Title	Towards best practice in the provision of respite services for people with intellectual disabilities and autism
Author(s)	Canavan, John; Merriman, Brian
Publication Date	2007
Publication Information	Merriman, B., & Canavan, J. (2007). Towards best practice in the provision of respite services for people with intellectual disabilities and autism. Galway: Child and Family Research Centre, NUI Galway.
Publisher	Child and Family Research Centre, NUI Galway
Item record	http://hdl.handle.net/10379/243

Towards best practice in the provision of respite services for people with intellectual disabilities and autism

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Foreword

Many parents, siblings and carers of children and adults with intellectual disabilities and autism experience significant challenges over extended periods as well as regular (and often severe) stress. Respite care offers a break for those who experience such stress and normally consists of temporary residential care in the local community. However, respite is not just about a break for parents and carers, nor should it be solely for those under stress. It also provides positive opportunities for young people and adults with disabilities to interact with their peers, to achieve a measure of independence and to enjoy relationships with people outside their immediate family circle. It also facilitates a transition pathway to independent, though perhaps sheltered, accommodation in later years. Such respite is therefore not just desirable; it is essential. Yet remarkably little research has been carried out to date on this important service.

This valuable Report, commissioned by the National Parents and Siblings Alliance, is a useful attempt to establish what is "best practice" in relation to respite care and suggests a number of key principles for progress in the future. While a comprehensive study of current facilities has yet to be done, it seems that provision is inadequate in many areas and little choice is available.

On the basis of a review of international best practice, the authors argue that respite care should be a critical component of a comprehensive and integrated range of services in the community for people with intellectual disabilities and autism. Respite services should reflect the specific needs of the person and family involved and should be provided as a right. Furthermore, such services should have clear systematic goals which should be regularly reviewed and evaluated.

This is a most useful Report which will be of considerable interest to service users, families and service agencies. It is to be warmly welcomed.

Professor P.J. Drudy

Chairperson

National Institute for Intellectual Disability

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Executive summary

Aim and method

This research was commissioned by the National Parents' and Siblings' Alliance (NPSA) and funded by The Daisychain Foundation. The primary aim of this research was to investigate best practice in respite care for people with intellectual disabilities and autism. A secondary aim of the research was to provide a resource for raising the policy profile of respite care, and for leveraging support for further research. A number of research questions were specified around the definition of respite care, its current level of provision, and best practice in respite care.

The methodology employed was a combination of a focused literature review and consultation with a number of stakeholders including service providers, academics in the policy field, and parents of people with intellectual disabilities and autism.

Policy and legislation

The context of social services provision has changed, both in Ireland and internationally. In 2006, the United Nations Convention on the Rights of Persons with Disabilities (2006) was finalised. On a European Union level, the Madrid Declaration (2002) offers a framework for progress and a set of ideals. These ideals underpin the Irish government's Disability Strategy (2004).

Definition of respite care and rationale

There is a broad range of definitions, depending on profession, era, types of services considered to be respite, and time-frame. This variation in definition can be seen to reflect the values and commitments of those offering definitions. The rationale for respite care has moved from maintaining carers in their roles towards improving their caring capacity and providing benefits for service users.

Forms of respite care

Respite care takes a number of forms and they were broadly categorised for the purposes of this project as follows:
- Informal help from friends and family;
- Formal respite care in the service user's home;

- Out-of-home respite facilities; and
- Recreation and holiday breaks.

Each of these categories of respite care has its advantages and limitations.

Intended benefits

Benefits for the carer were clustered around health and well-being, family functioning and concrete supports. For service users, social development and independence were the main benefits. A challenge for service providers is to ensure that these benefits accrue and are maintained. A major concern emerging from this project is the dearth of good quality research investigating the effects of respite care.

Respite care in the continuum of services

Fully functioning, integrated social services would include all social, medical, and paramedical services. Such services would be designed with the input of all stakeholders, fully integrated, and responsive to the changing needs of service users and families over time. In such circumstances, a number of standard support services would be available and might have the same function as respite. This is not to suggest, however, that stand-alone respite care will not also be needed. From a cost-benefit point of view, respite care seems to have potential as a service provision option.

Provisional principles of best practice in the provision of respite care services

In the course of this research, a number of principles of best practice in the provision of respite care emerged. The eight provisional principles are:

Principle One: That respite services be person-centred and family-centred;

Principle Two: That respite services be provided on a rights basis;

Principle Three: That respite be defined as a support service and regarded among a system of support services;

Principle Four: That there be a single point of access to respite care services in a given administrative area.

Principle Five: That respite services be designed in consultation with families in acknowledgement of their expertise in providing care;

Principle Six: That respite be designed to facilitate the service user in building relationships in their community;

Principle Seven: That respite services be age-appropriate and develop as the service user develops;

Principle Eight: That respite care services have clear goals and that systematic and regular review ensure achievement of those goals.

Abbreviations

ASD   Autism Spectrum Disorder

CACC   Canadian Association for Community Care

DDHC Department of Disability, Housing and Community Services, Australia

DoF   Department of Finance

DoHC   Department of Health and Children

DSFA   Department of Social and Family Affairs

EACD European Academy of Childhood Disability

EDF   European Disability Forum

HSE   Health Service Executive

NDA   National Disability Authority

NFVB   National Federation of Voluntary Bodies

NIDD   National Intellectual Disability Database

NPSA   National Parents' and Siblings' Alliance

Acknowledgements

Table of Contents

Contents

_____

List of Tables

List of Figures

List of Appendices

Chapter One
Introduction,
context,
and methodology

1.1 Introduction

The impetus for this project came from the National Parents' and Siblings' Alliance (NPSA) who are interested in exploring best practice in the provision of respite care for people with intellectual disabilities and autism. A comprehensive evaluation of current practices and comparison with international best practice standards is a substantial undertaking so this project can be considered a first step in a larger research programme. Funding for this research was provided by The Daisychain Foundation. This chapter describes the context of the project – specifically the scope and need of provision, and the legislative and policy position. The aim and objectives of the research are then outlined before a description of the methodology and the structure of the report.

1.2 Context

The specific needs of carers of people with intellectual disabilities and autism have long been known, both to carers themselves and to support services. However, the resources required to meet those needs have not always been available, or at least priority for allocation of resources has not been addressed. In recent times society and government have begun to catch up and there is now a greater recognition of those needs in legislation and of the responsibility on society to attend to them. Among the needs expressed by carers is respite care.

Historically, families of people with intellectual disabilities were encouraged to place them in an institution and "forget them" (Bain, 1998). The next step in the development of services for people with disabilities was the medicalisation of disability (Quin, 2003). While this was "instrumental in the creation of service provision", the emphasis on the medical aspects of disability distracted from other areas like education, employment,

transport and social relationships (Quin, p.84). Recent trends in policy have been towards a social model of disability and the consequent deinstitutionalisation of people with disabilities (Quin & Redmond, 1999) and this is certainly true of respite care.

A social model of disability sees the social world as causing disability by the imposition of barriers rather than disability being the effect of impairments (Light, nd; Quin, 2003). Deinstitutionalisation in the form of community care represents a move towards the social model. The ideal of community care was that people with intellectual disability could live a full, inclusive life nurtured by those around them (Quin & Redmond, 1999). Families assumed the duties of care, with the support of the community. However, there have been a number of negative consequences. Firstly, there were severe restrictions on the life choices of families, restrictions imposed by the responsibilities on them that come with community care (Bain, 1998). At the same time, the promised support and resources necessary for the system to function properly never materialised (Quin & Redmond, 1999). Perhaps more importantly, little or no attempt was made to identify who in the community was likely to help and to involve them in the planning of services (McConkey, 1987).

The National Disability Authority (NDA) is the Irish state body for policy development, research, and advice on standards in matters concerning people with disabilities. An NDA policy document *Towards Best Practice* (2004a) recognised some of the failures in planning and policy mentioned above, and stated that too often policy was framed from the policy maker's perspective with poor estimations of impact. Further concerns were raised in that document about the continued dominance of the medical model in certain parts of the services, about the lack of choice available to service users, and about the poor co-ordination between the health services and the community. The NDA recommended framing policy based on regional and national reports of needs and services (2004a). The annual reports of the National Intellectual Disability Database (NIDD) are developing towards providing information on services.

1.2.1 Scope of need and provision

The National Intellectual Disability Database (NIDD) is one of the most significant developments in disability services in recent years. Since 1995 the Health Research Board has published annual reports of the NIDD on the numbers of people with intellectual disabilities in Ireland registered on the database and these reports have been useful in framing policy. The reports include numbers receiving specified services and

respite care is one of those services. However, it is worth noting that the NIDD report is an aggregate of individual care plans, which includes well-resourced care plans, in which service users benefit from a number of different services, alongside less well-run services that leave some needs unmet. There is no clear picture of any individual case so the numbers can mask the reality of service provision. A separate issue is that of people who are not included in the NIDD figures. The database is compiled using individual database forms completed by service providers so those not in receipt of formal services are unlikely to be recorded. In 2006, there are just 963 (3.8%) people receiving no services included in the report (Barron & Kelly, 2006). Anecdotal evidence suggests that this does not reflect the true numbers of people receiving no services and it should be noted that inclusion on the database is voluntary. Other anomalies in the figures may be due to definitions of services. However, while the NIDD may not be exhaustive or perfect, it reflects the information provided to it and gives the best available description of services for people with intellectual disabilities in Ireland.

In 2006 there were 25,519 people registered on the database of whom 24,556 (96%) are receiving some services (Barron & Kelly, 2006). The majority of service users live in a home setting with parents, other relatives, or foster parents (16,245; 63.7%). This majority is larger for children under 19 years of age (8,382; 95.2%). There is, therefore, a substantial need for support services for people with intellectual disabilities living in home settings. With regard to respite care, there are two broad service categories in the NIDD report which include respite care: day programmes and residential service. Day respite programmes are either centre- or home-based and a total of 26 (0.1%) people used these services. Once again, this figure does not tally with the anecdotal experience and may be due to issues of categorisation. Respite care is also counted among residential services and 4,912 (19.2%) were in receipt of some form of respite. Among these people, there are 1,275 individuals who require additional residential services. A breakdown of the settings in which these services were offered is set out Table 1.1.

Table 1.1: Residential service provision for 2006 (from Barron & Kelly, 2006)

Residential service	Under 18	18 and over	All ages
Holiday residential placement	15	192	207
Crisis or planned respite	1258	2984	4242
Occasional respite with host family	56	104	160
Overnight respite in the home	5	3	8
Shared care or guardianship	0	3	3
Regular part-time care (2/3 days per week)	19	72	91
Regular part-time care (every weekend)	2	11	13
Regular part-time care (alternate weeks)	9	54	63
Other residential service	8	117	125
Total	1372	3540	4912

Table 1.2: Calculation from NIDD (Barron & Kelly, 2006)

	All ages
Home setting	16245
Less those in receipt of residential support services (Table 1.1)	- 4912
Less stated unmet need for residential support services	- 1954
Total	9379

According to the NIDD (2006) report's section on unmet need, 1,954 people require residential support services. Among this group, most demand is for centre-based respite services (56.4%, 1,102 individuals), semi-independent and independent living arrangement (20.6%, 402 individuals), and holiday residential placements (9.2%, 180 individuals). One possible interpretation of the NIDD report is that 9,379 people with intellectual disabilities (57.7% of those living in home settings) are either not in receipt of respite services or have not expressed a need for respite (see Table 1.2). Anecdotal evidence arising from contact with stakeholders in this research suggests that the database does not reflect the reality of demand for respite care services in Ireland.

1.2.2 Legislative and policy context

The National Disability Strategy (2004) aims to put in place the most effective combination of legislation, policy, and services to support equal participation for people with disabilities in Irish society. It provides for additional investment for the period 2006 to 2009 and includes a number of legislative components. These are the Disability Act 2005, the Education for Persons with Special Educational Needs Act 2004, the Citizens' Information Act 2007, which deals with advocacy, and six sectoral plans of government departments. The Strategy recognises the importance of best international standards and of an inclusive environment. These principles are consistent with the social model of disability and indicate the direction of the National Disability Strategy.

While the Disability Act 2005 does not address respite care as a specific issue, it does establish that every person with an intellectual disability is entitled to an independent assessment of needs and a statement of needs. An assessment of needs is independent in the sense that it is not constrained by available resources and can describe the ideal level of services to meet all the individual's needs. There is the possibility in the assessment of needs, then, to include respite care provision among the supports required. A statement of needs is made following from the assessment of needs. Finally a service statement is developed with a liaison officer in the context of available

resources. It must be recognised that the service statement is bound by limited resources and practicability and is therefore limited in its scope.

The Education for Persons with Special Educational Needs Act 2004 does not mention respite care. The Citizens' Information Act 2007 provides for a personal advocacy service for people with intellectual disabilities and autism. While children's parents most often act as advocates for them, at least when they reach 18 they can benefit from the independence afforded by an outside advocate. Personal advocates seek services, including respite care, on behalf of people with intellectual disabilities and autism.

The sectoral plans of the Department of Social and Family Affairs (DSFA, 2005) and of the Department of Health and Children (DoHC, 2006) are of particular interest. The DSFA provides for improving income support for carers and generally for supporting full-time carers in their role. The DSFA sectoral plan highlights the increased participation of women in the workforce and its consequences for the supply of family carers: there may be a 15% reduction over the next ten years. This demographic change is likely to place even more demand on support services for people with intellectual disabilities and autism and their families.

The DoHC sectoral plan (2006) lists respite care among the services provided by the Department through the Health Service Executive (HSE). Specific reference is made in the multi-annual investment plan to 255 new residential beds, 85 respite beds, and 535 day places per year for four years. This gives a total of 340 new respite places in the life of the investment plan. It should be noted that these figures are provided by the Department based on the budget for the plan divided by the estimated cost per bed.

Possibly the most important policy development in recent years was the Madrid Declaration (European Union, 2002) which made disability a human rights' issue. The preamble states that "the old approaches based largely on pity and perceived helplessness of disabled people are now considered unacceptable" (p.2) and advocates a social model of disability and the necessary changes in society. It is worth repeating part of its vision (p.3):

> "**Away from** people with disabilities as patients... and **Towards** people with disabilities as independent citizens and consumers;
>
> "**Away from** professionals taking decisions on behalf of disabled people... and **Towards** independent decision making and taking responsibilities by disabled people and their organisations on issues which concern them;

> "**Away from** unnecessary segregation in education, employment and other spheres of life... and **Towards** integration of disabled people into the mainstream".

The Madrid Declaration (2002) puts forward a number of ideals of service provision for people with intellectual disabilities. These ideals include the role of families as advocates who should be allowed to organise support for the person with a disability, access to mainstream health, education, vocational and social services, and all the opportunities available to non-disabled persons, and services co-ordinated across sectors. Another important principle is "Nothing about disabled people without disabled people" (p.7) which emphasises the need for person-centredness in all decisions.

The latest legislative development is the recently ratified UN Convention on the Rights of Person with Disabilities (UN, 2006). It is a rights-based declaration building on the UN Universal Declaration of Human Rights (1948). There are two points particularly relevant to respite care and its provision. The first has to do with the family being the natural and fundamental group unit of society and thereby entitled to protection by society and the state. The implication is that the family should be the context for care of people with intellectual disabilities and autism and that they should be supported in providing care. As will be detailed in Chapter Two, respite care is a fundamental form of support for families.

The second point concerns child-centredness and Article 7 states that "in all actions concerning children with disabilities the best interest of the child shall be a primary consideration". This means that the interests of the state and of the family should not over-rule those of children, something which has occurred in the past. A subsection of the same article states that the right of children to express their views should be ensured by state parties. This implies that children should be consulted and heeded in all matters concerning them.

A number of other EU and UN level legal positions make reference to respite care. A UN resolution on equalisation of opportunities (UN, 1993) is in a similar vein to the Madrid Declaration (2002), specifically in relation to the principle of integration. Part of the resolution is that States should remove all necessary obstacles to people who wish to foster or adopt a child or adult with disabilities (Rule 9.1). This rule supports the provision of respite foster care. There is also provision in the 1993 resolution that "Respite-care and attendant-care services should be made available to families which include a person

with disabilities" (Rule 9.1). Finally, Article 24 of the UN Declaration of Human Rights (UN, 1948) states that "Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay" (UN, 1948). This right can be applied to arguments for respite care provision on the grounds that parents have a right to rest and leisure.

1.2.3 Summary of context

The way in which people with disabilities are viewed and treated has changed. The social model of disability now prevails and demands changes in practices. In Ireland, the National Disability Authority is looking towards best international practice to guide our future practices. The National Intellectual Disability Database (NIDD) is developing towards providing the information on which planning decisions can be based. Most importantly, the government has published a National Disability Strategy and committed to improving services. It should be noted here, however, that there are sometimes substantial differences between the unmet need of the NIDD, the provisions of the National Disability Strategy, and the reports of those working directly in the disability services. At the same time, EU and UN policy is moving towards rights-based provision of services for people with intellectual disabilities and autism. Respite care is visible in some of these developments in its own right and implied in others as one of a range of support services. Given these changes, then, in social services provision and in national and international policy, the time may be right to assess the place of respite care in services for people with disabilities and to establish best practice.

1.3 Research aim and objectives

The primary aim of this research was to investigate best practice in respite care for people with intellectual disabilities and autism. This was undertaken through a focused review of relevant literature in the field and a limited consultation with policy and practice stakeholders. A secondary aim of the research was for its output to be a resource for raising the policy profile of respite care, and for leveraging support for further research.

A number of research questions were specified:
1. How is respite care in intellectual disability services defined and what is the broad rationale for its provision?
2. What are its specific intended benefits for service users, parents and carers, and service providers?

3. Does research evidence reflect the achievement of the intended benefits from respite care?
4. What is its nature and what forms does it take?
5. What are its recognised limitations?
6. Where does respite care fit in the continuum of services?
7. What are the key issues and challenges in respite care provision?
8. What is best practice in respite care provision?

A meeting between the researchers and the NPSA took place mid-way through the project, which clarified that part of the aim was to take account of respite care for people with autism. It was also decided to expand the consultation phase to include interviews with parents of people with intellectual disabilities and autism.

1.4 Methodology

The methodology for the present study comprises a literature review and interviews with a small number of stakeholders. The following were the main steps taken:

- Three broad categories of literature were identified:
  - Academic publications;
  - Commissioned reports to government and non-government organisations; and
  - Acts of government and official publications.
- Academic database searches yielded a number of review articles in academic journals.
- Broader searches elicited other useful literature, including a number of studies conducted in Ireland.
  - Some of these were non-peer-reviewed articles.
  - A number referred to respite provision for adults with dementing illness from which valuable insights were gained.
- Acts of government were retrieved through official websites.
- A number of international researchers and research centres were identified who had contributed most to the area of care for people with intellectual disability and to respite care in particular; as much of their work as possible was accessed.
- Interviews were conducted with four social workers active in the area of respite care for people with intellectual disabilities and autism, one director of services, two academics active in the legal and policy developments in the area, and four parents of people with intellectual disabilities and autism.

The literature review informed the questions put to interviewees and the interview schedules are in Appendices A, B, and C. However, as the literature review continued in parallel with the interviews, it was fine-tuned and re-focused in accordance with matters arising from the interviews. These phases should be seen as complementary rather then consecutive even though they are presented separately in this report.

1.5 Report outline

This chapter has described the context in which this research took place, its aims, and the methodology underpinning it. The next chapter is a critical summary of peer-reviewed literature and some non-peer reviewed sources which describe current practice in respite care and which look towards best practice. The following chapter presents some interviews with stakeholders in Ireland and follows the same research question-based structure. It should be noted that in Chapters Two and Three the term 'child' is used to refer to all children, including adult children, who are dependent on parents or guardians. Chapter Four is a discussion of the key points from the literature review and the interview process and draws conclusions from both. Chapter Five outlines some provisional principles of best practice in respite care provision based on that discussion.

Chapter Two

Literature review

2.1 Introduction

The aim of this chapter is to critically review existing published literature in the area of respite care for people with intellectual disabilities and autism. It is structured around the following six sections: definition and rationale of respite care; forms of respite care; specific intended benefits; limitations of respite care; respite care in the continuum of services; and best practice in respite care provision. The first task is to define respite care and to describe the rationale for its provision. The literature search was not limited to particular professions so a range of points of view is presented. Next, categories of respite care are defined and described. These broad groups may not do justice to the differences in detail when respite care is provided in the real world but help to avoid over-complicating this discussion. A number of specific benefits expected as a result of respite care, for the service user but mainly for the carer, are discussed next. A general discussion of the limitations of respite care is followed by a consideration of the place of respite care in the continuum of health and social services, both in Ireland and internationally. Finally in this chapter are some examples of best practice from respite organisations in other countries and from other parts of the social services in Ireland.

2.2 Definition of respite care and rationale

The National Disability Authority (2004a) defines respite care as

> "Temporary residential care, based either in a centre or community based, that is intended to support the maintenance of people with disabilities in their own homes. It can cover a crisis period, take place on a periodic basis to enable a carer to have a break, or can provide the person with disability with medical, therapeutic or support services" (p.212).

This broad definition covers the needs of carers and of people with intellectual disabilities and autism, a number of possible timeframes for respite, and a number of possible settings. There is also a clear commitment in this definition to facilitating people in

remaining in their own homes. Since this definition is given by an Irish organisation it is a useful starting point before turning to the international literature. Additionally, this definition is from a document on best practice and, therefore, represents a target for the provision of services.

The NDA's definition of respite is grounded in principles of community care. As mentioned in Chapter One, community care values keeping people with intellectual disabilities in their family home so they can live a full, inclusive life nurtured by those around them (Quin & Redmond, 1999). The original purpose of respite care was to facilitate people with intellectual disabilities to stay at home by allowing their carer a break from the pressure and responsibility of full-time caring (Cotterill, Hayes, Flynn, & Sloper, 1997). Cotterill et al. trace this purpose back to the 1940s when respite care as we know it began. The underlying rationale for respite care understood in this way is that carers who can benefit in some way from respite care in the short-term are more likely to continue to care for their family member full-time in the long-term (Chesson & Westwood, 2004). This can, at least, postpone the need for residential care for service users and can keep families together for longer (Cotterill et al.). These reasons for respite – a break for the carer, helping the carer to continue in that role, and postponing full-time care – are consistently highlighted in the literature (Chesson & Westwood; Cotterill et al.; McNally, Ben-Schlomo, & Newman, 1999) and are consistent with the NDA (2004a) definition.

A criticism of this conceptualisation of respite care is that it limits its focus to maintaining carers in their roles (Nolan & Grant, 1992). Ciferri, McGrew, and Mehdizadeh (2005) draw a distinction between respite as an outcome and respite as a service. Respite as an outcome is giving carers a break as described above, which is an end in itself. Respite as a service, however, uses the opportunity given to carers during periods of respite care to improve the nature of their care giving activities through training and emotional support. As pointed out by Redmond and Richardson (2003), full-time carers of children with special needs have to become expert in areas such as nursing and physiotherapy and they must have time to learn these skills. Carers also need support and information (Cotterill et al.) and respite care offers the time to meet other carers or friends and family and to seek information on services. Another way to look at how respite as a service can improve the nature of care giving is respite from housework (Olsson & Hwang, 2003). If the burden of daily household chores is lifted from carers, they have more time to concentrate on direct care. This may be particularly desirable as carers often develop

expert levels of knowledge and skill related to their caring (Redmond & Richardson) so may be the best people to be directly involved in caring.

An important point to consider when trying to define respite care is that the answer often depends on who is asked. For example, parents, nurses, and social workers in one study differed widely in their definitions of respite and expectations about services (MacDonald & Callery, 2004). Parents all had different answers depending on their family circumstances; services which parents called respite, nurses called 'baby-sitting'; and while parents and nurses favoured out-of-home respite, social workers disagreed. Appropriate provision of respite care requires understanding of the meaning of respite for stakeholders and a negotiation of these sometimes opposing points of view (MacDonald & Callery).

It is worth concluding this section by noting that most reviews in the area of respite care find flexible definitions of respite and a range of services included (Chesson & Westwood, 2004; McNally et al., 1999). The definition of respite care chosen is associated with the provision of services so this variability may be a reflection of the differing cultures of service provision and of families' needs. The definition of respite care also depends on who we ask. The NDA (2004a) definition, then, is useful in an Irish context. It may not go far enough, however, in acknowledging the positive opportunities afforded to service users by respite care. To find the fullest possible definition of respite care, all stakeholders – service users, carers, and service providers – should be consulted.

2.3 Forms of respite care

Almost every study seems to use different classifications of respite. For example:

- Special sitters, emergency support, residential respite in hospitals and units, non-building based in ordinary community facilities, activity-based services, holiday schemes, friendship projects (Cotterill et al., 1997);
- Short in-home breaks, overnight in-home breaks, respite facility placement (MacDonald & Callery, 2004);
- Hospital respite, emergency respite, family based respite (Chesson & Westwood, 2004);
- Hospital-based overnight care, overnight stays in a residential home, domiciliary service in the family home, breaks provided in another family home, residential

holidays, and breaks provided through leisure schemes organised after-school or during holidays (McConkey & Adams, 2000).

Even if schemes differ in their details from place to place, there are similarities among them. Jeon, Brodaty, and Chesterton (2005) define dimensions of respite care which are useful in understanding the similarities and differences among schemes. The dimensions are:

- Planned vs. emergency/crisis;
- Formal vs. informal;
- Short-term vs. long-term; and
- In-home vs. out-of-home.

Most of the different types of respite care mentioned in the literature fit broadly into the following four categories which were deduced based on Jeon et al.'s (2005) analysis of occasion, formality, duration, and location.

- Informal help from friends and family;
- Formal respite care in the service user's home;
- Out-of-home respite facilities; and
- Recreation and holiday breaks.

2.3.1 Friends and family

Respite care offered by friends and family can be either planned or emergency, is informal, and is usually short-term and out-of-home. This form of respite care is the most flexible and usually the most accessible. It does not involve any outside agencies and is arranged by the carer to suit their own needs and those of the service user. In terms of the social model of disability and attempts to diminish differences between families of people with disabilities and others, this kind of informal care is the closest form of respite to the regular family practice of leaving children with their grandparents or cousins. Examples of the kinds of respite provided by friends and family include taking the child for a walk, reading to them, and giving parents time to attend to unexpected events (MacDonald & Callery, 2004).

The main strength of this informal source of respite is its flexibility, especially at times of crisis. While this is the case throughout childhood, MacDonald and Callery (2004) point out that support from friends and family is most common in infancy. This may be because differences among younger children are less obvious and children are easier to manage (MacDonald & Callery). An important factor in asking friends and family to care

for children is a sense of reciprocity (MacDonald & Callery) and this is not always possible in the case of children with intellectual disabilities and autism.

Support from friends and family is clearly important to all parents, as it is to parents of children with intellectual disabilities and autism. This kind of support is usually based on reciprocity and returning the favour. However, in the case of children with intellectual disabilities who need a particular level of attention, parents sometimes find it hard to ask friends and family (Redmond & Richardson, 2003). There is a possible solution to the issue of reciprocity which involves paying friends and family for respite. In this way, the advantages of family support are retained and the difficulty of asking for help reduced. A pilot programme in America gave service users ('consumers') control over the entire budget for their care (Caldwell & Heller, 2003). Carers tended to hire friends, neighbours, and members of their extended families (Caldwell & Heller). Families with more control over services in this way were generally more satisfied with the level of service. Other consequences of the scheme were greater involvement of the service user in the community and increased employment of carers (Caldwell & Heller).

However, there are also a number of limitations to informal respite care from friends and family. Firstly, support from family and friends tends to diminish as the child gets older (MacDonald & Callery, 2004) and more difficult to manage. This may be because grandparents, for example, are themselves getting older or because carers do not want to "put others out" (MacDonald & Callery, p.282). Just as the ability of friends and family to offer help changes, the needs of the carer and the service user change over time and this form of respite may not always be the best (Chan & Sigafoos, 2001). Secondly, it should also be borne in mind that friends, family, neighbours are unlikely to have formal training in caring for people with intellectual disabilities and autism. In cases where the service user has particular medical needs, specialised staff may be required.

2.3.2 Formal in-home care

Formal in-home respite care is planned, formal, and short-term. It involves a professional providing care for the service user in their own home, usually for a few hours. Short breaks like this can allow carers to attend to their own social needs and to responsibilities like shopping. Formal in-home care was the preferred form of respite for carers and for social workers in MacDonald and Callery's (2004) interview-based study. The same preference was expressed by Irish carers in a number of small-scale qualitative studies (Hartrey & Wells, 2003; Redmond & Richardson, 2003).

The main advantage of in-home care is that it maintains the child at home. This has two major consequences. The first is that the child stays at home with the family in familiar surroundings rather than going to a residential centre, for example. Secondly, respite care in the home avoids the difficult task of preparing a person with an intellectual disability or autism to leave the house, especially if he or she uses a wheel-chair or has complex medical needs.

A number of specific limitations of in-home care were pointed out by nurses involved in providing such care (MacDonald & Callery, 2004). Firstly, having a nurse come into the family home impinges on privacy and may have an impact on family functioning. Secondly, in-home respite care does not allow the child to have a real break since the routine and day-to-day environment do not change. One participant emphasised the importance of peer interaction, outside educational contexts, for children with complex needs.

2.3.3 Out-of-home respite care

Respite care outside the home can occur in institutional settings like nursing homes, hospitals, and specialised respite care units but is now more likely to be in community-based group homes or in another family's home. Institutional settings are places like hospitals and nursing homes. Out-of-home respite care is planned, formal, and usually long-term. Though there are no detailed descriptions of these more formal settings in the literature, we can assume that they provide for basic needs as well as activities, outings, and opportunities for interaction with other service users. Institutional settings are also more likely to have support services like physiotherapy and occupational therapy available, as well as trained respite staff. Community-based respite facilities are part of the community care movement and are designed to situate people with intellectual disabilities and autism among the community so that they can better take their places in the community.

There are general concerns about institutional settings in the context of community care, as mentioned in Chapter One. A more specific concern about institutional respite is that service users might be placed in inappropriate units, for example on hospital wards where their specialised needs cannot be met (MacDonald & Callery, 2004). There is also the possibility that when carers begin to use out-of-home respite care it can lead to seeking more frequent and longer spells of out-of-home care (Chan & Sigafoos, 2001).

Respite care in another family's home is a growing source of respite care. It differs from the other formal out-of-home settings in a number of ways. Most significantly, the family setting mirrors the service user's usual surroundings and offers the potential for building relationships in the community. This model, known as family placement, home sharing, family based respite, or shared care, developed as a volunteer activity in response to families' needs (Volunteer Canada, nd). It involves recruiting families from local communities and matching them to people with disabilities (Hanrahan, 2005). Host families then provide breaks varying from daytime visits to overnight stays to annual holidays depending on circumstances. Home sharing' has proven successful in Canada (Volunteer Canada, nd) in integrating people with intellectual disabilities and as a source of volunteer activity.

Closer to home, Kelleher's (2001) report states some of the specific advantages of family based respite. Service users benefit from one to one attention with no staff changes and rotas. In this way, relationships between host and guest can develop. Furthermore, relationships with other members of the host family, children of a similar age for example, can expand the social network of the person with a disability. Family based respite is more flexible, especially at time of crisis, and may be less costly than professionally staffed institutional care.

In Ireland, the National Home Sharing Network is an umbrella body for service providers offering family-based respite care. Based on figures from the 2004 Directory of Services (NHSN, 2004), there were twenty-seven schemes serving twenty counties. Levels of service ranged from day service to week-long stays and rates of allowance for host families from €12.70 per night, to €66.00 for a twenty-four hour period, to €279.50 per week.

A detailed annual report was available from one of these schemes, FAILTE Adult Respite run in Co Louth by St John of God North East Services (Hanrahan, 2006a). Figures for 2004 and 2005 for this service are presented in Table 2.1. Allowances of €35 per night are paid to hosts (Hanrahan, 2006b). It is noted in the report that FALTE had not received an increase in funding since 2002 (Hanrahan, 2006a).

Table 2.1: FAILTE Annual Report 2005 (Hanrahan, 2006a)

	Guests	Hosts	Breaks	Nights	Waiting list
2004	36	36	215	618	11
2005	36	35	208	619	12

If home sharing is to be pursued as a strategy, adequate numbers of host families are essential. Hanrahan's (2006b) analysis of the perspective of hosts may prove useful. In their view, recognition for the contribution made was just as important as payment. In an attempt to understand the volunteer mentality, payments that are considered an allowance or a supportive payment are more consistent with volunteerism and so may be more attractive to potential hosts. Generally, host families were happy with allowance rates but suggested they could invest more time in hosting if they were paid more. At the same time, there are already schemes underway to contract host families in a more formal, professional way. If host families are employed as such, professional standards may be more likely.

2.3.4 Recreation and holiday breaks

Recreation and holiday breaks represent a less common form of respite care (DDHC, 2003). McConkey and colleagues have conducted much of the research on this form of respite care, primarily with adults (McConkey & McCullough, 2006; McConkey, Truesdale & Conliffe, 2004). McConkey and McCullough describe one project arranging holiday breaks for adults with intellectual disability. The project in question took groups of people with intellectual disability initially to a specialised facility in a seaside resort and later to 'mainstream' locations (p.68), including conference centres, outdoor pursuit centres, and education centres. Breaks usually lasted one week and some were shorter, depending on the needs and the capacities of the service users. Some specific benefits were reported and these are detailed in the next section.

The study by McConkey and McCullough (2006) is described in some detail here because there are so few like it, and because it is quite an innovative approach to respite care. As mentioned above, there has been little emphasis on the service user in respite care research and practice. Even though this research reports a project for adults with intellectual disability, many of the elements could be adapted for children and especially for older ones.

A distinct form of holiday breaks is to offer carers time away from home at a hotel. The Daisychain Foundation exemplifies this form and offers complimentary two night breaks at hotels to carers and other family members of people with intellectual disabilities, physical disabilities, and autism (Daisychain Foundation, 2006). In 2005, over 500 bed nights were offered and this was expanded to over 1,000 bed nights in 2006. The Foundation does not provide care staff or facilities at the hotels (J. O'Callaghan, personal

communication, 6th March, 2007). Depending on the family circumstances, the person with the disability or autism can join them at the hotel or respite care can be arranged in the usual way, as described above.

The main limitation on holiday breaks of this kind is cost. It remains to be established by further research how the cost compares to other forms of respite and whether it is justified by the benefits accruing to service users and their families. Nonetheless, creative and innovative approaches like this have much to offer the development of respite care services.

2.4 Specific intended benefits

Most research into the benefits of respite care has focused on the carer, which is understandable given a definition of respite which emphasised its function as a break for carers. This is not to say that there are no benefits to the service user and the smaller body of evidence for benefits to service users may be an artefact of the lack of research asking that question rather than anything else. The benefits to carers described in the literature fall into two broad categories: stress reduction and self-esteem; and improved family functioning. Among the benefits to service users are socialising, and enjoying experiences outside the home.

As stated above, the original purpose of respite care was to allow carers a break from their caring duties (Cotterill et al., 1997), with the implication and the expectation being that they would benefit from stress reduction and be better able to continue with full-time care. Significant reductions in stress levels are reported (Cowen & Reed, 2002) and psychological well-being (Shu, Lung, & Huang, 2002). The term 'revitalisation' is used (Ptacek et al., 1982, cited in Cotterill et al., 1997) to imply that the carer is refreshed and better able to face the challenges of full-time care. Research also exists suggesting that carers' self-esteem is improved by respite care (Rimmerman et al., 1989, cited in Cotterill et al., 1997).

If carers can benefit from reduced stress due to the provision of respite care, the assumption is that care is a source of stress. In interpreting research findings like these, it is important to consider in more detail what prompts carers to seek support in the first place. Carr and O'Reilly (1996) took a needs-based survey of carers. They report a variability of responses to caring for a person with an intellectual disability due to the different stresses entailed by different types of disability, to the resources available, and

to the coping strategies employed by carers. Importantly, they found that reported service need was related to carer adjustment to their responsibilities rather than their physical or psychological well-being. That is to say those carers who had come to accept their circumstances said they needed less support than those who had not. The health, including level of stress, of the carer was less of a factor in seeking support.

Alongside isolated reports of benefits like those already discussed, it is also worth considering a review of the effects of respite care on carers' well-being reported across a number of studies. In one review of 29 studies, McNally et al. (1999) state that there was little evidence that respite care had either a consistent or an enduring beneficial effect on carers' well-being. One possible reason for inconsistency in results is that there would be no benefit if services were offered too late and the carer was past "breaking point" (Cotterill et al., 1997, p.778). Similarly, if the carer has problems such as anxiety and depression, more than respite care is required (Chan & Sigafoos, 2001). McNally et al. go on to suggest that methodological problems in the original studies may go some way to explaining their conclusion. Nonetheless, the lack of consistent findings and the range of possible influences on the effects of respite care point to the complexity of the issue.

What has been shown more consistently is that respite care has positive effects on family functioning (Chan & Sigafoos, 2001; Cotterill et al., 1997; MacDonald & Callery, 2004). It is clear that having a child with intellectual disabilities has an impact on the whole family (Nolan & Grant, 1992). Some carers included spending time with the siblings of their child with intellectual disabilities among the reasons for seeking respite care in the first place (Damiani et al., 2004). Others have suggested that they need the time respite provides to be a 'normal' family (MacDonald & Callery, 2004, p. 283). One of the specific benefits found was that the more often families made use of respite care, the lower their scores of measures of perceived family conflict (Chan & Sigafoos). Furthermore, families reported spending more time on recreation and leisure activities (Chan & Sigafoos). This echoes MacDonald & Callery's identification of the importance for families to feel and to appear 'normal'. Parents described a sense of 'freedom' from the attention in public paid to problem behaviour or to procedures they had to perform and from the tedious planning usually associated with outings (MacDonald & Callery, p.283).

The study of holiday breaks described earlier (McConkey & McCullough, 2006) is in a minority considering benefits to service users. The specific benefits reported by the service users themselves centre on new experiences and activities, spending time with

and meeting new friends, having fun, and simply being away from home (McConkey & McCullough). According to carers, service users gained in self-confidence, improved communication and decision-making skills, and generally a better quality of life (McConkey & McCullough). While there may be benefits accruing from other forms of respite, they have not been investigated to the same extent.

2.5 Limitations of respite care

The limitations of respite care reported in the literature fall into two categories: difficulties accessing respite in the first place; and issues arising from the experience of using respite facilities. A number of these are listed below and some points are elaborated later.

Limitations reported in the literature around getting access to respite care include:

- The level of information about the availability of respite services (Damiani et al., 2004);
- Inflexibility in services (Beresford et al., 2005);
- A lack of choice of services (Cocks, 2000);
- The 'pot luck aspect' depending on where one lives (McGill et al., 2006); and
- The urban-centric nature of services (Redmond & Richardson, 2003).

Difficulties arising from the experience of using respite include:

- Preparation for travelling to respite facility (Redmond & Richardson, 2003);
- Concerns about the quality of care in respite centres (Hoare et al., 1998);
- Processes at the end of placements (Dagnan, 1997); and
- The changing needs of service users over time (Chan & Sigafoos, 2001).

It seems there are difficulties, and potential sources of stress, at several points in the process of using respite. For some service users with complex needs, preparing to go anywhere involves extra pressure – "You would need a cargo plane to carry all the stuff she needs when she leaves the house" (Redmond & Richardson, 2003, p. 214). Moving from home to a respite facility may be especially difficult for people with ASD for whom consistent routines are often important (Perry & Condillac, 2003). Concerns over the quality of care combines with the emotional conflict involved in using respite (Hartrey & Wells, 2003). This is not to suggest that there are anything other than high standards of care in respite centres but that carers want their family member looked after as well as they do themselves. A final concern has to do with returning home at the end of a stay in

respite. The same pressure of moving paraphernalia and the same concerns over routine for people with ASD apply, as well as the prospect of a long spell until the next respite placement. These pressures may undo any gains due to respite (Dagnan, 1997).

Another major limitation on respite services in Ireland has to do with the wider resource problem in the social services. Kelleher (2001) describes a situation in 1999 in a particular service in Dublin when there were 20 weekend respite beds and 10 midweek beds for 1500 service users. Kelleher estimated that with that level of provision every service user could expect a break once every two years. However, "as up to 50% of the beds were 'blocked' by people waiting for residential places, the reality was that only a third of service users ever used respite" (p.19).

Availability and range of services depends on the priority given to respite care by health and social service agencies (Hoare et al., 1998). Indeed, all of the limitations to access listed above can be seen as issues of prioritisation in the social services. These limitations also reflect the scarcity of resources. In order to understand these problems better, the place of respite care in the continuum of services will be considered in the next section.

2.6 Respite care in the continuum of services

The continuum of services can be seen as the range of services provided to people with intellectual disabilities and autism and their families. This section is concerned with the place of respite care in that continuum in terms of the design and integration of services, and the priority given to respite care in particular. In the context of limited resources, an understanding of how respite fits into the continuum of services is important.

Boxes 2.1 and 2.2 below give brief examples of how support services for people with intellectual disabilities and autism and their families are integrated in other countries. As well as these good examples, there are a number of examples in the literature of the failure to fully integrate services. There has been a narrow medical conception of the purpose of respite care prevailing in Britain (McConachie, 1997). This medical model fails to acknowledge the unique needs of service users, carers, and their families (King & Meyer, 2006). These needs are not just for services but also for emotional support (Hartrey & Wells, 2003; Redmond & Richardson, 2003). By focusing on only some of the needs of service users and their families, then, the medical model lacks the necessary integration.

Box 2.1: Integrated services in Sweden

International literature allows us to take Sweden as an example (Olsson & Hwang, 2003). Families are referred to multidisciplinary teams from the maternity hospital or from 'well-baby clinics' (p. 329) which serve the entire population. Free or highly subsidised access to a range of services, including respite care, is available. Fewer than 5% of families who wanted respite care had not yet received it (Olsson & Hwang). One of the few criticisms in this study was the level of bureaucracy involved in applying for services. The need to integrate social care and health care in this way is emphasised by a European Academy of Childhood Disability (EACD) report (2004).

Box 2.2: Respite services in Canada

Another international example of well-integrated services comes from Ontario, Canada (www.respiteservics.com). Respite care services are co-ordinated among the Ministry for Community and Social Services, the Ministry for Children and Youth Services, Community Mental Health Clinics, Family Counselling and Support Services, Parks and Recreation, the Children's Aid societies, school boards, service providers, and regional planning committees. Access facilitators work with service users to consider a range of respite options offered by service providers. An association called Community Helpers for Active Participation offers home sharing services as well as art and drama workshops for people with intellectual disabilities.

The literature on family support provides an example of how services can be integrated. Family support is grounded in social support theory which recognises the crucial part played by informal social networks. At the top of Dolan, Pinkerton, and Canavan's (2006) cupped model of family support (Figure 2.1) are the child and the nuclear family. These are supported by the wider family and by friends which are in turn surrounded by the school and neighbourhood and then by community, voluntary, and statutory agencies, services, and organisations. Support for these organisations comes from national policy and legislation. If this model is applied to respite care, it is clear from the forms of respite described above that extended family is a valuable source of support. There appears to be a gap, however, at the school and neighbourhood level. This gap is the same one, the community, which was overlooked in the quest for community care (McConkey, 1987). Family based respite schemes could become the local, community-based support that makes respite services more available.

A Cupped Model for Understanding Family Support

Child
ACHIEVING RIGHTS / MEETING NEEDS
Nuclear Family

Other Family / Friends
School / Community / Leisure Interests

Semi Formal / Formal Family Support Practitioners

Community / Voluntary / Statutory
Agencies / Services / Organisations

National Policy / Legislation

Figure 2.1: A cupped model of family support (Dolan et al., 2006)

A final concern about respite care has to do with its scope in the continuum of services. As described earlier, one of the primary aims of respite care is to relieve stress in the carer and there is evidence of this and other benefits from respite care. However, if there are more serious psychological problems such as anxiety disorders or depressive disorders, respite cannot address these (Chan & Sigafoos, 2001). Fully integrated services, then, might include links to all medical and paramedical services for service users and for their families.

An unavoidable issue in all social services provision, not least respite care, is cost. It might be useful to consider first the value of respite care in putting off entry to full-time residential care, which is another of the broad aims of its provision. One calculation by the National Respite Coalition (nd, 2005) in America suggested that if respite care delays institutionalisation of people with Alzheimer's disease by as little as one month it could save $1.12 billion dollars per year. They also estimate costs attributable to decreased productivity by stressed carers of between $11.4 and $29 billion per year.

In Ireland, the Department of Health and Children (DoHC) is responsible for attending to the needs of people with intellectual disabilities and their families. These services are administered through the Health Service Executive (HSE). A number of the specialist services are described by the DoHC (2006) in the sectoral plan for the Disability Act 2005. These specialist services are:

- Early childhood/family support services;
- Residential care;
- Respite care;
- Day services;
- Rehabilitative training;
- Sheltered workshops;
- Community-based medical, nursing and therapy services;
- Home support services;
- Financial support;
- Miscellaneous support services.

Budget 2007 announced a further €100 million as part of the €900 million multi-annual investment plan for health-related disability and mental health services (Department of Finance [DoF], 2006). This increase brings the HSE budget for disability services to approximately €813 million. Set out in Table 2.2 are the costs and numbers of places in

Table 2.2: Numbers of places and costs of disability services for 2007

Intellectual disability services	Number of places	Unit cost €
Residential	7,793	80,000
Respite	4,316	80,000
Day	13,782	20,000

selected relevant services for people with intellectual disabilities and autism for 2007 (T. McGuirk, personal communication, 8th March, 2007).

In terms of the level of priority of respite care, its value and its cost relative to other services is an important issue. It is also valid to consider respite on its own and to compare the costs and values of different forms of respite care. Of the forms described in this chapter, informal help from friends and family has yet to be quantified. The HSE uses baseline unit costs to determine the allocation of formal out-of-home respite services. For 2007, the unit cost of a residential place is €80,000 (€219.18 per night) and of a respite place is €80,000 (€219.18 per night) (T. McGuirk, personal communication, 8th March, 2007). Costs of home sharing are presented in some detail in this chapter and range from €12.70 per night to €66.00 for a twenty-four hour period (NHSN, 2004). Holiday breaks are expensive (McConkey & McCullough, 2006). A related issue, however, is value for money and McConkey and McCullough argue that holiday breaks of the kind described are an end in themselves and not a means to an end. They suggest that most people spend money on a holiday even when they cannot afford it and that people with intellectual disabilities are often denied this choice.

It is very difficult to compare services which have different functions and which incorporate different types of costs and provision. However, one of the arguments for respite care is that it can prevent entry into full-time residential services. Using a simple cost comparison over twelve months, full-time HSE residential care costs €80,000; HSE respite care for two nights per month costs €5,620; and home sharing at the highest 2004 rate for two nights per month costs €1,584. This simple cost comparison does not place any value on outcomes from respite care viz à viz those from residential care, which are discussed elsewhere in this report. Also accepting that a range of other services is provided alongside respite care, the cost differential is so significant as to suggest substantial potential savings.

2.7 Principles of good practice

This section outlines a number of principles of good practice in the provision of social services. Though there has been no systematic establishment of best practice in respite care in the peer-reviewed literature, a number of national associations have outlined principles of best practice, notably the Canadian Association for Community Care (1996) and ARCH Respite in the USA (ARCH, nd). We can also draw on broader principles of good practice in working for children and families (Brady, Dolan, & Canavan, 2003). Brady et al. propose service management principles and intervention principles. These management principles include:

- Offering a range of targeted services with clear objectives;
- Promoting a culture of learning and development in the service; and
- Measuring outcomes.

The relevant intervention principles are that the service is:

- 'Whole child' focused;
- Accessible;
- Attractive;
- Integrated; and that
- Staff are interested and able.

Some of the specific respite care principles (ARCH, nd; Canadian Association for Community Care, 1996) overlap with those above, such as service delivery, administration, and advocacy. Taking both of these sets of principles together, the following are the most important points:

- Service delivery:
  - A single point of entry to services;
  - Clarity as to what families need to do to receive services;
  - A broad range of service options;
  - Risk management plans;
  - Recruitment and sub-contracting; and
  - Support in managing the transition from childhood to adulthood.
- Child- and family-centred services:
  - Respite programmes should involve families in service design and implementation;
  - Each family's unique characteristics should be respected in the provision of respite services;

- o Each child receiving respite services should be treated as an individual, with his or her unique strengths and needs acknowledged and planned for accordingly.
- Community involvement:
    - o An evaluation of community needs and resources;
    - o Community-based planning;
    - o Community fund-raising and marketing.
- Evaluation;
    - o Stated missions and goals of programmes;
    - o Monitoring success of programmes in relation to mission and goals.

Closer to home, the National Parents' and Siblings' Alliance's Charter of Rights includes the right of people with disabilities, their parents, guardians, and siblings to participation and consultation in the formulation and implementation of policies. The principle of consultation is also one of the *National Standards for Disability Services* (NDA, 2004b) and in the *National Children's Strategy* (DoHC, 2000). In the National Federation of Voluntary Bodies' (NFVB) *Annual Report* (2006) a commitment to person-centredness is repeated. This means looking beyond what is currently available in specialised services to mainstream and community services and promoting the independence of the service user and interdependence in that community.

2.8 Conclusion

This chapter began with a definition of respite care put forward by the National Disability Authority. In the literature, there is a range of definitions which vary in their scope, their rationale, and in the service providers who adhere to them. In the broadest sense respite care is any service that allows a full-time carer a break from their caring responsibilities. There is also the potential to use that time to improve the nature of care-giving.

The next section described some of the forms of respite care. In spite of the range of terms used and the differences in practice from place to place and from time to time, four broad categories could be described: help from friends and family; formal in-home care; out-of-home respite facilities; and recreation and holiday breaks. These are used for the sake of the discussion in this chapter and are only intended as an aid to understanding, not as definitive categories. There is no consensus in the literature on which is the best, and each has its own limits and advantages. Researchers do, however, mostly agree that a range of co-ordinated services for service users and for carers would be best.

The question of the intended benefits of respite care to carers and to service users was addressed next. There are benefits accruing from respite care though the picture emerging from the literature is complicated and in some cases availing of respite care may be a source of stress for carers in itself. For carers, there is some evidence of benefits in stress reduction and in improved family functioning. For service users, socialising and enjoying experiences outside the home were the main gains.

A number of limitations of respite services were identified. Some of these have to do with accessing services and others have to do with the experience of using respite. The root cause of all of these problems may be a lack of resources.

This same issue of resources defines the place of respite care in the continuum of social services. A number of international examples of integrated services including respite were described. As a model for service provision, the family support model might also be useful in establishing the place of respite care.

The final section of this chapter looks to principles of good practice, in social services in general and respite care in particular. Once again, international examples are used but the principles can be usefully applied to any setting.

Chapter Three

Interviews

3.1 Introduction

This chapter reports the main findings from interviews with a number of stakeholders. While recognising the limits of what could be gained in these interviews, they help to contextualise the literature review and have great value in making this report more meaningful and more relevant. In total, four social workers, one director of services for a provider of services for people with intellectual disabilities, two policy makers, and four parents of people with intellectual disabilities and autism were interviewed. The interview protocols are in Appendices A, B, and C. Letters of information and consent for the interviews with parents are in Appendix D.

The findings of the interviews are presented in sections corresponding broadly to the research questions at the end of Chapter One. Since there are a small number of interviews, all interviews are considered together, rather than parents separate from social workers and so on. Also due to the small sample, these interviews should not be taken as representative of the views of all service providers, policy makers, or parents. The general issues around interviews should also be borne in mind. Among these are limitations on time and the range of questions asked as well as the tendency for people to talk about things that happened most recently rather than in general.

3.2 Definition of respite care and rationale

When asked what respite care is and to give a definition, most parents said that respite is a service offering a break for the service user, for the carer, and for the family. This point was echoed by the social workers, and is consistent with definitions in the literature. Going on to talk about the rationale for respite, one parent elaborated that "*Respite is fundamental to my sanity and my sanity is important in the sense of… for [child] and for [spouse]*". Other parents went on to give examples of the services offered to them and these are detailed in the section on forms of respite later.

One of the policy makers raised the questions of when respite is respite, citing examples like sports clubs and the scouts which give parents natural breaks from looking after their children. In the same way, according to one of the social workers, some specialised schools are no different from respite. Other natural breaks like the holiday breaks discussed in Chapter Two were mentioned. The suggestion here is that there are a number of services and activities which we do not necessarily consider respite but which meet the same needs of service users and their families as respite care does. Support for families and appropriate provision of services for people with intellectual disabilities and autism may mean that demand for conventional forms of respite care is lessened.

3.3 Forms of respite care

All the interviewees were asked about the forms of respite care that are currently available. The forms mentioned fell into the same four categories as employed in Chapter Two:

- Friends and family;
- Formal in-home respite care;
- Out-of-home respite facilities; and
- Recreation and holiday breaks.

There were two broad areas of interest discussed. Firstly, social workers provided background information and detailed descriptions of particular respite settings. Secondly, parents talked about their experiences of using respite care services. Parents also outlined the level of respite they currently receive.

Of the four parents interviewed, each used respite to varying degrees. One family interviewed has one weekend of respite per month and one week in the summer. Another has one night per month, two nights per month every six months, and would prefer one night per week. A third had one night every six to eight weeks, a weekend every two to three months, and a week in the summer; they also sometimes benefited from cancellations as they live close to a respite home. The last family had one night a week and one weekend per month.

To turn to the different forms of respite, some of the parents interviewed draw on the assistance of friends and extended family. In one case when the possibility of paying relatives for respite was raised, the interviewee said they already were paid in the forms of vouchers or hampers. This represents a significant expense for the family.

In-home respite was not used by any of the parents interviewed but one of the social workers was able to provide details on how it is administered. In-home respite is usually available for a number of hours per week to facilitate the carer in attending to other responsibilities. The upper limit is twenty-five hours but there is the flexibility in that particular service to provide, in one case, forty hours per week to allow a single parent to work.

The administration of home sharing is based on the foster care model with the same recruitment procedures, rigorous assessment of host families, training, and on-going support. Some details of the home sharing provisions in Ireland are in Chapter Two. For one parent, among the advantages for the family is that someone else is offering to help. This is consistent with the desire for as normal a routine as possible. The family network is the usual first source of these kinds of offers and should be maintained through communication with the family network, said a social worker. According to one parent, successful home sharing depends on the level of ability of the service user. It is also preferable in some cases to have children of similar age in the host family.

Holidays as respite was not often mentioned but one social worker raised the possibility of training hotel staff in the care of people with intellectual disabilities and autism so that families could take holidays together. Other recreation breaks like day care in the form of after school projects and weekend clubs can be considered with summer holiday projects. The intention behind these recreational projects is not only to occupy the children for the sake of the carers' respite but to educate, entertain, and socialise the children.

Interviewees all stated that giving families options and tailoring services to meet their needs was the best way to manage respite care services. One of the social workers compared this to a menu of services. Individual needs, both the child's and the carer's, are different in each case and especially so with children with more complex needs. Based on the complexity of some cases, a social worker went further than offering choice to suggest that families could design their own options. Parents are the experts in the care of their children and are aware of their own needs, and service users can be consulted on some level. The over-arching point was that the family must be well supported in whatever way they needed to help them to support the child.

3.4 Specific intended benefits

Interviewees were asked about the benefits of respite care, both for the carer and for the services user. An important general point about the value of respite was made by one of the parents: "*Other people might think 'respite' is a terrible word but what happens and the benefits to the family are great*". The specific benefits to carers cluster around three themes: mental health and peace of mind; family functioning; and concrete support. For service users, the benefits have to do with social development as well as greater independence in general.

As far as mental health is concerned, parents said respite is important so parents "*don't crack up*" and, as mentioned by another above, for "*sanity*". Parents have peace of mind when they know that respite care is offered in a safe environment with competent staff where the service user will be "*fed and minded*". This is both a strength of services and a benefit to carers.

Reflecting findings from the literature review, benefits to family functioning were repeatedly mentioned by parents. The needs for time as a couple and for time with other children were raised by the interviewees. One parent articulated the value of "*being able to normalise, to do things we want to do*". Another parent talked about a sibling's benefits from respite. She gets some time and space to herself, and time with her parents to go shopping or to a restaurant. These kinds of activities are not impossible but more difficult for the whole family.

The third cluster of carer benefits was around practical benefits. One simple example was not having a "*basket full of laundry*". A more serious concern for one parent was that respite is a break from the dependency of her now teenage son. Most children become more independent as they grow older but this is not the case for her family.

For service users, an important function of respite care was to prepare them for the future and for more independence. One parent said it is important that service users are comfortable being and sleeping in a place other than the family home. He stated that they need to define their own space outside the family home for their future independence. Perhaps with this kind of independence in mind, one social worker mentioned the intention of respite care to expand the social network of the service user. A parent of an adult with an intellectual disability confirmed that her daughter has lots of friends in the respite home.

Parents were also asked about how they would like to see respite services run. They all suggested services should be as close as possible to the ideal and offer a loving, caring, secure environment for children where they are not excluded from the family and the community and where they can build relationships. One of the parents said that "*ideally,* [his son] *would be looked after as well as we do*".

3.5 Limitations

A range of concerns, problems, and limitations to respite services arose in the interviews. There were some general concerns about access to all services, including respite. Other issues related to particular forms of respite and to services for people with autism spectrum disorders (ASD).

The greatest general concern among parents was the possibility of losing services. There were two possible reasons why this might occur. The first was the lack of a guarantee of services. There was one 'cliff-face' at age twelve after which children are no longer offered children's centre-based respite. A related concern was that there were no adolescent centres. A second 'cliff-face' was at age eighteen when the Department of Education and Science "*disown you*" and when adolescents should move into adult services.

The issue of information and communication was another general concern expressed by parents. A number of parents spoke of the lack of communication from service providers. A separate problem articulated by a parent who was a member of a parents' group was a lack of communication even in that parents' group. Parents fear that the more people who were aware that a service was available, the more it would be spread among service users. At the same time, there was a general sense from parents who did have respite care available that other families had a right to respite too. For some, this meant not asking for more than was offered. For others, it meant campaigning for more for everyone.

A challenge that will face service providers increasingly in the coming years has to do with the cultural sensitivity of services. At the time of the interview with the director of services, seven of the last ten referrals to the service were non-Irish nationals and this is to be expected given the socio-demographic changes in recent years. With specific mention of home sharing, the director of services suggested that plans are in place for

any adaptations to services necessary to provide for families with other cultural backgrounds.

A number of the limitations of residential respite were raised in the interviews. Firstly, the staff turnover and the staff-service user ratio mean that there are questions over the possibility of establishing relationships with service users. Secondly, there are cases where a service user is in residential respite so often that it becomes effectively full-time residential care. The result is that fewer beds are available for respite for other service users. Finally, in one specified respite centre, one parent reported that there were not enough toys and that the garden was too small. He would also prefer more outings such as walks or even bus trips.

With specific reference to home sharing, there are currently more host families who have come forward than there is the capacity to assess and train them, so the level of service provision is limited. According to one interviewee, the lengthy assessment process could be seen as a hindrance. However, it was defended as an important safeguard for the service user, their family, and the service provider.

A concern raised by the parent of a child with autism was that respite services are not autism-specific. Children with intellectual disabilities, with physical disabilities, and with autism all receive services in the same place. He would prefer a programme of activities including independence training as part of respite. Another problem related to autism specifically was the possibility of regression during school holidays, raising the suggestion of summer camps run by schools to maintain improvements gained during term time.

3.6 Respite care in the continuum of services

Interviewees were asked what they thought was the place of respite care in the continuum of services. The continuum of services can be seen as the range of services available for people with intellectual disabilities and autism and their families, in terms of the design and integration of services, their level or priority, and their cost. There is also a lifespan element to the range of services and this was raised by a number of interviewees. One service provider described the historical development of services and the direction in which they might develop. In general, the points raised here have to do with the nature of service provision rather than with respite care in particular. Nonetheless, the insights gained are applicable to the provision of respite care services.

The director of services interviewed was able to provide a review of the historical development of respite services, at least in his organisation. Before the ideas of community care emerged, most people with intellectual disabilities were in full-time residential care. Institutions often used large rooms with up to twenty beds for service users. This was undesirable for many reasons and led to the development of group homes on a campus. Some of these service users went to their family home at weekends so service providers began to offer their beds for weekend respite to non-residents. The next step was to offer designated respite beds in the group homes. These were replaced by designated respite houses. In recent times these in turn have given way to home sharing as the preferred respite care option. In the future, flexible services designed around the service user's needs will be the norm. The service user and their family will administer their own finances to procure whatever services they require.

Allied to the development of services, there must be, according to one interviewee, a change of mindset in service providers from 'our service user' to an individual whom we ask 'how can we help?' A parent suggested that service providers had spent the last fifty years "*caring*" and should spend the next fifty "*enabling*". These changes in attitude are driven, according to the service manager, by well-educated professional managers who are well-informed.

The most important point raised about the continuum of services at its current stage of development was that the standard package of services does not suit every case. According to the interviewees, one of the results of this is that carers take whatever services are offered, whether they really need them or not, because they might not be offered anything else. There is a difference between treating every case equally in terms of the equal allocation of resources and treating every case equitably in terms of matching resources to what they really need. As suggested above, the best way to do this may be to help families design their own care options.

Some service providers have already progressed further in the flexibility and breadth of services. One service provider has begun to offer staff contracts based on flexible hours of employment to allow service users to determine when they wish to receive services, often not between 9am and 5pm. Every attempt is made to match the skills of staff to the needs of service users in order to optimise the level of service. A number of service providers have now instituted systematic evaluation of services on an annual basis.

To turn to the life-span element, one interviewee raised a number of lessons learned from adults with intellectual disabilities and autism which could be applied to services for children. Some adults with intellectual disabilities have self-esteem and social problems which may stem from exclusion as a child, according to one social worker. One service user was quoted as living in a "parallel universe" where their only contact was with other service users and staff and, even though they lived in a community-based house, they did not know their neighbours. If this kind of on-going exclusion is to be avoided, segregation of schools and placing service users in institutions rather than with families must also be avoided. There is already anecdotal evidence for this change as children who use home sharing grow up to be the first adults in some service areas to use home sharing.

The life-span element of the continuum breaks down, according to one parent, when children reach twelve years of age and are no longer offered children's respite services. They should be moving to other services designated for adolescents but there are none available. He pointed out a lack of preparation and "*they've known since he was born that he was going to be twelve*". Even if children aged twelve and more stay in children's services they are just taking the places that should be available to younger service users. A similar problem occurs at age eighteen when children move into adult services. These problems have to do with the integration and planning of services.

There is a consensus among service providers that the continuum begins with the family as the primary carers and all other services should support the family. One social worker suggested that the parents are experts in the care of their child; a parent said that siblings can also be experts. Families, according to the social worker, should be the ones to train respite carers and the extended family should be recruited first. If families lack this kind of support, formal health and social services are provided. A parent suggested that families may lack support from an extended network because extended families are 'frightened'. It may be that taking care of their child with an intellectual disability is too much to ask.

3.7 Principles of good practice

There was an overwhelming consensus that giving families a range of options was the best way to run respite care services. There was little beyond minor, detailed suggestions from parents and this may be due, according to a policy maker, to parents not being aware of how things could be. The vision for the development of services as

outlined by the director of services is a clear indication of the direction of aspirations and of the possibilities for the future.

3.8 Conclusion

The interviews described in this chapter were intended to complement the literature review in Chapter Two and they provide reinforcement of many of the points raised as well as insight to the particular concerns in this country. It is clear from this phase of the project that consultation with stakeholders at all levels of the provision of respite care is necessary to properly understand it. Policy makers and service managers are responsible for planning and implementing service. Those who work on the front line of services can alert us to practical problems. Most importantly, people with disabilities and their carers can tell us whether the services provided actually make a difference to their lives and the lives of their families.

Chapter Four

Conclusions and recommendations

4.1 Introduction

This chapter draws together the findings from the literature review and the interviews to answer the stated questions at the end of Chapter One. The primary aim of this project was to investigate best practice in the provision of respite care services. While there was no ready-made model for respite care services, considerable information on how to go about establishing best practice was available. The most salient points raised in the literature review and the interviews are discussed here following the structure adopted in the previous two chapters.

4.2 Policy and legislation

The context of social services provision has changed, both in Ireland and internationally. The new context involves a commitment to evidence-based planning and practice, and to best practice examples from other countries and other areas of services. Evaluation of service delivery is also now widely acknowledged as a necessary part of provision. Systematic review of practices with reference to aims, processes, and outcomes acts to monitor standards and to improve the level of service. This project can be seen as a step towards establishing what the expectations and standards of respite care in Ireland might be.

As already mentioned, this work was undertaken in the context of major developments in legislation and policy in Ireland and internationally. In 2006, the United Nations Convention on the Rights of Persons with Disabilities (2006) was finalised. This Declaration will be ratified by the Irish government at such time as they meet the commitments it contains, some of which are mentioned in Chapter One. On a European Union level, the Madrid Declaration (2002) offers a framework for progress and a set of ideals. These ideals underpin the Irish government's Disability Strategy (2004). The Strategy includes the Disability Act 2005, the Education for Persons with Special

Educational Needs Act 2004, the sectoral plans of government departments, and the Comhairle (Amendment) Bill 2004 show a commitment on the part of the government to improve social and educational services for people with disabilities in Ireland.

Notably, respite care is not specified in the UN Declaration of the Rights of Persons with Disabilities (2006) and, while there are implicit references, there is as yet no right to respite. Neither does it figure explicitly in the Madrid Declaration (2002). Nonetheless, a commitment to respite is implicit in the value of the family since respite care is an important support of functioning for families of people with disabilities. In the Disability Strategy (2004), respite care is listed among a range of specialised services for people with disabilities. What can be gained from these declarations is momentum towards rights-based provision of services. A right to respite would make it a real option for families and would increase its priority in the continuum of services.

4.3 Definition and rationale

A broad range of definitions of respite can be found depending on profession, era, types of services considered respite, and time-frame. This variation in definition can be seen to reflect the values and commitments of those offering definitions. For example, a definition that emphasises the necessity of respite for the carer without addressing the impact on the child implies a particular value system. More person-centred and family-centred definitions recognise the flexibility required to address the unique needs of complex lives. Child-centred points of view might look for benefits to the child first and foremost. There is an emerging consensus, from the literature and from the interviews, that both the service user and the carer should benefit from respite.

While the definition offered by the NDA (2004a) can be seen as a useful working definition, it may be worth considering a number of other elements in defining respite care. Firstly, the distinction between respite as an outcome and respite as a service has been made (Ciferri et al., 2005). The potential extra benefits of respite as service, in terms of training and emotional support, could be emphasised in defining respite. Secondly, any definition of respite should be person-centred. In the cases of children with disabilities, person-centredness must be broadened to family-centredness. The health and well-being of the family, as primary carers, are inextricably linked to those of the child and this too can be reflected in a definition of respite. Thirdly, a definition of respite could acknowledge the expertise of parents in their own child's disability, their own child's communication, and their own family's needs.

4.4 Forms of respite care

Respite care takes a number of forms and they were broadly categorised for the purposes of this project as follows:

- Informal help from friends and family;
- Formal respite care in the service user's home;
- Out-of-home respite facilities; and
- Reaction and holiday breaks.

There was a consensus among interviewees that having a range of respite care options available was preferable. Each of the categories of respite care above has its advantages. For example, help from friends and family is part of the natural network of support described in social support theory. On the other hand, formal in-home respite might be particularly suitable to short spells. Residential respite has the potential to offer therapeutic interventions for service users, though this is subject to limited resources. Home sharing is closest to the community care model. Holiday breaks have a number of benefits for the service user as well as for the carer. There was also a consensus around the importance of quality care in any of those settings.

To turn again to the literature, preferences for particular forms of respite are sometimes clearly expressed. For example, social workers who have invested time and energy in establishing and running particular programmes might consider them the best (Cocks, 2000). Parents generally showed a preference for in-home care (Hartrey & Wells, 2003; Redmond & Richardson, 2003). Elsewhere nurses suggested care at a respite facility as the best form of respite (MacDonald & Callery, 2004). What is generally agreed in the literature is that a co-ordinated range of support services, including respite care, is important to all stakeholders.

4.5 Intended benefits

In the literature and the interviews, the benefits for the carer were clustered around health and well-being, family functioning and concrete supports. For service users, social development and independence were the main benefits. A challenge for service providers is to ensure that these benefits accrue and are maintained. This can be achieved, as mentioned above, by systematic evaluation.

Systematic evaluation of respite services requires measurement of outcomes. Outcomes in turn depend on the definition of respite. Some outcome measures used in previous literature are of psychological variables like stress and mental health (Chan & Sigafoos, 2001; Hoare et al., 1998; McNally et al., 1999; Shu et al., 2002). Others are qualitative evaluations of effects on well-being and on family relationships (Hartrey & Wells, 2003; Redmond & Richardson, 2003). These studies are consistent with a definition that is carer-focused and are part of a developing literature on carers' needs.

It was suggested above that service user benefits might also be part of a definition of respite. As far as assessment of service user benefits is concerned, there are no widely used methods of accessing the views of people with intellectual disabilities and autism. However, a recent report by Whyte (2006) suggests that it is indeed possible to attend to the metaphorical voices of children with disabilities. Merriman and Guerin (2006) propose drawing as a practical, simple, and non-verbal research method that can be used with all children.

4.6 Limitations

The main limitation of current respite services is that there are not enough. Other general concerns were raised by interviewees and in the literature about access to services. Specific issues were with certain forms of respite care and with services for people with autism spectrum disorders. While this was only one minor step in the process to establish best practice in respite care provision, any future development needs to reflect the sometimes negative experiences of service users and their families.

The problems with access to services stem from the lack of resources. There is an absence of choice and a 'pot luck aspect' depending on where one lives. Similarly, there are concerns about losing services. This is connected to another repeated point around life-span planning for services, and for respite care in particular. There are 'cliff-faces' at certain ages after which services which had been provided to a high standard are withdrawn.

4.7 Respite care in the continuum of services

Taking the literature review and the interviews in tandem, respite care in the continuum of services can be seen in two ways. The first has to do with respite as part of a fully functioning, integrated range of social services in the community care model. The second

is in the context of limited resources and has to do with the level of priority given to respite services.

Fully functioning, integrated social services would include all social, medical, and paramedical services, designed with the input of all stakeholders, fully integrated, and responsive to the changing needs of service users and families over time. This would facilitate people with disabilities in the community care context in gaining a range of benefits and participating as fully as possible in community life. It would mean that their carers are supported in their important role in whatever way they require, and that there is no negative impact accruing to siblings of a person with an intellectual disability or autism. In circumstances of a complete range of services, a number of standard support services – social support, family support, activity clubs, holiday projects, and any number of others – would all be available and might have the same function as respite.

Even then, however, there is no suggestion that respite as it has been described would not be needed. The important point here is that trying to establish best practice in the provision of respite care services assumes best practice throughout the continuum of services. It is not best practice for respite care to serve functions that might be better served by other parts of the continuum, and vice versa. It may be useful, then, to maintain a focus on what actually constitutes respite, on the intended effects of respite services, and on the place of respite services in a continuum of best practices.

Even in the context of limited resources, a focus on what respite is, what it does, and its proper place should remain. With limited resources, all support services cannot be treated as equal in value and each service has a different level of priority. The challenge for respite care is to establish its value relative to those other services. A clear understanding of what respite is, what it does, and what it costs is essential to establishing its value.

If value for money is a criterion for judging how best to invest resources, a thorough cost-benefit analysis is required. The crude cost analysis in Chapter Two indicates that home-sharing might be a viable alternative to residential respite. However, it is not simply a question of using the cheapest form or the traditional form or the one that fits the structures already in place. A good deal of creativity and imagination is required to foresee all the possible consequences of any investment but thoughtful analysis may be a good place to start.

4.8 Conclusion

This report presents an investigation of the practice of respite care with a view to establishing best practice. A comprehensive evaluation of the current status of practice nationally and internationally is a substantial undertaking and this project has begun to outline how that evaluation might be undertaken and some of the principles of best practice.

The context in which services are provided is the obvious starting point for an evaluation and the changes in the legislation and policy context in Ireland have been described here. The next step in understanding a service is to define it in terms of aims, processes, and outcomes. The NDA (2004a) gives a useful working definition in the Irish context. A number of points were also raised which might be included in a more comprehensive definition. A guide to understanding the different forms of respite care was described. This can be seen as a system by which to understand options available. The positioning of services within a continuum and at a particular priority level is also important in understanding those services. It may be instructive to consider real and ideal continua as a way of evaluating current practice.

The most important step in evaluation is determining the outcomes intended. There are clearly a number of benefits accruing from respite care, both for the carer and for the service user. However, what is less clear is how to go about measuring those benefits and thereby investigating any changes that result from respite care. Finally, by learning from the limitations of current practice and looking to examples of best practice, services can move towards the ideal level of provision. To that end, some provisional principles of best practice in the provision of respite care services are defined in Chapter Five.

Chapter Five

Provisional principles of best practice in the provision of respite care services

5.1 Introduction

The aim of this research was to investigate best practice in respite care for people with intellectual disabilities and autism. Currently, no ready-made models of empirically validated best practice exist. However, the literature does contain a variety of information based on which a set of principles might be devised. Laid out below is a provisional set of best practice principles arising from this research. It is more useful to see this set as a start-point for further research and practice development rather than as a definitive model.

5.2 Principles

Principle One: That respite services be person-centred and family-centred;

Respite services should focus on the service user, on their needs and desires, and on the best possible outcome for them. Since intellectual disability impacts the family of the service user, the needs and well-being of the family should be the next level of concern in provision of services.

Principle Two: That respite services be provided on a rights basis;

There is no statutory right to respite services nor any guarantee that they will be provided. Nevertheless, rights-based service provision is an ideal to which service providers aspire and towards which social policy and legislation are moving (the UN Convention on the Rights of Persons with Disabilities [2006] for example). Even though there is no statutory right to respite services, there is no reason not to provide them as if there were a right and let policy and legislation catch up. This would mean a strong

responsibility on the part of service providers that respite services be made available to any service user.

Principle Three: That respite be defined as a support service and regarded among a system of support services;

Respite services in isolation can only have a limited impact on service users and their families. Co-ordination among services and communication among service providers can ensure that all services have the maximum positive effect. For example, transport from school to respite ensures that parents benefit from all of the time available for respite.

Principle Four: That there be a single point to access to respite care services in a given administrative area.

At present there is a range of disconnected respite services available with mainly informal connections among them. There is also a range of points of referral to respite services. If one organisation had access to all the service providers and all the service users, matching cases to services and ensuring equitable distribution of resources might be easier.

Principle Five: That respite services be designed in consultation with families in acknowledgement of their expertise in providing care;

It is families who spend most time with service users, who know them and their needs best, and who tend to those needs most. If respite care is intended to imitate as closely as possible that level of care and understanding, it follows that families should be fully involved in the design of respite services. For example, primary carers and even siblings know the routine, the medication regime, and the particular preferences of their family member, and respite services might be better for listening to them.

Principle Six: That respite be designed to facilitate the service user in building relationships in their community;

Another ideal in social services provision is community-based services. Service users are members of communities and services should operate in the community to allow service users to be active members as far as possible. With reference to respite care,

community-based rather than campus-based respite homes and home sharing schemes can help service users to take their place in the community.

Principle Seven: That respite services be age-appropriate and develop as the service user develops;

The needs of children with disabilities are obviously different from those of adults and the design of services should reflect that. Equally importantly, the needs of younger children differ from those of older children, adolescents, young adults, older adults, and any number of other age categories. Rather than having 'children's services' and 'adults' services' it may prove easier, and be consistent with the principle of person-centredness, to allow flexibility in services so that they can grow and develop with the service user.

Principle Eight: That respite care services have clear goals and that systematic and regular review ensure achievement of those goals or change of provision.

The definition and design of respite services imply certain intended benefits. Rather than stop at the point of implied and unstated goals, clear targets for services can focus work towards those targets. Clear goals also make the process of evaluation all the easier. Systematic review, then, can monitor whether goals are achieved and, if not, can point to possible changes in service provision. Auditing as part of this review process can ensure the maximum benefit from investment.

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Appendices

Appendix A

Child and Family Research Centre

Respite care for people with intellectual disabilities and autism

Interview schedule for service providers

1. What respite care for is available people with intellectual disabilities?
   a. What forms does it take? (Frequency, duration, location)
   b. Is this the position in other organisations?
2. Where did the need for respite care first arise?
   a. Who benefits most from respite care?
   b. How are decisions around respite care made?
3. Where does respite care fit on the continuum of services?
   a. Is there open communication with and referral from other parts of the services?
   b. Are there dedicated staff or is it one of a number of their responsibilities?
   c. Is respite care explicit, in designated units, or implicit, when service users are admitted to hospital, for example?
4. Are there limits on availability?
   a. Geographical location
   b. Waiting lists
   c. Staffing
   d. Resources
5. Are there limitations to the services offered?
   a. Frequency
   b. Duration
6. Are there specific policies on provision?
   a. Legislation?
   b. Among service providers?
7. Are there plans to change the services on offer?
   a. What is the most important element in need of change?
8. What other organisations might we contact?
9. Have you had contact with the Social Policy Research Unit, York University?

Appendix B

Respite care for people with intellectual disabilities and autism

Interview schedule for policy makers

1. What is the position of respite care in relation to the Disability Act?

2. Is there anything that could be construed as a right to respite?

3. Are examples from case law useful in progressing a campaign?

4. Where is respite care in the continuum of services?
   a. What constitutes respite?
   b. What programmes are available?

5. What principles should drive the development of policy around respite care?

6. How valuable is the National Intellectual Disability Database in gaining a picture of the scope of need and provision?

Appendix C

Respite care for people with intellectual disabilities and autism

Interview schedule for carers

1. Introduction and explanation of the project
   a. "My name is Brian Merriman and I work for the Child and Family Research Centre at NUI,G. The National Parents and Siblings Alliance asked us to try to find out what is the best way to offer respite care for people with intellectual disabilities and autism. It's a short project, mainly based on published literature, but we thought it was important to include the perspective of the families who actually use respite. I have a few questions about the services on offer in the area and the impact they have on your family."
   b. Consent
      Recording and transcription (if applicable)
      Anonymity
2. What do you consider respite to be?
   a. When did the need for respite care first arise for your and your family?
3. What respite care for is available you and your family?
   a. What forms does it take?
   b. How often do you use respite?
   c. What information is available from service providers?
   d. Do you friends and extended family help out?
4. Do you feel you benefit from respite?
   a. Do you feel your child benefits?
   b. Do you feel your other children benefit (where applicable)?
5. Where does respite care fit with other services you use?
   a. And with school (where applicable)?
6. What are the restrictions on respite as presently available?
   a. Are there limits on availability because of
      1. Geographical location
      2. Waiting lists?
7. What would you most like to see done differently in respite care services?
8. What do you think the best way to offer respite services would be?

Appendix D: Letter of information for parent interviews

National University of Ireland, Galway,
University Road,
Galway.
www.childandfamilyresearch.ie

Respite care for people with intellectual disabilities and autism

Letter of information

Dear sir or madam,

Respite care for people with intellectual disabilities and autism is usually when the service user moves out of the family home for a short break, though it can take place in the home. The National Parents' and Siblings' Alliance commissioned a piece of research to try to find out the best way to provide respite care. As part of the project, we are interviewing a small number of carers about their views on respite.

- If you would like to and are able to help, I will ask you some questions about your experiences of respite care services.
- If there is anything in the questions that you would like me to clarify, please ask.
- The interview will be tape-recorded and the answers you give may be used in a report on best practice in respite care provision.
- Quotes may be used in the report but no identifying material will be used and you will not be recognised.
- All identifying records will be destroyed within ten years of the completion of the study.
- You have the right to refuse to take part. If at any stage after you start you want to withdraw, you have the right to do that too.
- You may not benefit directly by participation but others may benefit in the future.

Thank you very much for your help. If you have any further questions, please ask.

Yours,

_____

Brian Merriman
Researcher
Brian.Merriman@nuigalway.ie

Appendix E: Letter of consent for parent interviews

National University of Ireland, Galway,
University Road,
Galway.
www.childandfamilyresearch.ie

Respite care for people with intellectual disabilities and autism

Letter of consent

Please read the following statement and, if you agree, please sign your name.

"I agree to participate in this interview and for it to be tape-recorded. I also permit researchers to use my answers in their research, and for anonymous quotes to be published in a report, book, or article. I understand that I will not be recognised, as my name will not be used and all identifying material will be removed. I understand that all identifying data will be destroyed within ten years of the completion of the study.

"I can refuse my consent or withdraw at any time and this will not affect the services I receive in any way.

"I have spoken with researcher and have had the opportunity to ask questions about this study."

Name:_____

Signed:_____

Date:_____