Independent Living Movement in Scotland, signed up to a shared **Vision for Independent Living** in Scotland. No similar national strategy exists in Northern Ireland or in Wales.

Sweden is recognised as being at the forefront of deinstitutionalisation and mainstreaming of policy for people with disabilities. The main policy document is **From Patient to Citizen adopted by the Swedish Parliament in 2000**, which outlines a national action plan for disability policy. This action plan covers all sectors of society and shows disability policy to be of an inter-sectoral nature. The key objectives of the plan relate to diversity, participation and equality. Sweden has also been to the fore in promoting independent living, and personal assistance for people with significant mobility / physical impairments is considered a right and is financed by direct payments, allowing the users to employ personal assistants who may be members of their family.

2.3 Disability Policy in Ireland

Although Ireland was one of the first countries to sign the UN Convention on the Rights of Persons with Disabilities, it has yet to ratify it. In effect, Ireland takes a 'common law' approach whereby ratification will not take place until all necessary legislation has been brought into line with the Convention. Although in 2008 the Government stated its intention to ratify it as quickly as possible (Dail Debates, 2008), work remains to be done in the area of legislation, most notably in the area of Legal Capacity.

Notwithstanding this, what Conroy (2010) describes as a flurry of legislation in the area of disability was enacted throughout the 1990s. This was triggered by the establishment of the Commission on the Status of People with Disabilities in 1993. Its report, *A Strategy for Equality*, marked the modernisation of concepts and practice in the Irish context and by the middle of the decade, thinking about disability in Ireland, as elsewhere, had undergone significant change (Conroy, 2010). Central to this was a shift from a medical model of disability which emphasised care, to a social model which emphasised independent living. In line with the latter, the Commission on the Status of People with Disabilities made a number of recommendations on the basis of three guiding principles – equity, maximising participation, and enabling independence and choice. These recommendations echoed the demand for greater inclusion in all aspects of Irish society by people with disabilities (Report on Consultation with People with Disabilities (1995) and the emergence of a call for a rights based approach to disability.

Currently, the key framework in the area of disability in Ireland is the National Disability Strategy which was introduced in 2004. The National Disability Strategy comprises a number of components namely, the Disability Act 2005, the Citizens Information Act 2007, the Education for Persons with Special Educational Needs Act 2004, a multi-annual investment programmes for disability supports services and sectoral plans prepared by six Government Departments (Health and Children, Social Protection, Transport Tourism and Sport, Environment Heritage and Local Government, Enterprise Trade and Innovation, Communications Energy and Natural Resources). The Disability Act 2005 is recognised as the central element of the Strategy. The Act makes provision for the individual right to an independent assessment of need and a related service statement. It also provides a statutory basis for access to public buildings and services. The NESC referred to the Act as a major watershed in Irish social policy in recognising as never before the place of persons with disabilities in Irish society, and of the State's responsibilities to ensure they participate on an equal basis to other citizens (NESC, 2006).

Other Irish policy documents are also significant for people with disabilities particularly in the context of independent living. The ten year framework agreement drawn up under the social partnership process (*Towards 2016*) states: "parties to this agreement share a vision of an Ireland where people with disabilities have, to the greatest extent possible, the opportunity to live a full life

with their families and as part of their local community". Among the goals included in the document are that persons with disability would have support to enable them, as far as possible, to lead full and independent lives, to participate in work and in society, and to maximise their potential. The document also commits to acknowledging and supporting carers in their caring role.

An interim report on the policy implications of the ongoing 'Review of the Efficiency and Effectiveness of Disability Services in Ireland under the remit of the Value for Money and Policy Review Initiative 2008-2011' was published by the Office for Disability and Mental Health in December 2010. The report cited new policy goals including the goal of full inclusion and self-determination for people with disabilities, and the goal of a cost-effective, responsive and accountable system which will support the full inclusion and self-determination of people with disabilities. Under the former goal, key policy proposals include reframing provision from disability services to individualised supports. Individualised supports are defined as a personal social service which includes a range of assistance and interventions required to enable the individual to live a fully included life in the community. The interim review also proposes a support model which includes family / natural supports as the first line of support, (as well as friends and neighbours), informal supports such as those provided by community organisations and voluntary organisations, and formal supports such as those provided by mainstream service, health supports etc. Under the new policy proposals, a person living in the family home would also have access to individualised support packages and various models of respite support would also be available to families.

Ireland does not have an independent living strategy, but service development over the years has achieved some progress in supporting people to live independently. A report on the implementation of Irish policies supporting independent living for people with disabilities was produced by the Centre for Disability Law and Policy for the Academic network of European Disability experts (ANED) in 2009. Among the supports for independent living which that report identifies are personal assistance programmes, home help, and grants to cover housing adaptation and mobility aids. Social housing provision was also noted, as was supports to carers which include financial support such as the Carers Allowance and Carers Benefit.

2.4 Issues in Irish and International Policy

In Ireland, the Disability Act 2005 forms what has been called 'the legislative centrepiece' of the National Disability Strategy. However, it has been criticised for not being robust enough in its protection and underpinning of the rights of people with disabilities. Certain aspects of the Disability Act have been described as having a limited rights-based grounding, and the absence of a substantive role for the legal system in providing remedies has also been noted (De Wispelaere and Walsh, 2007). These authors argue that there appears to be no agreed foundational benchmarks that specify what rights must be protected, or at what level (De Wispelaere and Walsh, 2007).

Quinn (2010), has noted that some areas of legislation have not yet been made commensurate with the UN Convention on the Rights of Persons with Disabilities, most notably the Criminal Law Sexual Offences and Crimes Act 1993. This Act forbids people with a 'mental handicap' who are deemed unable to live independently to engage in penetrative sexual acts unless they are married. This legislation has led to concerns among service providers about supporting people with intellectual disabilities to develop relationships or express their sexuality (Quinn, 2010).

Services to support independent living have also been criticised. The Centre for Disability Law and Policy (2009), for example, states that significant barriers arise in relation to support for people with disabilities who want to live in their own homes but cannot afford to buy a property. Similarly services such as personal assistance and home help are underfunded, subject to waiting lists, and unevenly provided across the country. The report notes that "this underfunding and uneven access may indicate that Ireland is falling short of the standards required by Article 19 (b) of the UN Convention on the Rights of Persons with Disabilities". The Citizens Advice Board and Disability Federation of Ireland also noted that supports for independent living are under resourced, and that there is a lack of clarity about entitlements and options arising from different models of delivery in different parts of the state (Citizens Advice Board and Disability Federation of Ireland, 2007). A further problematic issue pertaining to independent living is that no formal mechanisms for measuring the quality of community-based assistance and services, or their impact on quality of life, are currently in existence (Centre for Disability Law and Policy, 2009; NDA 2009).

Ireland is not alone in falling short of commitments to achieve greater independence and inclusion for people with disabilities. Writing in the Canadian context, for example, Dunn (2002) notes that despite policy changes, most people with disabilities continue to confront multiple barriers including "profound and pervasive discrimination". Programmes across Canada, he writes, are a patchwork, with large disparities whereby some regions offer few supports and others offer none; rural areas frequently have poor services. In addition, many services have been eroded by government cuts in the 1990s and more services became privatized. Consumer control is limited because individuals with disabilities often have little input in developing and implementing government policies and programmes. Dunn also notes that limitations on personal supports also restrict the lives of individuals with disabilities. He argues that for Canadians with disabilities to have a real opportunity to live independently in the community, Government initiatives must actively incorporate independent living principles, ensure consistency of comprehensive services across Canada and establish concrete, enforceable human rights.

Similarly, despite placing the social model of disability at the cornerstone of the New Zealand disability Strategy, limited progress appears to have been made in advancing the social inclusiveness of New Zealand communities since the policy decision to close all New Zealand institutions in 1985 (Milner and Kelly, 2009). Clement and Bigby (2009) also note the gap between the policy objectives set by policy makers in promoting social inclusion in Australia and how these policies are

understood and implemented by service providers. Significant variation also exists across states in the USA. In 2004, for example, 80% of the state of Illinois long-term care funding is spent on nursing homes and other institutional care while the number of people with disabilities under 60 living in nursing homes had increased by 25% over the period 1997 to 2003 (Minkler et al, 2008). These statistics highlight the complexities involved in promoting independent living and the consequent challenges for policy and service development.

Summary of Key Points

- For the past three decades or so, policy for disability has been characterised by a focus on deinstitutionalisation, the promotion of independent living and the emergence of a rights based approach. The latter is evidenced by the UN Convention on the Rights of Persons with Disabilities and its ratification by Governments from 82 countries.
- In the European context, the rights based approach enshrined in the UN Convention is echoed in both the Council of Europe Disability Action Plan (which provides a framework to which policy makers in the member states can refer when designing, implementing and evaluating disability policies and strategies) and Disability Action Plan of the European Commission (which is focused on reinforcing the work of the Member States in relation to disability policy).
- Within individual countries, Disability Strategies and Independent Living Strategies emphasise inclusion, independence and participation and promote a range of activities to support these objectives. In some jurisdictions, the need to support those who provide support (including natural supports) is also recognised.
- In Ireland, the cornerstone of disability policy, the National Disability Strategy, reflects the international shift from a medical care model to a social independent living model and this is evidenced also in other policy documents, including social partnership agreements.
- Irish policy also acknowledges the potential of natural supports. The interim report on the policy implications of the ongoing 'Review of the Efficiency and Effectiveness of Disability Services in Ireland proposes a support model which includes family / natural supports as the first line of support, (as well as friends and neighbours), informal supports such as those provided by community organisations and voluntary organisations, and formal supports such as those provided by mainstream service, health supports etc.
- Despite progress in deinstitutionalisation and the development of policies and strategies to promote independent living, it appears that in many jurisdictions people with disabilities continue to experience social exclusion and problems with service delivery to combat this. These

problems include lack of adequate funding for services, geographical variation in services within countries and poor consumer control.

- Overall, the degree of social inclusion envisaged by international and national policy objectives has not been achieved. This highlights the need for ongoing review, monitoring and development of more appropriate and effective policies to support independent living on the part of people with disabilities.

Chapter 3

An Overview of the Reviewed and Contextual Literature

3.0 Introduction

This chapter provides an overview of the literature reviewed in Chapter 4. As noted in Chapter 1, literature directly relating to natural supports and their role in facilitating independent living could not be sourced. Consequently, the material reviewed in Chapter 4 relates to alternative concepts: social networks substitutes for natural supports and community participation for independent living. In this chapter, a brief discussion of definitions of natural supports prefaces an overview of the literature relating to social networks and social supports. Some current debates in community participation are then examined. The chapter concludes by drawing attention to a number of preliminary policy considerations.

3.1 Natural Supports: definitions and understandings

The use of the term natural supports can be traced back to the mid-1970s when an academic literature focused on communities began to identify the role of family, friends, and neighbours, in helping people cope with specific difficulties; including health and disability issues as well as the general activities of daily living. That literature emerged in the United States (see for example Hunter and Staggenborg, 1986) but was quickly reflected in similar studies in the EU context (for example Chanin and Vos, 1989). The 'discovery' of natural supports by researchers and policy makers at that time has been linked to the then fiscal crises, and the need for the State to find more cost effective ways of delivering welfare (O'Connor, 1973).

The early literature on natural supports specifically in relation to disabilities focused explicitly on how the family and friends of people with disability could, by working together in a structured way, promote independent living. Approaches such as Support Circles (following the now famous Joshua Committee established in the mid 1970's by Judith Snow and her friends), and similar interventions were widely discussed in this early literature (see for example Frost and Pearpoint, 1992). Over the decades since, the use of the term natural supports appears to

have abated within the academic literature, with the exception of that relating to the employment of people with disabilities, where it has been widely utilised and predominantly focused on the role of job coaches in supporting the emergence of 'natural supports' among co-workers in the work place. To date, the focus on natural supports in employment settings has not been replicated in broader community contexts.

Within the limited literature that does exist, few writers offer definitions of natural supports outside the arena of employment. Storey and Certo (1996) are an exception here, in that they provide a definition of natural supports which is explicitly linked to independent living and also stresses the distinction between natural supports and formal supports (i.e., disability service providers). Their definition covers both the employment and the broader community context.

"Natural supports are people who are not disability service providers but who provide assistance, feedback, contact or companionship to enable people with disabilities to participate independently, or partially independently, in integrated employment settings or other community settings" (Storey & Certo, 1996).

A somewhat different definition is offered by the USA Department of Developmental Services on their website. This definition stresses relationships developed in a broad range of contexts and puts the emphasis on quality and security of life rather than on independent living.

"Natural Supports" means personal associations and relationships typically developed in the community that enhance the quality and security of life for people, including, but not limited to, family relationships; friendships reflecting the diversity of the neighbourhood and the community; association with fellow students or employees in regular classrooms and work places; and associations developed through participation in clubs, organizations, and other civic activities" (Department of Developmental Services: www.ct.gov/dds/site)

The variation in definition, (and perhaps too the apparent reluctance to provide definitions of natural supports) may not be accidental. The proceedings of the Oregon National Forum on Natural Supports in the workplace (1993) favoured description by features rather than definition, on the basis that this should encourage innovation. Notably, however, natural supports tend to be implicitly understood as support providers rather than support functions. In references to natural supports, therefore, family members, friends and neighbours are the most commonly mentioned supports. Some writers (for example, Allen undated) extend this list to include others in the community who can help in fostering social interactions, such as bartenders and beauticians. An exception to this focusing on personnel rather than function is Bigby (2008), who writes: "Informal support is derived from relationships with family, friends, neighbours

and acquaintances, and is based on personal ties rather than payment. The different conceptualisations of informal support suggest its multidimensional nature and potential to meet social, emotional and instrumental needs". She cites Horowitz (1985), who divided the functions of informal support into four components: emotional support, direct instrumental support, financial assistance, and management of relationships with formal organisations. Significantly, Bigby suggests that the functions embedded in the last component (such as advocacy and monitoring the quality of services) are not easily replicated by formal services (given that these are directly involved in the provision of services and their objectivity thereby compromised) (Bigby, 2008).

Bigby's suggestion highlights an assumption that remains implicit or explicit in most understandings of natural supports, that is, that they are distinct from formal supports (i.e., that provided by paid workers) or informal supports (that provided through community facilities such as sports clubs, social groups etc). Within this, natural supports are implicitly defined in terms of who provides them (being exclusively seen as family, friends, neighbours) rather than what support is provided. More recently, however, there is some evidence in the literature of a tendency to diminish this distinction between paid and unpaid forms of support. McConkey et al, (2009), for example, in their work on building relationships and community with people who have intellectual disabilities, speak in general terms of 'supporters' regardless of whether they are formal or informal, paid or unpaid. Allen (undated) also develops a concept of natural support networks which includes paid workers: "These networks include individuals who are part of organisations or government structures, but who within their local communities provide a listening ear that could individually be viewed as providing natural support".

This blurring of the distinction between natural supports and formal supports is potentially significant for policy and service development, particularly given the growth in some jurisdictions of services such as befriending programmes. Frequently, these programmes are organised and funded by statutory or other service agencies, but the key role is invariably played volunteers (Heslop, 2005). This is a category which therefore straddles the natural / formal support divide.

3.2 Social Networks, Social Support and Social Integration

In the absence of a literature on natural supports and independent living, the closest comparable concept that is widely discussed, is that of 'social network', which as noted in Chapter 1 is seen as providing a potential source of natural support. Most studies recognise that the presence of social networks, per se, cannot not be understood to imply that effective support is available to people with disabilities; and a number have pointed out that relationships can, in fact, be abusive as well as supportive. As Kam-shing and Sung-on (2002) argue, social networks are a means to an end, rather than an end in themselves. Nonetheless, the size and composition of social networks can provide insight into the potential scale of natural supports that may be available to people with disabilities, as well

as some indications as to how the support they provide might promote community participation.

As noted in Chapter 1, the search for literature on social networks, social support and community participation produced 30 recent peer reviewed studies. The table below provides some details on these studies.

Table 3.1: Overview of Peer-Reviewed Studies included in this review.

Date	Author	Location	Overview of Study	Size of sample
2001	Robertson et al,	UK	A study of social networks among people with intellectual disability living in the community.	500
2001	Whitehouse et al,	UK	A study of friendship among men with learning disabilities.	4
2002	Fox Harker et al,	Canada	Independent living outcomes for those with acquired cognitive and physical disabilities.	440 people with spinal cord injury and 47 with traumatic brain injury
2002	Kam-shing and Sung-on	Hong Kong	Study of a befriending intervention for elderly people with disabilities living alone.	Not stated
2003	Helgoy et al,	Norway	Views of people with mobility disabilities and service providers on service provision for independent living.	18 people with disability and 20 service providers
2004	Dudevany and Arar	Israel	Comparison of friendships between people with intellectual disability living in residential settings and in foster families.	85
2004	Bates and Davis	na	Discussion of approaches to promoting social inclusion and developing social capital.	Na
2004	Emerson and McVilly	Northern England	Research into friendship activities among people with intellectual disabilities in supported accommodation.	1,542
2005	Heslop	UK	Review of good practice in befriending services.	25 people with intellectual disability, 15 befrienders
2006	Abbott and McConkey	Northern Ireland	Barriers to social inclusion as perceived by people with intellectual disability.	78
2006	Forrester-Jones et al,	UK	Follow up study of social networks of people with intellectual disability resettled in community.	113
2006 (a)	McVilley et al,	Australia	Study of friendship among adults with intellectual disability.	51
2006 (b)	McVilly et al,	Australia	People with intellectual disability comment on the above study.	11
2007	Anderberg	Sweden	Analysis of online discussions about personal assistance from a Swedish web forum for people with disabilities.	
2007	McConkey et al,	Ireland	Community participation of people with intellectual disability in various types of community settings.	620

2008	Bigby	Australia	Research into people with intellectual disability living in community settings.	24 people with intellectual disability plus family members of 20.
2008	Minkler et al,	USA	Research into outcomes of community care policy for people with physical, intellectual, cognitive and psychiatric disabilities.	200
2008	Traustadottir and Sigurjonsdottir	Iceland	Support networks of mothers with intellectual disabilities.	18
2009	Clement and Bigby	Australia	Study of supporting community participation of people with intellectual disability.	5 people with intellectual disability, 7 staff members.
2009	McClimens and Gordon	UK	Study of supported access to the Internet as a mechanism to develop social capital among people with intellectual disability.	
2009	Verdonschot et al,	International	Review of literature on community participation of people with intellectual disability.	23 quantitative studies
2009	Lemay	Canada	Review of literature on deinstitutionalisation.	54 studies
2009	Lipold and Burns	UK	Comparative study of social support amongst people with physical and those with intellectual disabilities.	30 people with intellectual disability 17 people with physical disabilities
2009	Milner and Kelly	New Zealand	Views of people in different disability categories (including physical, sensory and intellectual) on their place in community.	28
2009	Randall and Cumella	USA	Study of social relationships amongst people with intellectual disability living in an intentional community.	15
2009	Taub et al,	USA	Study of networks of rural women with physical disabilities.	24
2009	Van Alphan et al,	Netherlands	Views and experiences of people with intellectual disability on neighbouring.	39
2010	McConkey and Collins	Northern Ireland	Role of support staff in promoting the inclusion of people with intellectual disability.	245 support staff
2010	McConkey and Collins	Northern Ireland	The value of personal goal setting in promoting social inclusion of people with intellectual disability.	130
2010	Christensen	Norway	Study of careworkers' views of their roles.	526

These studies cover the period 2001 to 2010. Two of them are themselves literature reviews: Lemay (2009), who focuses mostly on USA literature relating to deinstitutionalisation from 1990 to 2005 (approximately, the author does not provide dates), and Verdonschot et al, (2009), which covers 23 studies of social networks and community participation from 1996 – 2006. By including these two reviews, the timeframe of the literature examined is extended considerably.

In assessing the extent to which the findings of these studies can contribute to an understanding of the role of social support in promoting independent living, a number of issues relating to focus and methodology must be borne in mind. Firstly, in many of the studies, the primary focus is on quantifying the number of members of social networks and identifying their composition. Less frequently is the extent to which these network members actually provide support explored. In addition, much of the literature is focused on people with intellectual disabilities who are in contact with service providers and, frequently, living in settings provided by service agencies. Material on the broader population of people with disabilities, or on those who are not in contact with service providers, is very limited.

Secondly, very little of the available literature refers specifically to independent living or community participation, and those studies which do take a narrow focus. Verdonschot et al, (2009) argue that on the basis of empirical evidence (drawing on 23 quantitative studies of social networks and community participation amongst people with intellectual disabilities), 'many researchers did not clearly define community participation and were concerned with limited areas of community participation'. There is also very little comment in the literature on variation across categories of people (with the exception of distinguishing between those with intellectual and other types of disabilities). There are some limited references to differences in the social networks relating to age and gender but few references to ethnicity, or the extent that service models based on a dominant culture or values are appropriate to ethnic minorities (Martinez and Duncan, 2003). In addition, much of the literature is focused on deinstitutionalisation and on comparing the social networks of those relocated to community settings in comparison to the social networks of those in institutions. Explorations of the kinds of community settings that can promote the development of social networks or promote social inclusion are less frequent. These omissions are in keeping with the lack of theoretical models to inform the studies (Verdenschot et al, 2009) or, more generally, with the lack of a sociological perspective that would allow the implications of social support for the lived experience of people with disability to be assessed.

Finally, a number of significant methodological limitations (sometimes acknowledged by the authors) are evident, including very small sample sizes (frequently as low as four or five), poor response rates, a lack of representativeness, and a tentativeness in drawing conclusions on the part of the authors. Verdonschot et al, (2009) in commenting on the studies they reviewed, note that 'research instruments were varied and were most often ad hoc and not validated' (p303). Bigby (2008) suggests that comparing findings on social networks is hampered by differing approaches to defining social relationships (for example some studies include paid staff, others exclude) and different methods of data collection. McConkey (2007) in acknowledging the limitations in his own study also argues for the need for more precise definitions if comparisons are to be made across different studies.

Notwithstanding all of the above, the review presented in Chapter 4 highlights a number of areas where there is broad consensus in the research findings. These relate to the following:

- the limited size of social networks amongst people with disability, and particularly those with intellectual disability;
- the predominance of family members and those associated with service settings in these networks;
- the importance of staff members in providing practical support to people with disabilities; and
- the significance of peers (i.e., others with disabilities) in providing emotional support.

These studies also provide some information on the extent to which support from peers and staff facilitates community participation and note, in particular, the often constraining role of the latter.

3.3 Contemporary Issues in Debates in Community Living

While de-institutionalisation has been state policy in many jurisdictions worldwide for up to three decades, just what is understood by the concept of community living, particularly on the part of policy makers, as well as on the part of service providers, is currently receiving attention in the literature. A number of the studies included here directly address the issue of community participation, although they tend to leave this concept undefined, and as Verdonshot et al, (2009) point out, operate without a theoretical framework.

Some literature (additional to that listed in Table 2.1) has also directly addressed the issue of community participation or social inclusion, in response to research evidence of the marginalisation of people with disabilities within community settings (Kendrick, 2009; Johnson et al, 2009; McConkey et al, 2009). A dominant theme within this body of work is the need for a deeper assessment of the reality of community living for people with disabilities, and particularly for those with intellectual disabilities. A key concern of this literature is to distinguish between having a physical presence in the community and actually belonging to the community. This dichotomy is presented in a number of ways in the literature including the peer reviewed material. Clement and Bigby (2009) contrast community presence (a passive location within the community with little or no interaction with other community members) with participation (actively participating with other community members); Milner and Kelly (2009) differentiate between participation and inclusion; Johnson et al, (2010) distinguish between an ordinary life and the more desirable aspiration of a good life; while Kendrick (2009) highlights the difference between having a life in the community and flourishing as a human being. An important contribution to this debate is the distinction between social inclusion and social capital approaches to community living (Bates and Davis, 2004) which is discussed further later.

Milner and Kelly (2009) trace the problem of social exclusion of people with disabilities living in the community in New Zealand, to the concept of community

which underlies policy developments there. They argue that in the process of depopulating total institutions (that is institutions which catered for the total life experiences of those living there), 'the community' became an epithet for places that looked least like the segregated spaces that were the historical experience of people with disabilities. This understanding of community, it was previously argued by Milner and Bray (2004) predisposed New Zealand policy makers to emphasise spatial presence in the community over other indicators of social inclusion. Interestingly, Clement and Bigby (2009), writing in the Australian context, note how service staff operated with a different understanding of inclusion (one that placed the emphasis on merely having a physical presence in the community) to that envisaged in policy (which stresses participation) to the detriment of people with disabilities. Kendrick (2009) goes further than most in critiquing the rhetoric of community living and highlighting the gap between this rhetoric and the reality of life in the community for people with disabilities. While noting that 'some kind of life' in the community is, on balance, better than the "impoverished lives lived in segregated lifestyles and locations", he argues "There is a profound difference between having a life in the community and flourishing as a human being, though this distinction is rarely examined closely".

A related concept, that of a good life, is proposed by Johnson et al, (2010), who argue that this concept underpins 'aspirations for all of us in the way we live our lives'. Like Milner and Kelly (2009), they link the gap between the aspiration and reality of community living to concepts implicit in policy. They contrast their term, the 'good life' to that of an 'ordinary life' which they argue has underpinned UK disability policy since 1980. An ordinary life, they observe is 'something we generally prescribe for others'. However, consultation with people with disabilities in a number of jurisdictions has found that an ordinary life is exactly what they wish for. As Abbott and McConkey report, "a number of recent studies have investigated people's choice of where they may live, which in the main tends to be in ordinary homes with family or friends and close to local amenities" (Abbott and McConkey, 2006). These writers also note that less attention has been paid to how, rather than where people live their lives, particularly in relation to social inclusion.

In discussing indicators of inclusion, Abbott and McConkey (2006) suggest that social inclusion has been more narrowly defined in the field of disability than in mainstream society. In the disability field, they argue, social inclusion is defined as "greater participation in community-based activities and a broader social network". In mainstream society, Abbott and McConkey note the work of Burchardt et al, (2002), who state that social inclusion embraces other dimensions, such as acting as consumers of goods and services, engaging in political activities, participation in economic and socially valued activities (such as employment and child-rearing), as well as, social engagement with family, friends and the community. Other studies reviewed also put emphasis on participation in valued activities, such as employment and availing of community facilities, but few deal with the issue of child rearing, or indeed, of intimate relationships amongst people with disabilities (exceptions here include Johnson et al, 2010; Traustadottir and Sigurjonsdottir, 2008; Taub et al, 2009).

Other authors also criticise the emphasis on physical presence in community settings as an indicator of quality of life for people with disability, and argue instead for focusing on more participative indicators. Johnson et al, (2010), for example, argue that community equals social ties, meaningful relationships and belonging. The most favoured indicators of social inclusion proposed in the literature include active citizenship (Johnson et al, 2010); opportunities to 'actualise self image' and engage in self-authored activity (Milner and Kelly, 2009; Kam-shing and Sung-on, 2002); a sense of belonging and long-term interaction in the community (Milner and Kelly, 2009; Kam-shing and Sung-on, 2002); and contributing to one's community and to decisions that affects one's own life and the lives of those with whom one is linked (Johnson et al, 2010, Milner and Kelly, 2009, Kam-shing and Sung-on, 2002).

Of more significance for this review is the consensus across the literature that it is social relationships that are the key indicator of the community wellbeing of people with disabilities. This includes being able to develop relationships with others (Johnson et al, 2010); enjoying mutual-support social relationships with other people with disability as well as neighbours, friends, volunteers and other members of the community (Kam-shing and Sung-on 2002); and having access to private worlds of intimacy (Milner and Kelly, 2009). For these and other writers, having meaningful relationships is the key indicator of social inclusion – an assertion that reinforces the need for natural supports and, indeed, one that is echoed in the views of people with disabilities themselves. Milner and Kelly (2009) elicited the views of people with intellectual disabilities on the factors which guided their sense of participation. The participants identified self-determination, social identity, participatory expectations and psychological safety. They also stressed the importance of relationships and reciprocity (Milner and Kelly, 2009). This is a particularly relevant finding, and one that has implications for policy, given the limited social networks which people with disabilities have, as discussed in the following Chapter, and also the limited opportunities for them to engage in reciprocal relationships.

A particularly interesting contribution to approaches on community living is that put forward by Bates and Davis (2004). They draw an important distinction between approaches which are based on social inclusion, and those that are based on social capital. For them, social inclusion means having full and fair access to activities, social roles and relationships. Social capital, on the other hand, goes beyond the issue of access. It is premised on the norms of trust and reciprocity that govern the depth and quality of social interactions (Bates and Davis, 2004). Thus, for a person with intellectual disability to be escorted to a sports club by a volunteer represents a social inclusion approach. For the same person to be actively facilitated to build a network of friends with whom to go to the sports club represents a social capital approach. This distinction has important implications for the development of interventions to support and promote natural supports, as is discussed in Chapter 5.

3.4 Developing and Mobilising Natural Supports

Material relating to interventions to mobilise natural supports, or help people with disabilities to develop natural supports, fall into discrete categories. These are reviewed in greater detail in Chapter 5 and are presented here as an overview.

The first category of intervention is comprised of models of support that, in general, are delivered by family and friends (although sometimes professionals or paid workers can be involved) and are usually targeted on just one disabled person, frequently referred to as the focus person. Included here are Support Circles, Support Clusters and Micro Boards. While these have been in existence in Canada and the USA since the 1970s, they have not been subjected to evaluation (the Irish pilot reviewed in Section 5.1.1 being an exception to this). This is not to suggest these approaches do not have benefits. Extensive case study material suggests they do have very positive outcomes (Frost and Pearpoint, 1992).

The second category of intervention examined is that comprising peer group approaches, including peer advocacy and the use of segregated or self-authored spaces. Peer group approaches have been positively evaluated as providing opportunities both for social networking and community participation, but they are also increasingly seen as having a role to play as advocates for people with disabilities. The concept of self-authored spaces has yet to find the same degree of acceptance, but some interesting examples of the effective use of such spaces are examined.

The third category is comprised of interventions to build capacity amongst people with disability in order that they can participate in social networks and in their community. The models looked at here include training in social skills for people with intellectual disability, the use of goal setting focusing on social inclusion targets, and interventions that use specific workers to support paid staff in promoting the social inclusion of people with disabilities. To an extent, these interventions may be seen as social inclusion approaches.

The final category of intervention examined is comprised of strategies to build friendship and community-belonging among people with disabilities, that is, to promote the development of natural supports. Examples of such interventions from a number of jurisdictions are examined here, which may be considered to be social capital approaches.

3.5 Some Preliminary Policy Considerations

There is a marked lack of empirical data relating to natural supports and to how these impact on independent living. This is particularly the case in relation to people with physical disabilities and to those who are not in contact with service providers. Ironically, therefore, it is the categories amongst the disability population which are most likely to be using natural supports that least information is available on. Secondly, among the studies that do exist, there is a strong tendency not to relate the availability of relationships or support to the actual experience of living in a community setting, or to the wishes and choices of

people with disabilities themselves. In consequence of this, the data tends to be presented as static and as abstracted from the real world of the individual with disabilities.

This chapter also identifies two important considerations for policy and practice in the area of natural supports which will be amplified in Chapter 6. These are:
(1) the need for clarity in conceptualising the goals underlying policy to facilitate natural supports and
(2) the need to develop appropriate means to measure the outcomes from these policies.

Summary of Key Points

- The concept of natural supports emerged in the mid-1970s and was subsequently widely taken up in the field of employment. It has been far less evident in other community settings.
- Natural supports have usually been defined in terms of those who provide them: that is primarily family, friends and neighbours. In this sense, natural supports are seen as based on personal ties rather than payment. More recently there is some evidence in the literature that this distinction may be becoming blurred in favour of a more fluid understanding of natural support based on function rather than provider.
- Given the limited material on natural supports per se, the material covered in this review relates to social networks, social supports and social integration. In all, 30 recent studies are included. Limitations to these studies include a predominant focus on quantifying social networks rather than assessing their role in providing support, on contrasting outcomes at community level with those at institutional level rather than exploring the types of community settings that are most likely to produce quality outcomes, and a number of methodological issues.
- Nevertheless, a consensus emerges across the literature in relation to the limited size of networks amongst people with disabilities and particularly amongst those with intellectual disabilities, the predominance of family members and those associated with service settings in these networks; the importance of staff members in providing practical support to people with disabilities; and the significance of peers (i.e., others with disabilities) in providing emotional support. The latter in particular has led to concern about devaluing peer based networks rather than building on their capacity to promote inclusion.
- These findings are contextualised by ongoing debates about the meaning of community living and community participation. Most notable amongst these is the rejection of mere presence in the community in favour of more meaningful forms of participation and the scope to flourish as a

human being. The distinction between social inclusion approaches to promoting community living and social capital approaches is particularly relevant.

- Various interventions were identified which seek to promote independent living and community participation. These include those models of support that, in general, are delivered by family and friends (such as Support Circles, Support Clusters and Micro Boards), those that comprise peer group approaches (including peer advocacy and the use of segregated or self-authored spaces), interventions to build capacity amongst people with disability in order that they can participate in social networks and in their community (such as the use of goal setting focusing on social inclusion targets), and interventions that use specific workers to support paid staff in promoting the social inclusion of people with disabilities and in building friendships.

Chapter 4

Social Networks: Their potential to provide natural support and facilitate community participation

4.0 Introduction

In this chapter, a detailed review is presented of peer-reviewed studies relating to social networks, social supports and the potential of the latter to support community participation as an aspect of independent living. Social relationships or social networks are demonstrated to have positive impacts on the health and wellbeing of people generally. For those with disabilities, these relationships are assumed to offer the additional benefit of being able to provide support for living in the community. Hence, they are seen as vital to quality of life and, as noted in Chapter 3, the extent of social relationships or networks is considered by many writers, to be the key indicator of community integration. Few of the studies reviewed here actually test this hypothesis. Many studies focus predominantly on quantifying how many people comprise a social network, who they are and, less frequently, what type of support they provide. None of the studies actually explore the link between the support provided and the realisation of independent living, but a small number do provide some insights into the links between social networks and one element of independent living: community participation. In the absence of a body of research evidence to review, therefore, this chapter attempts to glean from a sample of the most relevant research findings available, what the potential for natural supports to promote independent living may be.

The bulk of the literature examined here relates to intellectual disability and for this reason, along with the methodological considerations noted in Chapter 3, care must be taken in generalising from the findings. Nonetheless, as the overview presented earlier notes, there are two consistent findings across all of the studies. These are, firstly, the limited extent of social networks amongst people with intellectual disability and, secondly, the prevalence of people associated with service settings (that is, staff and other people with intellectual disability) within these networks. Clement and Bigby (2009) put this succinctly when they write: "People with intellectual disability whether they have a history of institutionalization or not, typically have small and highly restricted social networks characterized by interactions with co-residents or co-participants in day programmes, immediate family members, and service workers who are paid to support them" (Clement and Bigby, 2009).

Similarly, Forrester-Jones et al, (2006), conclude that 12 years of community care in the UK has not generally resulted in the social inclusion of people with intellectual disabilities: "Most remain living in relatively small-sized, high-density networks made up predominantly of people connected to intellectual disabilities services (p293). Milner and Kelly (2009) cite research to the effect that after three decades of de-institutionalisation, people with intellectual disabilities remain absent from the intimate social and interpersonal relationships characteristic of community membership and belonging for other community members.

It is also worth noting, that the recent studies reviewed here reinforce conclusions reached by Emerson and Hatton (1996) in their review of UK deinstitutionalisation studies from 1980 to 1994. That is, that people with intellectual disabilities in community-based accommodations have few friendships with people who are not co-residents, staff or family members, and frequently such friendships, where they do exist, are superficial (Emerson and Hatton, 1996, cited in Bigby, 2008). Thus, studies over a thirty year period – since the beginning of deinstitutionalisation – provide consistent findings on the limited social relationships of people with intellectual disability.

4.1 Size and Composition of Social Networks

Robertson et al, (2001), in one of the most widely cited studies, researched the social networks of 500 people with intellectual disability living in different types of supported settings. Of these, 86 people lived in three village communities, 133 lived in five residential campuses, and 281 lived in accommodation provided by ten community-based residential support providers. The research was based on data provided by service staff. The study found that the average number of people known by participants in the study was between three and eight, with the median being five. These numbers included staff from service organisations, as well as family members and other people with an intellectual disability. When staff members were excluded, the median number of people in a network declined to just two. Less than one third of the sample (30%) had a network member who was neither a relative nor someone connected to disability services. The authors concluded that people with intellectual disabilities were isolated, and they suggested that community residential services were not taking advantage of the increased opportunities for building social relationships available in community settings (Robertson et al, 2001). The study examined the relationship between size of social network and type of accommodation (discussed later) but did not report on the nature of the social support provided by network members.

Similar findings were reported by Bigby (2008) who assessed the size and nature of social networks amongst 24 people with intellectual disability living in Australia one, three and five years after they had moved to community settings. The participants were living in shared houses managed by non-government organisations and the data on their networks was gathered by interviewing staff members. The interview schedule consisted of a range of open-ended questions, standardised outcome measures, and global rating scales on the domains of living situation, general health and well-being, personal development, community

integration and interpersonal relationships. Informal social contacts were categorised as: friends with and without intellectual disability; co-resident and non co-resident; and relatives. The quantification of social networks was based on the number of people with whom participants had at least annual contact, who lived outside their household, and who did not know them in a paid capacity. On this basis, the average size of social network was 1.92.

Other research which explored the issue of social networks used methodologies which involved self-reporting by people with disabilities, and these have found larger numbers of social relationships. Forrester-Jones et al, (2006) investigated the social networks of people with intellectual disability who had been resettled in the community. They focused on 213 people twelve years after they had been resettled from long-stay hospitals. Using a Social Network Guide (developed by Forrester-Jones, 1998) they mapped the components of individuals' networks along the dimensions of structure (size, membership and density), interaction (reciprocity, frequency, duration and closeness) and function (i.e. the actual support provided). Participants defined the members of their social network based on them being considered important in their life, and that they could either name them or reference them situationally (e.g. the grocer). For each identified member, information was collected on the type of relationship (e.g., family, staff, friend), and on the area of life from which they were derived (e.g., household, residential home etc). Thus, someone classified as a 'friend' by the respondent, could be a staff member. This study found that the average social network size was 22 members with the range extending from 3 to 51. A quarter of all network members were other service users with intellectual disabilities and a further 43% were staff. Only a third of members were unrelated to disability services. These were comprised of family members (14%) social acquaintances and other friends (11%), and contacts working in shops, pubs and cafes. In terms of area of life, just over a third of the total network members were acquired from community contexts, including clubs, church and voluntary organisations as well as shops, cafes, neighbourhoods. Over half the network members (56%) were from residential care homes or employment and day centres (Forrester-Jones et al, 2006).

In their review of 23 studies focusing on the community participation of people with disabilities Verdonschot et al, (2010) also note the size of social networks reported in the studies they review. Most of the studies, in fact, did not report on the size of social networks but amongst those that do, the average size of network falls within the ranges reported by Robertson et al, (2001), and Forrester-Jones et al, (2006) (both of which were included in Verdonschot et al's review). Thus, it would seem that regardless of some inconsistency in findings across various jurisdictions, these two studies identify the extremes in terms of the size of social networks among people with intellectual disabilities: with average network sizes ranging from 5 to 22 (including staff members). The extent to which differences between studies at either end of this range may be due to the differences in methodology (studies that gathered data from staff tending to report lower network sizes than those that gathered information from people with intellectual disabilities) cannot be determined.

In a rare comparative study, Lipold and Burns (2009) researched social networks and social support amongst 30 people with mild intellectual disability and 17 people with physical disability, both groups recruited from specialist day centres. Data was collected directly from participants using a number of instruments developed in previous studies. Among those with physical disabilities, 35% lived with their family while 41% lived independently and 24% lived in a staffed home. Among those with intellectual disability, 43% lived with their family, a similar proportion in supported accommodation and just 10% lived independently. The study found that adults with intellectual disability had more restricted social networks than those with physical disability. The 30 respondents with intellectual disabilities had a mean network size of 11.67 members. In contrast, those with physical disability had a mean network size of 30.9. On this basis, the authors suggest that the social networks of those with physical disabilities are closer to the non-disabled population than to those with intellectual disabilities.

Among the physically and cognitively disabled too, however, patterns diverge. Fox Harker et al, (2002) found that independent living outcomes (including social interaction) differed for different type of acquired disabilities. In their study, which was based on a combination of a postal survey and face to face interviews, they found that independent living outcomes differed across two categories of acquired disabilities: traumatic brain injury and spinal cord injury. Those with traumatic brain injury reported much greater capacity for independent living than did those with spinal cord injury although both groups had good levels of community integration. The authors hypothesised that the greater degree of independence achieved by those with traumatic brain injury may be related to their lower levels of physical restriction and their lower levels of need for assistance to complete daily tasks and activities, leaving them freer to engage in employment and leisure activities. This study does not examine the role of support in assisting either group to live independently.

The research conducted by Fox Harker et al, (2002) and Lipold and Burns (2009) highlight the value of comparative studies across people with different types of disability. Within disability categories themselves, however, demographic characteristics are important, although as noted, people with disability tend to be viewed as homogenous by many researchers. Thus, relatively few studies report on social networks by gender and among those that do, no clear pattern emerges. McConkey (2007) found that women were more likely than men to report having friends. However, Umb-Carlsson and Sonnander (2006) (reviewed by Verdonschot 2009) found no differences between women and men with intellectual disabilities in relation to family and social relations. Ethnicity, as noted earlier is also under-reported in the literature. Age, however, has been shown to be negatively correlated with network size. In her longitudinal study, Bigby (2008) found that social networks can decrease as the person with disability ages, and importantly drew attention to how life events (the birth of a child, illness etc) can change the support behaviour of those who provided natural supports at a previous point in time.

4.1.1 Composition of Social Networks

A consistent finding across the literature is the tendency for social networks to be comprised of family, other people with disabilities and service staff. Robertson et al, (2001) reported that 44% of all network members were staff while 83% of participants had a staff member as a network member. Additionally, 72% had a member of their family, 54% had another person with intellectual disability, and just 30% had a person who did not fit into any of these categories in their social network. Forrester-Jones et al, (2006) found that a quarter of all network members in their study were other service users with intellectual disabilities, and a further 43% were service staff. Just one third of the network members were unrelated to learning disability services, and these were drawn from community contexts such as clubs, church and voluntary organisations, retail services such as shops, pubs, cafes and cinemas, and neighbourhoods. Similarly, Hatzidimitraidou and Forrester-Jones (2002) reported that the social networks of older people with intellectual disability, who had lived in their family home or in community settings all their lives, included 32% other service users, 12% care staff and 11% family members. The remaining 30% was comprised of neighbours, other friends, contacts from mainstream clubs and retail members (cited in Forrester-Jones et al, 2006).

Bigby (2008) also categorised data on social networks on the basis of composition, frequency of contact, and function. Her study collected data on the number of friendships people had, the quality of these friendships and the frequency and nature of contact with friends. Most residents (83%) identified staff members as friends and 50% had no friends other than staff. Half had friendships with co-residents, and only three (13%) had friendships with people who did not have intellectual disability. No residents identified an intimate friend and only one, a close friend. Emerson and Hatton (1996), in their review of UK deinstitutionalisation studies, also found that people with intellectual disability in community-based accommodation have few friendships with people who are not co-residents, staff, or family members. Milner and Kelly (2009) found that family and service agency staff were most often identified as the most important social relationships (Milner and Kelly (2009). Furthermore, Leopold and Burn (2009) note that many people with intellectual disability who report having a friend, in fact, experience a relatively superficial relationship more akin to that of an acquaintance without the expected mutuality and reciprocity.

When compared to people with physical disability, the distinct composition of social networks amongst those with intellectual disabilities becomes clear and, in particular, their greater reliance on family members. Lipold and Burns (2009) found that family members made up the majority of the support network (40.28%) of their participants with intellectual disabilities, followed by friends (28%) most of whom were also people with intellectual disabilities, and members of staff (21.14%). In contrast for those with physical disabilities, friends rather than family members made up the majority of their support networks, comprising 43% of networks with almost equal representation of friends with disabilities and friends without disabilities (21.9% and 21.1% respectively). Family members made up 38% of the network while service staff accounted for 10.6%.

A number of studies explicitly address the issue of friendship among people with intellectual disabilities. Forrester-Jones et al, (2006) cite research that shows that friendship seems to be the least successful aspect of resettlement when people with disability move from long stay to community settings (Carson & Docherty, 2002). In their own study, they reported that their participants stated that half of their relationships were reciprocal (p289) and most of these reciprocal relationships were with family and friends. Emerson & McVilly (2004) reported findings from a large population-based study which examined friendship activities amongst people with intellectual disabilities living in supported accommodation in ten geographical localities in Northern England. This study indicated overall low levels of friendship activities for adults with intellectual disability as well as most friendship activities taking place with others with disabilities. The authors also reported that most friendship activities take place in the public domain, rather than in more private settings such as the home. Milner and Kelly's (2009) research in New Zealand into people with a wide range of disabilities including physical, sensory and intellectual disability, found that they had a limited number of friends in spite of their determination to forge social connections. These authors also note the extent to which friendship activities take place in public rather than private settings.

Taub et al, (2009) is of the few studies to explore social networks in a rural context. Their study involved face to face interviews with 24 women with physical or visual impairments living in rural parts of the USA. All reported difficulties in forming friendships and the authors suggest that in rural areas attitudes and perceptions of disability change more slowly, and there are fewer role models. In addition, poor transport and fewer social occasions make it difficult for people with physical disabilities to meet as a group. This study also explored barriers to intimacy and sexual relationships experienced by the women. The women reported that they had all encountered barriers to forming romantic relationships which they perceived to stem from social pre-conceptions of disability and associated stigma.

Van Alphen et al, (2009) explored a social relationship that is frequently overlooked in the literature, that is, the role of neighbours. They explored this role from the perspective of people with disability themselves and their study focused on 39 people with intellectual disabilities living in neighbourhood housing facilities, some of whom had limited opportunities for interaction with their neighbours. They used semi-structured interviews with a topic list which covered topics such as daily life, work, hobbies and friendships, before focusing on the key theme of how well their informants knew and interacted with their neighbours. The study attempted to gain insight into their lived experience of neighbouring by inviting participants to describe and evaluate the interactions or relationships they currently have with their neighbours. Only half the informants knew a few neighbours, mostly those living next door, although in many cases these were people with disability living in similar settings to their own. The most common kind of interaction with neighbours was considered to be superficial. Overall, the authors suggest, the participants in this study appeared to prefer their social contacts to be with other people with intellectual disability, family or

volunteers, rather than people from outside the context of the organisation that provided support for them.

It must be borne in mind that almost all the studies looked at in this review were undertaken in the context of deinstitutionalisation, and almost all are focused only on those in contact with service agencies – with most participants living in settings that are provided and resourced by service agencies. The extent to which the size and composition of their social networks reflect the links to service providers, *per se*, is impossible to determine: that is, the extent to which they do not develop natural supports because they have service providers, rather than vice versa. Lemay (2009) notes, for example, that some studies suggest that service users are unable to break out of their service structures to take advantage of the opportunities in the neighbourhood. Similarly both Bigby (2008) and Clement and Bigby (2008) note how service staff can limit, rather than expand, the opportunities for developing relationships. In her study, for example, Bigby found that frequent staff changes in community residential settings made it difficult for family members to build a relationship with staff members and this, in turn, inhibited their level of contact with the person with intellectual disability. This echoes the suggestions in some of the literature regarding the relationship between life trajectory and network formation. There is some research evidence that staff can serve to restrict, rather than promote, the development of friendships. Both Bigby (2008) and Forrester-Jones et al, (2006), for example, suggest that participants in studies who have remained at home until well into adulthood may have larger networks than those who have been institutionalised for much of their life. Similarly, McVilly et al, (2006a) found that, in their study, those who had been educated in special schools had smaller social networks than those who had attended mainstream schools.

4.2 Social Networks as Natural Supports

It is not easy to draw out the implication of research findings on the size and composition of social networks for the actual provision of support. Clement and Bigby (2009) note that on their own, the structural features of networks do not tell us about the quality, amount, and experience of social support that they can or do provide. Further, they suggest that people with intellectual disabilities may perceive small networks to be more supportive than larger ones. The emphasis on size of networks ignores not just the actual capacity and reality of support given by network members; it also ignores the perception of the person with disability as to the effectiveness of any support they receive. McVilly et al, (2006) studied self-reported loneliness amongst 51 adults with intellectual disability. Data was collected using a Loneliness Scale for all participants, and a sub-set of participants also took part in semi-structured interviews. Their analysis did not find a significant relationship between ratings of loneliness and either the mean number of people in their social networks, nor the average frequency of contact with those people. However, there was a significant negative correlation between participant ratings of loneliness and the length of time they reported spending with their friends. Overall, their analysis suggested that connection with a social network, which could meet a diversity of emotional and practical needs, was a critical factor linked to the participants' experience of

loneliness. Importantly, the authors suggest that this finding affirms the importance of evaluating people's qualitative experience when seeking to understand friendship and loneliness, instead of relying solely on a quantitative analysis of their social networks (McVilly et al, 2006a).

In considering the research data on how much support is actually provided by members of social networks, it is worth recalling the emphasis put on relationships, and reciprocal relationships, by both people with disabilities themselves and researchers. McVilly et al, (2006a) note that the wider sociological literature stresses the role of relationships in providing individuals with practical aid, emotional support, information, assistance with decision making and opportunities to broaden existing support networks. Studies rarely use these or other classifications of function in a way that allows general conclusions to be drawn. Consequently, there is some inconsistency across studies in how these, or other functions of relationships, are conceptualised or explored in the literature on social networks and the supports they provide.

Robertson (et al, 2001) reported that staff were most likely to 'almost always' provide practical, emotional, informational support, and were also most likely to be defined as 'very close'. Family members were the next most likely to provide these forms of support. Bi-directional reciprocity was most likely to occur with friends with intellectual disabilities.

Forrester-Jones et al, (2006) explored the support provided by social network members in their study. They found that one in three network members provided support with personal care and domestic tasks; and over one third of network members provided material supports; around half of network members provided company and a similar proportion provided invisible support, such as looking out for or keeping an eye on individuals with intellectual disability. The proportion of network members providing support in decision making was lower at 28%, and the proportion with whom participants had confiding relationships was just 20%. Nonetheless, 80% of network members were described as being 'quite close' or 'very close'. This study does not address how adequately this support met the needs of people with disabilities or assisted them in living in the community, nor does it provide information on the overall proportion of network members who provide some form of support.

Significantly, however, the main providers of support by far in this study were staff of the service agencies, including ancillary staff such as cleaners. Service agency staff were much more likely to provide personal care, domestic help and material support than were other network members. They were also the most likely to receive confidences, and to support participants in making decisions. Staff were also the most likely to look out for, and to provide company for respondents. Respondents were more likely to have known staff members for longer periods than they knew other network members, but relationships with staff were less likely to be considered reciprocal. Nonetheless, a significant proportion of the respondents (42%) reported a close relationship with staff. This study also found that other people with intellectual disabilities were the second most frequent providers of all types of support, although to a much lesser extent

than staff members. Significantly, among the support provided by other people with intellectual disability, the dominant category was that of companionship. In this study, family members provided a relatively small proportion of the overall support received and amongst these, the highest proportion was in the category of material supported, which accounted for one in five support behaviours.

Lipold and Burns (2006) identified a similar pattern in relation to the support function of social networks among people with intellectual disabilities. They found that the most frequent providers of functional support to people with intellectual disability were members of staff, accounting for 53% of support providers. The next category most frequently nominated as providing support were friends (20.8%), of whom the great majority were friends with intellectual disability. Family members comprised just 14.6% of nominations. Among the comparison group of people with physical disability, the most commonly cited providers of support were family members (29.9%). The next most frequently nominated group were members of staff (28.5%), followed by friends and partners (28.3%), and 'others' (13.5%). Lipold and Burns (2006) note that the group with physical disability cited receiving support from family and friends without disabilities significantly more often than those with intellectual disabilities, while receiving support from service staff was significantly more likely to be cited by the latter. The study does not report on the type of support provided.

Bigby (2008) categorised the types of networks amongst participants in her study based on frequency of contact with network members, a perspective which provides some additional insight into the capacity of network members to actually provide support. The study found that 75% of the participants were in touch with a relative at least once a year, but only 50% had more than annual contact with a family member. The number of family members with whom residents had annual contact ranged from 1 to 4, with a mean of 1.38. Bigby found that 16% of participants had non-existent networks, with no contact with either family or friends outside their home. One quarter had a special occasion network, where they had no contact with any friends, and the main contact with their family was through visits and phone calls on occasions such as birthdays or Christmas. Thirty eight per cent had an engaged family network, with at least one family member undertaking instrumental tasks, as well as, providing emotional support, including some who were involved in the day to day lives of residents and actively monitored their wellbeing and the support provided to them by service staff. Just over one fifth (21%) had a friendship-based network where they enjoyed regular contact with friends outside their home. Thus, in this study, the majority of participants (59%) had at least some support provided to them by members of their social networks, but 41% appeared to have no social networks at all, or social networks that did not provide any support.

Bigby (2008) is one of the few studies to take a longitudinal perspective on the issue of social networks and the social support they provide and hence is able to capture changes over time. She draws attention to the decline in social networks over the period of the study, which was evident in fewer family members and fewer friends being in contact with the study participants. Frequently, this decrease was to do with changes in the circumstances of family and friends, for

example, deterioration in parental health, or a friend moving to another town. She also draws out the implication of this for ageing, such that older people with intellectual disability may be more at risk of social isolation than younger people, or than they were when they themselves were younger. They are, therefore, less likely to have social networks from which to draw support. Bigby suggests that changes in social networks over time challenge service staff to be more proactive in facilitating face-to-face family contact, and in finding mechanisms to retain the engagement of family in the life of residents and the house. In a similar vein, Duvdevany and Arar (2004) note that the nature of friendship changes significantly over time, as the individuals involved develop and mature and consequently, a wide variety of social relationships would appear to be necessary for social inclusion. They also note the related point that people with intellectual disability can have difficulty maintaining as well as forming relationships.

Van Alphen et al, (2009) explored the role of neighbours in providing support to people with intellectual disability living in the community. Ten of their 39 informants said they had received some help from a neighbour. This included watching the house if they were away, helping them move in, or helping in an emergency. Sixteen informants said they received visits from 'neighbours', but in ten instances the visitor was a member of staff, a volunteer or a person with disability living close by. Twenty five of the informants reported exchanging greetings with neighbours, but few reported small talk. As in other studies, staff (and volunteers) were very important in providing support to the informants, making arrangements for them to go places, and engaging in activities with them. This study also assessed the degree of satisfaction among participants with their interaction with neighbours. Most of the participants expressed no wish to know more people in their locality, or to intensify the relationships they currently had with their neighbours. Knowing too many people was considered a burden. However, they did consider being able to greet and share small talk with those they knew to be important. Neighbours were not considered important in determining how much 'at home' participants felt in their community, but if neighbours were noisy, aggressive or dirty, the sense of feeling at home was challenged. The authors conclude that neighbours may be deemed irrelevant, providing that they are openly kind or convivial and slightly in the background. McVilly et al, (2006b) also found that people with disabilities tended not to consider their neighbours to be candidates for real friendship.

McVilly et al, (2006a) noted that when the participants in their study had their need for emotional and social friendship effectively met, they did not rely on a single other, but on a network of people who performed a specific function or fulfilled a specific need. Like van Alphen et al, (2009), they too found that personal networks are more effective if they include relationships with people with and without intellectual disability. They note that while relationships with family members and professionals can address some important needs (for example, practical support and assistance with problem solving), relationships with those who had shared life experiences associated with, or linked to, their intellectual disability were also very important. Importantly too, they found that respondents' likelihood of feeling lonely was related to their aspirations regarding friendship, and how well their existing friendships met those aspirations. The

participants in their study also valued both the emotional and the social dimensions of friendship – having people with whom they could do things, and having people with whom they could be themselves. They write “Loneliness was least evident among those who perceived themselves to be part of a network of people, each member of which performed a specific function or fulfilled a specific need: the combined effect of which was to provide a safeguard against loneliness”.

The same study examined the views of people with disability on friendship and subsequently convened an expert group of people with intellectual disability to discuss the findings (reported on in McVilly et al, 2006b). This consultation confirmed the views of participants that empathy and companionship were the most important dimensions of friendship. However, practical support was also valued and friendships were reported most often in a context where practical needs were met. The expert group also discussed barriers to making new friends and their views here reflected other research findings: making friends as one ages becomes more difficult, with friends made while at school being the most likely friendships to be reported.

The expert group also referred to the practical difficulties involved in maintaining friendships and noted that they frequently did not have the support necessary to allow them to visit or maintain contact with their friends. Family members in particular were cited as frequently being too busy to provide assistance in helping them to stay in touch with friends. The expert group also expressed the view that their families and service staff did not fully grasp how important their friendships were to them. The authors, however, note that none of the group referred to the internet as a means of keeping in contact with friends. McClimens and Gordon (2009) assessed the potential of supported internet access to develop social capital for people with intellectual disabilities. They examined a supported blogging project which was promoted by a university and which ‘chaperoned’ participants in developing and using their own blogs. The participants also attended at training sessions and group discussions. The study found that the participants enjoyed the experience and the internet facilitated self-expression. But, overall, the authors concluded that “blogging per se has little to do with the development of social capital”. They suggest that people who lack the background characteristics associated with education, youth and wealth are less likely to increase connectivity, sociability, participation or engagement through blogging. However, Anderberg (2007) found positive outcomes from internet use amongst people with physical disabilities in Sweden (this is discussed in more detail in Chapter 5).

Overall, it appears from the limited number of studies that explore the actual provision of support, that staff members are hugely important across a range of supports, while other people with disabilities are also important but to a lesser extent, and primarily in providing empathy and companionship. What is also notable is the very limited role played by family in supporting the respondents in these studies: again, this is likely to reflect the fact that most of these studies researched people living in supported accommodation of various types and, therefore, de facto, were in receipt of support from staff members. The

relationship between type of accommodation and the scale of social networks, and provision of support, is looked at in more detail in the following section.

4.3 Social Networks, Social Support and Living Arrangements

Given that much of the focus on social networks occurs in the context of de-institutionalisation, it is not surprising that a considerable amount of the literature addresses difference in social networks across different living arrangements. However, the variation in sample sizes, and frequently limited information provided on the actual living arrangements, makes it somewhat difficult to draw emphatic conclusions across the range of studies that address this issue. An important exception here is the very unambiguous findings that those living in community settings have larger and more active social networks than those living in institutional contexts, and that the closer the living arrangements approximate to independent living, the larger and more active are those social networks.

Robertson et al, (2001) found that the size of network differed according to where people lived, with an average network size of 6.7 for people living in village communities, compared for 8.6 in community-based residences, and just 4.4 for those in residential campuses. They write that people supported in smaller community-based settings and supported living schemes had larger and more inclusive social networks. Verdonschot et al, (2009) cite Spreat and Conroy (2002) who found that people with intellectual disability living in supported living arrangements had twice as many family contacts per year as people living in an institution. McConkey and Collins (2010) suggest that there is a growing body of literature that shows that people with intellectual disabilities who live in smaller, individualised accommodation are more likely to engage in community activities, and to have wider social networks than those living in congregated settings – although they cite only two studies to support this, one of which is authored by McConkey (McConkey et al, 2007).

Emerson and McVilly (2004) examined friendship activities amongst people with intellectual disabilities living in supported accommodation. Supported accommodation included all forms of support provided to enable people live outside their family home such as supported living, group homes, hostels and cluster housing. In the context of overall low numbers of friends, and low levels of activities with friends who did not also have an intellectual disability, they concluded that the setting in which a person lives is a more significant determinant of the form and contact of activities with their friends than the characteristics of participants. However, both McConkey (2007) and Duvdevany and Arar (2004) reported that the more extensive the social skills of their participants, the more socially accepted and less lonely they feel.

McConkey (2007) contrasted the social networks and patterns of community participation across 620 people with intellectual disability living in different types of community settings. He constructed social network data based on (a) the number of friends outside of the home (defined as people whom the participants

met regularly and who shared activities, confidences and support) (b) the number of neighbours in the area who know the participant by name or who are known by the participant and (c) the frequency of contact with their family during the past month. The study found that people in supported living schemes (including those clustered on one site and those dispersed in neighbourhoods) have greater levels of social inclusion, as measured by their use of community amenities and number of social contacts, than did those in small group homes or residential homes. The differences, however, were not statistically significant and McConkey also reported that greater use of local amenities was associated with higher social competence.

Some variations according to living arrangements in the community were also noted by Duvdevany and Arar (2004) who studied of 85 adults with intellectual disability, of which 45 lived in community residential settings and 40 in foster families in Israel. The study collected information on demographic profiles, and also used previously developed instruments to assess quality of life, loneliness, social relationships and leisure activities. They found that those who lived in community residential settings had fewer friends than those living in foster homes, although they engaged in more activities. However, overall they found no significant differences in the extent of social relationships or feelings of loneliness amongst people with intellectual disabilities living in community settings and those living in foster homes. They concluded that the fact that people live together in the same setting does not guarantee a richer social life. They did find that both friendships and leisure activities were related to quality of life, and they suggest that people tend to enjoy their social life more in settings that encourage freedom of choice and offer an unstructured and independent way of life. This, they suggest, indicates that while community settings may encourage engagement in leisure activities, it is done in a more structured and less free way.

An important counterpoint, however, is that signalled by the longitudinal study undertaken by Bigby (2008). Despite Bigby's observation that studies of people with intellectual disability consistently suggest a trend of increased contact with family and friends following relocation to the community, in her own study she found that after a five year period of community living, the initial increase in informal network size and family contact after the relocation was not sustained, and only a very small proportion formed new friendships with people in the community.

The impact of accommodation type on social supports was also explored by Forrester-Jones et al, (2006). They reported 213 clients with intellectual disability who had been resettled from long-stay hospitals in the UK, and who at the time of the study, were living in residential and nursing homes, small group homes and supported accommodation. They found that the type of accommodation in which people were living had a strongly significant effect on the types of social support which they receive. They report that lower levels of personal support were associated with living in hostels, small group homes and especially supported accommodation. These living arrangements were also associated with higher levels of material support. In addition, they found that

people in hostels, small group homes and supported accommodation were significantly more likely to report close and companionable relationships than were those in residential and nursing homes (p.289). In these settings too, where contacts were most frequent, relationships were more likely to be described as reciprocal, compared with those in other settings.

Involvement in local communities also appears to be linked to residential setting. For example, Verdonschot et al, (2009) reported that people with intellectual disabilities who live in community settings participate in their community to a greater extent than those who live in segregated settings, but their participation level was still much lower than non-disabled and other disability groups. They define participation as the performance of people in actual activities in social life domains through interaction with others in the context in which they live.

McConkey (2007) found that people living in supported settings were more likely to access community amenities and to have at least one friend outside the accommodation, to be known by name to one or more neighbours, and to have visitors to their home for coffee or a meal. Those in clustered supported living were more likely to have friends outside the home they were also more likely to have had visitors to their home. This group were also the least likely to be socially isolated. McConkey concludes that this study confirms that the type of accommodation available to people with intellectual disability has an influence on the extent of their social inclusion as measured by contacts with other people and use of community amenities. Overall, people in either form of supported living scheme in his study tended to have greater levels of social inclusion than did those in small group homes or residential homes. He notes, however, that the social competence of the person was an additional significant predictor of friendships and use of community amenities. McConkey suggests that the results of his study should give service planners in Ireland some cause for reflection particularly in relation to the major investment in residential homes or campus settings, neither of which, he writes, appears to offer their residents opportunities for social inclusion to the same extent as do other options. This challenge, he suggests, replicates the move away from long-stay hospital provision that occurred in the past. Changes will only come about with an explicit policy commitment allied with increased financial resources.

Lemay (2009) suggests that the reason for variation across different types of accommodation is that social interaction and eventually social relationships are mediated by the roles that one has in any given setting. He argues that the community is rich in role opportunities and relationship possibilities, but social integration requires a deliberate and well-thought out strategy to move individuals with development disabilities out of their social isolation. In contrast, Randall and Cumella (2009) suggest that a possible explanation for these variations is the distinctive pattern of social relationships that exist in many intentional communities and the impact this has on the lives of their residents. Their study of 15 residents in a large intentional community included 10 men and 5 women aged between 38 and 78 years. All lived with the families of co-workers and valued the relationships they had with these. Respondents reported that they took part in both individual and communal leisure activities, and all but two had a

network of friends. Opportunities for friendship were enhanced by proximity to other people with an intellectual disability and a sense of personal security in the village. The authors note that their results confirm those from earlier studies of intentional communities, and suggest that positive outcomes derive from the absence of the overt subordination of residents to staff, the facilitation of friendship with other people with an intellectual disability, high levels of meaningful employment, and a sense of community. The authors argue that these factors contrast with the experience of living in small homes funded on a contractual basis by public authorities, in which cost pressures reduce wage levels for staff resulting in difficulties in retaining suitable staff and a consequent high staff turnover (Randall and Cumella, 2009).

A further theme on the issue of location is that of the home as distinct from community spaces, and the implications of this for forming friendships in community settings. Participants in Milner and Kelly's (2009) research, for example, described how in order for them to have relationships, they were required to move from the places they know best (such as their own homes) to public or shared community spaces. However, they also reported that few people made the equivalent journey to the places that they were most intimate with. These participants also noted that it was in their own homes, and in the vocational centres, that they had the most intimate relationships, which they had struggled to replicate in other settings. They felt most able to disclose their private selves and express their hopes and fears in these settings. These were also one of the few contexts where they felt able to add value to the lives of other people. The authors also note that relationships within friendship circles also tended to be bound to one particular setting (for example a vocational centre) and rarely to find expression beyond that setting (Milner and Kelly, 2009). This finding is frequently replicated in employment settings, where friendships established in the work place rarely, if ever, have expression outside of that setting (references); although Forrester-Jones et al, (2004) found that people with intellectual disabilities, who had worked in supported employment for one year, had more opportunities for making relationships and had less dense networks.

4.4 Social Networks and community participation

In this final section, the role of social networks in enabling community participation is examined. Community participation is understood here as one element of independent living, although for it to be assumed to be an accurate indicator of this, we would need more information on the extent to which the nature of community participation reflects self-determination and freedom of choice on the part of people with disabilities, and the extent to which it affords them a good life in the community. Few studies directly address this issue, but it seems from the research evidence presented below that there are significant shortcomings in this area.

In their review of 23 studies of people with disabilities living in various settings, Verdonschot et al, (2009) found that only 13 of them address the issue of community participation. They concluded on the basis of the empirical evidence

that little is known about the community participation of people with intellectual disability. They cite the reviewed research evidence to the effect that people with intellectual disabilities have low levels of participation in community activities overall (Abraham et al, 2002) and, in particular, low levels of involvement in activities which require a high degree of personal autonomy, such as having people to stay overnight, staying overnight with others, or having people to visit for a meal (Ager et al, 2001). Other research reviewed by Verdonschot noted that the leisure activities of clients attached to day services were solitary, passive or family oriented (Buttimer & Tierney, 2005; Luftig & Muthert, 2005). On the basis of the overall research evidence, Verdonschot et al, (2009) also note that the participation of people with intellectual disability in community, civic and social life increases when they have lived in the community for a longer period. However, they also note that those activities are most likely to be with co-residents and frequently accompanied by a staff member. Duvdevany and Arar (2004) also found high correlations between social contacts and involvement in leisure activities. This finding points to the importance of social contacts in underpinning life in the community, although the point is not developed in this study.

Research into participation in community-based leisure activities amongst those with sensory disabilities also indicates a lower level of participation than amongst those without disabilities, and some studies identify the link between lack of participation and the unavailability of social support (Hanrahan, forthcoming). Douglas et al, (2006), for example, found that people with visual impairments were much more likely to pursue leisure activities within the home than outside the home, and were considerably less likely to socialise at a pub or club than are the population generally. A study of blind and partially sighted people (SSMR, 2009) found that the need for assistance to undertake leisure activities also hampered spontaneity. The same study noted that when blindness is acquired, it can lead to a loss of sighted friends and an increase in the number of friends with visual impairments. However, a study by Audley (2002) found that the level of participation in physical activity among people with visual impairment was similar to that amongst people without disabilities, although the rate was lower among young age groups. Barriers to participation in sport included not having personal assistants, which was cited by one third of participants. Similarly Hannon (2005) identified a number of barriers to participation including the lack of companions to facilitate or assist participation when necessary (all cited in Hanrahan, forthcoming).

Milner and Kelly (2009) note the important point that the most highly valued forms of participation were self-chosen activities that people undertook with a degree of autonomy. Social identity was also important and people gravitated towards relationships and places where they felt known. Thus places of worship and a limited number of recreational settings were contexts where some participants had established positive social identities through continuous presence. Reciprocity and the opportunity to make a valued contribution were also important to participants, allowing them to challenge implied dependence. This, and other studies note how peers can help achieve reciprocity.

4.4.1 The role of peers in supporting community participation

Earlier in this chapter the importance of peers within the social networks of people with disabilities was noted, as was their role as providers of support. Significantly, support provided by other people with disabilities was found to be mainly empathy and companionship. In the following paragraphs research evidence on the role of peers in promoting community participation is discussed.

Milner and Kelly's (2009) study is one of a number which identified the importance of peers. In their study, participants who named more people with disabilities within their social network were more likely to report feeling comfortable, and participated in a wider array of community activities. Additionally, provided they chose when, where and who they participated with, many reported feeling more able to confront the social ordering of unfamiliar places in the company of other people with disabilities. The study also found that when participants in their study adopted a collective strategy to community participation, community spaces became more accessible, physically and socially. Other studies also identified the importance of peers in facilitating community participation and involvement in community activities. Emerson and McVilly (2004), for example, in their study of 1,542 people with intellectual disability in community-based accommodation in northern England, found low levels of shared activities with friends in general, and such activities as did occur tended to be with friends with disabilities. Similarly van Alphan et al, (2009) noted the value of segregated spaces. In their study, many of the people with intellectual disabilities had previously socialised in social clubs run by their service agencies. They had appreciated their participation in these and lamented their closure.

Participants in Milner and Kelly's study were also noted to be acutely aware of the values, policies and assumptions that under-scored service interpretations of 'community' versus 'segregated' settings, and that involvement with other people with disabilities implied a less valid form of community connection. The authors write "By locating community both beyond the ambit of their ordinary lives and beyond interpersonal intimacy, adult service users' initial reading of 'community' is at odds with the broader, societal understanding of the construct". This, the authors suggest, also reflects a devaluing of their disabled peers and the people and places they shared. Milner and Kelly also reported how socialising together helped people with disabilities deal with issues of self-confidence and social othering, and that being in segregated spaces or alongside other people with disabilities was important. They write "being in a place where bodily difference and support needs were unremarkable and anticipated added to people's sense of personal safety". However, participants were also clear about the danger of becoming ghettoised within disability settings and recalled their historical experiences of feeling unable to escape disabling identities in professionally authored contexts (Milner and Kelly, 2008).

Taub et al, (2009), in their study of barriers to social relationships with 24 women with physical or visual impairments living in rural USA, found that some of them preferred to have disabled friends because of their shared experiences, but believed their limited opportunities to interact with other disabled individuals reduced their opportunities for friendship with disabled others. The authors note

that social relationships with disabled others were less likely to be hampered by stereotypes about impairment than relationships with able bodied individuals. Also due to their shared marginalised experiences, disabled women could 'reveal their true selves', and were consequently less likely to devalue each other. Those with congenital disability had a longer history of having disabled women as their peer group. The authors suggest that difficulties could exist for women with acquired impairments in experiencing a new, stigmatized status and life style. Other respondents, especially those with acquired disabilities, reported preferring able-bodied friends.

In the Irish context, Douglas et al, (2006) found that people with visual disabilities have mixed opinions on the value of social groups specifically for people with vision impairments. Similarly, a study of blind and partially-sighted people also noted some variations in the extent to which such people wished to socialise with those with a shared impairment rather than those without, although it noted that, de facto, the former were more likely to have more friends with impairments and fewer without (SSMR, 2009). Commenting on this, and other studies of participation leisure activities on the part of the visually impaired, Hanrahan (forthcoming) comments 'the key factor is finding ways of ensuring individuals have the choice of who they socialise with by dealing with the challenges faced by those wanting to socialise fully with sighted friends'.

In discussing the lack of social networks among people with intellectual disability, Johnson et al, (2010) suggest that when segregated provision goes, there is a danger that the limited social ties, relationship and belonging that they offer also go. They suggest that to discard social networks defined by intellectual disability as part of a discredited past may be a mistake, and that building on them may have more value (Johnson et al, 2010). The issue of segregated or self-authored spaces is looked at in more detail in Chapter 5.

4.4.2 The role of staff in promoting community participation

Service staff are not usually considered as natural supports, but given their role in providing support evidenced earlier, and the possibility of a blurring of the distinction across paid and unpaid supporters noted in chapter 1, it is worth looking at the research findings on how they promote community participation and contribute to independent living. Abbott and McConkey (2006) identified four main themes in participants' discussions and reflections on the experiences of being present in community settings. These were talking to people, being accepted, using community facilities and opportunities. These participants also wanted staff to take a supportive rather than a caring role. The research evidence suggests that however well intentioned service staff may be, they frequently act as barriers to friendship formation. The reasons for this seem to relate to training, professional work practices and a lack of understanding of policy aims.

McConkey and Collins (2010b) investigated the role of support staff in promoting the social inclusion of people with an intellectual disability in a number of different service settings. They found that staff rated care tasks as having higher priority

than social inclusion tasks. They conclude that service managers may need to give more emphasis to social inclusion tasks and provide the leadership, training and resources to facilitate support staff to re-assess their priorities.

Milner and Kelly (2009) also suggest that the activities undertaken to support community participation on the part of people with intellectual disabilities reflect the horizons of service culture rather than the individual's aspiration. Bates and Davis (2004) suggest that it can be staff preference, rather than the service culture, which determines activities. They write "there is some danger of staff defining service users' lives by their own personal choice of lifestyle either by assuming that people with learning disabilities will not be interested in community engagement or by evangelically promoting their own personal interests". They also note that the boundaries of participants' community participation tended to be defined by professional social practices – for example, if fewer staff were working at weekends, there was less likelihood of community activities taking place. Lemay (2009) also reports that the activities that community participation centres on tend to reflect what staff want to do, and where staff want to go. Abbott and McConkey (2006) also identify social practice and organisational culture as barriers to community participation. They argue that a re-evaluation of approaches to risk assessment is required so that the support provided and the safety mechanisms in place do not become a barrier to social inclusion (p284).

Clement and Bigby (2009) undertook a study into a relocation programme from institutions to the community in Australia. The study was conducted over a period of time after the move had occurred, and a key focus was on how staff could facilitate the participants to form relationships within their new community. The group home in which the participants were living had the support of the Community Inclusion Officer, a post introduced to Local Authorities with the objective of helping group home staff to behave in line with the State Government's goal of building inclusive communities. On the basis of their research Clement and Bigby argue that the staff supported activities that were more likely to foster the residents' presence in the community, rather than their participation, and were, in fact, similar to activities undertaken while the participants were still living in the institution, such as group outings to the cinema accompanied by staff. The possibility of forming close friendships with people who do not have disabilities was considered unlikely as a result of these activities. The authors attributed this problem to a failure on the part of service staff to understand the stated aims of policy to support social inclusion, and reluctance on the part of leadership to embrace change (see Chapter 5 for fuller discussion of this).

Milner and Kelly (2009), on the basis of their research with 28 people with a wide range of sensory, intellectual and physical disabilities, argue that that forms of participation in the community were typically organised and moderated by the support service, and a narrow range of activities were pre-eminent. They conclude "out of cadence with the ordinary social life of the surrounding community and lacking a self-determined compass, the boundaries of participants' community tended to be defined by professional social practices: given the way community participation was organised, most people perceived a

presence within their community to be an element of service delivery". Their participants reported being escorted to community spaces as fleeting and irregular visitors. Being in the community in this way precluded the sustained presence they said helped others see beyond impairment, and for them to become assimilated with the social history of mainstream community settings. In addition, community participation supported from service settings tended to be steered towards public spaces rather than the private social contexts, where people were more likely to experience a sense of psychological safety and interpersonal intimacy. Overall, the authors conclude that community participation supported from service settings tended to be steered towards public space rather than the private social contexts, where people were more likely to experience a sense of psychological safety and interpersonal intimacy (Milner and Kelly, 2008).

Helgoy et al, (2003) introduce a somewhat different factor when they refer to severe tensions in the relationship between welfare state professionals and their clients. A key problem is the clash between services founded on the logic of welfare bureaucracy, and they argue, the demands by people with disabilities that are founded in their life worlds. In their study Helgoy et al, (2003) found that people with mobility disabilities mediated the service relationship in different ways depending on their understanding of independence. These ranged from the 'super-normal' who eschewed all help to the powerless and resigned who submitted to the service regime without question or complaint. They contrast these to service provider paradigms which include the 'rehabilitator', the 'servant' and the 'care giver'. Significantly, they found that people with disability who were very committed to independent living favoured the 'servant' role for their caregiver. Christensen, in her study of the career strategies of carers, draws attention to the aspirations and desires of those who provide care and, in particular, the complex welfare dilemma between user independence and the nature of care work (Christenson, 2009). This highlights a tension not just between services providers and people with disabilities, but between the former and those who can sometimes be their employers. Christensen (2010), in talking about carers providing support under Cash for Care systems, draws attention to the difference between caring for (work) and caring about (emotions), and notes that this is based on understanding of care as a relational phenomenon, different from an individually and psychologically based phenomenon.

A very interesting example of how independent living can be promoted by staff and natural supports working together is provided by Trussadottir and Sigurjonsdottir (2008). They studied 18 mothers with intellectual disabilities from three different age groups and their children over the period 1950 to 2005 in Iceland. Over that period, state support for people parenting with intellectual disabilities had increased, thus they were able to contrast the coping strategies of older mothers who had not enjoyed such support, from the younger ones who had. They found that despite formal support services, the importance of assistance from extended family was crucial in determining whether mothers with intellectual disabilities retained custody of their children. Women relatives played the most important role by providing practical and emotional assistance and advocacy on behalf of the disabled mother and her family. The mothers who

reported most satisfaction with their overall support level were receiving services from local community agencies, combined with assistance from extended family members. These mothers and their extended family were involved in planning the support, and selecting a support worker so they were less likely to see the services they received as a threat to their families. The mothers highly valued the support they received from their families in dealing with the service system. They note that when professionals recognised and accepted the supportive relative, and her importance to the disabled mother and her children, they usually planned and organised formal support services in co-operation with this relative. In these instances both formal and informal supports were well coordinated and effective, which led to a more successful family life and upbringing of the children (p337). The converse was also true – that is, if the professionals did not value the supportive relative's role, her effectiveness in working with the system was limited. The authors stress two key findings from their study (1) despite the emergence of formal support for mothers with intellectual disability, the most support comes from extended family members (2) the availability of formal support brings about changes in family support whereby advocacy and assistance in dealing with the service system becomes important. In this study, the authors report that in some instances the supportive female relatives received payment.

Summary of Key Points

- The research findings suggest that one should not assume that people with disabilities can readily establish social relationships and maintain them over a lifetime. Equally one should not assume that the existence of social networks, per se, is an indication of support being available.
- After three decades of deinstitutionalisation, people with intellectual disabilities residing in community settings continue to experience significant levels of social exclusion. At the most basic level, their social networks are small and comprised mainly of family members, staff members and other people with intellectual disabilities. Few studies looked at the role of neighbours as members of social networks but the evidence available suggests that these are not very important, providing they do not have a disruptive or negative impact.
- It also appears from the research that, for a variety of reasons, there can be difficulties in maintaining friendships over the life cycle and in particular that there can be difficulties making new friends as the person with disability ages.
- Investigations of the actual support provided by network members highlight the important role played by staff members in providing practical support on a day to day basis – most likely reflecting the fact that the studies focused on people living in residential settings of various sorts, rather than independently or with family members. Overall, staff were the most frequent providers of support, followed by other people with intellectual disabilities. Significantly, however, the support provided

by peers was most likely to relate to companionship and to fulfilling the need for reciprocity. Family members appear not to be active in providing support to any significant extent.

- Reconciling the research findings on the relationship between type of community accommodation and size of social networks is somewhat difficult. Some studies have identified clear links between the type of accommodation and the likelihood of having active social networks: in other studies, however, the key variable in determining social networks is not type of accommodation but social skills.
- In terms of network members actually promoting community participation, the research evidence appears unequivocal. Peers are extremely important in supporting community participation and those who socialised with disabled peers reported feeling more comfortable and having more access to community spaces. The value of segregated spaces was also highlighted by some of the literature.
- Service staff are very important as facilitators of community participation. However, the link between this and independent living would appear to be tenuous at best. Instead it seems that service staff are more likely to foster a shallow form of community participation and frequently undermine the choice and control of those they are supporting.
- Families feature largely in the social networks of individuals with intellectual disabilities, but they do not appear to be significant in facilitating social inclusion. Indeed some of the research suggests that families can inhibit the development and maintenance of friendships, and that key family members may not appreciate the need for friendships on the part of the disabled person.

Chapter 5

Strategies to Develop Natural Support Systems

5.0 Introduction

The literature reviewed in the previous chapter indicates that there is a substantial consensus that assistance is needed in the formation and facilitation of natural supports, particularly, although not exclusively, for people with intellectual disabilities. Notwithstanding the larger social networks amongst those living in community settings, rather than in institutions, the research evidence is overwhelming on this issue, and Abbott and McConkey (2006), amongst others, have argued that it has become apparent that physical presence within a community does not guarantee greater social inclusion. Moreover, facilitating people to simply take part in community-based activities and use local amenities and facilities, does not necessarily lead to meaningful social contact with others, and particularly with the non-disabled population. Consequently, as many of the reviewed studies, as well as some of the contextual material, looked at here argue, policies to support deinstitutionalisation, community participation and by extension, independent living, must be accompanied by policies and services to enable people develop real friendships and social relationships, that is, to enable them develop social networks. Bigby (2008) puts this precisely when she argues for the need to develop active strategies to nurture and build informal social networks, so as to enable the potential spectrum of informal network functions to be fulfilled.

This view also seems to be shared by people with intellectual disabilities themselves. Abbott and McConkey (2006) asked the participants in their study to identify strategies that they believed would help to overcome their social exclusion. The participants identified a number of strategies including:

- support to increase their own ability and skills to live independently,
- measures to help them get to know the neighbourhood, (such as providing information on what activities are available in the community and organising open days and similar events to help them make links with the community),
- encouragement from staff to socialise,
- support to make plans themselves for leisure activities and,
- notably in the context of natural supports or lack thereof, the provision of advocates and volunteers to accompany them to social events.

In this chapter, a number of interventions to promote natural supports among people with disabilities are described. These are:

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

As a preface to this, it is useful to note the views of the Department of Development Services in California which promotes the development of natural supports. Its website states: "Developing natural supports is based on what the consumer wants, not on what professionals recommend. There is no single method or easy answer for developing a system of natural supports. It's a matter of supporting and assisting consumers to be in a position to develop associations and relationships. The activity of someone assisting in developing natural supports for a consumer is in devising strategies to bridge the gap between the opportunities for and development of natural supports" (www.dds.ca.gov).

The discussion of these interventions also reintroduces the theme of social inclusion approaches as distinct from social capital approaches. Social capital differs from social inclusion in that it involves the building of social networks, including natural supports, rather than simply promoting community participation. The following two examples illustrate the contrast.

Bates and Davis (2004) describe a 'positive example of a social capital' approach as follows. Two women with learning difficulties wanted to learn yoga. No yoga group existed in their area, so a worker found a tutor and a community hall and put up notices around the neighbourhood. A mixed group of citizens joined and everyone welcomed each other, including the people with learning disabilities. Nine years later the group was still running (Bates and Davis, p 198).

McConkey et al, (2010) provide the following negative example of a social inclusion approach. A woman with learning difficulties wanted to attend yoga classes at the local college. Her key-worker found out the times and costs. She thought it best to phone the yoga teacher in advance and explain a little of the woman's needs. But when the teacher heard that her new client had special needs, she said her insurance wouldn't cover her if anything went wrong. (McConkey et al, 2010).

5.1 Circles of Support

One of the themes to emerge in the previous chapter was the extent to which the social networks of people with disabilities, and especially those with intellectual disabilities, are comprised of family members. For those in contact with service providers, however, it seems that family members infrequently offer support. For those not in contact with service providers – and, therefore, not receiving the practical support they provide – we may assume that this role is played to a greater degree by family members. The provision of support by family members, per se however, is not necessarily the same thing as support for independent living. As McVilly et al, (2006) reported, family members who provide practical support can, in fact, hamper the development or maintenance of friendships. The key issue here is the degree of choice and control which the person with disabilities can exercise over what type of support they receive, when and how it is provided, and to what end.

A model of formalised support which draws on family and friends, although not exclusively, and which gives control to the person with disability, is that of the Circle of Support. The idea of Circles of Support originated in Canada with the now famous Joshua Committee established by Judith Snow and her friends. It spread quickly to the United States where it was adopted, in particular, for use for those diagnosed with autism. In the mid 1980s the model spread to the UK, and recently it has been adapted there for use with older people at risk of isolation in the community (Bowers et al, 2009). Circles of Support do not appear to have been evaluated, although a number of case studies have been produced which highlight the benefits to the person with disabilities and their friends (for example, the account of Judith Snow's circle written by Pearpoint in 1990). A related model, known as a Microboard (see below), has been developed into a formal programme and is widely used in educational settings in the USA, again particularly for children with autism. This programme has been evaluated and found very positive results.

Although the term Circles of Support is widely used, it can sometimes refer to slightly different things; from very formalised arrangements with a quasi-legal structure and long-term objectives, to more fluid informal arrangements operating over a short time span. The Circles Network, a UK based organisation which promotes this approach, offers the following definition: "A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. The circle acts as a community around that person (the 'focus person') who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help" (www.circlesnetwork.org). Circles of Support, therefore, are not just about providing day to day supports for an individual but are instead focused on achieving the type of life and lifestyle that that person wants. They are potentially a mechanism to achieve independent living in the broadest sense.

The Ontario Adult Autism Research and Support Network (OAARSN) is one of a number of organisations in the USA and Canada that promotes this type of approach to supporting people with disabilities and in this case specifically

autism. It defines a Circle of Friends as follows: a 'tool to gather a supportive community around the person with a disability'. There are four concentric circles:

- (1) At the core is the circle of intimacy.
- (2) The second is the circle of friendship, including good friends and close relatives.
- (3) The third, the circle of participation includes people and organisations that the focus person is connected with.
- (4) The fourth circle is the circle of exchange and includes those who are paid to be in the person's life.

Members of the circle meet regularly to celebrate success, discuss problems and brainstorm solutions". (www.uoguelph.ca/oaar/strategies7.shtml).

Circles of Support can be initiated by the person with disability themselves or by a family member or friend. They can also be initiated by a paid worker, although there is no consensus in the literature as to the merit or otherwise of having paid workers involved. Regardless of the involvement of paid workers, a key principle of Circles of Support is that family and connections within the community are more important than the service system. A second key principle is that the focus person is in charge, both in deciding who to invite to be in the circle, and also in the direction that the circle's energy is employed, although a facilitator is normally chosen from within the circle to take care of the work required to keep it running. According to Circles Network, the circle "is not a service or tool to be applied to a certain group of people. Circles are about seeing people as individuals who feel they need support in order to take more control over their own lives. A circle properly facilitated is empowering to all of the individuals involved and, unlike many service systems, does not reinforce dependence" (www.circlesnetwork.org).

Person centred planning is central to the work of Circles of Support and a number of tools and resources have been developed to facilitate this. These include MAPS, and PATHS. The Ontario Adult Autism Research and Support Network describes MAPS (Making Action Plans) as a tool to help in gathering information to be used in planning actions to move the focus person into her / his future. PATH also involves a future-oriented strategy to plan for the focus person. In a paper on Circles of Support, Lord (1999) identified some of the learning for policy and service delivery generated by these models. He noted, in particular, that the potential for self-determination which Circles can achieve points to the need for an improved, flexible, and more individualised formal support system. He also noted that while the construction of social support may be attractive to service agencies, it may be best left to grass roots efforts and to the initiative of families and communities.

Lord, (1999) also provides a definition of Support Clusters which are linked to Support Circles. According to him, support clusters are not aimed directly at helping the person with the disability, but are aimed at working with and supporting the social network or cluster around the focus person. This theme, supporting the supporters, echoes a number of the Independent Living strategies noted in Chapter 2 which recognise the need to provide support to natural supporters. Lord notes that research into the Canadian support clusters project

found that the clusters did increase the flow of social support to families and individuals. Families reported a marked increase in their ability cope with stress, and they also referred to strengthened relationships with both their formal and informal supports in the cluster. The role of professionals was particularly significant in achieving this and their participation was valued by families.

5.1.1 Microboards: the Irish experience

Microboards have been defined as a “small group of committed family and friends who join a person with a disability to form a non-profit society. Together they address the person’s planning and support needs tailored to the individual’s needs and circumstances” (www.velamicroboard.org).

A Microboard is distinct from other forms Circles of Support by the fact that it may assume a legal status– effectively acting as a ‘Board’ to take decisions with, and on behalf of, the focus person. In British Columbia, for example, a microboard is a legally incorporated entity and can receive (and share responsibility for spending) the individualised budgets for which the focus person may be eligible. As noted above, the Microboard model has been widely used in educational settings in the USA to positive effect.

Microboards, like Circles of Support, operate with a large degree of flexibility but there are some essential components (Kavanagh, 2008). These are:

- The process must be focused on the needs, dreams and wishes of the person for whom the board is being created.
- All Microboard members must be in a close, voluntary and committed relationship with the person for whom the board is being created.
- These close relationships are the foundation of the board and must be honoured above all other activities.

Microboards are established throughout Canada, in parts of the USA, and some European countries. They are also established in Northern Ireland. In March 2006, a pilot Microboard Project was introduced in Ireland by an organisation based in Offaly, and ran until April 2008. The stated aim of the project was to pilot a model of practice for individualised services, that is, person centred and uses direct payments to purchase such services for persons with a disability. The final report of the evaluation of the project defines Microboards as not having a specific legal meaning, instead being “a small (micro) group of committed family and friends who join together with a person with a disability to create a non-profit society (board)” (Kavanagh, 2008).

The Microboard Project employed a facilitator to support the development of the Microboards, and to provide resources and assistance with Person Centred Planning to the members of the Microboards. Over the two year lifespan of the project, it established six Microboards, two short of its original objective. The evaluation notes that Microboards ‘by their nature take considerable time, effort and support to establish’. The six Microboards catered for people with physical and intellectual disabilities, and included also a number of people with acquired

disabilities. One Microboard was incorporated as a company limited by guarantee. This Microboard submitted an application for a direct funding payment to the HSE in May 2007 but, at the time of drafting the evaluation, no response had been received (Kavanagh, 2008). The Microboards, therefore, had to work within the constraints of the existing service regime.

Feedback from the Microboard members indicated a very high level of satisfaction with the Microboards, with the achievement of self-determination being a recurring theme. The Microboards provided opportunities for the focus person to widen their circle of friends and to participate in their own community. Increased self-esteem and increased confidence in their abilities to make decisions was also reported. Overall one of the main findings of the evaluation of Microboards is an improvement in the quality of life for people with disabilities, resulting in what the author suggests were 'obvious wider benefits for their families, friends and society in general'. Families were reported to have benefited from the sharing of responsibility, the ability to take time out, and the greater security that Microboards provide for both the focus person and family members. The author concludes "The results of this evaluation clearly indicate that the level of choice and control that the focus person has over their life is greatly increased with the use of a Microboard."

One of the suggestions Kavanagh (2008) makes is that the Microboard model be assessed to establish its wider application in the Irish context. That suggestion would seem to be supported by a survey of service providers which was also undertaken as part of the evaluation. Of the nine who responded, four believed that between 50% and 100% of their clients would benefit from Microboards, three believed that between 10 and 50% would benefit. Just two felt that fewer than 10% of their clients could benefit from a Microboard. In contrast, however, it must be noted that the evaluation also reported opposition to the involvement of family members in Microboards. One leader from a Centre for Independent Living (CIL) questioned the objectivity of family members and suggested that for CIL leaders, family members' involvement on a Microboard "goes against the philosophy of independent living" (Kavanagh, 2008).

5.2 Peer- Based Approaches and the use of self-authored spaces

The previous chapter indicated the extent to which people with disabilities, and again particularly intellectual disabilities, value the support and companionship of their peers. This is true to an extent also for those with physical disabilities, although they tend to be more nuanced on this issue. The companionship of peers appears to be readily achievable by those living in community contexts, given the composition of social networks looked at earlier. However, it is also clear from the literature that the high percentage of people with disabilities within the social networks of others with disability is seen as a marker of social exclusion and, therefore, as problematic. Clement and Bigby (2009) for example, suggest that relationships with people who do not have disabilities tend to be privileged (by researchers and others) over relationships with people with intellectual disabilities and, as a consequence, activities in segregated day programmes,

specialist leisure programmes and other residential settings are not highly valued. Consequently, the benefits of self-segregation are often ignored, as are the wishes of people with intellectual disability in this regard. The comments made by Johnson et al, (2010), cited in Chapter 3, are relevant again here. They have drawn attention to the danger that when segregated provision ends, the limited social ties, relationships and belonging that it offers may also go. They suggest that it may be more valuable to build on the social networks defined by intellectual disability, rather than discarding them as part of a discredited past (Johnson et al, 2010).

A number of methods and interventions are in evidence for building on social networks defined by disability, and for fostering a more progressive role for these in providing supports for independent living. One such model is peer support. Peer support has been defined as follows: "social / emotional support, frequently coupled with material support – e.g., financial resources or housing – that is mutually offered or provided by persons with certain conditions or experiencing certain difficulties to others with similar conditions or difficulties to bring about a desired social or personal change" (www.upennrrtc.org). Peer-delivered services for people with disabilities can include operating drop-in centres, delivering crisis services and offering support for independent living, such as employment services. The delivery of these and other services may involve partnering with non-peers but peers still maintain control of the service. Peer-advocacy groups are also seen as having a greater role to play vis-a-vis the development of policy and services to support independent living, and in advocating with service providers on behalf of people with disability. Finally, peer counselling also has been identified as having a role in consciousness raising. In the USA, this approach has been used by peer groups to educate each other and establish their own pool of shared experience. Martinez and Duncan (2003) suggest that this method can act as both an educational effort and a liberation tactic.

Johnson et al, (2010) have suggested that unlike most segregated networks, self-advocacy groups have been praised rather than condemned. Such groups differ from most forms of segregation in the sense that membership is voluntary rather than forced or by default and they are at least in name controlled by the membership. They argue that, viewed in social capital terms, self-advocacy groups and other such associations of people with disabilities are a form of bonding on the basis of a set of ascribed characteristics and commonality of experience that give people common ground. Johnson et al, (2010) suggest that these bonded groups appear to give people the strength to develop an alternative narrative to that of failure and rejection. But they warn, this is not always the case and the capability to do so requires relatively sophisticated stewardship. They cite Riddell et al, (1999), who have argued that there must be protected space for social capital to be developed by people with disabilities, and that from this understanding people will be able to engage in bridging relationships and rejoin mainstream social life. Bates and Davis (2004) also suggest that advocacy groups that have traditionally focused on long-term bonding could build bridging relationships with local community organisations and campaigns. This could encourage people with learning disabilities to eventually leave the advocacy

group in order to join other advocates for the local community improvements that most interest them as citizens (Bates and Davis, 2004).

Peer-based services and especially advocacy groups appear to have considerable potential in relation to independent living, most notably in the area of policy development. Many writers consider that in the context of ongoing service development in this area, such groups could also play a greater role in acting as advocates vis-a-vis service providers, and generally, in relation to service development, monitoring and evaluation (Clement and Bigby, 2008; Kendrick, 2009). An interesting example of peer groups responding to service delivery issues was investigated by Anderberg (2007) in Sweden. His study of peer support was based on an analysis of online discussions from a Swedish web forum for people with disabilities. In Sweden personal assistance for people with significant mobility / physical impairments is considered a right and is financed by direct payments, allowing the users to employ personal assistants. The web site run by people with disabilities provided a forum where people with disabilities could discuss and share information on a range of topics including personal assistance. Anderberg (2007) states "Disabled people live in a predominantly able bodied world, where the practices related to living with a disability are rarely visible. The Internet provides opportunities to increase your number of contacts and build personal networks, as well as giving increased visibility to the disabled individual, both inwards (to your own group) and outwards (to people who do not normally meet disabled people). The internet also allows peer support and role modelling to be made more easily available to a larger number of people. By using the peer-assisted website, Anderberg reports, participants were able to share their views and experiences of their personal assistance programmes and, in this way, develop shared learning across a significant service issue for them. The author concluded that the possibility of creating and maintaining a learning system of this kind could not exist in the same way without the Internet (Anderberg, 2007).

5.2.1 Segregated or Self-Authored Spaces

A less consensual issue in the literature is the value of what some may call segregated, but others, self-authored spaces. In essence, the difference between the two terms is linked to the objectives of these spaces and the decision making processes within them. Whereas, segregated spaces represent a mechanism to shut people with disabilities away from wider community, and render them invisible in social terms, self-authored spaces provide a protected space where people with disabilities can develop forms of social capital that include not just personal relationships, but also the development of self-generated discourses of disability. Kendrick (2009) writes: "There is a decided link between what we place importance on and what the tenor and effect on our lives will be. It is therefore quite reasonable to look for the ways in which shared and collective values and decisions may propel communities in directions which are facilitative and enabling of the kind of personal fulfilments sought by people with disabilities". For those who argue the case for self-authored spaces, these are seen as enabling people with disabilities to be involved in the development of shared and collective values by ensuring that their experiences and their voices are taken into account.

Milner and Kelly (2008) also argued that framing community participation and inclusion as occurring only within the communities where people with disabilities tend to be absent, blinds us to the value of the multiple communities to which they have always belonged. They suggest that limiting the appropriate contexts for inclusion to spaces of the social and economic majority places legitimate community beyond the experiences that shape the value and social practices of people with disabilities. Not only does this devalue the community of peers (as well as family and other support relationships) in which a person is embedded, it excludes the alternative imaginings of people with disabilities from the discourse of inclusion. They suggest that peer groups and self-advocacy groups have a role to play in building social capital for people with disabilities. They also argue that 'we can reasonably anticipate that people with disabilities will find community in other ways that challenge the existing paradigm, perhaps within self-authored segregated spaces and activities that harness their collective energy'. They cite Goodley (2005) who argued that people with intellectual disabilities can reclaim a sense of self by stepping beyond the curriculum of service provision and challenging disabling rules and identities from the safe space of common community.

This same issue is discussed by Hall (2010) who draws attention to the absence of people with intellectual disabilities from mainstream social spaces. He cites Cameron (2005) to the effect that by not defining social inclusion, and by paying no attention to what people are to be included into, the focus is placed entirely on the excluded individuals and the broader structural factors are obscured. So, he concludes, social inclusion becomes more about a set of normative practices than the transformation of society. Hall refers to his own previous work in which he examined the ways in which a significant number of people with intellectual disabilities have expressed their lack of desire and / or ability to reach the standards set by social inclusion policies by seeking out and developing other ways and spaces (i.e., self-authored spaces) within which to experience inclusion.

In his paper, Hall also reports on an ongoing study into arts based interventions which provide self-authored spaces for people with intellectual disabilities while also facilitating them to develop social capital within their wider community. One of these is a theatre company which uses only actors who have an intellectual disability and auditions annually for up to 25 such actors. The theatre also employs professional musicians, writers, designers, stage managers and so on, but membership of the company, and the spaces of rehearsal are exclusive to those with intellectual disability. Those running the theatre claim this exclusiveness is crucial to the operation of the theatre company and to its artistic and social success, as the people with intellectual disabilities are able to operate in a supportive, safe and non-judgemental environment. However, involvement in the theatre also provides an opportunity to develop social and work relationships beyond the company itself. Hall writes that involvement in the theatre can equip people with vocational skills, provide a form of inclusion within theatre networks in Edinburgh and Glasgow while also allowing them to form friendships and gain support within the safe spaces of the rehearsal room and the networks of the company.

The second case study looked at an arts and crafts organisation based in two sites in Edinburgh. The two sites are also exclusive in terms of the participants having intellectual disabilities, and again this is considered to be a crucial element of their approach, providing a safe and supportive community of members. Both sites have a café where members, staff and guests meet for lunch with food prepared by a group of members. For those who attend the two sites, the main rationale is primarily therapeutic. But the production of art work, the exhibitions held and the high prices often paid for exhibits, Hall suggests, represents a means of including the participants in mainstream society that can eliminate processes of othering. He concludes: "To belong is to feel attached, to feel valued and to have a sense of insidership and proximity to 'majority' people, activities, networks and spaces". He suggests that, arguably, it is only through projects such as those he describes that people with intellectual disabilities can take part in continuous active processes of 'insidership' and proximity, and thus begin to dismantle the deeply set structures of society which serve to exclude them.

Self-regulatory or self-authored spaces are essentially about enabling people with disabilities to construct new discourses and new imaginings of disability, and in so doing, to challenge dominant discourses. Their value in supporting independent living through, for example, developing bridging capital and thereby enabling the establishment of new social relationships, appears to be derived in the first instance at a group rather than an individual level. The following section, which looks at interventions to develop social skills and approaches to social inclusion, includes approaches that are focused on individuals as well as an intervention which involved a collective dimension.

5.3 Interventions to Develop Social Skills and Individual Goal Setting

A theme that emerged from a number of studies reviewed in Chapter 4 was the positive link between social competence and social inclusion (McConkey et al, 2006; McVilly et al, 2006a). People with intellectual disability themselves have also recognised the negative impact of low social skills on their likelihood to form friendships or experience social inclusion (Abbott and McConkey, 2006).

The role of training or social skills development in enabling people with intellectual disabilities to participate in their communities and to form friendships has also been highlighted by a number of studies. Whitehouse et al, (2001) summarised the literature relating to the most common approach in helping people with learning disabilities to develop social skills. This is the use of targeted training programmes in social skills groups. These training programmes, they note, have tended to focus on people with milder learning disabilities and have largely concentrated on 'fixing unsuitable behaviours'. While this type of training has led to improvements in social skills in the controlled settings of the group, these did not always generalize into the natural environment (Whitehouse et al, 2001).

Duvdevany and Arar (2004) also note that training provided by service staff was often directed toward preparing people with intellectual disability to adjust to a life in the community by focusing on vocational training and independent living skills, the latter mostly relating to domestic tasks. But, the authors argue, this training often failed to recognise the importance of leisure and social relationships and the necessary training needed for utilizing leisure opportunities and resources. The authors argue that unless effective programmes to facilitate the establishment and maintenance of supportive relationships and leisure activities are developed and implemented, the goal of full inclusion in the community will remain unrealized (Duvdevany and Arar, 2004). This theme is addressed also by Forrester-Jones et al, (2006) who suggest that a more structured approach would be to teach people with intellectual disabilities social skills and, thereafter, to support them in ordinary activities in much the same way as supported employment schemes operate. In this model, the emphasis is on skills training to foster and maintain relationships (Forrester-Jones et al, 2006).

One such structured approach to training for community participation is described by Minkler et al, (2008). Their study reports in detail on a Moving Out of the Nursing Home project implemented in the USA. The project, as noted in Chapter 4, had three main aims: (1) to document the experiences, concerns and goals of people with disabilities who were attempting to move out of nursing homes and into the community; (2) to develop, implement and test an intervention that would support people with disabilities making this transition, through peer-led education about their rights, and by helping them access resource and supports for community living; (3) to encourage participants to apply the knowledge gained through participation in the latter programme in concrete efforts, to help bring about policy change promoting community reintegration, and local and state-level compliance with mandates and legislation supporting such reintegration.

The second of the stated objectives noted above was to be achieved by providing training to the participants through a community empowerment and policy change intervention known as the Social Action Group programme. The Social Action Group included a variety of activities that would support participants in:

- (a) accessing resources and information on community living rights, housing, transportation, and community supports;
- (b) developing advocacy networks and becoming a part of collective activism to change policies;
- (c) building strong support networks to facilitate life in the community and reduce the risk of returning to a nursing home; and
- (d) building consciousness about disability community identity, pride and culture.

The 5-week Social Action Group programme was grounded in a social learning approach through which people with disabilities who were living in nursing homes,

their community-based peers (many of whom had previously been institutionalized), disability activists, and academic partners in disability studies learned from and mentored each other in areas that included disability rights advocacy, community living strategies, social networking and support and community building (Minkler et al, 2008).

The authors conducted a study of the Social Action Group as part of the overall Moving Out of the Nursing Home project and found that at the end of the project 37% of the participants in the Social Action Group intervention had successfully transitioned out of nursing homes to the community, compared to 20% of the control group. Results showed that living environment (i.e., whether people remained living in nursing homes or transitioned to community living) was the most significant predictor of key outcomes related to increased choice and control over living situation, social support and networking, and to quality of life at 3 months and 12 months post-intervention (p.117). People who were in transition from the nursing home also talked about new sense of community and about increasing personal feelings of power and control as a result of their participation in the project. The authors conclude that "increasing sense of community and perceived individual and community empowerment were both processes and outcomes of the project and laid important groundwork for subsequent efforts to help effect policy and other systems changes".

This study also found that participants who moved out of the nursing home expressed significantly higher levels of dissatisfaction in relation to what was referred to as 'quality of life', including financial and economic status, access to housing and aspects of social relationships. While this is contradictory to the findings relating to increased sense of community and empowerment, community partners to the project interpreted this as a positive outcome suggesting the participants had become more aware of the oppression people with disabilities face, and that this was a positive step in potentially motivating them to work for policy and other changes to address these issues, rather than internalizing the problem as being due to some personal deficit. This interpretation is supported by the fact that they report how people with disabilities who had left the nursing home became activists and worked to help others make transitions to the community. The project was acknowledged to have helped nurture a new generation of disability rights mentors and advocates from among one of the most oppressed social groups. The Social Action Group programme also allowed the participants a role in defining policy problems, agenda setting and creating awareness, constructing policy alternatives and deciding on the policies to pursue.

5.3.1 Goal setting and individual planning approaches.

The Moving Out of the Nursing Home project may be seen as a social capital approach to community living. Goal setting and individual planning approaches involve a more social inclusion type approach. A specific example of goal setting as a means to support social inclusion is reported on by McConkey and Collins (2010). Goal setting has been used in a variety of circumstances with people with disabilities, including in relation to engagement in household tasks and skills

acquisition but it has infrequently been used in supporting social inclusion. Indeed the authors note that social inclusion goals are less likely than others to be chosen within person-centred plans.

McConkey and Collins (2010) set out to examine the usage and outcomes of a goal setting approach amongst 130 people with intellectual disabilities living in different types of supported accommodation over an 18 month period, and also to identify the variables that helped or hindered individuals in achieving their stated goals. Four types of accommodation and support services were contrasted: two forms of congregated settings and two forms of supported living services. The congregated settings had designated individual support hours for each tenant in the house, the supported living services consisted of people living in a cluster of dwellings and those who lived in dispersed housing within the community but both had individual support available to them. According to key worker reports, a person centred plan was in place for most participants in both housing types but community involvement was more likely to feature in the plans of those living in shared housing or dispersed supported living. The study requested and facilitated participants to set goals to be achieved over the following nine month period and to keep records as to whether or not they had been achieved. Reasons for non achievement were also explored.

At the outset, participants in all settings were equally likely to select goals but as time progressed the proportion setting goals fell to approximately half of participants. Those who had friends outside the houses and who could travel independently were the most likely to set goals as time progressed. The goals set covered a range of activities, among which, social activities were the most frequently cited. Others regularly cited were entertainment activities, sporting activities, and work or training activities. Increasing social contacts with friends or family were less frequently mentioned. At the end of the first nine month period, those in shared congregated living arrangements were the most likely to have achieved their goals, followed by those in clustered housing. Over time, however, the most likely groups to achieve goals were those in congregated shared living and those in dispersed living. The study also notes that those with friends were more likely to continue to set goals over a longer time frame.

Factors that helped in the achievement of goals were also investigated and this showed that the most important factor, by far, was staff assistance in arranging or booking activities. The main barrier to the achievement of goals was a lack of planning. The study highlights the role of staff in supporting social inclusion through goal setting, and the authors suggest it confirms other studies of the importance of staff in facilitating the social inclusion of people they support. However, the study found that at the end of the 18 month period, participants' level of social inclusion on indicators such as visitors to their home, and number of activities done in the company of friends, showed little significant improvement.

Clement and Bigby (2009) report on similar outcomes from an Australian programme known as the Community Inclusion Framework in a group home for five adults with severe intellectual disabilities in Victoria, Australia. A particular

focus of the study is to reflect on why a culture of community presence, rather than community participation, evolved and endured which had the effect of retaining people within a distinct social space, rather than perforating its boundaries. The study worked with staff teams in five new group homes which were supported by a Community Inclusion Officer – a post created to work across group homes in the region to support staff to enable clients to establish themselves as members of the local community. The overarching aim of the Community Inclusion Officer was to get group home staff to behave in ways that were in line with the Government's goal of building inclusive communities. The Community Inclusion Framework was premised on a belief about the benefits of facilitating relationships with people who do not have disabilities, and aimed to expand peoples' social networks by facilitating relationships with people who were not staff members, relatives or people with intellectual disabilities.

Clement and Bigby (2009) in their study found that despite the publicity and attention given to the State Disability Plan, the staff team were generally unaware of its specific content. While every one publicly agreed that building inclusive communities was a laudable over-arching goal, the reflective space provided for staff uncovered individual variations about its meaning, how it might be achieved, the implications for staff practice and whether it could be achieved at all. Their findings show that a pattern evolved over a nine month period where staff supported activities that were more likely to foster community presence than participation. By the end of 16 months, staff did not have an understanding of inclusion that mirrored the one held by the Community Inclusion Officer which had been explicitly stated in the Framework and discussed in work with staff. Typically their understanding of community inclusion was that of presence not participation. Staff did not share a common vocabulary nor did they have an accepted definition of inclusion. Staff also stated that they did not know how to build relationships for the residents of the group home. Most of the staff had worked in institutional settings for a significant number of years, and the authors suggest that the training they received did not equip them with the knowledge, skills and abilities to promote community inclusion; a clear definition of community inclusion was not provided to them. In retrospect, the authors suggest that the scope of the programme (the Community Inclusion Framework) was not clear to staff, the need for it was not apparent, nor could they see any positive consequences for the residents.

5.4 Forming Friendships, Creating Community

A key principle of the social model of disability is that it is environmental factors, not personal characteristics that inhibit the capacity of people with disability to live independent lives in their communities. This is reflected in the degree of consensus across the literature reviewed in the previous chapter, that the wider community does not always readily accept previously marginalised people moving into community settings (Whitehouse et al, 2001).

Kendrick (2009) stresses the key links between the potential for personal fulfilment for people with disabilities and the supportive nature, or not, of the communities around them. He suggests there is a role for community leaders in

establishing 'beach heads of progress' and thus bringing out the good in others. He writes: " As such progressive social views grow they will in turn create role models for others, thereby establishing, person by person and network by network, many mini environments within community where hospitality and supportiveness to people with disabilities are more likely to flourish".

Bates and Davis (2004) also argue that when there are more bridging relationships between groups in small communities (that is relationships which help to build links between different social groups), positive reputations (and therefore positive attitudes) can also spread quickly. However, so too can negative reputations and, therefore, such bridging relationships can both create or deny a new resident a chance of a fresh start in a new social setting. The implications of this, the authors argue is that workers engaged in community relocation should recognize informal networks as sources of social capital and develop strategies in supporting service users to navigate them successfully. Abbott and McConkey (2006) also argue that positive attitudes follow on from increased social contact, thus a priority should be to provide opportunities for people with disabilities to engage in social contact (Abbott and McConkey, (2006). In this final section, a number of interventions to achieve this are discussed.

5.4.1 Befriending Strategies and Network Building

One model of intervention which has been used in a number of jurisdictions is that of befriending strategies. In general befriending is a service that aims to help people increase their friendship circles. Helsop (2005) defines befriending as acting as a friend to a person. Yet, while the offer and provision of friendship is a key element of befriending, there are two other elements to befriending that distinguish it from friendship; (1) the involvement of a formal service provider and (2) the purposive nature of the relationship between the individuals concerned. Befriending strategies are typically organised by service providers, including community organisations, but the befrienders are invariably volunteers.

Heslop (2005) provides a summary of research finding into befriending strategies. The research was based on the views and experiences of 15 workers at seven befriending schemes for children and adults with learning difficulties in England. The schemes catered for 34 people with learning disabilities and involved 42 befrienders. The interviews noted a number of similarities in the way the schemes operated, including the vetting and training of volunteers. The interviews also highlighted the difficulties in meeting the demand for befrienders and also the importance of these to the people with learning disabilities, all but one of whom said their befriender was a good friend to them. This, in turn, leads to the need to handle very carefully the cessation of the friendship for whatever reason. Overall Heslop concludes that although befriending strategies are generally seen as a good thing, there are few studies which actually demonstrate this.

A second networking approach which used in a number of jurisdictions is that of Community Connecting. This method has been noted as being a very successful, cost-effective and sustainable method of supporting individuals in the community

as it fosters natural supports around the person, rather than relying solely on state run agency services (CDLP, 2009). Examples of this approach include the PLAN Institute in British Columbia, Canada and In Control in the UK (cited earlier). The Community Inclusion Officers who are deployed by local authorities in Australia are another example of this. In terms of the operation of community connecting agencies, the 'community connector' tries to identify resources within the community in which an individual lives and spends time. They will, therefore, look at places where the person would be welcomed, find someone who enjoys spending time with the person, and try to foster reciprocal relationships (CDLP, 2009).

An alternative intervention to build networks is described by Walker and Cory (2002). Their work relates to a locally based agency called Neighbours which provides planning and support services for people with disabilities. At the request of the person with disability Neighbours meets with them, outlines the supports it can offer them and, if the person then wishes, they will together draw up a support proposal. Upon approval of the plan by the funding authorities, the money comes directly to the focus person. Each individual can determine how they want to spend their money, as long as they stay within their overall budget. Neighbours supports 32 people and it believes this is the optimum number as they fear that if they become much larger they would be in jeopardy of being too bureaucratic and losing their person centred quality. The support they provide includes assisting people to find housing, to find work and other meaningful things to do during the daytime, and to develop relationships and circles of support. The agency acknowledges that helping people to have community connections and friendships is slow ongoing work. Walker and Cory report that in the experience of Neighbours, it can take many months to establish a network of friends and they also make the important point (echoing Clement and Bigby, 2008) that once established, a network may be short lived as network members experience changes in their own lives: they give the example of a client who became friendly with local college students but who had to renew his circle of friends as they graduated.

Kam-shing and Sung-on (2002) report on a befriending initiative which was embedded in a social capital approach undertaken by the Good Neighbour Centre in Hong Kong. This initiative was described as 'a natural locality-based supportive networking approach for disabled elderly people living alone in a public housing estate'. The Initiative lasted from 1991 to 2000 and involved 14,308 elderly people with disabilities and over 6,651 volunteers. As part of this approach, various psycho-social interventions were developed over the nine year time frame to strengthen mutual support among the volunteers, the elderly disabled person they were befriending, and also the neighbours of the elderly person. In this way, it was hoped a locality-based naturally supporting community would develop. The ideals of stable and constant mutual support, mutual development and mutual concern were stressed, as was the concept of reciprocity. In line with this, the potential for the disabled elderly to care for and support others was facilitated. They describe the approach as establishing a locally-based supportive and integrative community for the client. In this approach, a social worker tries to establish a supportive, mutually concerned and

normalized community for the client in need. The social worker tries to link up the client with nearby people such as relatives, friends, neighbours, volunteers from churches or social welfare organisations. Once linked, all these form a mutual support community which allow the clients care for others, and ultimately the dichotomy of carers and carees turns into shared and reciprocal support within a community. The authors contrast this approach with a social networking model in which the social worker analyses the personal support network of individual clients and tries to pull in either formal support networks in forms of services or resources, and / or informal support through relatives, friend or neighbours to help the client to deal with vulnerable situations or crises.

Kam-shing and Sung-on (2002) argue that their experience shows that the approach implemented by the Good Neighbour Centre can transcend what they refer to as 'mere social networking' and enable the establishment of mutual support and normalized community in which the disabled person becomes a normal functioning member living happily with their neighbours in the community. The authors note that the establishment of a natural, locally-based supportive community is undermined when the helpers live outside the locality.

Over the nine year duration of the project, the authors report that feedback from clients and workers was positive and encouraging, but they provide limited evidence of this other than to note that a number of types of social networks were formed and that numerous encounters of impressive and humanistic interactions in these networks were observed. The most convincing outcome they argue was that after the intervention, many disabled elderly people changed from living a dependent, depressive lonely life to having a helping, caring and optimistic life-style, but, the authors do not quantify this.

5.4.2 Interventions to Create Communities

A slightly different approach to networking is to provide opportunities for people with disabilities to contribute to their communities. Bates and Davis (2004), in their discussion of social capital, make reference to a number of these opportunities. One they refer to is the VALUES project based at Leicester Volunteer Centre which supports people with learning disabilities to contribute their time and skills to the local community. The individuals work in the local museum, in charity shops, and on social projects including environmental projects and lunch clubs. A second project they described facilitated seventeen people with learning disabilities to fence gardens on an estate in Bridgend. As well as forming a tight-knit team, the participants have gained work experience and qualifications in amenity horticulture by linking with the local college, plus, they feel safe and welcome on the estate. Local residents hold the project in very high esteem and they advocate for and defend its members if the need arises. The estate also benefited from knock on environmental and social effects. For example, stolen cars used to be driven onto the lawns between the houses but now that the gardens are fenced in, this has stopped, and overall vandalism has been reduced (Bates and Davis, 2004).

An alternative community creating intervention which also has a peer dimension is described by Poll and Kirkpatrick (2009). They discuss a project called the

KeyRing Living Support Networks function. In 1990, an organisation called KeyRing decided that nine people who might otherwise be in residential care could be supported to live in their own place in an ordinary community by a volunteer working only 12 hours a week. At the time the idea was considered extraordinary but by 2009 there were 900 KeyRing members living in ordinary places in 54 local authority areas.

The model involves placing about eight or ten participants in flats that are scattered around a neighbourhood but each within walking distance of each other. A Community Living Volunteer lives in his/her own accommodation at the centre of this created neighbourhood. The participants are facilitated to live independently in the community through a number of supports and strategies. These are support from the Community Living Volunteer (with back up support from a central office), mutual (peer) support, self-reliance and community connections. The idea is that the participants form their own network, with support from the Community Living Volunteer and through community connections.

Support from the Community Living Volunteer

The Community Living Volunteers (three per network of nine members) work 12 hours a week and divide their support between the network members. The CLVs are in turn supported by a Supported Living Manager who supervises them and also engages in inter-agency negotiations about individual network members.

Self-Reliance

Network members themselves were the first to articulate the strategic importance of self-reliance to their quest for independent living. Consequently, over a period of time the CLVs began to see their role as helping people to mobilise their own capacities rather than doing too much for them.

Mutual support

The concept of mutual support (involving the essential friendship quality of reciprocity) is central to the creation of the networks. Members are required to sign a contract that they will offer each other neighbourly support when needed and it is part of the function of the CLV to reinforce and support this mutuality.

Community connections

Establishing connections with the wider community is the final element of the approach. Some network members could make their own community connections but some strategies were used to reinforce this. The most frequently used strategy was mapping which involved producing drawings of the localities with positive and useful people identified. So the maps identified where the useful associations are located, where the people likely to be helpful were located, good places to hang out, safe meeting places as well as the more general locations of local amenities and services.

This model is deemed by those involved to be highly beneficial to the network members and also to be cost effective. It draws both on the benefits of peer networks while at the same time extending links to other community members. Those involved in implementing the model believe that local authority areas that have multiple networks work better because they can increase the range of possibilities and options available.

Summary of Key Points

- The above interventions take very different approaches to promoting independent living, social inclusion or the development of natural supports. They include those which draw predominantly on family members and friends (such as Circles of Supports), those which draw on peers, those which draw on service agency staff, and finally those which attempt to harness the community as a backdrop to achieving a lifestyle more approximate to independent living.
- Within the literature the focus tends to be on the concept of support, *per se*, rather than on that of natural supports. The role of volunteer befrienders as well as that of paid workers suggests supports need to be considered across a broad spectrum with the inter-relationship of supports, the balance across different types of support, and the overall benefits to the person with a disability being more important perhaps than a single domain of support.
- The interventions examined in this chapter also reintroduce the distinction between social inclusion and social capital approaches and it would seem that those approaches which seek to build social capital are likely to be more effective in promoting independent living.
- Support Circles and related models which are widely used in North America draw on family and friends to provide a range of supports for people with disabilities and are explicitly focused on ensuring a full life rather than on meeting specific needs. Although not extensively used in Ireland, the experience of the Micro-Board project has suggested the value in exploring further the potential for using this model, but highlights also the need for policy to facilitate this.
- Peer based approaches including self-advocacy are generally considered in the literature to have considerable potential in promoting independent living, including in relation to service delivery and policy development. A less consensual issue relates to self-authored or segregated spaces. For some, these hark back to the era of enforced segregation, but for those that espouse this approach, they are seen as enabling people with disabilities to develop shared and collective values by ensuring that their experiences and voices are taken into account.

- Interventions to develop social supports can include both social inclusion and social capital approaches. The examples looked at in this chapter suggest that models that seek to build the capacity of people with disabilities to form relationships and support networks are more effective than those which rely solely on staff members to develop links between people with disabilities and the wider community.
- Befriending strategies and network building interventions combine both capacity building and assisted network formation. Examples of these can be found in a number of jurisdictions and a common feature is the development of dedicated personnel to resource, develop and support friendships and community linkages at community level.

Chapter 6

Facilitating Natural Supports: a discussion of the barriers and enabling factors and policy considerations

6.0 Introduction

In this final chapter, the factors which inhibit or contribute to the development of natural supports are discussed. These factors are identified primarily on the basis of the literature reviewed in Chapter 4 but the contextual material used in other chapters is also drawn upon. The chapter ends with a discussion of the implications of this review for the development of policy and services to facilitating the development of natural supports and to promote their role in supporting independent living.

6.1 Barriers to the development of natural supports and their potential to promote independent living

The research findings reviewed earlier have shown that people with disabilities can experience social exclusion because they do not have natural supports that enable them to participate as they wish in their communities. The findings also suggest that the barriers to social inclusion are also barriers to the formation of social relationships or natural supports. Hence, it seems that many people with disability, and particularly those with intellectual disability, experience a catch 22 type situation such that they find it difficult to live independently and engage in community activities because they have few friends who could support them with this, but they have difficulty making friends because they are not involved in their communities.

Among the barriers to the development of natural supports identified by research are those that attach to the individuals themselves, those that derive from the community or environmental contexts, and those that are associated with service provision. Various studies have identified one or more of the above (see Whitehouse et al, 2001; McConkey et al, 2010). Interestingly, research into the barriers to social inclusion as perceived by people with intellectual disabilities themselves also identified barriers at all these levels (Abbott and McConkey, 2006).

At the level of the individual, a number of studies have noted that the severity of disability and underdeveloped social skills on the part of people with intellectual disabilities are associated with low numbers of friends and small social networks. The converse has also been identified: those with higher levels of social skills are more likely to know people in their neighbourhoods and to engage in community activities (Whitehouse et al, 2001; McConkey et al,). In their study of the perception of barriers to social inclusion on the part of people with intellectual disabilities, Abbott and McConkey (2006) record that personal abilities and skills was one of the main factors mentioned by participants including lack of self-motivation, poor confidence and poor literacy and numeracy skills.

Community level factors identified by the research include the lack of community amenities and opportunities which can be particularly problematic in deprived housing estates and also in rural areas (Taub, 2009; McConkey et al, 2010; Whitehouse et al, 2001; Abbott and McConkey, 2006), the location of the houses where people lived, and poor public transport or difficulties using public transport (Abbott and McConkey, 2006). Lack of finance and community level stigma are additional barriers to friendship formation at this level (Taub, 2009). Lack of funding also intensifies the need for social networks and natural supports. According to the National Disability Survey, 42% of individuals with disabilities who require specialized features in and around their homes cannot afford to install them. Lack of funding is also the most common reason why persons with disability cannot access help with everyday activities (CSO 2006).

Barriers relating to service settings include the over-determining of activities and community participation by staff who may not fully understand the aims of policy, who may not have appropriate training, or who may not be operating in an organisational culture conducive to supporting the development of friendships on the part of those with disabilities (Kam-Shing and Sung-On 2002; Bigby, 2008). A more overarching theme is that of risk and, in particular, what has been identified as a degree of risk aversion on the part of service providers. McConkey et al, (2010) write: "New regulations responding to physical, sexual, social or financial abuse have tightened up checking procedures for people recruited to services either as staff or as volunteers. Likewise health and safety concerns prohibit certain activities from taking place unless safeguards are in place. If these safeguards are prohibitively expensive, then the activity cannot happen" (McConkey et al, 2010).

Morris (2004) also identifies a number of attitudinal factors which undermine the choice and control of people with disabilities, and hence their ability to live independently. These include assumptions about capacity which are sometimes reflected in law; concerns about risk, assessments and care plans being resource led rather than need led, and the failure to meet some needs including the needs of adults who are parenting.

Overall, it seems managing the risk of people engaging in community participation is a major challenge to service providers (and to natural supports), and one which can lead to a very conservative approach to supporting people to socialise, make new relationships, and generally assume more self-determination

in their own life (McConkey et al, 2010). The participants in Abbot and McConkey (2006) also identified the staff and management of service organisations as presenting barriers through not allowing them to make their own plans or go out alone, and through not treating them as adults. Abbot and McConkey (2006) argue for a new approach to risk management to overcome this issue. Poll and Kirkpatrick (2009) note in relation to the KeyRing project discussed in Chapter 5 that sometimes things do go wrong and it is not possible to give the assurance that they won't. Some of their network members were burgled, mugged and targeted by someone unscrupulous. But they suggest that whether those people would have been fully protected from such difficulties in a group home or hostel is a moot point, given that most reported abuse takes place in institutions.

Other studies have identified additional barriers to the development of social relationships. The life trajectory of people with intellectual disability, for example, can prevent opportunities to add or replace network members based on family home and school with new ones based on work interests and friendship (Tyne, 1989, cited in Forrester-Jones et al, (2006). McVilly et al, (2006) found that having attended a special school was positively correlated with loneliness in later life. Bigby (2008) also drew attention to the impact of the life cycle on the availability of natural supports. As people with disabilities age, so too do those who support them experience life changes such as the birth of a child, a move to a new region, ill health and even death. Consequently people with disabilities experience a decrease in their social support systems over time. The relationship between life trajectory and natural supports points to the need to take a life cycle approach to promoting wellbeing of those with disabilities (Carney et al, 2011).

Finally, it is worth reiterating the findings of McVilly et al, (2006) who found that family members – who have been referred to as the frontline of natural supports – can actually inhibit the development of other social relationships and especially friendships on the part of people with intellectual disability.

6.2 Factors that can facilitate natural supports

One enabling factor, evident from the research, is appropriate cultural change at service delivery level and at policy development level. Included here is the articulation of clear definitions and statements of policy objectives, particularly those relating to what is understood by independent living and self-determination.

Other factors that would support these developments are appropriate indicators and appropriate monitoring systems to measure effectiveness. It also seems clear from the research that any such developments at policy or service level need to be clearly communicated to staff, and that training for them to implement such interventions must be provided.

New financial instruments to promote independent living are also indicated as valuable. The Centre for Disability Law and Policy, Galway, has argued that

providing persons with disabilities with financial products creatively designed to encourage savings and incentivise family members and friends to help out financially, can be an effective way of bridging the gap for the much-needed services not provided by government programmes. The Centre suggests that the ABLE Act introduced in the USA in 2009 which provides tax incentives to people with disabilities and their family members to contribute to savings accounts, may be an effective instrument (Centre for Disability Law and Policy, No 3, 2010).

Christensen (2010) notes that of all the changes introduced into disability services over the years, none of them changed the role of those receiving services to the extent that the 'Cash for Care' system does, whereby the receiver of care, in various ways becomes the employer of the care workers. Christensen notes that there are two perspectives within the literature on cash for care systems. One is an organisational perspective which suggests that these systems are the only way to solve the increasing demands of social services caused by an ageing population. The second is a users' perspective literature which argues that independence has increased with cash for care. Comparison between the UK and Norway cash for care systems suggests the former empowers the user to a greater extent than the latter and this was related to the fact that the UK system delegates more decision making to the user (Christensen, 2010). Again, this highlights the extent to which the introduction of policy, per se, may not achieve the desired objective if the associated instruments do not enable the target person to have control and decision making.

Over and above the overall culture of policy making, a further factor in enabling the development of natural supports and independent living appears to be the establishment of dedicated support workers who can build community and social relationships for people with disabilities. Bigby (2008) suggests that her study points to the need to develop active strategies to nurture and build informal social networks of people with intellectual disabilities so as to enable the potential spectrum of informal network functions for each individual resident to be fulfilled. One approach to this, she suggests, may be the implementation of a dedicated function, whereby a skilled inclusion worker is employed to work across a cluster of residents. The worker would be responsible for mapping residents' family constellations and creatively tackling the continuing engagement of families in the lives of residents, as well as developing individual strategies for fostering friendships or advocacy relationship. It is noteworthy however, that Bigby's later co-authored study (Clement and Bigby, 2009) described how the lack of understanding of policy objectives on the part of service staff undermined social inclusion strategies, even when supported by a Community Inclusion Officer.

McConkey et al, (2010) also describe what they call a new meaning to a professional relationship in the context of supporting people with intellectual disabilities. They argue that paid supporters are the most important people in any service system because of their role in helping to form and deepen relationships in people's lives, thereby addressing their emotional and social need as well as giving practical supports in daily living. The relationship between paid supporter and the focus person, they suggest, is not a usual social relationship, nor a professional-client relationship, nor is it an employee – employer

relationship. It is, instead, a support relationship and among the responsibilities of the paid supporters should be that of enabling community participation by building bridges between the people they support and the wider community. Earlier, the same theme had been addressed by Whitehouse et al, (2001) who argued that owing to the lack of autonomy that many people with learning disabilities experience within their environments, developing and maintaining relationships is virtually impossible without an adequate level of organizational support. Most important, they argue, is the presence of a 'keyworker' who knows the person well, and can facilitate social contacts and provide travel etc.

The interventions discussed in Chapter 5 would suggest that establishing such a role on its own without clear definitions, training and perhaps a focus on social capital approaches will not be sufficient to fully achieve community participation, social inclusion and a move to greater independence on the part of people with disabilities.

6.2.1 Supporting the supporters

An issue that has been touched on in earlier chapters is that of supporting those who provide support, including natural supports, and those who try to develop natural supports. McConkey et al, (2010) argue that supporters need to work in partnership with one another to foster team-working and leadership. All supporters need to have a shared understanding of the people they support and common expectations about how their support is offered and delivered. They argue that supporters must build up a shared sense of purpose as this is the basis for effective team-work. Leadership is needed that guides and supports supporters and which co-ordinates their diverse contributions towards common goals. This echoes Lord's early findings on the importance of Support Clusters for families providing support in the context of Support Circles and also Kavanagh's (2008) evaluation of Microboards in Ireland which stressed the importance of the facilitator in providing training and other resources to Microboard members.

Studies suggest, however, that in general, providers of natural supports do not themselves receive sufficient supports. Vecchio (2009), for example, used data collected from the Australian Survey of Disability, Ageing and Carers in 2003 to investigate the factors that influenced the assistance received by primary caregivers of non-institutionalised people aged 15 and over with either profound or severe disabilities. The study found that 61% of primary caregivers did not receive any main source of assistance, and those that were spouses of the person with disability or who were younger, not in the labour market, and living in remote regions, were least likely to do so. Reasons for limited assistance included the caregivers' perception that they were managing at that point in time, their lack of awareness of the services available, and cultural and ethnic influences.

In Ireland, Hanrahan (2006) undertook an assessment the provision of respite by 23 schemes which involved 430 households. Two thirds of the households hosted children while over three quarters (78%) hosted adults. He noted that that 21 of the schemes were 'robust', but some were stalled due to a lack of resources which were identified as a major challenge to family-based schemes. Another theme to emerge was the feeling that schemes are not appreciated by service

provider management, and do not receive the recognition that they deserve compared to centre-based or congregated services. Indeed, insufficient support from sponsoring agencies, as well as under-funding, has led to some very good, and even pioneering schemes either closing down or continuing at a reduced capacity.

If the issue of developing natural supports is to be given serious policy consideration, it will be necessary to recognise the need to resource and support those who provide them.

6.3 Policy Considerations

The main considerations from this literature review are as follows.

In the first instance, the lack of data relating to natural supports and independent living is a significant obstacle to the development of policy and services in this area. Additional studies and data collection are required to address this deficit and these need to be designed and implemented in such a way as to allow a critical mass of comparable data with generalisable findings to emerge.

A second clear policy consideration relates to the need for absolute clarity in the formulation of policy particularly in relation to policy aims, and a clear description of the mechanism to achieve these aims. This needs to be accompanied by the development of appropriate impact indicators and monitoring systems.

The provision of training for service agency staff in relation to the objectives of these policies is a clear policy consideration arising, and the creation of new roles (e.g. community connectors) to support policy and service implementation should be considered. The linkage of these roles to mainstream areas service provision should also be considered.

The involvement of people with disabilities themselves in policy making and service development has also been shown to be valuable and should be further developed. The inclusion of natural supporters in decision making regarding service development and policy development may also be considered.

The need to pilot and evaluate a variety of interventions to support the development of natural supports, and to underpin their role in promoting independent living, should be given serious consideration. The piloting of new financial packages should be included here. Given the heterogeneity of people with disabilities (and not just in terms of their disabilities), it is unlikely that a one size fits all approach will be sufficient.

The need to support the natural supporters must be considered. That could take the form of direct support for them (for example respite), as well as support to reinforce their ability to promote independent living (for example the provision of resources including training in areas such as building self-determination and friendship, promoting healthy lifestyles and so on).

A final policy consideration is the need to acknowledge that a move to natural supports is likely to have resource implications, and if it is to be successful in promoting independent living in line with the UN Convention, the level of resourcing will need to be appropriate to the needs of people with disabilities.

Summary of Key Points

- Barriers to the formation of social networks (and therefore social support) include those at the level of the individual (including severity of disability and social skills), those at community level (such as lack of amenities, poor public transport, lack of finance and stigma).
- Service settings themselves can also present barriers to network formation and social inclusion arising from staffing issues, staff practices and the priority given to care over community participation. Risk management emerges as a key barrier to service staff promoting social inclusion or greater independence.
- Facilitating factors are also diverse and include cultural change in relation to service delivery and policy development, the establishment of clear definitions and objectives for policy and the introduction of appropriate indicators and monitoring systems. Financial instruments can also be facilitating factors but they must ensure that decision making and control is vested in the person with disability.
- Staff training has also been identified as having a role to play in facilitating the development of natural supports and so too has the deployment of dedicated personnel to work with people with disabilities in building relationships with and linkages to their local communities. The need to support those who provide natural support is also acknowledged.
- Key policy implications arising from the literature review include:
 - The need for improved data collection and additional research to address current knowledge deficits.
 - Absolute clarity in the formulation of policy particularly in relation to policy aims, and a clear description of the mechanism to achieve these aims, accompanied by the development of appropriate impact indicators and monitoring systems.
 - The provision of training for service agency staff in relation to the objectives of these policies, and the creation of new roles (e.g. community connectors) to support policy and service implementation.
 - The involvement of people with disabilities themselves in policy making and service development. The inclusion of natural supporters in decision making regarding service development and policy development may also be considered.

- Piloting and evaluating a variety of interventions to support the development of natural supports; new financial packages should be included here.
- The provision of support for natural supporters.
- An acknowledgement that a move to natural supports is likely to have resource implications, and, if it is to be successful in promoting independent living in line with the UN Convention, the level of resourcing will need to be appropriate to the needs of people with disabilities.

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