A Host of Opportunities

Second NHSN Survey of Family Based Short Break Schemes for Children & Adults with Intellectual & other Disabilities in the Republic of Ireland

Des Hanrahan

for

National Home-sharing & Short-breaks Network

First Published 2010 by NHSN, Mullingar and Drogheda.

Cover photo: A special thanks to DPE Camera Club members Mr. M D'Arcy and Ms. R. Malone.

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National Home-sharing & Short-breaks Network

NHSN is the premier association of people and organisations engaged in using, promoting, and providing host family based services for Irish citizens with intellectual disability, physical disability and autism.

Activities include, promoting best international practice, lobbying Government, research and an annual conference to mention just a few. NHSN is a not-for-profit organisation

NHSN was founded in 2003 to support host families who provide short breaks to children and adults with intellectual disability. Since then, it has expanded to include guests with other disabilities. It also includes contract family schemes and home-sharing services that provide part-time and full-time family based accommodation to adults and children.

NHSN's vision is of an Ireland where people can enjoy full social inclusion.

NHSN's mission is to support family based short breaks and inclusive living.

The aims of NHSN are:

To promote host family based services
To develop good practice and standards
To assist schemes to recruit hosts
To retain an up to date directory of schemes
To represent the sector at national and international level
To promote research and disseminate findings

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Acknowledgements

Many people were instrumental in some way in making this survey happen. However, there are a few that I would like to single out for special acknowledgement. Maura Lardiner, for helping with compiling a list of schemes; Suzanne Igoe, for helping make sense of the NIDD templates for recording 'respite' data; Vickie Jones, of Shared Care Network UK, together with Jeanne Carlin and Helen Cramer, for making their questionnaire available; and Karen Lockheart, for proof reading the penultimate draft and making some very helpful suggestions. However, this survey would not have been possible without the extraordinary co-operation of all the respondents who grappled with a very complex questionnaire and responded in such numbers. I would like to thank the National Home-sharing & Short-breaks' Executive Committee for their patience in putting up with all the delays, and I can say, with some personal relief, that Louise will get our dining room table back, for Christmas! Finally, I would like to thank Deirdre Carroll of Inclusion Ireland for all her support and encouragement.

Des Hanrahan

Foreword

'Respite' services have always been a crucial component in the mix of services provided to children and adults with disabilities. Currently, the HSE funds residential, day, and residential support services (respite / short breaks). Under this model of funding, the money is allocated to a service provider to supply the specific services for people. Too often, this is in segregated settings.

The most recent national intellectual disability database (Kelly *et. al.,* 2009) shows that there are 26,023 children and adults registered as having an intellectual disability. Of those aged under eighteen (31 per cent; n=8095), nearly all (98 per cent; 7,896) live at home. This compares with 49 per cent (8,812) of those aged eighteen and over (69 per cent; n=17,928).

In 2008, 4,549 children and adults received planned respite breaks; 216 received crisis respite breaks (Kelly *et. al.,* 2009:40). There is no breakdown by age group. The report stated that, despite 4,549 people availing of such support, the demand had increased steadily since 1998 and was continuing to do so.

The majority of respite services are centre based and funded accordingly by the HSE. It has been estimated that the average rate for such respite is at least €80,000 per annum; most services providers estimate €100,000 per bed per year. However, as the recent annual report 2009 of the Comptroller and Auditor General (Government of Ireland, 2010) points out, it is still not possible to determine average cost comparison between service providers delivering services or to determine the calculation of costs per service users for different types of services. All that can be said with certainty is that current respite services are extremely costly, are provided in segregated settings, with some units located on the grounds of large institutions, and meet only a small proportion of the need and demand.

A review of the efficiency and effectiveness of disability services is currently being undertaken by the HSE, the Department of Health and Children, and the Department of Finance. A significant element of the project is a policy review focussing on the creation of a cost effective, responsive system, to support full inclusion of all people with disabilities. Such a review is essential with further cuts being proposed to HSE services in 2011.

In 2010, service providers selected respite as an area for cuts. This is causing huge concern and upset for people with disabilities and their families. This will happen to an even greater extent next year, as the HSE continues to look for further reductions in spending.

The high staff and capital costs associated with residential respite are no longer sustainable either in terms of cost or quality. The National Home-sharing & Short-breaks Network (NHSN) has been to the forefront in calling on Government and the Department of Health and Children to develop a policy on short breaks (aka respite) for people with intellectual and other disabilities. Specifically, the NHSN has called for the promotion of enjoyable, inclusive, individualised, host family short breaks, over the traditional congregated and isolated respite services. It has produced information to show that the cost of providing quality personalised breaks with volunteer host and contract families costs considerably less and provides people with a service of choice of proven quality.

This report from the NHSN could not have come at a more opportune time. For policy makers, it provides concrete evidence on what is currently happening with

such short-breaks schemes in Ireland, and it makes a number of excellent recommendations. Unfortunately, during the boom years, it was easier to continue to do thing as we have always done, and this new innovative model of service never received the attention or funding streams that it deserved. Nonetheless, it still managed to provide an estimated over 12 per cent of all respite to children and adults through such short, personalised, breaks with host families in 2008.

Short inclusive breaks, with host families, can provide an alternative to traditional residential respite in specialist units and group homes. They aim to give people with disabilities, and their relatives, a break from their everyday routine and to provide positive opportunities for *real* and sustainable social contact. There is no doubt that they are the way forward and are fit to support families to nurture their children at home and to keep their adult sons and daughters within their local communities. This report provides a vital contribution to this policy debate.

Deirdre Carroll
Chief Executive, Inclusion Ireland

Two letters that 'speak for themselves'

"Dear Des,

I enclose completed forms. As I already explained, the [scheme] has not been expanded for several years. The only placements, now, are for two adults who would have commenced using this service over 10 years ago. This service has given breaks to many children, adults, and families over the years and some really excellent families were recruited. It has been a very flexible service responding to families' needs. We as a Social Work Department see the great value of the service and would be most interested in future campaigns to recommence the scheme, but not within current limited resources within the Department.

This is a very cost effective way of supporting families. It does require, however, considerable social work input. We will be reviewing our current situation regarding a number of areas which this survey highlights as needing clarification.

Good luck with the collating of all the information. You have a busy time ahead! We look forward to hearing about the completed work".

"Apologies for delay in getting back to you – I was on annual leave.

Des, we currently only have 3 adult placements who have been going to these families for many years since they were children and we are maintaining these placements. Due to serious under resourcing we have not recruited new families for some years but from feedback from families/service users over the years we see how valuable this scheme has been. So it might be better to say that we have some ongoing placements in [county]. There is no scheme in [county].

Des, we are keen to look at putting time into this area of respite again and would be keen to keep linked in with Home Sharing Network".

A word about terminology

Before reading this report it is import and be clear about the terminology used in order to navigate what can be a confusing array or words that are used to describe host-family schemes.

Traditionally, services were divided into respite care and residential care. In the host-family model these terms are replaced with short breaks and home-sharing.

Short breaks

The word respite is no longer used by most inclusive services because of the pejorative implication that someone with a disability is a 'burden' on those who support him or her. It ignores the 'positive aspects of caring' reported by supporters including 'giving pleasure' to the recipient of support, 'maintaining the dignity and maximizing the potential' of the person, 'enhanced relationships, meeting perceived responsibilities, mutual love and support, and personal development' (Savage 2002;2). Instead we use the term 'short breaks' as it is 'generally used by the public to denote an activity which is a break or different from the usual activity carried out on a daily basis by an individual'. The emphasis is on the person with a disability who is receiving the break (Carlin and Cramer. 2007;2).

In this report hosts that provide short breaks are described as either voluntary short-breaks families or paid contract families.

Short-breaks families

Short-breaks families can be individuals, couples or whole families that offer short breaks to children and adults. They are usually volunteers but are paid an allowance or expenses. They can offer both sleepovers and daytime visits to their homes.

Contract families

'Contract families differ from short-breaks families in that each approved contract family is contracted to provide a specific number of overnight breaks (usually up to 16 nights a month) in return for an annual payment plus expenses for each night completed. These additional expenses are based on the needs of the guest. There is a greater level of commitment required, compared to volunteer hosting and the guests usually have high dependency and complex health care needs. The duration of breaks will vary and contract families may have a succession of guests, to which they have been carefully matched' (www.nhsn.ie, 2010).

Home-sharing

Similarly, when describing 'residential care' provided by host families we do not call it residential care. Instead we refer to it as home-sharing which implies that the person is part of a home with reciprocal relationships. This can be a part-time arrangement where the person lives for three or four days a week, with the host family, or it can be a full-time 7-day week arrangement. Note that home-sharing is two words, usually hyphenated. This is to distinguish it from a model of supported living called 'homesharing' (all one word), 'where someone who needs some help to live independently in their own home is matched with someone who has a housing need and can provide a little support' in return for accommodation (NAAPS, 2010:3).

Rules of thumb!

Residential care = Home-sharing

Respite care = Short-breaks with volunteer host families or contract families

Chapter 1

Introduction

> *"Family-based short-break schemes link disabled children* [and adults] *with individuals, couples or families who can care for them for short periods on a regular basis. The amount of care provided can vary from a few hours a week to several days each month. The traditional model is one weekend's care a month. A small number of schemes offer more regular shared care, perhaps a few days a week for children with more complex or demanding needs. These schemes sometimes use retained or salaried carers. Many schemes also offer sitting and befriending services"* (Tarleton, 2003; 36).

1.1. What are family based short breaks?

The family-based model of providing short breaks to people with disabilities (referred to here as 'guests'), involves recruiting approved individuals, couples, and families ('hosts') who agree to provide these personalised breaks in their own homes.

The model was pioneered in Canada, America and Britain in the early 1970s, as an alternative to traditional residential 'respite' (Stalker, 1990: 17-19). Initially the service was designed to provide alternative respite options for family carers who, until then, had sought this support for their children from hospitals, smaller residential units and specialist institutions, many of which had been discredited at the end of the 1960s (DHSS, 1971; King *et al.,* 1971). However, with a shift in emphasis towards putting the needs of services-users first (Flynn *et al.,* 1996; Laverty and Reet, 2001), the family based model has developed as a destination choice for people requiring out of home breaks, with sustainable social contact. Today this involves daytime befriending, weekend breaks and short holidays. The aim is to give service-users and their relatives a break from their everyday routine and to provide "opportunities" for disabled and other vulnerable people (Carlin *et al.,* 2004:3).

1.2. Historical context

The family-based overnight short-break model, as currently in use in the Republic of Ireland, was adapted from the Canadian, American and British model, referred to above (Walsh, 1983: 14). It has its precursor in the American deinstitutionalisation movement of the 1960s, although Intagliata *et al.,* (1981; 253) claim that it predates this movement by at least thirty years and that it is likely to outlive it! A number of sources credit the first recorded use of family-based-placement for people with intellectual disabilities (ID), to the local psychiatric hospital in Geel, in Belgium, in the sixth century, which placed patients with local

families (Fiedler, 2005; Goldstein and Godemo, 2003). There is evidence of support for the idea in post famine Ireland (Finnane, 1981), but it was not until much later that the Commission of Inquiry on Mental Handicap (1965) advocated the boarding out of children as an alternative to traditional institutional care.

The first contemporary family-based overnight short break service, in the Republic of Ireland, dates from 1981, when a scheme called *Break Away* was set up as a joint venture between four voluntary bodies and the old Eastern Health Board (O'Flynn, 2010; Redmond and Jennings, 2005; Walsh 1983). Initially *Break Away* catered for children with ID, but later it included adults.

The first contemporary service for adults with ID is credited to St. Michael's House, in Dublin, This service was established in 1988 (Boland, 1991). However, there is evidence of boarding out of adults with "mild mental handicap" in Co. Westmeath in 1983 (Gilligan and Keogh, 1985; 68).

In Ireland 'host family' schemes have traditionally recruited volunteers who are paid a stipend (Hanrahan, 1996; Hearne and Dunne, 1992); but more recently there have been successful attempts to recruit contact families (Hanrahan, 2006). The core difference is that families are contracted to provide a specific number of "sessions" per month in return for a generous annual retainer and payment for each session (Murphy, 2009:3).

1.2.1. Attempts at measurement

In 2004, it was estimated that there were 28 family-based overnight short break schemes for children and/or adults with ID operating throughout the Republic of Ireland (NHSN, 2004). In addition, there were 87 young adults with intellectual disabilities (ID), reported to be still in the care of foster carers with whom they had been placed (Barron and Mulvany, 2004).

While some attempts have been made to measure the total national number of people with ID who benefit from such services, no comprehensive source is available, and no details have been published regarding the number of hosts that are involved, nationally (Carroll, 2003; Barron and Kelly, 2006; Barron and Mulvany, 2004a; Barron and Mulvany, 2004b; Barron and Mulvany, 2005; Mulvany, 2000; 2001; and 2003; Mulvany and Barron, 2003; Kelly *et al.,* 2007; Kelly *et. al.,* 2009;).

The latest figures, for 2008, from the National Intellectual Disability Database, record 90 children and 147 adults (total 237) in receipt of occasional 'respite' with host families (Kelly *et al*., 2009; p 39). The Database figures would suggest that there are also between 278 and 292 children and adults living in foster care or boarded out (Kelly *et al.,* 2009; 39).

This lack of detail contrasts with services in Northern Ireland where such particulars have been included in four British surveys in 1990 (Orlik *et al.,* 1991), 1992 (Beckford and Robinson, 1993), 1998 (Prewett, 1999), and in 2004 when children's' services were surveyed by Carlin and Cramer (2007).

The information gleaned from such surveys is important for informing planners, policy makers, decision takers, funders, service providers and other stakeholders.

1.3. Background to the second survey.

The National Home Sharing Network (NHSN) was formed on the 27th. February 2002 from an *ad hoc* group of practitioners who were interested in setting up a national network. The group had received a mandate to explore this at its first national conference, '*Family Based Respite in a Changing Ireland: The Way Forward'*, held on the 6th. November 2001, at All Hallows College. The actual decision to set up the network was taken on the 30th. January 2002, at a specially convened 'workshop'. The Network was then formally launched in Galway in June 2003 by Mr. Tim O'Malley T.D., Minister of State at the Department of Health and Children.

One of the first things the NHSN did, before this launch, was to invite membership and publish a directory of members. In order to produce this directory a general survey of members was undertaken. While some figures and sections of manuscript are available to our research team, it has not yet been possible to locate either the final report or the raw data of this First National Survey of Family-based Overnight Short-break Services (Carroll, 2003).

The first NHSN Directory was published in 2003 and updated in 2004. A proposal to undertake a second update was accepted at the 2007 AGM (8th. November); and this new Directory was subsequently published in early 2009.

In the meantime, it was suggested that this exercise would provide a useful opportunity to carry out a survey of all known family-based overnight short break services in the country. The aim was to explore the prevalence and scope of Family-based overnight short break services, for the purpose of informing members and legislators as regards future development. At a meeting of the NHSN Committee held in January 2008, it was suggested that the survey should go ahead and that the format should be based on the 4th. UK survey undertaken by Jeanne Carlin and Helen Cramer, on behalf of Shared Care Network. Their survey was carried out between 2004 and 2006, and published in the following year (Carlin and Cramer, 2007). Using this survey would allow for comparison and benchmarking against a well-established service model. The researcher, a member of NHSN, undertook to explore the feasibility of this and to report to the next committee meeting in April 2008.

The researcher requested a copy of the Shared Care Network questionnaire in January and received a draft copy in February. He received the complete questionnaire in March 2008, along with permission to use an amended version for our purposes.

1.4. Methodology

The first task was to compile an up-to-date directory of schemes that provided overnight breaks with host families. This was done with the assistance of Maura Lardiner, a Galway NHSN member. It involved consulting old and recent registers of NHSN members and lists of delegates from past short break conferences, and also word of mouth.

A 'Request for Information Form' was submitted to the National Intellectual Disability Database (NIDD) requesting:

> a) the number of "people with intellectual disability (children and adults) placed with host families and/or foster families for either short-term breaks (respite) or longer term arrangements (such as foster care and/or as an alternative accommodation to institutional or group home housing), by service provider" and
> b) whether it was "possible to identify which services are responsible for these placements".

The NIDD returned some data on main and secondary residential circumstances by agency returning records in 2008. However, as the information was restricted to less than or more than five people and included almost every service in the country, it proved too cumbersome to be helpful to this exercise. Some random checks were carried out to no avail.

A similar request was made to SWIFC a special interest group of the Irish Association of Social Workers for social workers employed in foster care. They didn't respond. In the meantime, a draft questionnaire based on the UK example was prepared.

While this questionnaire was extended to include adults (the UK survey covered children's' services, only), we excluded the sections on sitting and befriending services, and the community and leisure activity sections, which form part of the services offered by up to a quarter of UK schemes with overnight care in a family based environment (Carlin and Cramer, 2007: 10). We also shortened the remaining sections and amended some questions to reflect the Irish context, after consultation with the NHSN Committee.

The questionnaire was piloted among members of the NHSN Committee, in June 2008. Amendments were made following feedback from this exercise and the final draft was distributed to potential respondents between November 2008 and January 2009. The questionnaire was not distributed to services provided by private agencies, nor was it posted to domiciliary services that make grants and subsidies available to service-users to purchase their own overnight breaks (Hanrahan, 2005).

Upon receipt of completed questionnaires the data was transferred to an electronic database (PinPoint®, 1993), and analysed anonymously, as aggregate statistics, using that database's descriptive statistical tools.

The timeframe included having a final report ready for the International Short Breaks Association's conference in June 2010, with interim findings for presentation at the NHSN AGM scheduled for October 2009. This timeframe slipped by three months due to problems with running old analytical software on current operating systems. This software has not been updated and, after numerous web searches failed to turn up a patch or a more recent version, the problem was addressed by bringing in an older PC capable of running PinPoint®.

1.5. Survey response

The questionnaire was posted to thirty schemes run by twelve separate organisations. Table 1.1. gives a breakdown of these schemes by organisation or agency.

Table 1.1. Organisations and the no. of schemes run by each of them

Organisations	**(Comments)**	**No. of schemes**
St John of God Services		7
Brothers of Charity (BOC)	(1 with AbilityWest)	5
Health Service Executive (HSE)		3
St. Michael's House		3
AbilityWest	(1 with BOC)	2
Cheeverstown House		2
Doughters of Charity	(1 with BOC & HSE)	2
Sis. Of Charity of Jesus & Mary		2
Co-Action West Cork		1
Enable Ireland		1
St Joseph's Foundation		1
Western Care		1
Total		**30**

Twenty-seven schemes (90 per cent) were run by voluntary organisations and three by the Health Services Executive (HSE).

The latter includes the HSE's *Adult Placement Scheme* in Limerick, which, technically, is not a short break service, although it represents an example of where some short break schemes are heading, both here at home, and internationally (Fay, 2007; Hanrahan, 2007:3; Heslop *et al.*, 2003; Murphy, 2009; NAAPS, 2006)

Of the thirty schemes surveyed, most (n=19; 63 per cent) operated in mixed urban and rural areas; nine operated in urban areas only, and none operated exclusively in rural areas. This information was not available on the remaining two schemes.

Of the thirty schemes surveyed, twenty-six returned the questionnaire. However, one questionnaire was mislaid in the Christmas post and was never found. This resulted in a total of twenty-five questionnaires received, giving a response rate of 83 per cent.

We were able to include some very basic information on the five schemes, for which there were no questionnaires. This was obtained from informal contact, from published data, from phone contact to firm up numbers for the Department of Health & Children, and from other personal contacts. Such basic information includes some totals of children and adults placed in 2008 and whether the schemes are still active, etc. Because of this a small number of findings, in this report, are based on data from all thirty schemes.

Twenty-two schemes provided information about when they were inaugurated. Six of these were started in 1981; another six were started between 1983 and 1989 inclusive; five were set up during the 1990s and five commenced between 2002 and 2008.

1.5.1. Viability of schemes surveyed

Four of the thirty schemes were found to be inactive and they no longer have any host families. Another five schemes were found to be 'in trouble', in that they might not survive without extra resources and outside help. Some of these had stopped recruiting. The remaining 21 schemes were all found to be robust. Some of these were thriving while others were consolidating having had to retrench because of lack of resources (see section 4.1 'Recruitment', below). One new scheme was in the process of recruiting its first ever hosts.

Excluding the inactive schemes, there were twenty-six schemes 'up and running' in 2008. Eight catered for children only, ten catered for both children and adults, and the remaining eight catered for adults only.

Chapter 2

The Hosts

2.1. Information on hosts

Of the 26 schemes with active hosts, 23 provided information about their hosts.

2.1.1. Number of hosts

There was a total of 430 households involved in hosting across these 23 schemes in 2008. Fifteen of them (65 per cent) hosted children and 18 (78 per cent) hosted adults. Table 2.1 gives a breakdown of adults and children by each scheme.

This total does not include those households that hosted 11 children and 13 adults in the scheme whose questionnaire was lost in the post; nor does it include the households that hosted 22 adults in the Limerick Adult Placement Scheme, nor the scheme that was still recruiting its first hosts.

Extrapolating from this missing data (some hosts may or may not have welcomed more than one guest), it is very probable that there were at least an 'estimated' 476 Irish host families active in 2008. Most of these would belong to schemes of twenty-five host families or less, with almost five per cent (n=28) of all hosts in ten schemes comprising of just six households or less (u=476). Half of these ten 'small' schemes were found to be 'in trouble', unless they received help (see Table 2.1., on the next page, for details. Schemes with brackets are those 'in trouble').

This *minimum* estimate does not include hosts in a small number of schemes that were not identified, before the survey was conducted; nor does it include incidental once off arrangements and some young adults who have remained with their former foster families, who are not part of a scheme. Accounting for these unidentified households might be a goal of future research.

2.1.2. Couple and Single Hosts

Thirteen of the 15 schemes that placed children in 215 households provided information about the structure of 148 of these households (Table 2.2). Of these 148 households, 126 (85 per cent) included a male and female host couple. One included two female hosts, and 21 (14 per cent) consisted of a single female host.

Thirteen of the 16 schemes that placed adults in 215 households provided

Table 2.1: Number of hosts [households] per scheme by child/adult placements (n=23 schemes)

Number of active households per scheme hosting **children**	Number of active households per scheme hosting **adults**	Total number of active households per scheme. **(#)** = Scheme in trouble
	1	**(1)**
1		**(1)**
	2	**(2)**
	2	**(2)**
	2	2
3	0	3
	3	3
3		3
5		5
4	2	**(6)**
	9	9
12		12
14		14
6	8	14
7	8	15
12	5	17
17	1	18
	18	18
22	0	22
10	15	25
	35	35
33	33	66
66	71	137
215	**215**	**Total recorded households =430***

* This total does not include those households that hosted 11 children and 13 adults in the scheme whose questionnaire was lost in the post, nor does it include the households that hosted 22 adults in the Limerick APS Scheme, nor the scheme that was still recruiting it's first hosts.

Table 2.2: Structure of hosting unit

Hosts	**Child** **13/15 schemes**		**Adult** **13/16 schemes**		**Total**	
	#	(%)	#	(%)	#	(%)
Male & female couple	126	(85%)	94	(75%)	220	(81%)
Single female	21	(14%)	31	(25%)	52	(19%)
Female couple	1	(1%)			1	
Total	148	(100%)	125	(100%)	273	(100%)

information about the structure of 125 of these households. Of these 125 households, 94 (75 per cent) included a male/female host couple and the rest, (31), consisted of a single female host.

Combining the children's and adult's hosts (n=273), gives a total of 220 (81 per cent) male with female host couples, one all female couple and 52 (19 per cent) single female hosts

2.1.3. Gender

Based on information about 273 households, the hosts were made up of 274 females (55 per cent) and 220 males (45 per cent).

2.1.4. Sexual orientation

Ten of the 15 schemes that placed children and 12 of the 16 schemes that placed adults provided information about the sexual orientation of hosts. Of the 224 households cited, 192 (86 per cent) were described as heterosexual couples; 28 (13 per cent) were described as heterosexual single females and the sexual orientation of four single females (2 per cent) was described as "unknown"

2.1.5. Ability

Nineteen schemes provided information about whether any of their hosts had 'a significant or notable disability'. Just one scheme indicated that they had one person who had a disability.

2.1.6. Age

A total of 15 schemes provided information about the current age of their hosts. Eleven schemes that had placed *children* provided this information. Of the 128 females that had hosted these children, four (3 per cent) were 25 years or younger (Table 2.3). Eighty-seven women (67 per cent) were aged between 26 and 50 years old; 36 women (28 per cent) were aged 51-65 years and one woman was aged over sixty-five.

Of the 115 males that had hosted *children* in these eleven schemes, none was aged 25 years or younger. Sixty-nine men (60 per cent) were aged 26-50 years; 44 men (38 per cent) were aged 51-65 years, and two men were over 65.

Eleven schemes that had placed *adults* provided information about the current age of their hosts. Of the 109 females that had hosted adults in these schemes, three (3 per cent) were 25 years or younger; 34 women (31 per cent) were aged 26-50 years; sixty-two women (57 per cent) were aged 51-65 years, and ten women (9 per cent) were aged over 65 years.

Table 2.3: Age profiles of male and female hosts in child and adult schemes (n= 15 schemes)

	Child schemes				Adult schemes				Total all Schemes			
	Female		Male		Female		Male		Female		Male	
Age	#	%	#	%	#	%	#	%	#	%	#	%
≥ 25yrs.	4	*3*			3	*3*	2	*2*	**7**	***3***	**2**	***1***
26-50yrs.	87	*67*	69	*60*	34	*31*	31	*37*	**121**	***51***	**100**	***51***
51-65yrs.	36	*28*	44	*38*	62	*57*	35	*42*	**98**	***41***	**79**	***40***
65<	1	*1*	2	*2*	10	*9*	15	*18*	**11**	***5***	**17**	***9***
Totals	128		115		109		83		**237**	***100***	**198**	***100***

Of the 83 males that had hosted *adults* in these eleven schemes, there were two men (2 per cent) aged 25 years or younger; 31 men (37 per cent) were aged 26-50 years; 35 men (42 per cent) were aged 51-65 years, and 15 men (18 per cent) were over 65 years.

When those women who hosted children are combined with those women who hosted adults, the age profile for all 237 female hosts is as follows: seven women (3 per cent) were aged 25 years or younger; 121 women (51 per cent) were aged 26-50 years of age; 98 women (41 per cent) were aged 51-65 years, and 11 women (5 per cent) were aged over 65 years.

Similarly, the age profile of all 198 male hosts, from the 15 schemes that provided this information, is as follows: two men (1 per cent) were aged 25 years or younger; 100 men (51 per cent) were aged 26-50 years; 79 men (40 per cent) were aged 51-65 years, and 17 men (9 per cent) were over 65 years old.

2.1.7. Ethnicity

Information about the ethnicity of hosts was provided by 18 schemes. Of a total of 443 hosts (including couples) all were either white Irish (n= 439; 99 per cent) or white other (n=4;1 per cent). There were no Irish Travellers, no African or other black background hosts, no Chinese or other Asian background hosts, including mixed background and 'not known'.

2.2. Assessment, training and approval of hosts

Information about assessment of hosts was given by 20 of the 26 active schemes.

2.2.1. Assessment protocols and forms

Of those that responded to this question, 17 (85 per cent) used their own assessment protocol form and three (15 per cent) used the 'NHSN Guidelines'

form. Two of those that used the guidelines form said that they either made some minor adjustments to it, or added their own interview questions to it.

One of the schemes that used its own form explained that this tool was based on a fostering assessment form plus an assessment tool used by an established family based overnight short-break scheme.

Another scheme that used its own form also encouraged 'self assessment' and emphasised that assessment was "seen as a two-way process".

None of the schemes reported using a standard foster care form.

2.2.2. Competency based assessment

The same 20 schemes also gave information about whether their assessment was competency-based or not. Only three (15 per cent) reported that it was competency based, while the other 17 (85 per cent) said that it wasn't.

2.2.3. Background checks

Of the 26 active schemes, 20 gave information about the various background checks that they carry out on prospective hosts (Table 2.4).

All 20 who gave information require Garda Clearance; 19 (95 per cent) require character references; 17 (85 per cent) require medical references; and ten (50 per cent) require professional references, such as a reference from the local Public Health Nurse (PHN). Five schemes (25 per cent) also said that they carried out 'other' checks. One of these five schemes reported that it followed up character references with phone calls, while a second said that it phoned one of the character references. A third scheme reported that it carried out a health and safety check on the house and garden and the fourth scheme looked for fostering and adoption references, where applicable The fifth scheme requested an additional reference from either a local Garda, G.P., or member of clergy.

Table 2.4: Type of background checks carried out by schemes (n=20)

Type of checks	Number of schemes	(%)
Garda (police) clearance	20	(100)
Character reference	19	(95)
Medical reference	17	(85)
HSE child protection check	15	(75)
Professional reference	10	(50)
Other	5	(25)

Fifteen (75 per cent) of the 20 active schemes that gave information about checks said that they require HSE child protection checks. These included 11 schemes

that provided services to children and ten schemes that provided services to adults. The latter takes in four schemes that provide services to adults only.

Thirteen schemes (65 per cent) require a minimum of *two* personal or professional character references and seven schemes (35 per cent) require a minimum of *three* personal or professional references, in addition to Garda (police) Clearance.

2.2.4. Moving and handling training

Training of hosts in moving and handling takes place on two levels; general training, and individualised training specific to the child's needs.

2.2.4.1. General training in moving and handling

Nineteen schemes provided information about general training in moving and handling. Sixteen of these (84 per cent) stated that this training was a requirement for all hosts matched with guests who required moving and handling. Two others (11 per cent) said that they sometimes provided this training to individual hosts for specific guests. Another scheme (5 per cent) didn't provide this training as "the agency does not place children with physical disability".

Table 2.5. summarises the professional background of the trainers providing hosts with 'general' training in moving and handling. Physiotherapy was the most frequently cited profession (n=8; 42 per cent). However four schemes used more than one

Table 2.5: The professional background of trainers providing general training in moving and handling (n=19 schemes)

Moving and handling trainer – general	#	(%)
Physiotherapist (along with "other staff", in two schemes)	8	(42)
Manuel Handling Trainer (profession not known)	4	(21)
Nurse	3	(16)
Social worker (in both cases with the MH trainer or a nurse)	2	(11)
Occupational therapist	2	(11)
Total	19	(101*)

* Total may not equal 100% due to rounding

professional to carry out this training. In one scheme the physiotherapist was identified as the designated moving and handling trainer, while in another scheme a nurse was identified as the designated moving and handling trainer.

Seven (44 per cent) out of the 16 schemes that required their hosts to undergo moving and handling training stated that this training was updated. Five of these provided information on how frequently this training was updated. One stated that

it was updated “every two years” and the other four stated that it was provided “as required” or “as needs change”.

2.2.4.2. Individualised training in moving and handling

Seventeen of the schemes provide individualised training to hosts, around the needs of a specific guest. Sometimes this is moving and handling training but, for other hosts, it involves different training and advice. Consequently, a broad range of professionals (summarised in Table 2.6.) is enlisted to provide this individualised training, sometimes with one or more other professionals.

Table 2.6: The professional background of trainers providing individualised training in moving and handling (n=17 schemes)

Moving and handling trainer – individualised	#	(%)
Nurse	7	(41)
Physiotherapist	5	(29)
Social worker	4	(24)
Family of the guest	3	(18)
Occupational therapist	3	(18)
Psychologist	2	(12)
Relevant therapist	2	(12)
Speech and language therapist	1	(6)
Scheme coordinator	1	(6)
Other	1	(6)

2.2.5. Invasive procedures training

Seventeen schemes provided information about the training of hosts to carry out invasive clinical procedures required by guests. Five of these schemes said that this training didn’t apply (Table 2.7). One of these explained that their scheme doesn’t place guests who have complex health care needs.

A nurse seems to be the most likely person to provide this training, with at least ten (59 per cent) out of the 17 schemes involving a nurse in some capacity. In five schemes the nurse alone provides the training, while in three schemes the nurse works alongside an Occupational Therapist (1 scheme) or a relative of the guest (2 schemes). Another scheme said that it only placed people requiring invasive procedures with hosts that are qualified nurses, while a second scheme said, “usually, the host would be required to be a qualified nurse.” The remaining two schemes said “staff” and “relevant professional”, provide this training.

Eleven schemes provided information about refreshing or updating such training. Seven schemes (64 per cent) said they update this training and four schemes (36 per cent) said that they didn’t. The frequency of such updates was dependent upon “changing needs” (1 scheme), “upon request” (2 schemes), “when

Table 2.7: The professional background of trainers providing instruction in invasive clinical procedures (n=17 schemes)

Invasive procedures trainer	#	(%)
Nurse	5	(29)
Nurse with a member of guest's family	2	(12)
Nurse with occupational therapist	1	(06)
Staff and/or relevant professional	2	(12)
Only/usually place guests requiring procedures with nurse	2	(12)
Not applicable	5	(29)
Totals	17	(100)

Considered necessary" (2 schemes), and "if required" (2 schemes). One of the schemes pointed out that it had no separate refresher module.

2.2.6. Training in behaviour management

Twenty schemes provided information about who trains their hosts in behavioural management and methods of intervention. Three (15 per cent) of these schemes said that this training didn't apply; one explained that its scheme doesn't place adult guests who have Challenging Behaviour. At least half (n=10) of the schemes said that a Psychologist carries out this training. In one scheme this was in conjunction with a Social Worker, while in another it varied between a Psychologist, Social Worker or Nurse, depending on the circumstances. In one scheme a Psychologist provides a formal generic training session to prospective hosts.

Table 2.8: The professional background of trainers providing instruction in behaviour management (n=20 schemes)

Behaviour management trainer	#	(%)
Psychologist	10	(50)
Multidisciplinary approach	7	(35)
Not applicable	3	(15)
Totals	20	(100)

In seven schemes (35 per cent), training in behavioural management and methods of intervention is provided using a multidisciplinary approach. Two of these schemes make use of a designated Behavioural Support Team; five others use the relevant therapists or clinicians and/or members of staff such as unit heads, training course personnel, behaviour specialists, teachers and other school staff, nurses, psychologists and social workers. In one scheme multidisciplinary input

takes the form of a “formal behavioural session” which is built into the standard preparation course.

Two schemes (12 percent) had experienced difficulty in accessing this training. One said that it had difficulty finding time to give to hosts [for the purpose of instructing them in behaviour management/intervention]. The other stated that there was “no formal assessment [of behaviour] available” and “no staff available [for training] when needed”.

Thirteen (13) schemes provided information about updating their behavioural management and intervention training. Nine (69 per cent)) of these schemes said they update this training and four schemes (31 per cent) said that they don’t update it. Of the nine schemes that updated their behaviour management and intervention training, one said that they updated this training “every three years or more often if needed”. The rest said “as indicated”, “as required”, “when needs require”, and “based on need” .One of the nine didn’t comment on the frequency of updates.

2.3. Terms and conditions for hosts

The survey looked at rates of pay, payment towards house adaptations, and whether schemes had equipment budgets. Most (between 62 and 81 per cent) of the active schemes provided information on all three areas.

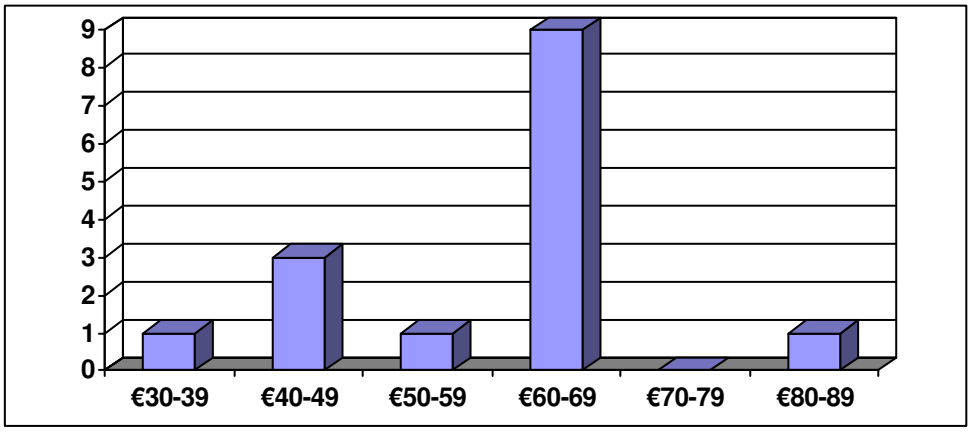
2.3.1. Payments

The structure of payment rates for hosts varied considerably across schemes. Some schemes had a single payment rate, others had rates that varied according to age, e.g. whether the guest was under or over 12 years of age and/or whether he or she was a child or an adult. Some schemes paid different rates depending on the complexity of the guests’ needs. Rates also varied across schemes according to whether the guest stayed mid-week or at weekends, and whether they stayed for a day, or part of a day, or overnight. In some cases hosts were paid a higher rate, per night, if they had a guest for an extended period, i.e. more than seven consecutive nights.

In the case of volunteer-based schemes (n=18) hosts were usually paid a fixed stipend to cover expenses. This sometimes depended on the number of hours worked and the ability of the guest. Contract family schemes (n=1) paid an annual retainer plus a rate per night.

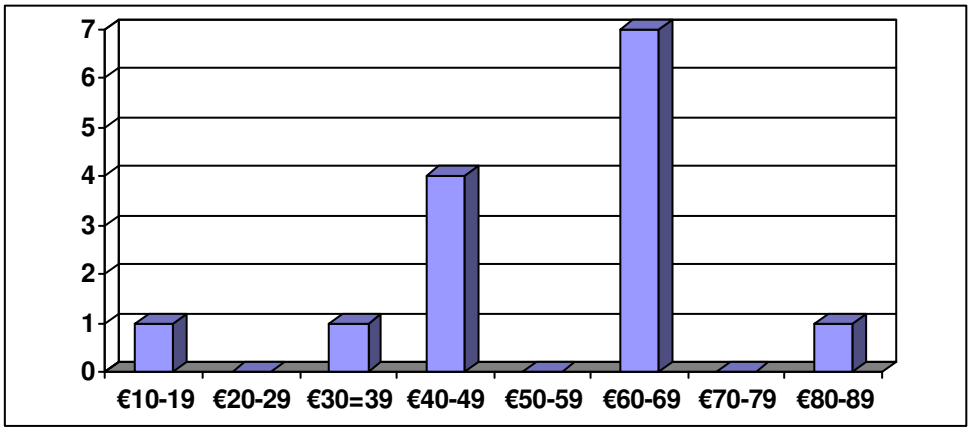
In order to compare rates across schemes, the night rate (i.e. 24 hours), for weekends, is shown overleaf for children over 12 years (Figure 2.1) and below that for adults (Figure 2.2).

Figure 2.1: Overnight payments by schemes for children (n=15)



Nineteen schemes returned data on how host families were paid. In the case of *children*, 15 schemes paid between €35 and €80 per. night (mean=€58). The majority (n=9; 60 per cent) paid between €60 and €80.

Figure 2.2: Overnight payments by schemes for adults (n=14)



Fourteen schemes catering for *adults* returned payment data (Figure 2.2). These schemes paid between €15 and €80 a night (mean = €55). Half of them paid between €60 and €70 per night.

2.3.2. House adaptations

Sixteen schemes provided information about funding for house adaptations. Ten of these schemes (63 per cent) had no provision to fund house adaptations. Five schemes (31 per cent) said that hosts who offered overnight breaks, could have their homes adapted to facilitate the guests. A sixth scheme said that this could "sometimes" happen, "especially if it is for a guest in a long-term" living arrangement.

Two of the six schemes that arranged funding did not indicate where this money came from. Of the remaining four schemes, two obtained this money from the

sponsoring agency. Another scheme got this funding from a combination of HSE, Co. Council and voluntary donations. The fourth scheme had yet to draw down such funding.

2.3.3. Equipment

Twenty-one schemes provided information about whether they had an equipment budget or not (Table 2.9). Seven schemes (33 per cent) said that they had a budget and 14 (66 per cent) said that they had not. Of those that had a budget, five said that it was sufficient; one said that it wasn't sufficient and the other didn't comment.

Of the seven schemes that had a budget, one conceded that it was an "unofficial" budget.

> *"we have an 'unofficial' equipment budget. The [name of parent organisation] has been quite supportive of this, using its own fundraising. We also 'sometimes' get equipment from the HSE's Community OT Dept. We could do with more support from the HSE and Co. Council"*

Table 2.9: The number and percentage of schemes that had a budget for equipment (n=21 schemes)

Budget	#	(%)
Schemes that have a budget	7	(33)
Schemes that don't have a budget	14	(66)
Totals	21	(100)

Of the 14 schemes that had no budget for equipment, five commented on how they went about funding equipment in the absence of a dedicated budget. Two use petty cash:

> *"While we do not have an equipment budget, and don't usually purchase equipment, there is some scope, using petty cash, for small but necessary items such as smoke alarms and child monitoring systems".*

Two schemes make 'special' requests to their parent organisation and the fifth asks for funding from the HSE or a charitable organisation.

For six schemes, funding of equipment was not an issue. This was because they didn't have anyone who needed special equipment (three schemes) or because they require the guest's family to provide equipment to the hosts (two schemes) or because they lend the hosts equipment from the guests' day services. The remaining three schemes didn't comment on this.

Table 2.10: The type of equipment mentioned by respondents

Type of equipment	Number of schemes
Safety equipment	10
Beds and bedding	8
Hoists	4
Garden equipment	2
Other	5
Totals	29

2.3.3.1. Type of equipment

The types of equipment most needed (Table 2.10) were, safety equipment such as stair gates, car seats, monitors and smoke alarms (ten schemes); beds and bedding, including specialist beds and incontinence sheets and a travel cot (eight schemes); hoists (four schemes), and garden equipment (two schemes). Other items included sensory equipment (one scheme) sitting equipment (one scheme), a feeding chair (one scheme) bathroom equipment (one scheme) and an extra buggy (one scheme).

2.3.4. Incentives towards qualifications

Eighteen schemes provided information about offering rewards or incentives for hosts to work towards a qualification. Only one scheme, which catered for both children and adults, detailed incentives. This scheme encouraged hosts to complete a FETAC Level 5 childcare course.

2.4. Number of guests linked to each host

Information about the number of guests linked to each host was received from 20 schemes. The greatest number of children that any one host was linked with was four (in one scheme only); the least was one (11 schemes). On average, hosts were linked to 1.2 children (n=12 schemes).

The greatest number of adults that any one host was linked to was seven (one scheme). The least number was one (15 schemes). On average, hosts were linked to 1.2 adults (n= 15 schemes).

Chapter 3

The Guests

All of the 26 schemes, that had active hosts in 2008, provided information about their guests. This information is presented here separately for children and for adults

3.1. Children

There were 18 schemes that claimed to cater for children. However, one of these schemes was still recruiting its first hosts when the survey was carried out. Another scheme, which catered for both children and adults, had not placed children in the year surveyed; although it had placed adults that year.

3.1.1. Number of children

Of the 18 children's schemes surveyed, 16 of them had placed a total of 308 children, during 2008.

3.1.2. Gender of children

Of the 16 schemes that placed 308 children in the year surveyed, 14 of them gave a breakdown of boys (n=160; 54 per cent) and girls (n=136; 46 per cent). The two other schemes, with just one and 11 children, respectively, did not give a gender breakdown.

3.1.3. Age of children

Thirteen schemes provided information about the ages of 273 children who were placed by them. The majority (n=149; 55 per cent) were older children aged 12 years or more. Thirty-five of these were between 16-18 years of age (Table 3.1).

Table 3.1: Age profile of children placed with hosts. (n= 13 schemes)

Age band	Number of children	(%)
0 – 4 years	22	(8)
5 – 11 years	102	(37)
12 – 16 years	114	(42)
Over 16 years	35	(13)
Totals	273	(100)

3.1.4. Ethnic or cultural background of children

Twelve children's schemes, comprising of 158 children, provided information about ethnic or cultural background, based on categories taken from the Irish Census 2006 (CSO, 2007). Almost all of the children (n=155; 98 per cent) came from 'white Irish' (153), 'white other' (1) and 'white traveller' (1) backgrounds. Two of the remaining three children came from an 'African' background and the other came from a 'non-Chinese Asian' background.

Table 3.2: Ethnicity of children placed with hosts. (n= 13 schemes)

Ethnic or cultural background	Number of children	(%)
White Irish	153	(97)
African	2	(1)
White Traveller	1	(1)
White Other	1	(1)
Non-Chinese Asian	1	(1)
Totals	158	(101*)

* Total may not equal 100% due to rounding

3.1.5. Ability of children

Fourteen schemes provided information about the ability levels and needs of children who were placed with hosts. The majority of these schemes placed children with Intellectual Disability (13 schemes), Physical Disability (ten schemes), Sensory Disability (ten schemes), Challenging Behaviour (ten schemes) and Autism (nine schemes).

Table 3.3: Ability/needs of children placed with hosts. (n= 14 schemes)

Ability and needs	Number of schemes	(%)
Intellectual disability	13	(93)
Physical disability	10	(71)
Sensory disability	10	(71)
Challenging behaviour	10	(71)
Autism	9	(64)
Complex health care needs	7	(50)
Mental health needs	2	(14)
HIV/AIDS	0	(0)

Half of these schemes placed children with complex health care needs (n=7) but only two of the schemes (14 per cent) placed children with Mental Health Needs, and no scheme reported placing children with HIV/AIDS.

3.2. Adults

Eighteen schemes gave information about adults. All of them had placed adults in 2008.

3.2.1. Number of adults

The total reported number of adults placed with hosts was 280.

3.2.2. Gender of adults

Of the 18 schemes that returned information about the number of adult guests placed with host families, three did not distinguish between male guests and female guests. These three schemes accounted for one, 13, and 22 guests respectively. Of the remaining 244 adult guests, 135 (55 per cent) were women, and 109 (45 per cent) were men.

3.2.3. Age of adults

Thirteen schemes gave a breakdown of their adult guests by age (Table 3.4) The most frequently placed age group was young adults under 30 years old (42 per cent). This was followed by guests in their thirties (38 per cent), forties (15 per cent) and fifties (11 per cent). Nine of the guests (4 per cent) were aged 60 or older.

Table 3.4: Age profile of adults placed with hosts. (n= 13 schemes)

Age band	Number of adults	(%)
18 – 29 years	99	(42)
30 – 39 years	67	(28)
40 – 49 years	36	(15)
50 – 59 years	25	(11)
60 years or over	9	(4)
Totals	236	(100)

3.2.4. Ability of adults

Fourteen schemes provided information about the ability levels and needs of the adults who use their services. All of the 14 schemes placed adults with intellectual disability. The majority of these schemes also placed adults with physical disability (n=11; 79 per cent), sensory disability (n=8; 57 per cent), challenging behaviour (n=8; 57 per cent) and autism (n=8; 57 per cent).

Table 3.5: Ability/needs of adults placed with hosts. (n= 14 schemes)

Ability and needs	Number of schemes	(%)
Intellectual disability	14	(100)
Physical disability	11	(79)
Sensory disability	8	(57)
Challenging behaviour	8	(57)
Autism	8	(57)
Mental health needs	7	(50)
Complex health care needs	6	(43)
HIV/AIDS	0	(0)

Half of these schemes placed adults with mental health needs (n=7) and less than half (n=6; 43%) placed adults with complex health care needs. No scheme reported placing adults with HIV/AIDS

3.2.5. Ethnic or cultural background of adults

Ten schemes, comprising of 128 adults, provided information about ethnic or cultural background, based on categories taken from the 2006 Irish Census (CSO, 2007). All of these adults came from a 'white Irish' background.

3.3. Same race policy

A 'same race' policy is where a scheme tries to match the ethnic background of the guests (service-users) with hosts from a similar ethnic group (Carlin and Cramer, 2007: 104).

None of the nineteen (19) schemes that answered the question on 'same race' policy had one. Three of them made the following comments:

> *"I have not followed a SRP because, through discussion with parents who are from different countries, some have preference for families of the same race, but the majority do not. Same race preferences are respected if requested"*

> *"As this is a scheme for adults, there are not yet as many non-white Irish adults with ID as there are non-white Irish children with ID in need of short breaks"*

> *"to date, given ongoing problems recruiting hosts, this is not an area we have explored, despite that, as a service, we have a high proportion of children from different social and cultural backgrounds"*

3.4. Unmet needs

Waiting lists are often used as measures of unmet need. When they are reported to the National Intellectual Disability Database (NIDD) they are used to inform the planning of future services (Barron and Kelly, 2006; 64).

3.4.1. Waiting lists

Seventeen schemes provided information about whether or not schemes kept lists of people waiting for short breaks. Of these, eight schemes (47 per cent) kept a waiting list of unmet needs, while nine (53per cent) did not.

3.4.2. Numbers of people waiting for a service

A total of 212 people were reported to be on lists of unmet need in the 17 schemes that provided this information. The numbers on each list ranged from four to 64 (mean average = 26; median = 15; sd=25).

3.4.3. Profiles of people waiting for services

Schemes were asked to give a profile of three groups of people that wait the longest for a service, and to take account of factors such as age, gender, ethnicity, ability and other issues of importance to their scheme. Only five schemes responded to this question. Consequently it is difficult to list the most frequently mentioned profiles. Nevertheless, some ranking of common characteristics is attempted, below.

ASD: was mentioned five times by two schemes. This ranged from “Children aged 5-11 years. with ASD” (two schemes), through “Children with Autism aged 12-16 years” (two schemes) to “Adults with ASD” (one scheme).

Older children and teenagers (12-18 years): was mentioned five times by three different schemes. This included older “children with autism” (two schemes), “Older children with high physical dependency needs” (one scheme), “15-18 year old girls with high physical dependency needs” (one scheme), and “Older children 12-18 years (one scheme).

Challenging behaviour: was mentioned three times by three separate schemes for adults. This included “young adults aged 18-29 years with challenging behaviour” (two schemes) and “adults with challenging behaviour and/or ASD with severe to profound ID” (one scheme).

High physical dependency: was mentioned three times by two different schemes. Comments included, “15-18 year old girls with high physical dependency needs”, “Older children with high physical dependency need”, and “Adults who require a lot of assistance”.

Complex Health Care needs: was mentioned by one scheme for adults, which noted that these adults "tend not to be referred to [our scheme]."

3.4.4. Managing unmet needs

Ten schemes out of only 11 that provided information, said that they reviewed their waiting lists. Seven of these said that they removed people from their lists. Three of these said that they removed people after a specific time period.

Table 3.6: Reasons for removing potential guests from waiting lists

Reasons cited
"As a result of a review between the social worker and the family"
"Changed" service-user needs
On waiting list for 12 months and "parents no longer interested"
Upon reaching "adulthood" (in the case of a children's service)
"On waiting list for 6 months"
Needs "met through other support arrangement"

The reasons for removing people from waiting lists have to do with reviews, changed needs, length of time waiting, and eligibility. These are catalogued in Table 3.6.

Four schemes said that they referred people removed from their waiting lists, to other services.

Eight out of the ten schemes said that they regularly keep in contact with families waiting for a service. Three schemes said that they did this through the family social worker. One scheme reviewed the waiting list annually and telephoned the parents but another scheme kept in touch with families on a 'hit and miss' basis only and "not always".

Chapter 4

Other issues

4.1. Recruitment

Twelve schemes provided details of their recruitment trends during the previous five years. Five (42 per cent) reported that their recruitment trends had gone up since 2003. A further five (42 per cent) reported that recruitment trends had stayed the same since 2003. Two schemes (17 per cent) had reported that recruitment trends had gone down during the five years since 2003.

Table 4.1: The most successful recruitment methods (n=13 schemes)

Recruitment methods	Schemes	(%)
Newspaper articles and advertisements	9	(69)
Church and parish newsletters	9	(69)
Word of mouth	7	(54)
Targeted advertising using posters and mail-shots	6	(46)
Advertising on shop till receipts	1	(8)
Self-referral	1	(8)

Schemes were asked to list the three most successful recruitment methods, over the past three years (Table 4.1). The most successful methods, as indicated by 13 schemes, were newspaper articles and adds (nine schemes), church and parish newsletters (nine schemes), and word of mouth (seven schemes). Two of these schemes specified word of mouth among staff in disability services. The next most successful method of recruiting hosts was targeted advertising using posters and mail-shots (six schemes). Two of these schemes placed advertisements with volunteer agencies; two did a mail-shot to their staff; and one carried out a mail-shot to local pre-school assistants and SNAs (Special Needs Assistants in mainstream schools). Other reported successful recruitment methods included, advertising on shop till receipts (one scheme) and self-referral (one scheme).

4.1.1. Unsolicited enquiries

Twelve schemes gave details about the number of enquiries that they receive from potential hosts in a year; and the number of hosts subsequently approved. These details are largely subjective and so the following findings should be interpreted with caution.

Two schemes (17 per cent) received no enquiries and two schemes (17 per cent) received four enquiries each. The rest (n=8; 67 per cent) receive ten or more enquiries. Ten schemes stated that this level of interest (194 aggregated enquiries) leads to a total of 56 hosts being approved. This equates to one host approval for every three and a half (3.5) enquiries received, which is almost a 29 per cent return rate.

4.2. Attrition rates among hosts

Fourteen schemes supplied information about the "approximate" percentage of hosts that left their scheme each year. This varied widely from five schemes (36%) that managed to hold on to all of their hosts, in recent years, to two schemes that each lost 20% of their hosts. The average was seven per cent (mean =7; median =5; mode =0; sd =7). This equates with a total of approximately 23 hosts, leaving these 14 schemes every year.

One of the five schemes that tended to retain all their hosts said that "most" of its eighteen hosts "took a year or two out" but then usually returned afterwards. Another scheme with just three hosts explained that "none [of our hosts] has left in years", while a third scheme, with two host families, had lost no hosts in the previous year. The fourth scheme that managed to hold onto it's three remaining hosts noted "since I took over four years ago, the same three host families, linked to three specific school-age children, are what comprise the [name] scheme." The fifth scheme, which had retained its four hosts "for years" lost one host family last year.

4.2.1. Exit interviews

Fifteen schemes provided information about conducting exit interviews when hosts retired. Nine schemes (60 per cent) said that they did carry out exit interviews, one scheme said that it "sometimes" conducted interviews and five (33 per cent) said that they don't interview hosts who retire.

In the ten schemes that always or sometimes conducted exit interviews, it was usually a social worker (nine schemes) who did the interviewing. In one scheme exit interviews were carried out by the scheme manager.

4.2.2. Reason for hosts leaving schemes

Thirteen schemes contributed details of why hosts leave their schemes (Table 4.2). The most frequently cited reason was, a change in the hosts' individual circumstances (n=12; 92 per cent). This included hosts having extra and competing family commitments (11 schemes), hosts moving house out of the catchment area (three schemes), and hosts having extra and competing work commitments (two schemes).

The next most cited reason was that the arrangement had run its course, or outlived its original purpose, and come to a 'natural ending'. (n=7; 54 percent).

Table 4.2: Reasons given for hosts leaving schemes (n=13 schemes)

Reasons for leaving	Schemes	(%)
A change in the hosts' individual circumstances	12	(92)
A natural ending	7	(54)
Guest (child) moving to another service	1	(8)
Hosts unable to meet scheme requirements	1	(8)
Not applicable	1	(8)

Other reasons included children (guests) moving to another service (one scheme) and hosts being unable to meet the scheme's requirements (one scheme). One relatively new scheme had not yet had any hosts leave it in the short number of years since it began recruiting.

4.2.3. Main reasons for break down of placements

Schemes were also asked to give their three main reasons for placements ending prematurely. Twelve schemes replied. A total of 33 reasons were grouped into the following seven categories (Table 4.3). However there was often overlap between some categories.

The main reason that placements ended was a change in the host families' circumstances (n=14; 42 per cent of reasons cited). This included extra demands on the hosts family, ill health, securing employment, changes in their work pattern, caring for an elderly relative, change of house, and pregnancy.

The second reason was the hosts' inability to continue to meet the needs of their guest (n= 6; 18 per cent). This could be due to challenging behaviour, increased need for extra breaks, or to some of the changed circumstances referred to above.

The third reason was a change in the guest's circumstances (n=4; 12 per cent), such as the guest moving to another service or moving house. In one instance the placement had to end when a child reached eighteen years and was no longer eligible for this children's service.

The next reason had to do with the natural family being unhappy with some aspect of the arrangement (n=3; 9 per cent). Some parents were reported to have reconsidered the suitability of the scheme. They may feel that the host family is not in a position to meet their child's needs. Some families did not get along with each other.

Table 4.3: Reasons that placements ended prematurely (n=13 schemes)

Reasons for ending	#	(%)
Change in a host family's circumstances	14	(42)
Hosts inability to continue to meet needs of guests	6	(18)
Change in a guest's circumstances	4	(12)
Guest's family unhappy with arrangement	3	(9)
Insufficient support from scheme	3	(9)
'Natural' ending	2	(6)
'Difficult' relationship between host and guest	1	(3)
Total reasons cited	33	(99*)

* Total may not equal 100% due to rounding

The fifth reason had to do with the placement not being supported sufficiently (n=3; 9 per cent). Some hosts were not able to obtain sufficient support to deal with challenging behaviour. In one instance the hosts had not realised the level of commitment needed, which reflected on their preparation for hosting.

Some arrangements ended naturally and without fuss (n=2) and in one instance placement was said to end due to difficulties in the relationship between host and guest.

4.3. Service-user involvement

Four (29 per cent) of the 14 schemes that answered this section said that they had a service-user (i.e. a family member) involved in the administration of their scheme. Three of these schemes have a parent on their 'approval' panels. The third scheme has invited parents to join their executive committee, but has had difficulty retaining them.

Thirteen (87 per cent) out of the 15 schemes that answered this section of the survey, said that they had a guide or leaflet describing the service.

4.4. Emergency or unplanned placements

Twenty-one schemes provided information about emergency or unplanned placements. Eleven schemes (52 per cent) were able to offer emergency placements to either children (n=9 schemes) and/or adults (n=10 schemes). A total of 88 households (20 per cent of total households) throughout these 11 schemes, were identified as being available to accept emergency or unplanned placements from children (n=30; 14 per cent of households hosting children) and adults (n=58; 27 per cent of households hosting adults).

4.5. Day placements

While most hosts provided overnight breaks, 12 schemes said that they had some hosts (n= 65) that provided 'day only' breaks to children (21 hosts) and adults (44 hosts)

4.6. Moving and handling

The findings on moving and handling are presented separately, below, for overnight breaks and daytime visits

4.6.1. Overnight breaks

Twenty schemes provided information about moving and handling. A total of 17 (85 per cent) out of the 20 schemes placed children and/or adults with moving and handling needs for overnight visits. Only three schemes (15 per cent) said that they didn't. One explained:

> *"while we used to place children with moving and handling needs in the past, the current scheme is only geared up for young attendees. Families whose children have more complex needs opt for residential respite"* .

Another explained that training in moving and handling was "not available" to it. The third said that while it placed people with moving and handling needs, in the past, it had no one with such needs placed "at present"

4.6.2. Day Placements

Sixteen schemes provided information about moving and handling in relation to day placements. Twelve of these schemes (75 per cent) were able to place children and/or adults with moving and handling needs for daytime breaks. Four schemes (25 per cent) said they didn't. One of these explained "as all of our hosts are working full time outside the home, this limits the opportunities to provide day care". Another said that while it had placed adults with moving and handling needs in the past, it had not placed anyone requiring moving and handling during the year surveyed.

4.7. Clinical/invasive procedures

The findings on clinical/invasive procedures are also presented separately here, for overnight breaks and daytime visits

4.7.1. Overnight breaks

Eighteen schemes provided information about their ability to place adults and children requiring clinical/invasive procedures for overnight breaks. Thirteen of these (72 per cent) said that they were able to place people. Two added the following provisos "but only if hosts are comfortable with caring for a child who requires invasive procedures" and "only if a host family has someone with nursing skills". Five schemes (28 per cent) were unable to place people requiring invasive procedures for overnight breaks. One explained "It has not been agency policy to place such complex needs children with 'non-professional' trained carers". Another explained that none of their hosts had a medical/nursing background. Two schemes cited the absence of available training and the fifth just said, "not at present".

4.7.2. Day Placements

Fifteen schemes provided information about their ability to place adults and children requiring clinical/invasive procedures for daytime breaks. Nine of these schemes (60 per cent) said that they were able to place people for daytime breaks and six (40 per cent) were not able to. Three schemes gave reasons for this inability. One explained that all of their hosts worked full time outside the home, which limited the opportunities to provide day care; another was awaiting someone to provide this training and the third explained that none of its hosts had the necessary medical or nursing experience.

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4.8. Managing risk taking

Eighteen schemes provided information about risk taking assessments. Twelve of these (67 per cent) stated that they carried out these assessments, prior to placement. One of these added the proviso "but only if required". Another stated that it did not have the required staff to provide a "full" risk taking assessment.

Six schemes (33 per cent) reported that they did not carry out a risk taking assessment, prior to placement. One added that this was "not applicable at present"; another added that the then active "placements had started before risk assessment became part of the [parent] service".

Social workers were to the fore in carrying out risk taking assessments (n=9). In three schemes they shared this responsibility with the approvals 'panel'; and in another with the rest of the multidisciplinary team. One scheme used an Occupational Therapist and another used the scheme Co-ordinator "depending on the area of risk". One scheme that used a social worker, in conjunction with the approvals panel, stressed that it did not use the Health and Safety officer and that there was "not enough staff to provide a full risk taking assessment"

4.8.1. Reviews

Of the twelve schemes that carried out risk taking assessments, two-thirds (n=8) reviewed the assessments. Four of these carried out reviews "when required"; another stated that reviews "depended on changes in family" and yet another stated that reviews were conducted when there was "a change in physical or social environment of the host or adult [guest]". The remaining two schemes set specific review dates; one of these used its annual and three-monthly meetings to review risk taking, if the necessity for this didn't arise in the interim.

4.9. Insurance

4.9.1. Personal injury and damage

Fifteen schemes provided information on insurance for hosts. All 15 insured their hosts for damage or injury to others. Two-thirds (n=10; 66.6%) insured their hosts for damage to their property and buildings; and slightly less than that (n=9; 60%) insured their hosts for accidents to themselves.

4.9.2. Home contents

Eighteen schemes provided information about requiring hosts to carry home contents insurance. Ten of these schemes (56 per cent) required their hosts to have this cover. Two of the other eight schemes only "advised" their hosts to have such cover.

4.9.3. Motor insurance

Nineteen schemes provided information about requiring hosts to have fully-comprehensive cover on any vehicle they may use to transport a guest. Seven of these schemes (37 per cent) required their hosts to have this cover. Two of the other 12 schemes only "advised" their hosts to have such cover.

4.9.4. Insurance difficulties

Seventeen schemes provided information about whether their hosts had experienced any difficulty with obtaining insurance. Only one scheme (6 per cent) reported problems. It stated that when "some" of their hosts inform their insurance companies about having guests, "they have difficulties". The respondent could not be sure if all hosts were covered in the event of a motor accident, involving a guest as passenger. This scheme did not require its hosts to take out comprehensive motor insurance.

4.10. Scheme evaluations

Schemes were asked whether they had ever been formally evaluated. Seventeen active schemes responded to this question. Nine (53 per cent) said that they had been evaluated and eight (47 per cent) said that they hadn't. Of those who said that they had been evaluated, two had been evaluated in the 1980s, three in the 1990s and four since 2000. One of the schemes was in the process of being evaluated.

Four schemes (44 per cent) were evaluated, 'in-house', by the scheme manager (two schemes), or by the Social Work Department responsible (one scheme), or by an in-house research officer in conjunction with the scheme social worker (one scheme). Three schemes, (33 percent) were evaluated by an outside independent third party and two schemes (22 per cent) were evaluated jointly by the local Health Board/HSE and the voluntary agency responsible for the schemes. All nine evaluations were written up and three reports were published.

4.11. Redundant schemes

Respondents were asked if they had closed down any schemes during the past five years. Two replied that they had. One, categorised as currently 'in trouble', had closed the children's part of its scheme while the other, a 'robust' adult scheme had closed its separate children's scheme. They cited "lack of manpower and resources" and "lack of resources" as the reasons for these closures.

4.12. Respondents 'wish list'

Respondents were asked to list three things that would most improve their schemes. Answers were received from 16 schemes.

Respondents from 14 of these schemes (88 per cent) said that they would wish for more staff (ten schemes), and/or increased funding (six schemes) and/or more resources (three schemes). See Table 4.4., below.

Table 4.4: Distribution of respondents' wish lists (n=16 schemes)

What respondents wished for	#	(%)
More staff (10), funding (6), and resources (3).	14*	(88)
More host families.	12	(75)
National and local links & networks.	6	(38)
More efficient procedures.	6	(38)
More support from management	5	(31)
Total reasons cited	48	(100)

* These 14 schemes accounted for 19 closely related 'resource' wishes

Twelve schemes (75 per cent) would like to expand by recruiting more hosts. Six schemes (38 per cent) would like to see more movement at national level such as links with NHSN, a national co-ordinator and recognition at national level, including legislation. Six schemes (38 per cent) would like to see more efficient procedures at local level including better coordination and management of schemes and less bureaucracy; and five schemes (31 per cent) would like more support and recognition from management. The complete 'wish list' is reproduced in Appendix A.

Chapter 5

Discussion

The aim of this survey was to explore the prevalence and scope of family-based overnight short break services, for the purpose of informing NHSN members and legislators as regards future development. This aim has been achieved with the documenting of the above findings. However, it is hoped that this discussion chapter will initiate a debate on the future of these services. Consequently, a number of pertinent issues and themes are discussed below under headings, equivalent to some of the headings used in the body of the report. The discussion is not definitive and does not necessarily represent the opinions of the *National Home-sharing & Short-breaks Network* (NHSN).

5.1. Survey response

The response rate of 83 per cent is very respectable for such a lengthy and complex postal survey, and reduces the potential for bias. (Asch *et al.,* 1997; Engel and Schutt, 2010: 192). It compares to a response rate of 37 percent for a not unrelated survey (Merriman, 2009) and to 64 per cent in a recent UK survey (Carlin and Cramer, 2007). This is partly due to the interest of respondents in helping to develop this model of service, which is reflected in their 'wish list' (Appendix A).

Despite this high response, there are many gaps in the data. While some of this may be attributed to the questionnaire design, it is also apparent that some services do not maintain accessible electronic databases or other forms of record keeping. For example, some respondents were unable to give basic information about when their schemes started or how many informal enquiries they received. Others were unable to report on the ability level or ages of their guests; or on why hosts left their schemes. Some schemes admitted to not keeping a retrievable record of hosts' ages, apart from their original paper application forms. There should be a national minimum standard of information required, key performance indicators, and retention and storage of such data. This needs to be coordinated with data held on the National Intellectual Disability Database (NIDD), so that robust and compatible figures are available to planners (see section 5.13. "Number of guests compared to NIDD", below).

Perhaps related to the lack of co-ordinated record keeping is the unusual finding that the names of some schemes are not stable and tend to change from answer to answer or are spelled differently in different sections of the questionnaire. For example, the seminal scheme *Break Away* (Walsh 1983) is referred to as *Breakaway* by some of the respondents who belong to this originally multi-agency project.

These gaps and inconsistencies in data are partly due to a change in personnel, especially the loss of coordinating posts and staff responsible for instigating schemes. They are also due to poor record systems, to a lack of continuity and focal governance, such as is provided by dedicated coordinator/managers (Hearn and Dunne, 1992;97). In the case of schemes that haven't recruited hosts for some time, it is probable that 'niche' skills in public relations, recruitment campaign design, and assessment of hosts, have been lost.

5.2. Voluntary organisations

It is not surprising to find that most schemes are run by large voluntary organisations, as these organisations provide the majority of services for people with intellectual and other disabilities. This finding may account for the lack of services in counties where these organisations don't operate such as Donegal, Monaghan, Meath etc. On the other hand, some counties with a significant voluntary presence, either have no schemes or have had schemes closed down, e.g. Co. Cork.

The prevalence of so many disparate voluntary organisations may also account for a fragmented and uneven service delivery and application of standards. However, this has to be measured against the amount of resources given to these schemes. On the positive side, these services have been innovative and many of them have been creative in keeping their schemes intact, despite the challenge of funding for more traditional 'respite' options.

5.3. Viability of schemes

Despite the tendency to build centre based respite units and houses during Ireland's recent economic building boom, five schemes were started between 2002 and 2008. This is a hopeful sign and may signify a resilient 'belief' in this model of service delivery, despite it's perceived bridesmaid image among policy makers and centre led services (O'Malley, 2003). However, it can't be denied that four schemes have closed and five are 'in trouble'; and that of the twenty-one remaining 'robust' schemes, some are stalled, due to a lack of resources. Indeed resources are identified in this survey as a major challenge for these family based schemes.

Schemes differ greatly in that some have less than a handful of hosts while others have appreciably more. Many of them are relatively small with host numbers in the high teens to low twenties. However, one notable scheme has 137 host families.

However, it should be noted that the number of hosts is not as significant as the number of nights that each host can offer. For example to provide forty guests with a short three-night break, every month, would require just eight contract families providing one hundred and eighty nights each (NHSN, 2010).

Another way of increasing efficiency, at the micro level, might be for a number of schemes in a region to share resources such as joint advertising, recruiting etc. It would make sense for very small schemes to join with local and larger services when holding information evenings and training courses. Skills could be traded so as not to place an undue burden on either party. For example, smaller schemes could help out with screening and home assessment in return for access to group training. Advertising costs could be shared in proportion to the numbers of hosts required by each service.

There would also appear to be a need for more co-operation among schemes in the east of the country, particularly in Dublin. It was noted that this area, with a couple of exceptions, is falling behind the rest of the country in innovation, recruitment and general development of schemes.

5.4. Total hosts

The survey was able to identify 430 of the estimated 475 households that are known to be actively hosting. This is a minimal estimate but it is a step forward and should help with planning future services and with identifying households that might be covered by future national quality standards.

5.5. Gender and ability of hosts

The finding that heterosexual couples make up the majority of hosts probably reflects the strong emphasis on traditional families in recruitment campaigns (Hanrahan, 2006b). However, nineteen per cent of households consist of single females. Only one host has a family member with a disability. This finding might indicate a lost opportunity, as there are probably some untapped experienced households that would make excellent hosts, including households where there is a person with intellectual or other disabilities. This opportunity is reinforced by the long tradition of parent co-operatives in other countries (Ferguson and Lindsay, 1986).

5.6. Age of hosts

The age profile of people hosting children is much younger than that of those hosting adults. In the children's schemes, the majority are under fifty years while in the adult schemes, the majority of hosts are over fifty. This finding is not surprising as schemes prefer to link children with families where there are children; and to link adults with either single people or with families where there are young adults who can involve the guest in age appropriate social and recreational activities (Hanrahan, 2007). However, there is some evidence that some children placed with hosts are continuing to stay with these hosts as adults. This can give rise to an aging pool of hosts. It is interesting to note that nine per cent of female hosts and eighteen per cent of male hosts are aged over sixty-five years.

5.7. Ethnicity

The survey highlights the current reliance on non-ethnic households. This is to be expected, given the traditional make-up of the population. It may also reflect the fact that ninety-seven per cent of children and all adult guests are 'White Irish' (CSO, 2007). While it is not surprising to see no non-White Irish adults placed with hosts (because most immigrant families are relatively young) one might expect to see more children, given that one service reported that it had "a high proportion of children from different social and cultural backgrounds". The absence of these children might be due to a number of reasons including a lack of resources to develop schemes to meet local demand. However with the increase in services-users with other ethnic and cultural backgrounds, schemes need to be proactive in meeting their needs, as they tend to get left behind along with other minorities such as children with challenging behaviour and other complex needs (Flynn, 2002; Kaushal and Nawaz, 2006; Prewett, 2000; Wolkind and Kozaruk, 1986). It may be time for the NHSN to consider staging workshops on the recruitment of hosts for difficult to place children including children from ethnic and cultural minorities.

5.8. Assessment and training of hosts

The survey identified a bias in favour of relational based assessment over competency-based assessment. While most schemes don't use competency-based assessment, some of them do assess skills in crisis management and parenting, as part of their appraisal. Overall, there is a strong emphasis on assessment and background checks. However there are some gaps identified, especially in the area of moving and handling and training in invasive procedures and challenging behaviour. Where such training is provided, it seemed to be done well, with noted co-operation from a range of relevant disciplines. Follow-up and review of the need for on-going training is somewhat arbitrary and appears to be due to a lack of prescribed reviews, and possibly to resource issues. The number of "as required" responses to questions about follow-up and training probably reflects the pressure that staff are under to keep up with their workloads.

The lack of competency based assessment of prospective hosts may reflect social work's tradition of favouring tried and tested 'relational' assessment (Broadhurst *et all.*, 2010; 1059). The latter can be good at detecting the subtle nuances (Kempshall, 2010) of hospitality, family dynamics and resilience, that competency based assessment doesn't. This is especially so when the latter is driven by a managerialist and/or risk adverse agenda (Murrow, 2010; Reinders and Holland, 2008). This is an area that could benefit from rich debate in national fora, such as conferences and workshops; and the NHSN may have a role in ensuring a balanced debate, given the traditional bias referred to above.

5.9. Expenses and other payments to hosts

A striking finding is the wide range of payments to hosts. Some receive as little as €15 per night while others receive €80 per night, per guest. The payment to

contract families can be as high as €138 (NHSN, 2010). This has to be placed in a context in which efficiently run centre based respite costs €261.04 per guest per night and 'less efficient' centre based respite costs as much as €417.79 per night (Hanrahan, forthcoming). Indeed some 'respite' can cost up to €821.92 a night and in some cases the 'cost is more for people with complex and high support needs' (Inclusion Ireland, 2009)

Although payment was not identified as an incentive, one scheme, that expressed a wish to have more mid-week breaks, paid their hosts less for mid-week breaks than they did for weekend breaks. Indeed some schemes had a very complex scale of rates depending on age, ability, length of stay, day of the week, status of hosts (whether volunteer or contract family) etc.

In one scheme the hosts received €30.30 for visits lasting up to twelve hours and €46.20 for visits over twelve hours but less than twenty-four hours. In another scheme there was a night rate of €40 and a day rate of €25, so that a weekend would cost €170, made up of three night rates and two day rates. Yet another scheme differentiated between overnight visits where the adult continued to attend their day service (€38) and when they didn't (€65). Some schemes paid a day rate of €40, but if the guest stayed overnight and this included six or more waking ours, the hosts received twice this amount.

It is questionable whether the administrative cost involved in maintaining such complex arrangements, justifies the effort, in the absence of an easily administered electronic payment system. At the same time schemes need to be able to negotiate flexible arrangements for exceptional circumstances.

Some of the collateral information, volunteered by respondents, suggests that the lower payment rates have not been reviewed and/or updated for over ten years, due to resource issues. This is noteworthy, given the large injection of funds that intellectual disability services received during the same period. (NDA, 2004). It is possible that this is indicative of either a lack of appreciation of the benefits of host family schemes (see wish list, previous chapter) or a bias towards nurse-led centre based 'respite,' or both, in some organisations. In one case, staff running a successful host family scheme, were redeployed to run a previously vacant purpose built 'respite' house. This scheme soon began to loose hosts as replacement hosts were not recruited.

It is also possible that some schemes continue to pay very low 'expenses' as their volunteers are motivated by public good or public benefit sentiments (Segal and Weisbrod, 2002) rather than some form of impure altruism (Sardinha, 2003); and would have hosted without monetary reward. To over compensate such hosts can lead to them hosting less, due to a reduction in 'opportunity cost' linked motivation (Frey and Goette, 1999; Frey and Jagen, 2001; Hanrahan, 2006a). Nevertheless, it is unlikely that these schemes would have continued to pay out-of-date rates, had they had the resources to bring them into line with comparable schemes.

There should be a national minimum standard rate of expenses for volunteers, equivalent to at least the current fostering allowance. Like fostering and similar host family schemes in Northern Ireland and elsewhere, these expenses should

not attract tax (BCFFPA, 2004; Commission on Taxation, 2009; HMRC, 2008; McConkey *et al.,* 2005).

5.10. House adaptations and equipment

There is poor provision for house adaptations and equipment for hosts and this is an area that perhaps needs to be given more attention when negotiating funding and planning new schemes. There should be provision for reasonable and necessary house adaptations and special equipment. At present, most schemes don't have a budget for this and have to go about funding adaptations and equipment in an unsatisfactory, round about, and/or furtive manner. This raises equity issues in that guests who require these aids (especially expensive lifting equipment) lose out on opportunities for host family short breaks. It also raises safety issues as over a third of schemes report that the type of equipment that is most needed by hosts is safety equipment. This equipment is considered 'standard' in centre-based services.

5.11. Incentives towards qualifications

Lack of resources may be responsible for the lack of incentives given to hosts to work towards a relevant qualification. This area needs to be examined further.

5.12. Number of guests linked to each host

Although some hosts welcome more than one guest, and one family welcomes up to seven guests, the vast majority have just one guest. Indeed the average number of guests linked to hosts is just 1.2. There is perhaps potential for the more efficient deployment of hosts by encouraging them to welcome more than one guest.

The more guests that hosts welcome, and the more nights that they can provide, means that larger schemes will need fewer hosts. This has implications for recruitment, assessment, training, supervision and monitoring costs, as fewer social work and other staff are needed to ensure an enjoyable and safe break for all concerned. For example, although contract families cost more in payments to the hosts, their efficiencies mean that eight families can provide the same amount of overnight breaks as thirty to forty volunteer hosts. This allows scheme social workers more time to recruit and supervise additional contract families if needed, as well as attend to future national standards implementation (NHSN, 2010).

However, schemes need to avoid the temptation to place a number of guests with one host, at the same time. There is a danger in doing so, that host families will be turned into mini-institutions or boarding houses (Allen Consulting Group, 2003; Young, 1988), thus undermining the personalised nature of the short breaks. Multiple placements should only be considered for close friends who would like a

break together and in other exceptional circumstances where there are good reasons for doing so in order to benefit the respective guests.

5.13. Number of guests compared to NIDD.

The survey identified 588 guests, including 308 children and 280 adults. This is 351 more guests (148 per cent more) than is recorded on the National Intellectual Disability Database (NIDD) as being in receipt of "occasional respite with a host family", for the same year (Kelly *et al.,* 2009:39). It is even more than when all those identified on the NIDD as being in foster care and boarded out (n=292), are included in the NIDD total. This is remarkable when one notes that this survey was not exhaustive and that, consequently, there are some children and adults not included in the above total of 588.

In the same NIDD report (Kelly et al., 2009: 60), there were 94 people, not receiving any residential support services, in 2008, and recorded as requiring future '*Occasional respite care with a host family'*. This figure contrasts sharply with those requiring future '*Crisis or planned respite'* (1,290 additional service-users) and those requiring future '*Holiday residential placement'* (166 additional service-users). It also stands in contrast with the 212 people who are reported, in this survey, as waiting to be matched with a suitable host family. (See 3.16. "Unmet needs," below). Given that most host family schemes don't keep waiting lists, this figure of 212 is a minimum measure of unmet need.

The NIDD is the main database used in planning for future ID services, including short break schemes using host families. Consequently, it is important that every guest who stays with a host family, or who requires a future placement with a host family, is recorded on this. Otherwise, the Department of Health and Children, and others, will have no reason to plan for increased host-family resources.

There are many reasons for this under-recording. Some of them include:

a) some agencies are not reporting that individuals are staying with host families;

b) some agencies are reporting that individuals are in receipt of '*Holiday residential placement'* when they mean '*Occasional respite care with a host family';*

c) some agencies are reporting that individuals are in receipt of '*Crisis or planned respite'* when they mean that individuals are in receipt of crisis or planned respite with host families (i.e. '*Occasional respite care with a host family');*

d) when an individual receives more nights in a residential respite centre than he/she does with one or more host families, that individual is recorded as being in receipt of '*Crisis or planned respite'*. The NIDD database code for '*Crisis or planned respite'* is #174. The code for '*Occasional respite care with a host family'* is #175.

e) some agencies completing the NIDD data form have multiple sites. Staff in these sites might not be aware that some of their service users are staying with host families; or, they may, confusingly, fill in 'holiday' or 'planned respite' for these people instead of the correct #175 code.

f) until 2009, it was not possible to return multiple residential services for a service-user. In addition to a main residential service (i.e. "where the person lives most nights of the week", such as at home or in some residential service) a service-user can only be recorded as attending one other, but secondary, residential service i.e. *'Crisis or planned respite'* or *'Holiday residential placement'* or *'Occasional respite care with a host family'.* In 2009 a slight, but possibly significant, change in this criteria was introduced and it remains to be seen whether this improves the situation. Anecdotal evidence would suggest that there are still recording anomalies. However, the recording of future service requirements (in other words, the short break needs of people on waiting lists for host family services) may be slightly easier, provided that these people don't also require a full time, permanent, residential service within the next 5 years.

g) There are other idiosyncratic reasons why under-recording takes place but the subject is complex and needs to be addressed elsewhere.

Schemes should be encouraged to keep a 'planning' waiting list i.e. immediate or future service requirements (up to 5 years), and to report the people on this list to the NIDD .

5.14. The guests' ages and backgrounds

Compared to some other countries (Carlin and Cramer, 2007**),** older children seem to be reasonably well catered for in Irish schemes, with 55 per cent aged over 12 years and 13 per cent aged over 16 years accounting for the bulk of child placements.

The situation is not as clear-cut when it comes to immigrant children. Given the recent migration of people to Ireland, one would expect to see more non-'white Irish' children (CSO, 2007). However, their absence may be due to a corresponding lack of resources to increase the number of host families to accommodate these children, rather than any identifiable bias. For example the eight schemes that kept waiting lists had a combined list of 212 children and adults. Only time will tell, whether the under-representation of non- 'white Irish' children is due to resource or system failure. This may be an area for further research.

5.15. The guests' abilities

It is encouraging to find that at least half the schemes are catering for children with complex health care needs (50 per cent), autism (64 per cent), and challenging behaviours (71 per cent). The corresponding percentage for schemes catering for adult guests is 43 per cent (complex health care needs), 57 per cent (autistic spectrum disorder) and 57 per cent (challenging behaviours). It is also noteworthy that half of adult schemes cater for people with mental health needs. This finding, together with the high proportion of childrens schemes (71 per cent) and adult schemes (79 per cent) catering for guests with physical disabilities, underlines the potential of host family schemes to accommodate a wide range of children and adults. It also supports the need for house adaptations and equipment to be made available to these schemes.

5.16. Unmet needs

Most schemes don't keep waiting lists. Despite this, 212 people were reported to be waiting to be matched with a suitable host family, in 2008. This is more than double the 94 children and adults not receiving any residential support service and registered on the 2008 National Intellectual Disability Database as requiring "occasion respite care with a host family" (Kelly *et al.,* 2009;60). For a detailed discussion of this under-reporting, see section 5.13. "Number of guests compared to NIDD", above.

5.17 Recruitment of hosts

Some schemes placed a lot of emphasis on recruiting from among their own staff, while others didn't advertise among staff at all. Given the recommendations to close congregated settings (Irish Times, 2010; Lynch 2010), this source of hosts may increase as paid staff are redeployed from centre based services to supporting individuals in independent living arrangements. This could lead to a transfer of the institutional culture into hosting, to the detriment of service-users, and needs to be guarded against. For an expansive discussion of recruiting host families, the reader is advised to read Hanrahan (2006).

5.18. Unsolicited enquiries from hosts

The percentage of hosts recruited from unsolicited enquiries (29 per cent) appears to be quite large. This might be due to the subjective nature of this data, with respondents possibly ignoring, or forgetting, some enquiries that didn't materialise. On the other hand, it might suggest that people who make unsolicited enquiries are more suitable and/or more motivated to become hosts. More research is needed to clarify this.

5.19. Attrition rates among hosts

Some of the smaller schemes that don't lose hosts are only 'robust', for this reason. However, all were bigger in the past and have retrenched due to a lack of resources. With new resources they have the potential to grow strong again. However, without resources they are in danger of having to struggle in order to replace their loyal but aging hosts.

It is interesting that some schemes are able to retain hosts by giving them a break to attend to pressing family needs, which might otherwise require them to retire from hosting, altogether. This form of 'sabbatical' should be encouraged, when host family circumstances change, necessitating their withdrawal from hosting. They should continue to receive newsletters and be included in any ongoing training and social events, where possible.

5.20. Service-user involvement

Most schemes are not successful in involving service-users or their relatives in administering schemes. Having these stakeholders involved would help revitalise some schemes and inject fresh ideas and energy and help counteract low morale. It may be necessary to offer relatives incentives such as payment and/or travel and other expenses. However these relatives, especially parents, may themselves be 'time poor', due to their nurturing responsibilities. It may be necessary to think of innovative ways to involve them such as more use of email, teleconferencing, short prepaid questionnaires targeted at eliciting their opinions and/or asking for advice and ideas. Perhaps larger services could reach out to smaller struggling services to include them in such initiatives.

5.21. Emergency or unplanned placements

Just over half the schemes could offer emergency placements with 20 per cent of households in these schemes available for emergencies. While this is encouraging, it indicates that with some extra resourcing, it should be possible to build on this, given the flexibility that can be had from such individualised arrangements.

5.22. Moving and Handling & other procedures

The proportion (85 per cent) of schemes that place guests that require moving and handling is encouraging. However, some schemes don't have any guests requiring moving and handling and this might indicate that these potential users are being neglected and/or being redirected to congregated respite or other supports such as domiciliary options.

The same might be the case for guests who require invasive procedures although some schemes didn't provide for guests who required clinical/evasive procedures.

5.23. Insurance

Contrary to anecdotal evidence and discussions at national fora, only one scheme reported that some hosts had difficulty obtaining insurance. This finding is surprising, as insurance, and especially motor insurance has often been raised as a concern. Some respondents didn't know whether or not their hosts were required to have home contents insurance and this uncertainty needs to be clarified.

5.24. Redundant schemes

Four of the original thirty schemes identified by the researcher are no longer active. Another five are considered to be 'in trouble', in that they might not survive without extra resources and outside help. Some of these no longer recruit hosts.

Some schemes stop recruiting long before they finally close down. This winding down period can take years as loyal hosts continue to provide short breaks until their ability to do so is compromised by competing life circumstances. A scheme's inability or reluctance to recruit new hosts, as older hosts retire, is an obvious indicator of a scheme that is in trouble. Perhaps the NHSN should considering providing consultative support to such ailing schemes in order to diagnose the problem and help with finding solutions. The NHSN might consider nominating a local mentor who could provide advice and coaching support. A National Co-ordinator would be useful in providing administrative back-up to such a service. However, no amount of support and goodwill can make up for lack of funding and insufficient staff to run host family short break schemes. In Co Meath, for example, the co-ordinating social worker was not replaced and the local host family scheme was suspended, resulting in an "increase in referrals to the residential respite service". (O'Donnell, 2004: 4).

The fragile reliance on a steady supply of resources for the survival and growth of schemes is reflected in the wish list, (Appendix A) which is remarkably consistent across respondents.

5.26 Cinderella!

Finally, another theme to emerge is the feeling that schemes are not appreciated by management and do not receive the recognition that they deserve compared to centre based or congregated services. Indeed insufficient support from sponsoring agencies as well as under-funding has led to some very good and even pioneering schemes either closing down or continuing at a reduced capacity. This lack of support can have an effect on staff morale. Perhaps the NHSN should have a role in marketing family based services proactively, both nationally and at individual service level, by offering to address Department officials, local service-

provider managers, and service-user groups, on the benefits of these inclusive and personalised short break alternatives.

Chapter 6

Summary & Conclusion

While some attempts have been made to measure the total number of people with intellectual disability who benefit from host family schemes, no comprehensive source is available, and no details have been published regarding the number of hosts that are involved, nationally.

This survey set out to explore the prevalence and scope of host family short break services, for the purpose of informing the planning and operational procedures of NHSN members and influencing national policy. It is modelled on the fourth national survey of short break services for disabled children in the UK, which was undertaken by Jeanne Carlin and Helen Cramer for Shared Care Network (Carlin and Cramer, 2007). This allows for comparison and benchmarking against the schemes of our nearest neighbour.

The questionnaire was posted, between November 2008 and January 2009, to 30 schemes run by twelve separate organisations. A total of 25 questionnaires were received, giving a response rate of 83 per cent. Some very basic information, on the five schemes for which there were no questionnaires, was included from informal contact, and from published data. Because of this, a small number of the findings in this report are based on data from all thirty schemes.

Twenty-seven schemes (90 per cent) were run by voluntary organisations and three by the Health Service Executive (HSE).

Four (13 per cent) of the thirty schemes were found to be ‘inactive’ and they no longer have any host families. Another five schemes (17 per cent) were found to be ‘in trouble’, in that they might not survive without extra resources and outside help. Some of these have stopped recruiting. The remaining 21 schemes were all found to be ‘robust’. Some of these are thriving while others are consolidating, having had to retrench because of lack of resources

Eight of the schemes surveyed cater for children only, ten cater for both children and adults, and the remaining eight cater for adults only.

Of the 26 schemes with active hosts, 23 provided information about their hosts. A total of 430 households were identified. However, it is estimated that at least 476 Irish host families welcomed 588 guests in 2008.

Eighty-five percent of households include a male and female host couple. The rest are comprised of female hosts, only.

Most (67 per cent) of the female hosts and slightly less of the male hosts (60 per cent) who welcome children are aged 26-50 years. This contrasts with those

hosting adults where most (63 per cent) of the females and males (60 per cent) are aged over 50 years. All of these hosts are either 'white Irish' (99 per cent) or 'white other' (one per cent).

Eighty-five percent of schemes used their own assessment protocols. Fifteen per cent reported that their assessments are competency-based. All of the schemes require that their hosts have Garda Clearance. Twenty-nine per cent have a service-user (i.e. a family member) involved in the administration of their scheme, mainly on approvals panels. There is some concern about being able to attract and/or hold on to these people.

Eighty-four per cent of schemes require their hosts to undergo Moving and Handling training, before they are paired with guests who require such proficiency. Only 44 per cent update this training.

Almost 90 per cent of schemes provide training focused on the individual needs of the guests. For example, 71 per cent provide training where a guest requires some invasive clinical procedure. A nurse usually carries out this training. Eighty-five percent of schemes provide training in behaviour management. In 59 per cent of schemes this is provided by a psychologist and in the rest by any one, or more, of a number of multidisciplinary team members.

The survey looked at rates of pay, payment towards house adaptations, and whether schemes had equipment budgets.

The structure of payment rates for hosts varies considerably across schemes.

In order to compare rates, across schemes, the night rate (i.e. 24 hours), for weekend 'sleepovers', is chosen as a reference point, for children over 12 years and for adults. In the case of children, schemes pay between €35 and €80 per. night. Sixty per cent pay between €60 and €80. Adult schemes pay between €15 and €80 a night. Half of them pay between €60 and €70 per night.

Sixty-three per cent of schemes have no provision to fund house adaptations, and 66 per cent don't have equipment budgets.

Some hosts are linked with more than one guest. In one scheme, for example, there is a host linked with four children and in another scheme there are seven adults linked with one host. However, the vast majority of hosts are linked with just one guest; so that the average number of guests per host family is 1.2 children and 1.2 adults.

The survey identified 588 guests, including 308 children and 280 adults. This is 351 more guests (148 per cent more) than is identified on the National Intellectual Disability Database (NIDD) as being in receipt of "occasional respite with a host family", for that year (Kelly *et al.,* 2009:39). It is still more when all those identified on the NIDD as being in foster care and boarded out (n=292), are included in the NIDD total.

Boys make up 54 per cent of guests in the children's schemes. Most of the children (55 per cent) are older children aged 12 years or over. Ninety-eight per cent come from 'white Irish' and 'other white' backgrounds (CSO,2007). In 71 per cent of schemes, there are children with physical disabilities, and in half of the schemes there are children with complex health care needs

All of the adults placed with host families come from a 'white Irish' background. Women are more prevalent (55 percent). Fifty-eight per cent of all adult guests are aged 30 years or older. In 79 per cent of schemes there are adults with physical disabilities. In half the schemes there are adults with mental health needs and in 43 per cent of schemes there are adults with complex health care needs.

Most schemes (85 per cent) place children and/or adults with moving and handling needs for overnight breaks. Most schemes (72 per cent) are also able to place adults and children requiring clinical/invasive procedures for overnight breaks, and just over half (52 per cent) are able to offer emergency and unplanned placements.

Sixty-seven per cent of schemes carry out risk taking assessments prior to placement and two-thirds of these review the assessments, although this tends to be 'when required' or as necessary. Social workers are to the fore in carrying out the assessments.

Twelve schemes provided details of their recruitment trends during the previous five years. Five of these (42 per cent) reported that their recruitment trends had gone up since 2003. A further five reported that recruitment trends had stayed the same. Two schemes (17 per cent) reported that recruitment trends had gone down.

The most successful methods of recruiting hosts are newspaper articles and advertisements (69 per cent of schemes), together with church and parish newsletters (69 per cent of schemes) followed by word of mouth (54 per cent of schemes). Sixty-seven per cent of schemes reported that they receive ten or more unsolicited enquiries, per year.

Fourteen schemes supplied information about the 'approximate' percentage of hosts that leave their schemes each year. These attrition rates vary widely, but the average is seven per cent. In 60 per cent of schemes no exit interviews are undertaken with these hosts. However, 92 per cent of schemes claim that the most frequently cited reason for hosts leaving is a change in their individual circumstances. They also report that the main reason that placements end is a change in the host families' circumstances (42 per cent of reasons cited).

Fifteen schemes provided information on insurance for hosts. All fifteen insure their hosts for damage or injury to others. Two-thirds insure their hosts for damage to their property and buildings; and slightly less than that (60 per cent), insure their hosts for accidents to themselves.

One scheme reported that some of their hosts have difficulty getting motor insurance when they mention having a guest with a disability.

Respondents were asked if they had closed down any schemes during the past five years. Two replied that they had closed the children's part of their schemes. They cited "lack of manpower and resources," and "lack of resources" as the reasons for these closures. Indeed this lack of resources is reflected in the respondents wish list (Appendix A), where respondents from 88 per cent of schemes say that they would wish for more staff, increased funding, and/or more resources.

To conclude, this survey found that there is a wide range of family-based short-break schemes throughout the country. They vary in robustness and quality depending on the amount of resources that they have managed to acquire, and hold on to, over almost 30 years, during which centre-based 'respite' services were the model of choice. Despite this 'Cinderella' role, these family-based short-break schemes cater for over 12 per cent of children and adults in receipt of short breaks (aka respite). Most of them are well placed to provide the foundation of a strong individualised and inclusive choice for service users. This opportunity needs to be nurtured by all concerned, if Irish services are to move away from congregated, centre based, and isolated settings. This opportunity needs to be realised of we are to build 'real' relationships that, not only met the support needs of people but also, help them "to find a niche within their community" (NAAPS, 2010:5).

This is an opportunity for 'real' inclusion.

Chapter 7

Recommendations

Hosts contribute beyond what they can be said to have been paid for and when a match works, it stops looking like a service and starts feeling like life.

(NAAPS, 2010:10)

The following recommendations are organised around who they are directed to, including the Government and policy makers, the NHSN, and local scheme managers. Some research areas are also highlighted.

Policy makers:

The Department of Health & Children should immediately endorse the host-family model as a viable choice for service users.

The Government should back this endorsement by releasing resources available to provide host family alternatives for people who are currently availing of centre-based 'respite. This could be achieved through the 'transformation agenda' and would demonstrate cost neutral, or better, results.

The Government should also invest in current host family schemes in order to allow staff to recruit more hosts and contract families, and to comply with best practice.

A priority should be to salvage schemes that are 'in trouble' before they and their specialist skills are lost to the system.

There is an opportunity to build on the sound practice and procedural foundation of 'robust' schemes and to expand them to meet local need.

The HSE should become more proactive in providing host family schemes. It could do this in joint ventures with established schemes run by voluntary bodies, in order to share skills and resources.

National minimum standards and corresponding regulation need to be put in place, as part of this investment

The NHSN should be consulted about the type of standards that would best support positive outcomes, based on key personalisation indicators such as inclusion, choice, flexibility, control and the formation of lasting mutual relationships.

Regulation of schemes should avoid creating institutional barriers to inclusion that contravene the vision of such an individually tailored 'normative' service.

There needs to be a national minimum standard for data collection, retention and storage, so that schemes can be benchmarked against each other and national trends measured.

The Health Research Board (HRB) should redesign the NIDD data form and procedures in order to capture the actual level of host activity in the country. Every host family should be accounted for.

There should be a National minimum standard rate of expenses for volunteer hosts equivalent to at least the current fostering allowance. These expenses should not attract tax.

There should be an enhanced payment for contract families commensurate with their additional commitment and more challenging role.

There should also be provision for reasonable and necessary house adaptations and special equipment to ensure equity and safety for more challenging guests.

The appointment of a National Co-ordinator would be useful to providing continuity across schemes and to providing administrative back-up to the NHSN.

Local managers:

It would make sense for very small services to join up with other local and/or larger schemes to share resources such as joint advertising, recruiting, training etc., in order to foster support and achieve efficiencies.

There would appear to be a need for more contact and co-operation among schemes in the east of the country, and in Dublin in particular, in order to support each other.

There is, perhaps, potential for the more efficient deployment of hosts by encouraging them to welcome more than one guest.

Hosts should be encouraged to take a sabbatical from hosting, instead of leaving for good, when changes in their circumstances compete with their willingness to continue hosting.

Schemes need to be proactive in meeting the needs of service-users from ethnic and cultural backgrounds, and also other 'hard to place' guests, such as older

children and adults with ASD, challenging behaviour and guests with complex health care needs.

Each schemes should keep a 'planning' waiting list, i.e. immediate or future service requirements (up to 5 years), and to report the people on this list to the NIDD.

It may be necessary to offer service-users and relatives incentives and practical supports to encourage them to take a more active part in the running of their local schemes, including consultation with guests.

Each scheme should have a contingency plan to address the issue of aging hosts. Regular recruitment will not only attract new hosts, but help hone skills that can be inadvertently lost when a stable and loyal pool of hosts is the mainstay of a scheme.

Schemes should review their payment criteria and ensure that they are compliant with best practice.

NHSN:

The NHSN should play a more proactive role in marketing host-family based schemes both nationally and at individual service provider level, by offering to address policy makers, local managers, and service-user groups on the proven benefits of such schemes.

The NHSN should consider providing consultative, mentoring, and coaching support to ailing schemes in order to diagnose the problem and help with finding solutions, including assisting them to obtain funding and other resources.

It may be useful to consider staging workshops on the recruitment of hosts for difficult to place guests including children from ethnic and cultural minorities.

The NHSN might devise a user-friendly survey format which could be used to track national trends and, possibly, key performance indictors.

Perhaps the NHSN might explore the possibility of designing a practical database and recommend it to members as the standard. This should be done in consultation with the NIDD.

The NHSN should instigate a balanced and informed national exploration of the most suitable form of assessment for volunteer and contract individuals, couples, and families, including those who participate in part time or full-time home sharing. The product should be to recommend a nationally approved format that best meets the needs of the guests, having regard to outcomes and safety.

The NHSN should broaden its appeal to all stakeholders and aim to reflect this in its national structure, and representative committees.

Research:

It would be useful to study the under-representation of non-'White Irish' children in schemes, in order to establish whether this is related to resource or system failure, including the need to provide choice for culturally acceptable short breaks.

There is a need to study the pattern and outcome of unsolicited enquiries from possible hosts, in order to maximise the potential of this incidental source of quality hosts.

This study should be repeated when a system has been put in place to account for every active host in the country, and within five years, whichever comes first.

Appendices

Appendix A

Respondents' wish list

We need more hosts;

I would wish for a steady growth of the scheme into the future;

We need an increased numbers of hosts offering Monday to Friday breaks on a regular basis;

I would like to see every service-user linked to a host family [for when they are needed];

I would love a request from management to expand the scheme;

I would wish to expand Break Away for children;

To expand our adult Break Away;

I would like it if hosts would take children more frequently;

I'd wish to be able to train more carers together at the same time, in a group;

To recruit hosts with more nursing skills in order to be able to place children with more nursing needs;

There is a need to value what the hosts do and to support them more, but this takes resources;

I would like to re-launch our scheme with emphasis on very young children, who might not benefit from residential respite;

My wish would be for a dedicated team to recruit and support host families & volunteers;

I'd wish for an increase in personnel to run scheme;

I'd wish for a protected social work position to head up our scheme;

I'd wish for a Co-ordinator for the present scheme;

I'd like extra staff. Currently a half Social Worker post to run the scheme is very restrictive;

More ring fenced staff and resources to develop scheme;

Extra manpower/staff e.g. an extra social worker and a dedicated secretarial or administrative assistant;

WE need an additional post, where social worker could focus on recruiting Break Away families;

I'd wish for an increase in staff strength. Allow a full time/part time social worker post dedicated to Break Away;

Provide a dedicated post to scheme so that one could focus on recruiting and supporting hosts.

We'd like sufficient funding to recruit contract families for children and adult services

I'd wish for more funding;

More funding;

I'd want a budget increase to perhaps look to other innovative ways to recruit hosts i.e. 'salaried carers'.

Increased funding for the service;

I'd wish for an annual budget increase to keep pace with inflation and steady growth;

Resources need to be ring fenced;

Sufficient resource;

I would like a link with the National Home Sharing Network (sic);

I'd wish for better legal backing;

A greater Dublin Area Break Away Committee of social workers for adults to develop strategy; for exchange of ideas; common recruitment drive etc.;

we are keen to link with NHSN;

I'd like to see a national co-ordinator to co-ordinate recruitment and advertising for new hosts and to elevate the profile of Home Sharing, nationally;

I want home sharing on the national agenda in terms of services for people with ID;

I'd wish for a change in agency policy to accept complex children with volunteers;

More commitment by organisation;

Its [hosting] value to be recognised by management;

Its [hosting] potential to be realised by management;

I would love a request from management to expand the scheme (in other words a challenge and some recognition);

We need better co-ordination – but this is being undertaken at present;

We need better Links to host families –but this is being undertaken;

We need better reviews of placements – but we are addressing this now;

Better co-ordination;

This scheme should be linked to our main host scheme;

We need a less bureaucratic system of assessment.

This scheme has not recruited new hosts due to lack or resources and does not offer home based respite to families (therefore no waiting list.

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