Respite/Residential Care with Host Families in Community Settings

Working Group Report

February 2012

NHSN
National Home-sharing
& Short-breaks Network

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

“I felt like a pressure cooker about to explode with the stress and pressure that was building up. Now the breaks give us a chance to breathe and think.”

“I could not see us going without it. It’s a lifeline for her and us – everyone gets a break. What would be of benefit would be more of the service.”

The above quotes are taken from a recent Science Shop Research Project, *An evaluation of St Michaels House Contract Family Short Break Scheme,* carried out by Mary Ryan, School of Applied Social Studies, University College Cork, April 2011; and *Room for One More: Contract Families Pilot Scheme 07-09* - Evaluation Report September 2009, Tony Murphy on behalf of Brothers of Charity Services, Galway & Ability West

Table of Contents

Executive Summary

Background

In June 2003, The National Home Sharing and Short Breaks Network (NHSN) was launched by the Minister of State in the Department of Health and Children. It was established with a view to service providers adopting a more collaborative approach in the areas of host family respite care and home sharing. The Network has representatives from various service provider organisations throughout the country and aims to a) promote uniformity and high standards amongst organisations throughout Ireland that offer host family services, b) promote the development of good practice in the field of host family based services both short and long term and c) assist those who offer support in their homes to people with disabilities.

In 2010 the (NHSN) made representations to the Junior Minister for Health with regard to the placement of people with disabilities in an alternative family settings for respite or shared/full time care. The Network requested, through the Minister's office, that issues of tax exemption for some host families be addressed and that common national standards be put in place.

Following these representations, a working group was established by the National Director, Integrated Services Directorate, HSE, to undertake an overview of models of respite and residential care with host families in community settings, nationally, and to determine the viability of these models of service delivery for future development for people with an intellectual disability. The working group comprised representatives from the HSE, the NHSN and the Department of Health.

Host Family Service Provision

Respite Care with a host family is where a child or adult with a disability is offered a short break/ holiday (less than 104 days per annum) with a host family in the community. It links the person to another local family or individual carer who is specifically recruited and prepared for this purpose. Family based respite is based on the conviction that children and adults with a disability have a right to enjoy the same type of experiences, life style and environment as others.

Residential Care with a host family offers short term/ long term accommodation, care and support to children or adults with a disability in a family setting. It can be part time, three or four days a week or it can be full time, seven days a week. This model provides a viable support plan for children or adults with mild, moderate, severe or profound disabilities and provides an alternative to the current traditional residential type care settings.

Overall host family service provision gives the person with a disability an opportunity to participate in the community in a socially inclusive manner and offers his or her family a break from their routine of giving continual care and a chance to enjoy their own interests and space.

Future Need

The main aim of the National Intellectual Disability Database (NIDD) is to provide a comprehensive and accurate information base for decision making in relation to the planning of specialised health and personal social services for people with intellectual disabilities.

The NIDD demonstrates that a total of 2298 individuals, who received no residential service in 2009, will have future full time residential service requirements in the period 2010 to 2014. It also shows that for the same period (2010 -2014) Residential Support Services such as Respite and Regular Part Time Care is required by 2115 individuals. This indicates a requirement to expand the host family model of service provision to meet this demand and offer choice of service to persons with a disability and their families.

Drivers for Change

As a society, the supports provided for people with disabilities are driven by the values of equality, the rights of individuals to be part of the community, to plan for their own lives and make their own choices; and to get the personal supports they need for their independence. It is well documented that respite care/ shared care is a vital part of the continuum of services for persons with a disability and their families. It helps prevent out of home placements, preserves the family unit, and supports family stability.

The time is opportune to examine this model of service provision and the basis for its current and further development such as - the legislative framework, choice, value for money, the availability of innovation funding, and the continuous lobbying made by service providers for change.

Methodology

The working group carried out a mapping exercise to determine the number of service users, the number of host families, the number of staff and the associated costs in the provision of this model of service. Policies and procedures governing placements with host families were reviewed as were the monitoring and review arrangements for such placements. A literature review was undertaken.

Main Findings

Currently there are 579 persons with disability availing of service provision in a host family setting of which 263 are children and 316 are adults. Approximately 70% of the adults are in the age range 19 to 39 years, with the majority of service users in the mild to moderate range of disability. Nationally there are 500 host families approved with the vast majority in receipt of payments / allowances.

Data returned demonstrates that this model of service provision is provided by both the statutory and non statutory service providers, but is primarily provided through the non statutory sector. This model of service provision has twelve different titles or names. Data also shows that this model is more developed in some regions than others. It further demonstrates that approximately 12% of the population of persons with intellectual disability in receipt of residential support services avail of this model of service provision. This finding is not in keeping with the statistics for this type of service provision reflected on the NIDD, as the NIDD only currently records occasional respite with host family (5.2% in 2009) and other forms are not identified e.g. part time care with a host family.

Host family payments/ allowances varied considerably from service provider to service provider. A very small number of Host Families (5%) are in receipt of a retainer fee whereby host families are provided with agreed annual payment/ allowance in addition to the approved rates of payments a tax anomaly was noted with regard to host family payments. This anomaly is proving to be an obstacle for service providers with regard to the further development and expansion of the scheme.

Due to the overall lack of robust financial data, the working group could not definitively comment on the efficiency or otherwise of this type of service model, however it was evident from a small number of service providers that host family service provision both for short term (respite) and long term (residential) could be provided in a cost effective manner.

Inconsistencies were also noted across service providers with regard to the staffing to client ratio with some organisations having a dedicated staff team to deliver the service while the majority had no additional staffing and was carried out as part of their day to day work.

While service providers had polices and procedures in place to govern this model of service, these were primarily local polices. Inconsistency was noted in the data returned from service providers with regard to the review and monitoring process for this model of service provision.

Currently this model of service provision is unregulated.

The literature review demonstrates that this model of service provision is very beneficial to the person with an intellectual disability and their family and society in general. It is in line with national and international trends towards meeting the needs of people with intellectual disability in more appropriate inclusive settings and offering greater choice and more person centred services.

Trends from the NIDD show that there is a growing need for the provision of residential and residential support services i.e. respite care, regular part time care etc

Main Recommendations

Future development

1) The HSE must plan how best to develop, implement and monitor this model of service provision within disability services.

2) The report must be considered by the working group charged with the review of respite services at two specific pilot sites committed to in the HSE service plan 2011.

3) The service must be renamed and known nationally as “Host Family Support”

Costs

1) Payments and allowances to host families must be standardised. The working group have made recommendations on payments based on the foster care allowances and are detailed in the appendices.

2) Other associated costs must be examined following the publication of the value for money report to allow for a comparative costing with the more traditional models of service provision.

3) The Department of Health must address with the Department of Finance the taxation anomalies identified in the report in order for this model to succeed and continue to further develop.

Staffing

1) The working group recommend that the staff ratio outlined in the report be reviewed on an annual basis.

2) A staff team based on 40 host families on a pro rata basis comprising:
Social Worker – 1.5 Whole Time Equivalent (WTE)
Clerical Officer - 0.5 WTE

Governance

1) Clear national / standardised policies and procedures that govern the development, implementation and monitoring of this model of service provision must be put in place.

2) Consideration must be given by the DOH with regard to the regulation of this model of service provision in the future.

3) Consideration must be given to the provision of information and training sessions on the roll out and implementation of a national approach to this host family support service.

Communication

The National Disability Unit must inform HIQA and the National Children’s office of this model of service provision.

Data Recording

The working group must link with the National Database Committee in order to ensure that an accurate account of service provision is reflected on the NIDD.

National Review of Respite Service Provision

It is timely to instigate a review of all respite services currently on offer nationally to determine if people with an intellectual disability are in receipt of respite services appropriate to their needs and in accordance with the principles of equity, accountability, quality and person centredness outlined in the National Health Strategy

1.0 Introduction

1.1 Background

The National Home-sharing & Short-breaks Network (NHSN) was launched by the Minister of State in the Department of Health and Children in June 2003. It was established with a view to agencies adopting a more collaborative approach in the areas of host family based respite care, and home-sharing. The Network has representatives from various provider organisations throughout the country and aims to a) promote uniformity and high standards amongst organisations throughout Ireland that offer host family services, b) promote the development of good practice in the field of host family based services both short and long term and c) support those who offer support in their homes to people with disabilities.

Representations were made by the NHSN to the Junior Minister for Health in 2010 with regard to the placement of people with disabilities in an alternative family situation for respite or shared/full time care. The Network requested, through the Minister's office, that issues of tax exemption for some host families be addressed and that common national standards be put in place.

Subsequently, a working group was established in late 2010 by the National Director, Integrated Services Directorate, HSE to undertake an overview of models of respite and residential care with host families in community settings, nationally, and to determine the viability of these models of service delivery for future development for people with intellectual disability. The group comprised representatives from the HSE, the National Home-sharing & Short-breaks Network and the Department of Health.

1.2 Respite Care

Families of children or adults with disabilities often require a number of services to enhance the health, well being, and quality of life of their child/adult and their family. Respite services are an important resource to families that have extra care giving demands, and are viewed as a positive support to enable parents and families to catch up with work at home and spend time with other members of the family. Respite also affords the person with a disability the opportunity to have enjoyable experiences outside the home including age appropriate activities with peers. The underlying goal of respite is to provide a positive experience for the person with a disability, the carer and other family members so that in the long term, their relationships are supported.

Inclusion Ireland (formerly known as NAMHI) defines respite care as "planned breaks for children/adults from their parents or main care giver at a time that is suitable to that family". It further endorses the idea that respite provision should be flexible and responsive to meet the identified need of the parents/care givers, but not to the extent of *de facto* becoming a residential provision because of the frequency of utilisation.

In accordance with the National Intellectual Disability Database Guidelines 2010, people requiring respite care on a more frequent basis i.e. greater than or equal to 104 days per annum, may be more appropriately recorded as requiring regular part-time residential care.

1.3 Residential Care

Residential care is provided by the HSE and contracted service providers to a person with disability where it is not possible for him or her to live with his or her family. It is provided in a variety of settings such as independent and semi-independent living, community group homes and residential centres, on a five day, seven day or shared care basis ranging from high through to low support.

1.4 Host Family Service Provision

Needs and Abilities: A Policy for the Intellectually Disabled (1990) recommended that "if an intellectually disabled person has to leave the family home either permanently or for a period of time, the substitute home should have all the characteristics of a good quality home."

1.4.1 Respite

Respite with a host family is where a child or adult with a disability is offered a short break / holiday (less than 104 days per annum) with a host family in the community. It links the person to another local family or individual carer who is specifically recruited and prepared for this purpose. Family based respite is based on the conviction that children and adults with disabilities have a right to enjoy the same types of experiences, life style and environment as others. Such breaks include day, evening, overnight or weekend visits. The host family assists and supports the service user with a variety of activities such as personal care, meals, social /leisure activities and community participation as documented in the individual's personal plan.

> "*Respite care in another family's home is a growing source of respite care. It differs from the other formal out-of-home settings in a number of ways. Most significantly, the family setting mirrors the service user's usual surroundings and offers the potential for building relationships in the community"*
>
> Merriman & Canavan (2007)

1.4.2 Residential Care

Residential care with a host family offers short-term /long term accommodation, care and support to children or adults with a disability in a family setting. It can be part time, three to four days a week, or it can be full time, seven days a week. This model of service provides a viable support plan for children or adults with mild, moderate, severe or profound disabilities and provides an alternative to the current traditional residential type care settings. It may provide the person with disability a pathway to independent or semi-independent living.

1.5 Objectives of Host Family Service Provision

According to current service providers, service provision with a host family has many objectives some of which include the following:

- To provide the person with disability accommodation in a home environment.
- To provide for socially inclusive participation in the community.
- To provide a positive and beneficial living experience for children and adults with disability.
- To offer the family of the person with disability a break from their routine of giving continual care and the opportunity for them to enjoy their own interests and space.
- To give local communities the opportunity to actively support people with disabilities and to create greater awareness of their needs and lifestyle.
- To extend the choice of inclusive community service provision.

1.6 Benefits of Host Family Service Provision

Current service providers believe that there are many benefits associated with this model of service provision for the service user, his/her family, the host family and society in general.

1.6.1 Service User

- It is individually tailored to meet the needs of the service user.
- Provides for opportunities for new experiences.
- Strengthens family relationships.
- Provides opportunities to socialise with people outside the family and creates a wider social network.
- Offers participation in a range of leisure activities within ordinary community settings.
- Helps the person with disability to integrate into everyday activities and into groups that share hobbies and interests.
- Provides for a positive experience of separation for the person with disability from the family home.

1.6.2 Parent / Primary Care Giver

- Provides an opportunity of a break from the full time care of the person with disability.
- Provides the opportunity to devote time to other family members and friends.
- Provides for additional options for care during crisis or emergencies situations.

- Enhances awareness that there are people who are willing and available to befriend, care for and support their family member.
- Enhances the development of relationships with host families and their extended family, thus providing ongoing emotional and social support for the parent or care giver.

1.6.3 Host Family

- Provides opportunity to host family to forge friendships with the service user and their family, often leading to long lasting positive relationships amongst all involved.
- Host families acquire new knowledge and skills which they may not otherwise have the opportunity to learn. These skills are continually being developed by caring for the service user and are transferred to other areas of their lives.
- Host families report benefits for themselves and their own children e.g. display more altruism, deeper understanding of disability issues. Some children of host carers have been influenced by their experience in choosing a health care profession or have become host carers themselves.

1.6.4 Society

- Encourages the development of sustainable social capital in local communities.
- Provides opportunities to develop a civil society. Not only increases awareness of intellectual disability, but promotes this awareness in a positive light.

1.7 National Intellectual Disability Database Trends

The main aim of the National Intellectual Disability Database (NIDD) is to provide a comprehensive and accurate information base for the decision making in relation to the planning of specialised health and personal social services for people with intellectual disabilities. The database informs the regional and national planning for disability services by providing information on trends in demographics, current service use and future service needs. The database is managed by the Health Research Board on behalf of the Department of Health.

1.7.1 Current levels of respite & residential care provision

The following statistics are taken from the Annual Report of the National Intellectual Disability Database Committee 2009 (Health Research Board, 2010).

Table 1 reproduced below, combines 'main' and 'secondary' residential service provision in 2009. *Main residential circumstances* refers to the place in which the individual resides most of the time while *secondary residential circumstances*, as the term suggests, refers to supplementary residential services like respite and other occasional accommodation. The table shows that 8251 individuals live either in community settings (n=3971), residential settings (n=2924), and other full time residential settings such as psychiatric hospitals, intensive placements etc. (n=1356).

The table also demonstrates that there are 5336 individuals accessing residential support services such as crisis or planned respite, part time care, shared care, etc.

The most commonly availed of residential services, outside of the original parental home, are community group homes. The year 2009 was the sixth consecutive year in which the data indicated that more full-time residents lived in homes in the community (n=3,971) than in residential centres (n=2,924). The numbers of people accommodated in community group homes have increased and in residential centres have decreased on an almost continuous basis since data collection commenced. This trend reflects a shift towards community living in the provision of residential services to people with an intellectual disability.

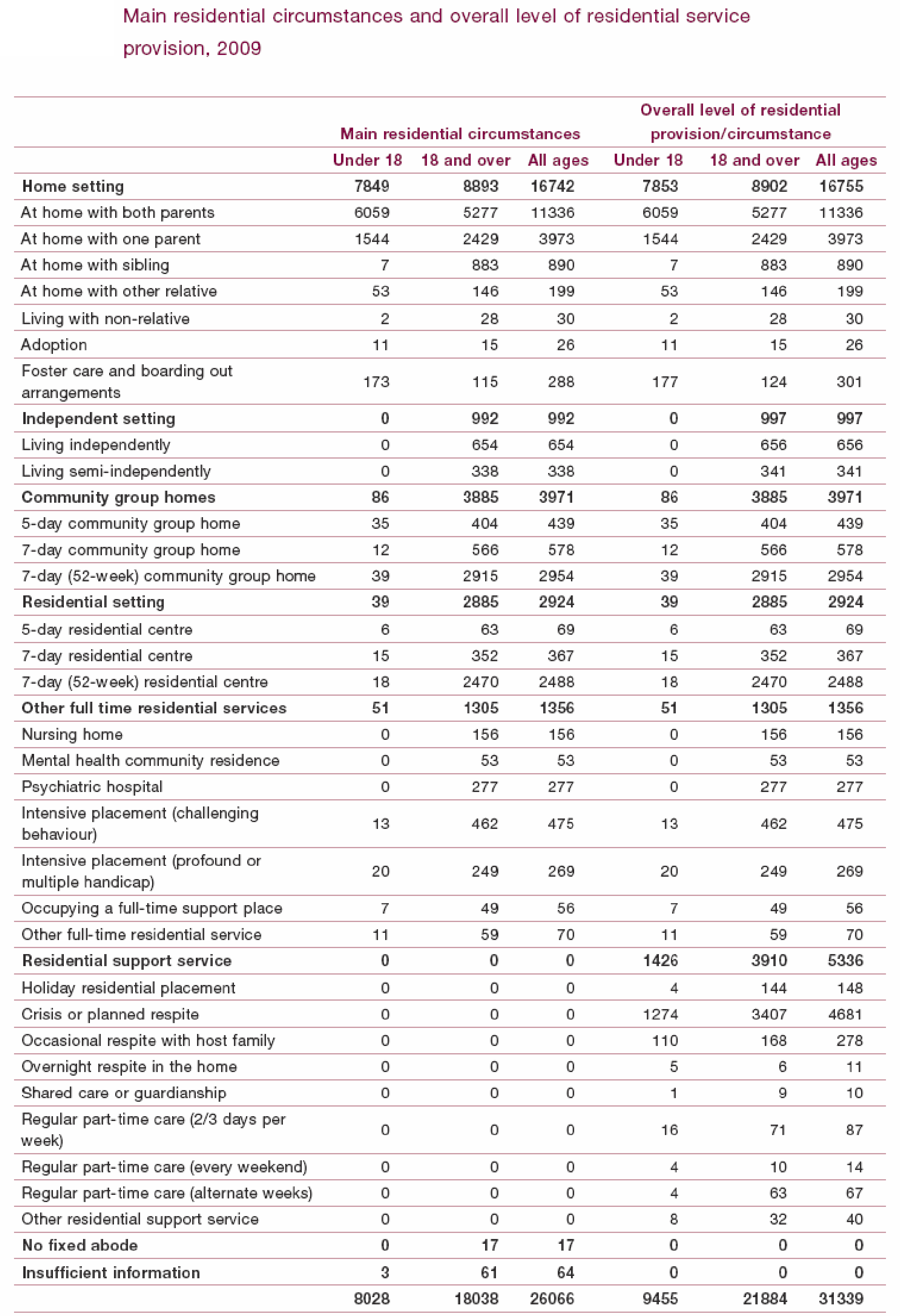
It should be noted that the table does not reflect specifically part time or full time residential care in a host family setting. However, respite with a host family is recorded on the database as *Occasional Respite with Host Family* and for 2009 is recorded as 278 service users for all ages. This equates to approximately 5.2% of all Residential Support Users.

However, data returned as part of the mapping exercise undertaken for this report in 2010/2011 showed that there are a minimum of 579 service users accessing some form of respite/shared/full time residential care in a host family setting. This would indicate that a minimum of 11% of service users accessing Residential Support Services are availing of host family service provision.

Furthermore, the NHSN, according to it’s report, *A Host of Opportunities*, (Hanrahan with NHSN, 2010) estimates that the real percentage is nearer to 12%, and probably more, as some of the people who are recorded on the NIDD as having received 'Crisis or planned respite' probably also received 'occasional respite with a host family. Results from the mapping exercise associated with this review would tend to bear out this finding.

Between 1996 and 2009 there has been significant growth in the number of residential support places available. In particular, the data show a significant increase of 437.4% (3,810) in the number of individuals who availed of centre-based respite services, either as a planned or emergency intervention, bringing the total number of people who avail of respite services in 2009 to 4,681 (Table 1).

Table 1



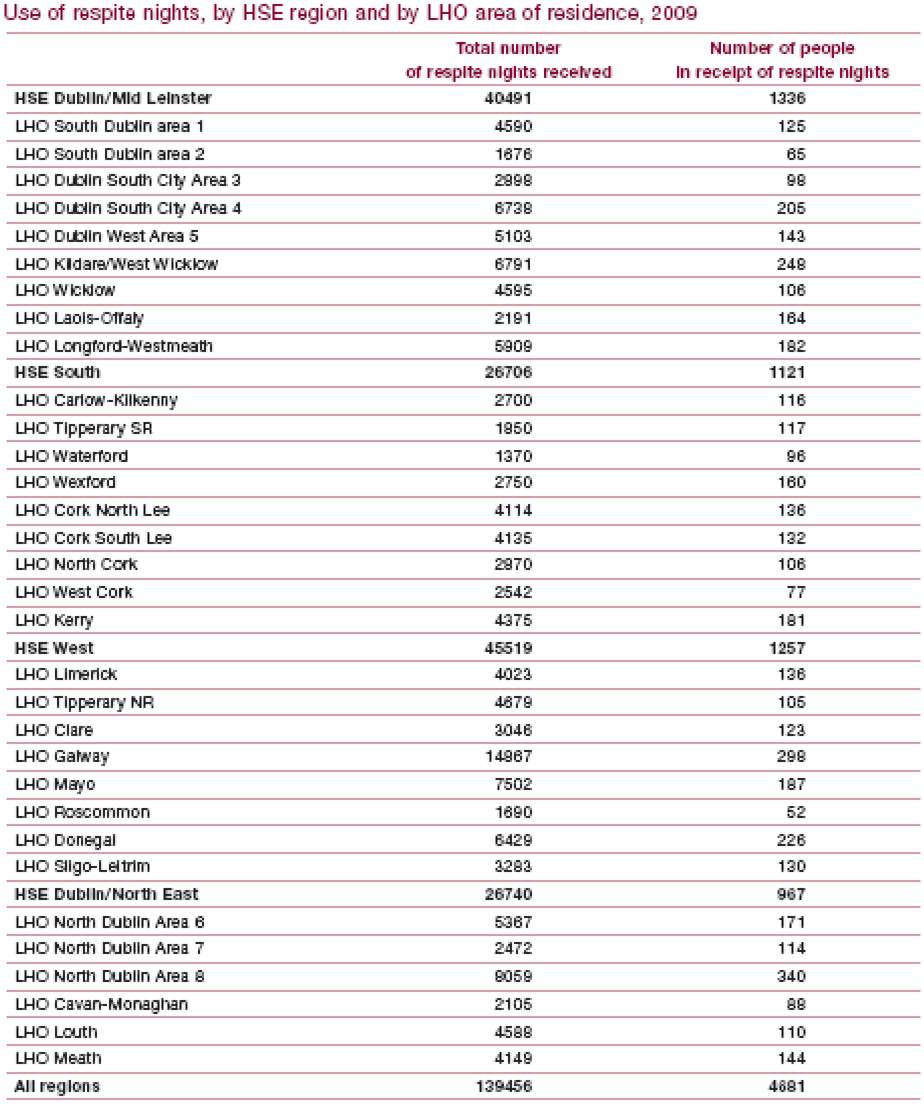
Main residential circumstances and overall level of residential service provision, 2009

	Main residential circumstances			Overall level of residential provision/circumstance		
	Under 18	18 and over	All ages	Under 18	18 and over	All ages
Home setting	**7849**	**8893**	**16742**	**7853**	**8902**	**16755**
At home with both parents	6059	5277	11336	6059	5277	11336
At home with one parent	1544	2429	3973	1544	2429	3973
At home with sibling	7	883	890	7	883	890
At home with other relative	53	146	199	53	146	199
Living with non-relative	2	28	30	2	28	30
Adoption	11	15	26	11	15	26
Foster care and boarding out arrangements	173	115	288	177	124	301
Independent setting	**0**	**992**	**992**	**0**	**997**	**997**
Living independently	0	654	654	0	656	656
Living semi-independently	0	338	338	0	341	341
Community group homes	**86**	**3885**	**3971**	**86**	**3885**	**3971**
5-day community group home	35	404	439	35	404	439
7-day community group home	12	566	578	12	566	578
7-day (52-week) community group home	39	2915	2954	39	2915	2954
Residential setting	**39**	**2885**	**2924**	**39**	**2885**	**2924**
5-day residential centre	6	63	69	6	63	69
7-day residential centre	15	352	367	15	352	367
7-day (52-week) residential centre	18	2470	2488	18	2470	2488
Other full time residential services	**51**	**1305**	**1356**	**51**	**1305**	**1356**
Nursing home	0	156	156	0	156	156
Mental health community residence	0	53	53	0	53	53
Psychiatric hospital	0	277	277	0	277	277
Intensive placement (challenging behaviour)	13	462	475	13	462	475
Intensive placement (profound or multiple handicap)	20	249	269	20	249	269
Occupying a full-time support place	7	49	56	7	49	56
Other full-time residential service	11	59	70	11	59	70
Residential support service	**0**	**0**	**0**	**1426**	**3910**	**5336**
Holiday residential placement	0	0	0	4	144	148
Crisis or planned respite	0	0	0	1274	3407	4681
Occasional respite with host family	0	0	0	110	168	278
Overnight respite in the home	0	0	0	5	6	11
Shared care or guardianship	0	0	0	1	9	10
Regular part-time care (2/3 days per week)	0	0	0	16	71	87
Regular part-time care (every weekend)	0	0	0	4	10	14
Regular part-time care (alternate weeks)	0	0	0	4	63	67
Other residential support service	0	0	0	8	32	40
No fixed abode	**0**	**17**	**17**	**0**	**0**	**0**
Insufficient information	**3**	**61**	**64**	**0**	**0**	**0**
	8028	**18038**	**26066**	**9455**	**21884**	**31339**

Note: The total number exceeds the actual number of people with an intellectual disability as a number of people availed of two residential services.

Table 2 would indicate that 4681 persons with disability received a total of 139,456 respite nights, which equates approximately to 30 nights per year for each user, an average of 2.5 nights or one weekend a month. There is no indication from the data base to show whether this level of respite meets the needs of these service users or if there is a need for additional respite for this cohort of service users.

Table 2



Use of respite nights, by HSE region and by LHO area of residence, 2009

	Total number of respite nights received	Number of people in receipt of respite nights
HSE Dublin/Mid Leinster	40491	1336
LHO South Dublin area 1	4590	125
LHO South Dublin area 2	1676	65
LHO Dublin South City Area 3	2898	98
LHO Dublin South City Area 4	6738	205
LHO Dublin West Area 5	5103	143
LHO Kildare/West Wicklow	6791	248
LHO Wicklow	4595	106
LHO Laois-Offaly	2191	164
LHO Longford-Westmeath	5909	182
HSE South	26706	1121
LHO Carlow-Kilkenny	2700	116
LHO Tipperary SR	1850	117
LHO Waterford	1370	96
LHO Wexford	2750	160
LHO Cork North Lee	4114	136
LHO Cork South Lee	4135	132
LHO North Cork	2870	106
LHO West Cork	2542	77
LHO Kerry	4375	181
HSE West	45519	1257
LHO Limerick	4023	136
LHO Tipperary NR	4679	105
LHO Clare	3046	123
LHO Galway	14867	298
LHO Mayo	7502	187
LHO Roscommon	1690	52
LHO Donegal	6429	226
LHO Sligo-Leitrim	3283	130
HSE Dublin/North East	26740	967
LHO North Dublin Area 6	5367	171
LHO North Dublin Area 7	2472	114
LHO North Dublin Area 8	8059	340
LHO Cavan-Monaghan	2105	88
LHO Louth	4588	110
LHO Meath	4149	144
All regions	139456	4681

1.7.2 Future Need 2010 - 2014

The NIDD demonstrates that a total of 2,298 individuals, who received no residential service in 2009, will have future full-time residential service requirements in the period 2010 to 2014.

Over the past seven years, the number of new residential places required has increased by 41% or 665 places. The 2009 figure of 2298 places is the highest since the database was established. Seven out of ten of those requiring a new residential place (1629 individuals) have a moderate, severe or profound intellectual disability. Trends demonstrate that this increase is due to a cohort of service users born in the 1960's and mid 70's currently moving through the services. It is envisaged that the requirement for residential services is likely to continue to increase over the coming years as this cohort advance in age.

The Database also shows that for the same period (2010 -2014) Residential Support Services, such as Respite and Regular Part Time Care, is required by 2115 individuals.

The demand for residential supports (Crisis or planned respite, regular or part time care, shared care, overnight respite in the home, occasional respite with a host family)has increased steadily since 1998. This high level of need continues to present even though there were over 5000 people availing of residential support services in 2009.

There is clearly a requirement to expand the host family model of service provision to meet this demand and to offer choice of service to persons with a disability and their families.

1.8 Drivers for Change

It is well documented that respite care is a vital part of the continuum of services for persons with disability and their families (SCIE, 2004). It helps prevent out-of-home placements, preserves the family unit, and supports family stability (Savage 2002; Robertson *et al.,* 2010).

1.8.1 Choice element

The introduction of respite and residential care with host families in community settings provides service users with an alternative model of service provision. It should ideally form part of a menu of services that would endeavour to meet the needs of individuals in the most appropriate manner and setting.

1.8.2 Value for Money

There are many challenges experienced by service providers in the provision of services to persons with a disability. In this context, it is vital that all service providers work creatively and cooperatively with the HSE to ensure that the maximum levels of services are maintained for service users within the funding resources available. Government policy and international best practice recognises that persons with a disability should and need to be at the centre of service delivery. It is imperative, therefore, that both the HSE and service providers examine, on an ongoing basis, the way in which services are currently delivered to ensure that people with disabilities are provided with the best possible respite and residential services in the most efficient, cost effective and in an inclusive manner.

1.8.3 Lobbying for Change

The NHSN was established in 2003. From its inception, it continuously lobbied and made representations to policy makers advocating for the further development of host family service provision as a proven, evidence based suitable alternative to traditional residential and respite service provision.

1.8.4 Innovation Funding for Mental Health and Disability

The announcement by the Minister for Disability and Mental Health in the 2010 Budget, of the €3m Innovation Funding for Mental Health and Disability led to a service agreement with GENIO involving the HSE and the Office for Disability and Mental Health. The allocation for the disability service was €1.5m.

Applications were invited from groups and organisations for funding to enhance individualised supports that enable people with disabilities and mental health difficulties to live meaningful lives as inclusive members of their communities.

Priority was given to applications from those who demonstrated capacity to use resources to best effect for sustainable initiatives. Five of the fifty successful grant-aided projects were from service providers proposing host family based services.

1.8.5 Legislative Framework

As a society, the supports provided for people with disabilities are driven by the values of equality, the right of individuals to be part of their community, to plan for their own lives and make their own choices, and to get the personal supports they need for their independence (UN Convention on Human Rights, 2002). These expectations for people with disabilities are underpinned by Irish legislation and policy (Disability Act, 2005 and the National Health Strategy, 2001) and our knowledge of evidence-based international best practice.

Although the Health Act (1970) first paved the way for the development, by the country's Health Boards, of a community-based approach to the provision of services to people with disabilities, it was not until the 1990's that the move towards community based living arrangements was clearly endorsed by Government policy.

A number of reports such as the Report of the Review Group on Mental Handicap Services (Needs and Abilities, 1990) made recommendations in relation to enabling independence and choice; maximising participation in society; and integrating services for people with disabilities into mainstream services, where possible.

In more recent years, the National Health Strategy 'Quality and Fairness', setting the national goals (Better Health for Everyone; Fair Access; Responsive and Appropriate Care Delivery; and High Performance) and guiding principles (Equity; People-centredness; Quality and Accountability) for the development of the health service, was launched in 2001. Three years later, the National Disability Strategy was introduced to promote equality and social inclusion for people with disability. It included the following key elements:

- Disability Act 2005
- Education for Persons with Special Educational Needs Act 2004 (EPSEN Act)
- Citizens Information Act 2006
- Six Outline Sectoral Plans
- A commitment to a Multi-annual Investment Programme for Disability Support Services

The State has, over many years, moved to ensure that people with disabilities have choices and options based on these values; most recently, the Multi-Annual Investment Plan (MAIP) provided additional funding for a five-year period (2005 – 2009). A total of 307 new respite places and 62 enhanced respite places were funded, recognising the clear evidence that providing respite is a key element in supporting families to remain in their communities and avoid admissions to residential settings.

In an international context, the Madrid Declaration (European Union, 2002) emphasised disability as a human rights issue, advocating a move towards the integration of disabled people into the mainstream rather than their unnecessary segregation in almost every sphere of life. Similarly, the UN Convention on the Rights of Persons with Disabilities added a right-based dimension to efforts to prohibit discrimination against persons with disabilities in all areas of life, with specific reference to areas such as rehabilitation, education, health and access to information, public facilities and services.

In 2006, the Committee of Ministers of the Council of Europe adopted the Council of Europe Disability Action Plan 2006-2015 to promote the rights and full participation of people with disabilities in society. The core of the Council of Europe Disability Action Plan 2006-2015 consists of fifteen action lines which set out key objectives and specific actions to be implemented by member states. The key objective of the Disability Action Plan is to serve as a practical tool to guide in developing strategies to bring about full participation of people with disabilities in society and ultimately mainstreaming disability throughout all policy areas and programmes of member states. This policy of mainstreaming is in keeping with the National Disability Strategy.

In the context of these national and international trends towards meeting the needs of people with disabilities in more appropriate inclusive settings, and offering greater choice and more person-centred services, it is timely to explore the feasibility of developing and expanding the host family model of providing both respite and residential care.

2.0 Methodology

2.1 Introduction

The National Home Sharing Network report significant benefits with regard to the host family model of service provision. The HSE and the Department of Health acknowledge this and are keen to explore the potential for its further development. All stakeholders recognise the requirements for consistency, standards, good practice, support and supervision for host families.

Following representations made by the NHSN to the Minister for Disability in 2010 and subsequent discussions by the Minister with the Assistant National Director for Disability Services in the HSE, a working group was established to examine models of respite and residential care with host families in community settings nationally. The group consisted of representatives from the NHSN, the Department of Health and the HSE.

2.2 Terms of Reference

To provide an overview of models of respite and residential care with host families in community settings nationally and to determine the viability of these models of service delivery for future development for people with intellectual disability.

Specifically the overview will include:-

a) A mapping exercise of these models to include:

   (i) The number of service users.
   (ii) The number of host families.
   (iii) The number of staff associated with operating the service.
   (iv) The breakdown of costs to include payments to host families and overall costs associated with the service.

b) The current policies and procedures governing host family placements.

c) The monitoring and review of arrangements for placements with host families.

On completion, to furnish a written report with findings and recommendations to the Assistant National Director for Disability Services.

2.3 Mapping Exercise

A questionnaire was developed to determine the location of service providers (statutory and non statutory), the number of service users and the number of host families and individuals engaged in these models of service provision nationally. It was circulated to all known service providers engaged in the provision of respite and residential care with host families in community settings. Information gleaned from this process included details of service model; profile of service users/hosts; staffing; funding; governance and the costs associated with providing the service.

The questionnaire was circulated, through the NHSN to a total of 20 service providers, 15 of which confirmed they provided home sharing services. In addition, 29 local health areas were contacted with regard to provision of this model of service; 15 areas responded, with four confirming that this model was provided in their area on a statutory basis. A supplementary form requesting additional specific financial data was sent out to all service providers who returned questionnaires.

2.4 Establishment of Sub Groups

A number of sub groups were established in order to expedite the work of the working group. These included:

- Literature Review
- Data Analysis
- Governance
- Funding

3.0 Literature Review

3.1 Introduction

Following an extensive examination of robust literature reviews and numerous individual studies, there is no doubt that families' place a high value on their need for, and use of, different forms of respite care. However, scientific evaluation of the benefits of respite care is not conclusive

Respite has been identified as a challenge for systematic reviewers, particularly regarding how best to identify appropriate evidence for inclusion.[1] While family carers are consistently positive about respite care, they use and value short breaks for different reasons.[2] This variety of need, type of breaks and range of impacts leads to difficulties with evaluation.[3] Among the many reasons cited for a failure to evaluate the benefits of respite are concern about existing research methodologies,[4] ethical issues,[5] sample sizes,[6] and the use of inappropriate outcome measures.[7]

Nonetheless the consistency with which some findings have been reported lends weight to evidence for the effectiveness of short breaks, including host-family breaks, in impacting upon particular aspects of the well-being of disabled children and their families.[8]

3.2 Emerging Themes from Literature Review

A strong theme to emerge from the literature is that respite should not be a stand alone service and should not be confined to just overnight out of home breaks. There is a growing consensus that respite, and especially traditional centre based respite, is being used to meet needs for which it was never intended; that it is being offered in lieu of

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[1] Golden, S., Mason, A., and K. Spilsbury (2008) Systematic Searches for the Effectiveness of Respite Care. *Journal of the Medical Library Association.* 2008;96(2):147-52.

[2] Savage, S (2002) *An Overview of the Literature on Sustaining Caring Relationships*. Australian Capitol Territory: Deakin University and Department of Human Services.

[3] Langer, S., Collins, M., Welch, V., Wells, E., Hatton, C., Robertson, J. and E. Emerson (2010) *Report on Themes Emerging from Qualitative Research into the Impact of Short Break Provision on Families with Disabled Children*.

[4] Chadwick, O., Beecham, J., Piroth, N., Bernard, S., and E. Taylor (2002) Respite Care for Children with Severe Intellectual Disability and their Families: Who Needs It? Who Receives It? *Child and Adolescent Mental Health* 7 (2): 66-72.

[5] Bruns, E., and J. Burchard (2000) Impact of Respite Care Services for Families With Children Experiencing Emotional and Behavioral Problems. *Children's Services: Social Policy, Research, and Practice* 3 (1): 39-61.

[6] Stalker K. (1988) Family-based Respite Care for Children with Severe Learning Difficulties: An Evaluation of the Lothian Scheme. *Social Services Research* 1 :1-10.

[7] McNally, S., Ben-Shlomo, Y., and S. Newman (1999) The Effects of Respite Care on Informal Carers' Well-being: A Systematic Review. *Disability and Rehabilitation* 21 (1): 1-14.

[8] Robertson, J., Hatton, C., Emerson, E., Wells, E., Collins, M., Langer, S., and V. Welch (2010) *The Impact of Short Break Provision on Disabled Children and Families: An International Literature Review*. Lancaster: Centre for Disability Research.

social support, educational programmes, technological innovations,[9] domiciliary support,[10] and in the absence of available long term accommodation, especially when families have past breaking point.[11]. There is strong evidence for the importance of providing short breaks that include greater community participation and more socially inclusive activities as part of a menu of service provision to families.

Another theme that emerges is that insensitive, inflexible, and bureaucratic access to respite services can cause more problems for stakeholders that it purports to ameliorate. Carer stress may actually increase causing users to value supports with a low administrative burden.[12]

There is also evidence that, while carers benefit from the use of short breaks services, this can be accompanied by feelings of guilt,[13] loss,[14] and concerns about safety.[15] Nevertheless, out-of-home respite is especially favoured by parents of older and adult children.[16] Children themselves especially enjoy breaks with host family carers and holiday schemes, but a minority have had unhappy experiences of residential short breaks including acute homesickness.[17] It is often the same for adults.[18]

A recently published evidence based guide to good practice in innovative services for children with complex health care needs and their families,[19] these children were found to not always want to have breaks without their families and be away from home. However while their parents preferred home-based care, some found that this does not give them a complete break. In such circumstances, specialist minders such as hosts were preferred to traditional type services as "children and their families want to avoid feeling like they are going into hospital.[20]

Host family services have responded to the challenges referred to above "by increasing the diversity of services on offer, with less reliance on the traditional overnight placement [where it is not necessary]; increasing the use of contract carers –initially for children

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[9] Savage, S (2002) *An Overview of the Literature on Sustaining Caring Relationships*. Australian Capitol Territory: Deakin University and Department of Human Services.

[10] Tarleton B. Macaulay F. (2002) *Better for the Break?* Barnardos. Basildon, Essex.

[11] Cotterill, L., Hayes, L., Flynn, M., and P. Sloper (1997) 'Reviewing Respite Services: Some Lessons from the Literature', *Disability and Society,* 12 (5): 775-778.

[12] Matthiessen, B., Avdagovska, M., Mardhani-Bayne, L., and A. Price (2009) *Respite Care Demonstration Project. Final Report: Summary of The Findings,* Alberta Disabilities Forum.

[13] Hartrey, L. Wells J. (2003) The Meaning of Respite Care to Mothers of Children with Learning Disabilities: Two Irish Case Studies. *Journal of Psychiatric and Mental Health Nursing* 10: 335-342.

[14] Stalker K. (1988) Family-based Respite Care for Children with Severe Learning Difficulties: An Evaluation of the Lothian Scheme. *Social Services Research* 1 :1-10.

[15] Duff G. (1992) Respite Choice. *Nursing Times* 88 (33): 65-66.

[16] Matthiessen, B et al - ibid

[17] Oswin M. (1984) *They keep going away: a critical study of short-term residential care services for children with learning difficulties*, King's Fund, London.

[18] Flynn, M., P. Willoughby, P. Eley, and R. Tizard (1996) 'Reviewing Respite Services for Adults with Learning Disabilities "I think parents should go to respite and stay there for a few days"', *Learning Disability Review*, 1 (2): 9-12.

[19] Staley, K (2008) *SCIE Guide 25: Having a Break: Good Practice in Short Breaks for Families with Children who have Complex Health Needs and Disabilities*. London: Social Care Institute for Excellence.

[20] Ibid

with complex health /moving and handling needs, and more recently for children on the autistic spectrum; providing innovative services to meet the more age appropriate needs of older children; focusing work on the barriers to finding placements for children from [minority] families and addressing the risks, training, and support required."[21] In particular, the inclusion of autism awareness training for host families has addressed the tendency for these placements to break down.[22]

In studies where traditional residential respite has been compared with host family alternatives, positive outcomes and preference for the latter seems to always prevail[23] with high levels of parental satisfaction.[24]

In Britain "the Social Services Inspectorate claims that they are "almost universally regarded by parents as a critical service in supporting families within their community."[25] While these parents' value qualifications and training held by short breaks carers, the most important factor for them is that a relationship of trust exists between parent and carer and that the carer can establish a rapport with the child or adult. "When a match works, it stops looking like a service and starts feeling like life." [26]

This emphasis on relationship and the accompanying social support offered to the family by hosts is a finding that emerges from the many Irish studies. An unforeseen outcome is the *real* inclusion of the guest in the extended family and local community network of the host family,[27] which also accounts for some 'word-of mouth' recruitment.[28] Indeed one of Merriman and Canavan's eight principles of 'best practice' states "that respite be designed to facilitate the service user in building relationships in the community."[29] Despite these 'inclusive' benefits, many families that are used to segregated respite are nervous about trying a family based service, and require lots of reassuring preparation and careful matching before they accept such a placement, especially when they are fearful of the risk of mistreatment of their family member,[30] where nursing care is required or where their relatives have challenging behaviours.[31]

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[21] TDC (2009) *Transforming Short break Services –an Introduction for Local Areas. Birmingham:* Together for Disabled Children.

[22] Preece, D. (2009) Effective Short Breaks Services for Families with Children with Autism Spectrum Disorders: How One Local Authority in the United Kingdom is Working to Meet the Challenge. *Practice: Social Work in Action*, 21(3): 160-174.

[23] Oswin M. (1984) *They keep going away: a critical study of short-term residential care services for children with learning difficulties*, King's Fund, London.

[24] Department of Health (2002) *Quality Protects Research Briefings: 6. Meeting the Needs of Disabled Children*. York: Research Unit, University of York.

[25] DoH SSI quoted in Shared Care Network (2007) *Still Waiting? Families of Disabled Children in the UK Waiting for Short Break Services*. Bristol: Shared Care Network.

[26] NAAPS (2010) *Cuts or Putting People First? Having a Life as well as Making a Saving.* Liverpool: NAAPS UK Ltd. www.naaps.org.uk

[27] Walsh, J. (1983) *Break Away -A Study of Short-term mily Care for Children with Mental Handicap.* Dublin: Break Away.

[28] Merriman, B. (2009) *The Joy of Anticipation: National and International Perspectives on Enhancing Home Sharing*, Dublin: HSE

[29] Merriman, B. and J. Canavan (2007) *Towards Best Practice in the Provision of Respite Services for People with Intellectual Disabilities and Autism*. Galway: Child and Family Research Centre, UCG.

[30] Cousins, J. (2009) Disability: Still Taboo in Family Placement? *Adoption & Fostering,* 33(2): 54-65.

[31] Walsh, ibid

Host family services for children who require moving and handling, or who have invasive clinical needs, are much better developed than those for children with challenging behaviours.[32] For many children in this latter group, and older teenagers with ASD, residential short break services have been their only option.[33] With creative approaches, the transformation of short break services should change the situation, aided by the dissemination of good practice, such as that described by David Preece.[34] One such approach is the use of paid contract or salaried families.[35]

A report of a two year evaluation of a contract family scheme for 38 children and adults with the "highest needs" within two organisations in Galway[36] concluded that the roll out of this model has the potential to be "more cost effective" than traditional respite, to provide "greater choice" to participants and to provide "greater synergies" among legislation, Government strategy, service delivery and personal needs[37]. In addition to demonstrating the "efficacy and cost effectiveness" of the scheme it stressed the benefits of "this model of service" to all the recipients and found that it "significantly enhanced the quality of life of service users (p65).[38] Murphy recommended that a "thorough cost benefit analysis" be prepared in order to inform the "strategic mainstreaming" of this model of care.

Other research examining the use of salaried carers to address carer recruitment problems found benefits including improved stability of placements, a greater level of commitment by carers and a more experienced pool of carers.[39] In the UK "local areas have tended to see contract families as a better investment for the provision of equipment, adaptations, transport and training in comparison to carers who offer a placement to one or two children."[40] They are the fastest growing providers of short breaks in the UK[41] and are making significant inroads here in Ireland.[42]

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[32] SCIE (2004) *SCIE Research briefing 5: Short Breaks (respite care) for Children with Learning Disabilities*. Published April 2004 and updated April 2005. London: Social Care Institute of Excellence.

[33] Tarleton B. Macaulay F. (2002) *Better for the Break?* Barnardos. Basildon, Essex.

[34] Preece, D. (2009) Ibid

[35] Heslop P. Byford S. Weatherley H. (2003) *Better Rewards: The Costs and Effectiveness of Employing Salaried Support Carers to Reduce Waiting Lists for Short-term Care.* Shared Care Network. Bristol.

[36] Murphy, T. (2010) *Room for one More. Contract Families Pilot Scheme 07-09*: Galway: Brothers of Charity Services Galway and AbilityWest.

[37] *Ibid*

[38] *Ibid*

[39] *Ibid* - Heslop P. Byford S. Weatherley H. (2003)

[40] TDC (2009) *Transforming Short break Services –an Introduction for Local Areas. Birmingham:* Together for Disabled Children.

[41] Cramer, H., and J. Carlin (2007) 'Family-Based Short Breaks for Disabled Children: Results from the Fourth National Survey' *British Journal of Social Work,* Advanced Access published February 7, 2007.

[42] Hanrahan, D. (2006a) 'From Volunteer to Professional Respite: An Emerging Trend in Short-break Services', *Frontline of Learning Disability.* Issue 68: 29-30.

3.3 Conclusion

In summary, host family services have been found to be most beneficial for all the stakeholders especially the adults and children who use them. They are certainly suitable for the vast majority of people who currently use traditional congregated settings, and who need out of home placements, other than play schemes, summer camps, etc. However, they should be provided as part of a menu of support services and only then after 'careful assessment of individual needs.'[43]

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[43] Savage, S (2002) *An Overview of the Literature on Sustaining Caring Relationships*. Australian Capitol Territory: Deakin University and Department of Human Services.

4.0 Analysis of Mapping Exercise

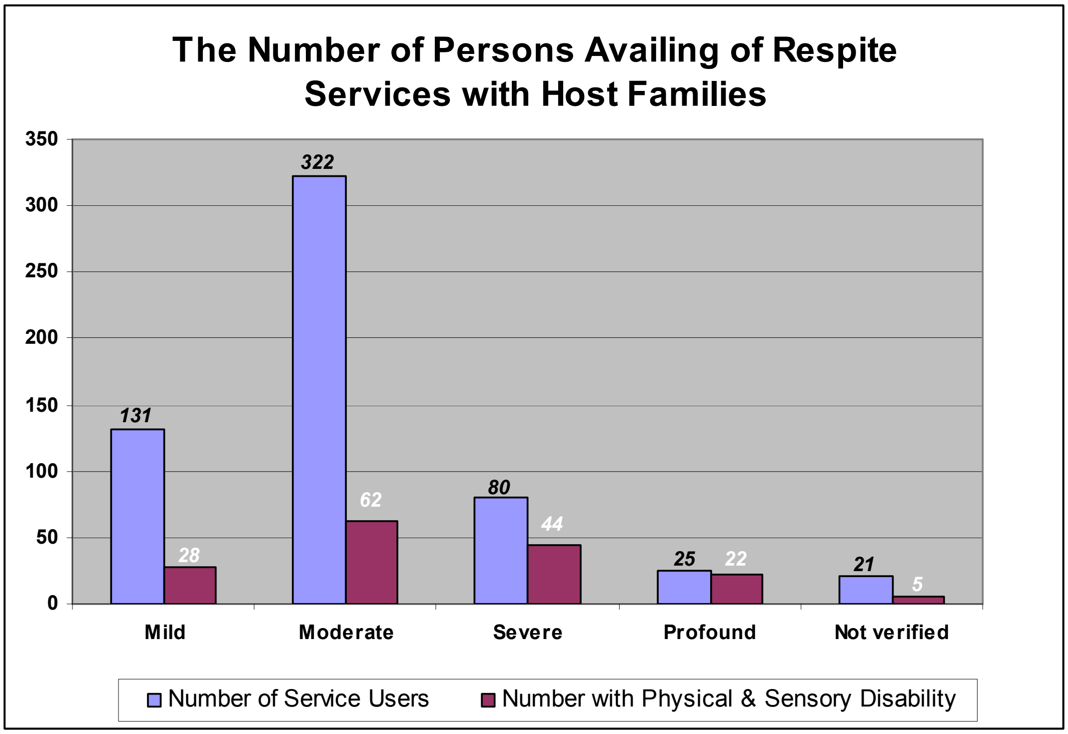
4.1 Demographics

The sub-group identified both respite and residential care with host families in community settings in nineteen (19) locations nationally. In fifteen (15) locations this type of service model was provided by the non-statutory service providers and in the remaining four (4) it was directly provided by the HSE. A list of service providers and locations is contained in Appendix IV.

The majority of services, both statutory and non-statutory are based in HSE West (with n=nine returns, five of which are non-statutory). Dublin Mid-Leinster returned five services, all from non-statutory providers, while Dublin North East returned three services, two non-statutory providers and one statutory. There were also two returns from HSE South Region, all non-statutory providers.

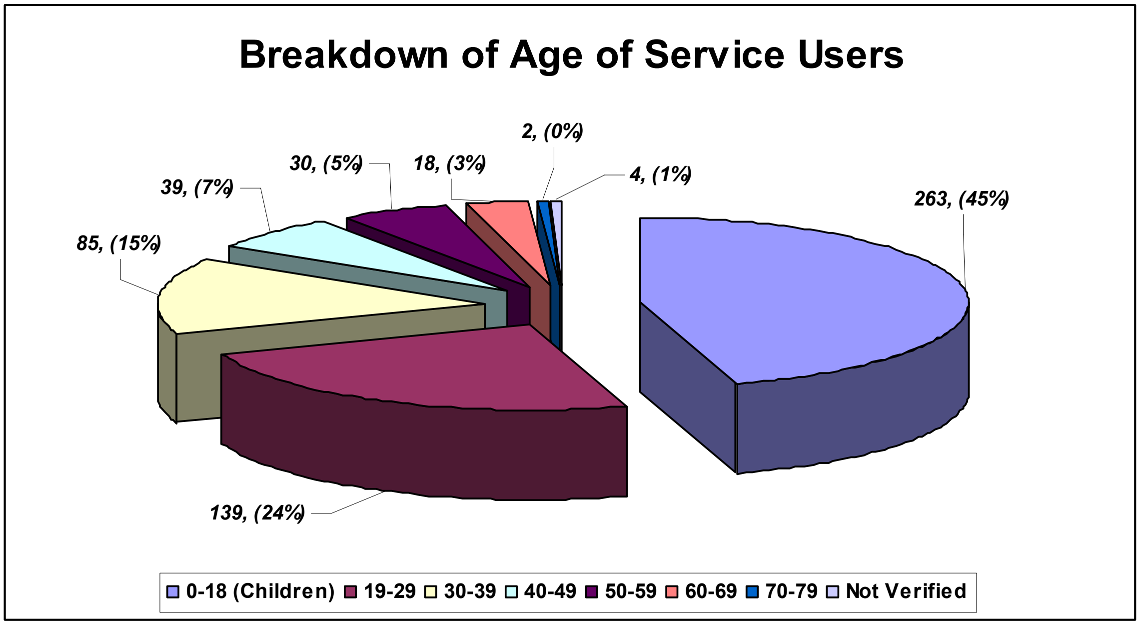
4.2 Service User/Host Family

Questionnaires identified that there are a total of 579 persons with disability availing of both residential and respite services in a host family setting of which 263 are children and 316 are adults. A significant number of adults are in part-time or full-time residential care with the host family.



The majority of service users are in the mild to moderate category (almost 71% children and 84% adults). In addition, 37% of children and 20% of adults also have a physical & sensory disability. As expected, these percentages of those with additional needs rise significantly in the severe to profound range of disability.

Over 70% of adult service users are in the age range 19-39 years, which clearly indicates that there is a future for this model of service provision as these people continue to age.



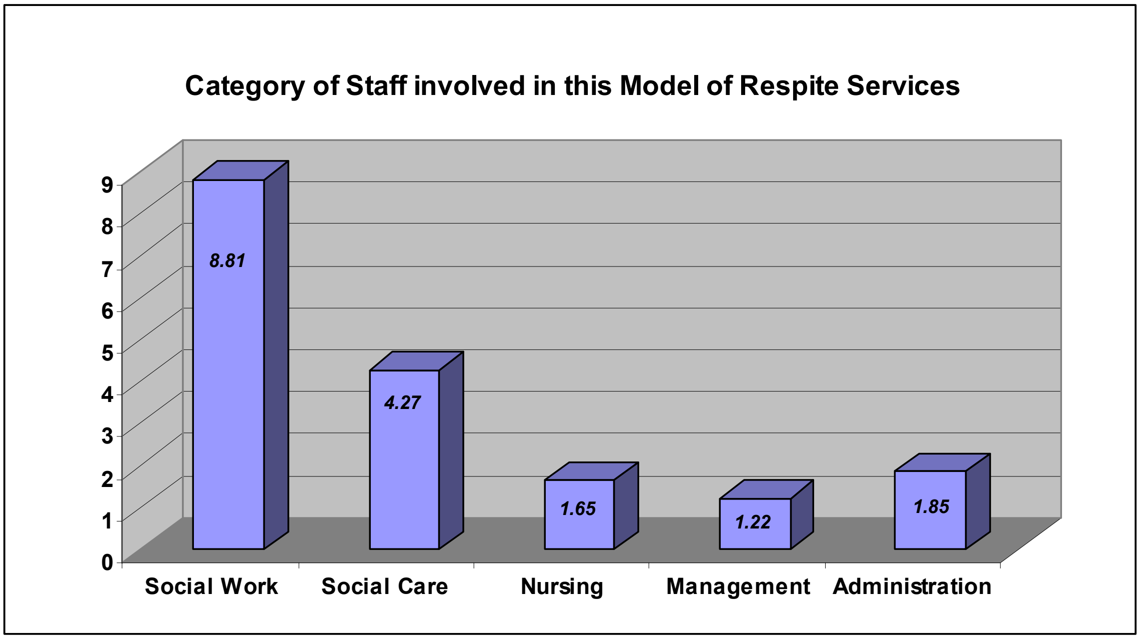
Details were provided on almost 500 approved host families. The vast majority of these are in receipt of a payment/allowance with a very small minority operating in a voluntary capacity. A growing but still relatively small number (23) 5% of hosts received a retainer fee. The maximum number of service users per host family varied from one service user per host, to a high of four per host (mean =2.8) at any given time.

Details supplied by some of the respondents suggested that an additional 231 children and 158 adults would benefit from this model of service provision if it were developed further and adequately funded, which indicates that there is a real requirement for this model of service to be further developed.

In addition, it is estimated that approximately 25% - 30% of children in foster care have a mild to severe learning disability. Given that there are around 5,000 children in foster care nationally and that 300 exit every year as adults at 18 years of age, this would indicate that as many as 70 young adults with disabilities will either remain in their foster families or require residential services from the HSE. Historically there has been a tradition for a number of children with a disability exiting foster care to remain with the foster family. However, it must be noted that these placements are not governed by the foster care regulations and are in effect unregulated. All of this would indicate a need for the further development of this model of service provision in the future.

4.3 Staffing

The completed returns show a total of 17.8 Whole Time Equivalent's (WTE), roughly one WTE per 33 service users. Over 50% of staff (9 WTE) are in the social work field, 12% (2 WTE) provide clerical support, while a further 25% (4.27 WTE) are in the social care/home support field. In addition, four of the respondents indicated an involvement at CNM II grade in service provision, totalling 1.65 WTE.



Analysis showed that the staffing to client ratio was inconsistent across the services. For example, one service provider provides services in a host family setting to 93 clients with a staff compliment of 0.8 WTE; whereas another service provider has 30 clients with a staff compliment of 1.25 WTE.

4.4 Description of Service Model

Most of the respondents who replied to the mapping exercise provided a description of their service model. Although there were twelve different titles/names for the service ranging from Room to Share Schemes to Fáilte Short Breaks and from Home Sharing Services to Adult Family Placement Schemes, the majority of respondents described similar models of service provision.

During their stay with the host family, the child or adult is fully involved in all aspects of family life. The main emphasis is on a home away from home, and the service users are encouraged to participate in everyday family activities, such as shopping, going for walks or to the cinema, football matches, etc. It is also an opportunity for the child or adult to meet new people. Host families are encouraged to introduce the service user to their extended family and friends.

Most services have flexible arrangements, with children and adults going to host families for day, overnight or weekend breaks. One respondent to the mapping exercise outlined how a number of service users continued to avail of weekend breaks with their host families even though the scheme was no longer in operation.

Host families are expected to attend to a child's daily care needs, including hygiene, nutrition, and medical needs. Host families are expected to assist adult service users with the taking of medications and the keeping of medical and other appointments that coincide with their visit.

Most persons with disability live at home with their own family; however, some adults living in residential settings, mainly group homes avail of the service also. They may have no family contact and the host family will act as a substitute. This often facilitates some group homes in closing for long weekends around holiday periods such as Christmas and Easter.

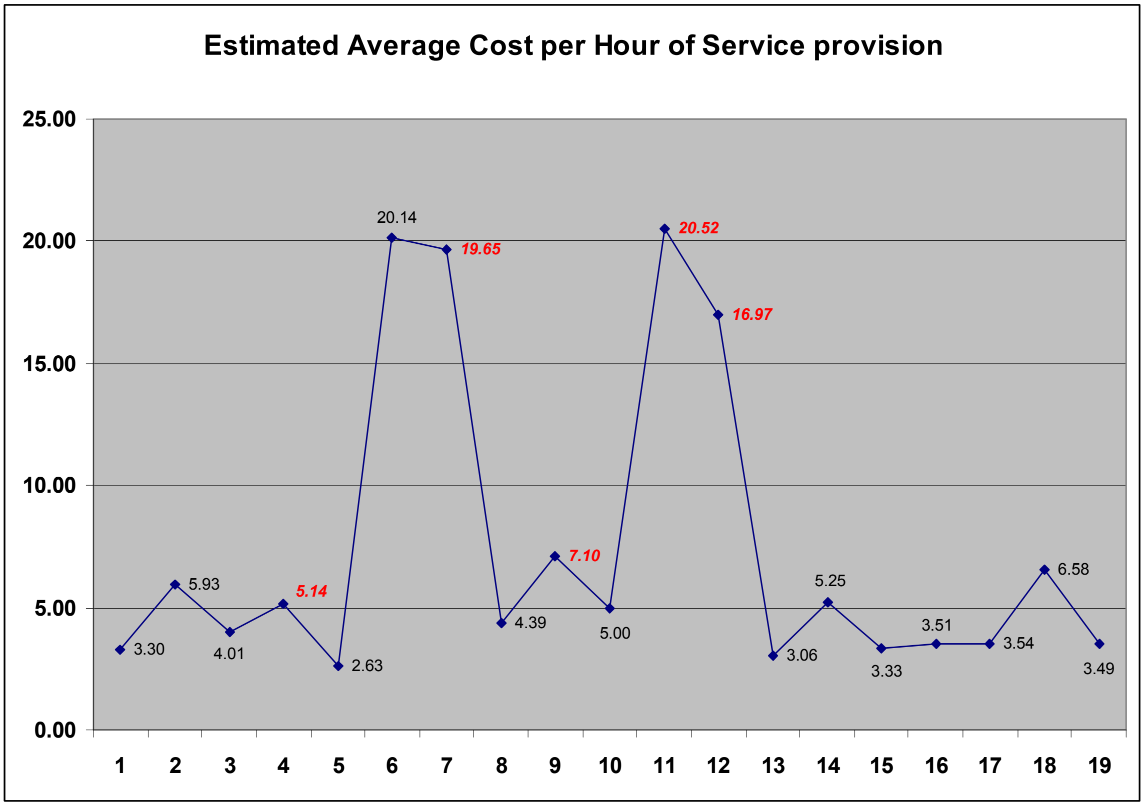
In services for adults, host families are required to provide opportunities and space for privacy, including a separate bedroom. In services for children, the sleeping arrangements will depend on each individual child's needs, although some outlined that many children were happy to share a bedroom with another child as this is often the only time they will be invited to a sleepover.

In the residential model of service provision, service users are provided with more long term, permanent care in a host family setting, with many placed in the same families for up to eighteen years. Service users would normally attend a day service whilst with the host family and would have individual goals, which are reached within their home sharing arrangements.

Respondents identified a number of positive outcomes for all stakeholders of this kind of model of respite and residential care with host families, aside from its flexibility. The service user's family is provided with much needed respite, while the service user is provided with a family situation where they can work on social skills or developmental goals within a family setting. The host family is also provided with an opportunity to share their home, their friends and their time with a person with an intellectual disability.

4.5 Cost of Service

The average payment to host families for day session (approximately 5-8 hours) was €36 (this varied from €20 to €60). The average payment for overnight session (roughly 24 hours) was €61 (ranged from €39 to €120). The average payment for weekend session (approx. 48 hours) was €110 (ranged from €65 to €170). A retainer was also paid in a limited number of locations, ranging from €1,200 to €10,000 per year.



The above graph is an estimated average cost per hour of service provision for each of the 19 service locations that submitted completed questionnaires. There was considerable variation in the amount of detail provided in this section. Some organisations did not include WTE costs or organisational costs in the overall running costs of the service. In fact, it was difficult to ascertain in some returns whether this information was included or not. Staffing costs were estimated where applicable and added to overall costs. This was necessary in order to get some comparative figures around overall costs and hourly rates. There were significant discrepancies in organisational costs, where this information was provided, but in many cases this was omitted. In many returns additional costs, e.g. non-pay was not specified. Given that there were no separate figures for the number of children or adults receiving respite service as against residential services, it was difficult to ascertain actual costs for each service.

The above concerns were identified in an initial analysis of returned questionnaires and an attempt was made to elicit more robust financial data from service providers through a supplementary one page form requesting additional specific information. However, only two providers responded to this request.

Therefore, it was not possible, due to the wide variation in the cost data provided, to accurately ascertain the overall running cost of this service in Ireland; nor to provide an exact account of its overall cost effectiveness, in an Irish context.

However, there were a small number of providers that returned data robust enough to be analysed. These are referenced in the above graph in red font. With regard to respite service provision, the cost per hour ranged from just over €5 to €7 in two of the service providers to approximately €20 in three of the service providers. It was noted that service with the least number of clients had the higher costs. It is also worth noting that in most cases the amount of respite hours provided per month per client was limited. One could assume from the data collated with regard to two specific locations that this model of respite service provision has the potential to be developed in a cost effective manner.

In relation to the cost of residential care with a host family there were indications that this is a cost effective service. For example, for one service provider who had services in a number of locations, the cost of maintaining 20 clients in full time care averaged €8,500 per client per year or €175,000 in total. This represents payments to host carers only and does not reflect other costs associated with the service e.g. staffing, organisational, etc. In another area, the full cost of full-time care for adults in a host family setting averaged at €29,000 per service user. This costing is inclusive of all costs. In both these areas a contribution of €80-€90 was paid by the client from their Disability Allowance. These costings compare favourably with the national agreed cost of a residential placement standing at approximately €80,000 per service user per year in 2010.

In summary, with regard to the costs of service provision in a host family setting, it would appear that in some services, respite and residential care can be provided in a cost effective manner. However, due to the overall lack of robust financial data, this group cannot definitively comment on the efficiency or otherwise of this type of service model. It is envisaged that more accurate costs may be established following the VFM review and the current review of respite service provision in HSE West.

4.6 Funding of Service

The majority of services were fully funded by the HSE with several partially funded by the HSE and through donations, fundraising, and grants from the National Lottery. There were no grants or funding from other Government sources.

Two service providers asked service users to make a contribution of €12.50 towards the cost of respite services in Host Families while service users accessing full time residential care with Host Families were requested to contribute between €80 and €90 a week from their disability allowance to the Host family.

4.7 Governance

Respondents were asked to provide a comprehensive list of current policies/procedures/protocols governing service arrangements with host families. A total of 15 out of 19 returns provided information in this area. All respondents who completed this section said they had Information Packs or booklets for prospective host carers providing details on recruitment procedures and eligibility criteria and referrals procedures. These packs would also contain application forms and guidelines for completing forms.

Some respondents who completed this section also stated that they had put in place standardised assessment procedures involving home visits by Social Worker or Clinical Nurse Manager II, Garda vetting guidelines (on all adults in household), HSE checks with Public Health Nursing, Social Work Departments, Fostering, Child Protection, etc: Reference Request Forms and Medical Reference Guidelines; and Health & Safety checks on the house.

The vast majority also stated they had written recruitment and induction procedures/guidelines covering training (such as Disability Awareness, Children First, Manual Handling, First Aid, Epilepsy Awareness, Behavioural Management etc) and contract agreements.

Most respondents stated they had Guideline re Insurance in place with some specifically stating that families were encouraged to have Public Liability Insurance in place as part of their Home Insurance Policy.

Many respondents said they had procedures for placing service users for the first time, approving hosts/payments to hosts/matching guests to host families and panels for approving hosts.

A few programmes had guidelines relating to infection control, such as Hepatitis B, and guidelines to deal with contact with blood/body fluids

Very few of the respondents provided specific information on guidelines for administering medication or perhaps more significantly on handling complaints or reporting allegations. However, these policies may be incorporated into their induction programme and therefore not individually listed.

Given that this section pertained to Governance, the majority of respondents did not refer to care planning / person centred planning, however members of the Network on the working group expressed the view that the majority of service users accessing host family service provision have a care plan in place.

The vast majority of respondents stated they carried out reviews with service users on an annual basis or more frequently, through both home visits and telephone communication. However, only seven service providers confirmed that their service had been internally or externally reviewed.

A number of respondents stated they had guidelines/procedures on supervising and supporting host carers.

5.0 Findings

The working group carried out a review of this type of service provision nationally. The main findings of the review are outlined as follows:

Current Service Provision

- This model of services exists throughout the country; however, it is more developed in some regions (Appendix IV).
- It is a service that is provided by both statutory and non-statutory service providers, but it is primarily provided through the non-statutory sector.
- There are twelve different titles or names in usage for the host family model of service provision.
- There are 500 approved host families nationally with the vast majority in receipt of payments/allowances while 4% operate in a voluntary capacity.
- There are currently 579 persons with intellectual disability identified from the questionnaires availing of the host family model of service provision, of which 263 are children and 316 are adults.
- Approximately 70% of the adult population availing of host family service provision are in the age range 19-39 years with the majority of service users in the mild to moderate range of disability.
- Approximately 12% of the population of person's with intellectual disability who receive residential support services avail of this model of service provision; however, this finding is not in keeping with the statistics for this type of service provision reflected on the NIDD, as the NIDD only records occasional respite with host family (5.2% in 2009) and other forms are not identified e.g. part time care with a host family etc.

Future Need

- In the majority of cases the amount of respite hours provided through host family service provision per month per client was limited. This finding is in line with figures recorded on the NIDD for service users in receipt of centre based respite services. This would indicate the need for additional respite service provision.
- Trends from national sources (NIDD) demonstrate that there is a growing need for the provision of residential and residential support services i.e. respite care, regular part time care, etc.
- Approximately 70 young adults with a disability exit foster care on an annual basis. These young adults will either remain with their 'foster carers' or require some form of residential support services from the HSE. Those young adults that remain with their 'foster carers' on reaching 18 are outside foster care system and thus in an unregulated environment.

Best Practice

- Service providers currently facilitating host family service provision believe that there are many benefits associated with this model of service. In their view it is not only beneficial to the service user and his/ her family but also to the host family and society in general.

- The literature review demonstrated that this model of service provision is very beneficial to the person with intellectual disability and their family. It provides service users with opportunities for improved quality of life and social integration into the community, a widened range of activities and increased independence. It also impacts significantly on the quality of family life by reducing stress and pressure. This finding is also in keeping with the service provider's description of the type of service being provided by host families in their respective areas.
- This model of service provision is in line with national and international trends towards meeting the needs of people with intellectual disability in more appropriate inclusive settings and offering greater choice and more person centred services. The congregated settings report just recently published recommends that all those moving from congregated settings should be provided with dispersed housing in the community where they may "*Live with their own family or opt for long term placement with another family.*"

Finance

- Payments/allowances to host families vary considerably from service provider to service provider.
- A very small number (5%) of host families receive a retainer fee, whereby host families are provided with agreed annual payment/allowance in addition to the approved rates of pay.
- It was not possible to ascertain the overall running cost of this model of service provision and establish its overall cost effectiveness as details of all costs requested were not identified by every service provider. However it was evident from a small number of service providers that this model of service provision both for respite (short term) and residential (long term) can be provided in a cost effective manner. There is also evidence from other jurisdictions that this model of service provision is cost effective.
- Host families providing this service to children and adults with intellectual disability are liable to pay tax on the host family payment. In comparison foster carers, who care for the child who may or may not have a disability are not liable for taxation on their foster care payments. In addition, foster parents who continue to care for the child with a disability on reaching eighteen years and into adulthood continue to have this tax exemption. This leads to an anomaly in the system.
- Representations to the Department of Finance have resulted in a compromise situation where the Rent a Room Scheme can be deployed. This scheme was introduced in 2001 and allows for the letting of accommodation in a person's private residence with tax exemption. The gross annual amount must be less than a prescribed threshold of €10,000. The income is exempt from PRSI, Health Levy and Income Levy. The income must be reported on an individual's annual income tax return. Exceeding the prescribed threshold makes all of the income liable to tax and the other levies. Those providing Rent a Room are not obliged to register with the Private Residential Tenancy Board.
- The preferred option of all those involved in Home sharing is that host families would enjoy the same benefits as apply to foster carers under the Child Care (Placement of Children in Foster Care) Regulations 1995. The absence of this is proving to be an obstacle to the development and expansion of the scheme.

Staffing

- Staffing levels associated with this type of service vary considerably with some organisations having a dedicated staff team to deliver the service while the majority had no additional staffing and was carried out as part of their day to day work.

Governance

- The majority of services had their own individual local policies and procedures around recruitment, induction, disability awareness, manual handling, contract agreements, etc in place.
- The review and monitoring process for this type of service in some instances was inconsistent and did not appear to be robust.

6.0 Recommendations

Future Development/Implementation

- It is a model of service that must be considered by managers within the HSE at operational level when allocating funding for the provision of services for people with intellectual disability requiring services.
- The HSE must plan how best to develop, implement and monitor this model of service provision within disability services.
- The findings of this report must be considered by the working group charged with the review of respite services at two specific pilot sites committed to in the HSE service plan 2011.
- Persons with a primary physical and sensory disability should also be considered for this model of service provision.

Data Recording

- In order to reflect an accurate account of current service provision in a host family setting on the NIDD, the Working Group must link with the National Database Committee and provide an outline of the requested amendments and the rationale for same.
- The service to be renamed and known nationally as 'Host Family Support'.
- For the purposes of recording this type of service and for office use only it is imperative that it is sub-divided into the following categories:
    - Host Family Support – Respite (n=<104 days).
    - Host Family Support – Residential regular part time care (n>=104 days).
    - Host Family Support – Residential full time care.

Finance

- Payments/allowances to host families must be standardised. The recommended payments/allowances are based on the foster care allowances and are detailed in Appendix III.
- The once off, non pay and operational costs associated with this model of service should be examined following the publication of the Value for Money Report. This may allow for a comparative costing with the more traditional models of service provision.
- The Department of Health must liaise with the Department of Finance to reach consensus on taxation anomalies identified in the report in order for this model of service provision to succeed and continue to develop.

Staffing

- A staff team based on 40 host families on a pro rata basis comprising:
    - 1.5 WTE Social Worker.
    - 0.5WTE Clerical Officer.

  This recommendation is based on the information received through the analysis, the views of the working group involved in this model of service provision and consultation with a number of individuals external to the working group with prior experience in this area. In other jurisdictions there is evidence to suggest that the staff ratio to host families is somewhat higher, therefore the working group recommend that staff host family ratio is reviewed on an annual basis.

Governance

- This model of service must have clear national policies and procedures that govern the development, implementation and monitoring of this model of service provision. See Governance Process Flow Chart (Appendix II)
- The working group should continue on the development of a National pack to assist both the statutory and non statutory service providers engaged in this model of service provision with regard to the relevant policies, guidelines, and procedures contained within the Governance Process Flow Chart.
- Consideration must be given by the Department of Health with regard to the regulation of this model of service once National policies and procedures are in place.
- Not more than two service users per host family should be placed at any one time. Any exception to this must be agreed with the appropriate management.
- Consideration must be given to the provision of information and training sessions on the roll out and implementation of a National approach to Host Family Care.

Communication

- The National Disability Unit must inform HIQA of this model of service provision as it is an extension of traditional residential and respite services.
- As a large number children access host family service provision it is imperative that the National Children's Office are made aware of this model of service and formal linkages put in place both nationally and locally if so required.

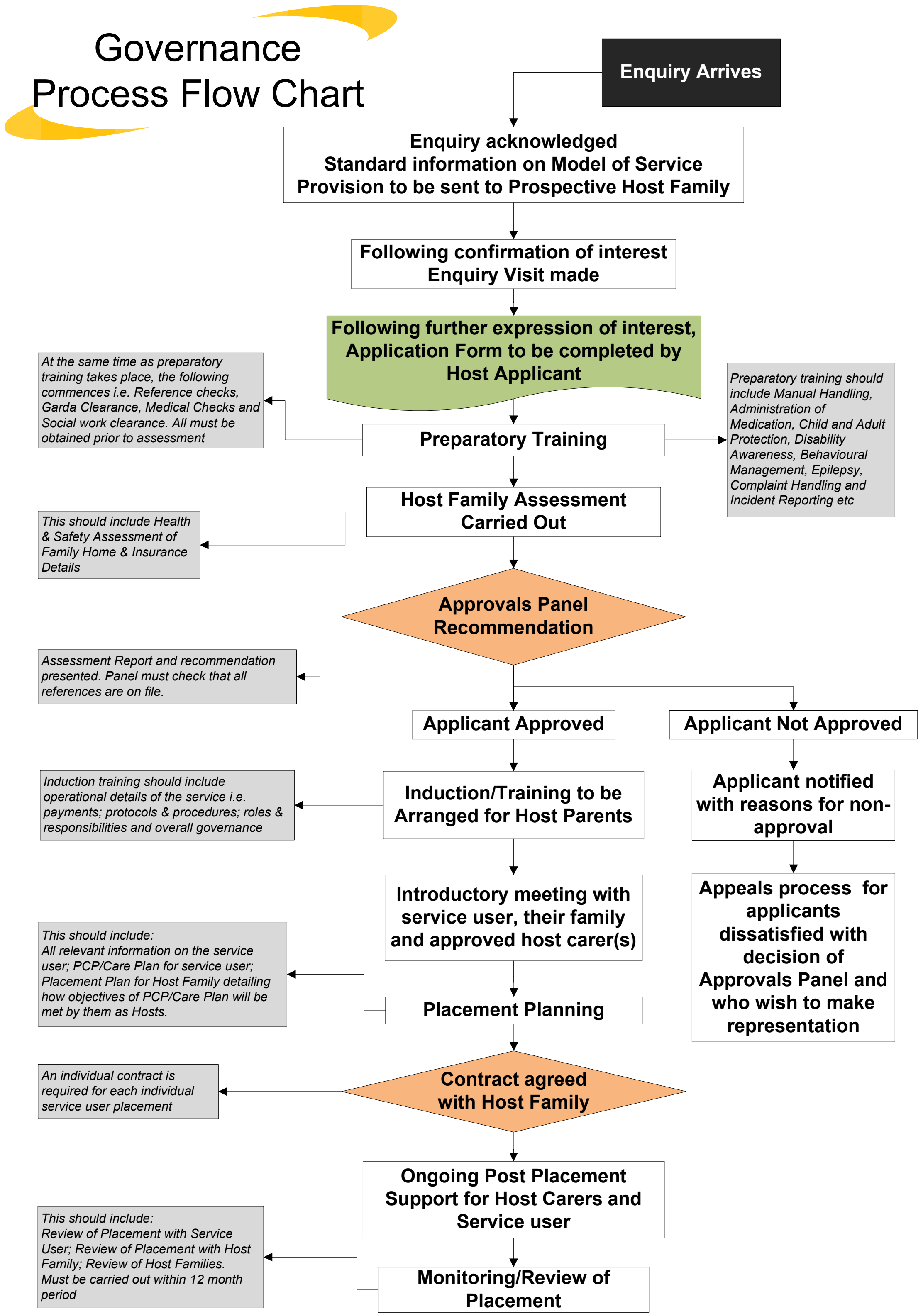
National Review of Respite Service Provision

- It may be timely to instigate a review of all respite services currently on offer nationally to determine if people with intellectual disability are in receipt of respite services appropriate to their needs and in accordance with the principles of the national health strategy of equity, accountability quality and person centeredness.

Appendix I: Membership of the Working Group

- Mr Brian Dowling, Assistant Principal, Disabilities, Department of Health, Hawkins House, Dublin
- Dr Bernie Fay, Principal Social Worker, Sisters of Charity of Jesus and Mary, 2 Valley Bungalows, Mullingar, Co Westmeath.
- Mr Donal Fitzsimons, Manager of Disability Services Midland Area, HSE, Regional Disability Services, Arden Road, Tullamore, Co Offaly.
- Mr Tim Hanley, Regional Manager of Foster Care, HSE, Raheen, Co Limerick.
- Mr Des Hanrahan, Senior Social Work Practitioner, St John of God Brother's, St Mary's, Drumcar, Co Louth.
- Ms Breda Mulvihill, (Chairperson) HSE Manager, National Disability Unit, Catherine Street, Limerick.
- Ms Sheelagh McInerney, Team Leader Family Support, Brothers of Charity, Galway.
- Ms Therese McDonnell, Principal Social Worker, St Michael's House, Dublin.
- Ms Catherine O'Sullivan, Principal Social Worker, St Vincent's, Lisnagry, Co Limerick.

Appendix II: Governance Process Flow Chart



Enquiry Arrives

Enquiry acknowledged
Standard information on Model of Service Provision to be sent to Prospective Host Family

Following confirmation of interest
Enquiry Visit made

Following further expression of interest, Application Form to be completed by Host Applicant

Preparatory Training

At the same time as preparatory training takes place, the following commences i.e. Reference checks, Garda Clearance, Medical Checks and Social work clearance. All must be obtained prior to assessment

Preparatory training should include Manual Handling, Administration of Medication, Child and Adult Protection, Disability Awareness, Behavioural Management, Epilepsy, Complaint Handling and Incident Reporting etc

Host Family Assessment Carried Out

This should include Health & Safety Assessment of Family Home & Insurance Details

Approvals Panel Recommendation

Assessment Report and recommendation presented. Panel must check that all references are on file.

Applicant Approved

Applicant Not Approved

Induction/Training to be Arranged for Host Parents

Induction training should include operational details of the service i.e. payments; protocols & procedures; roles & responsibilities and overall governance

Applicant notified with reasons for non-approval

Appeals process for applicants dissatisfied with decision of Approvals Panel and who wish to make representation

Introductory meeting with service user, their family and approved host carer(s)

Placement Planning

*This should include:
All relevant information on the service user; PCP/Care Plan for service user; Placement Plan for Host Family detailing how objectives of PCP/Care Plan will be met by them as Hosts.*

Contract agreed with Host Family

An individual contract is required for each individual service user placement

Ongoing Post Placement Support for Host Carers and Service user

Monitoring/Review of Placement

*This should include:
Review of Placement with Service User; Review of Placement with Host Family; Review of Host Families.
Must be carried out within 12 month period*

Appendix III: Recommended Payment for Host Family Care

The HSE pays a maintenance allowance of €325 - €352 per week for each child in foster care. In recommending a funding model for respite/residential care with host families in community settings, the higher foster care rate of €352 per week applies.

Plan one (Respite with Host Family)

An average day ranges from 8.00am to 8.00pm, equating to a 12 hour day. An average night ranges from 8.00pm to 8.00am, equating to 12 hours. In one week, there are 84 day hours, therefore, 84 day hours at a cost of €352 equate to €4.20 per hour.

Proposal is to charge €4.20 per hour for day hours and provide a 'sleepover' payment of €30 per night. Please note the sleepover payment is in addition to the foster care allowance.

- **Example A:** Day respite from 8.00 am to 6.00pm (10 hours) The total for example A is €42 (this compares to average day session from mapping exercise of €37).

- **Example B:** Overnight respite from 5.00pm to 10.00am next morning. This equates to three day hours @ €4.20 per hour (€12.60) and a sleepover payment of €30 and two day hours the following day @ €4.20 per hour (€8.40). The total for example B is €51 (this 17 hour session compares to average of €62 in mapping exercise for 24 hour overnight session).

- **Example C:** Weekend respite from 5.00pm Friday evening to 5.00pm Sunday evening. This equates to three hours Friday evening @ €4.20 per hour (€12.60) and 12 hours Saturday (€50.40) and nine hours Sunday (€37.80) and two sleepovers (€60). The total for example C is €160.80 (this compares to weekend session of €105 (48 hour period) in mapping exercise).

- **Example D:** Long weekend respite from 5.00pm Friday to 9.00am Monday morning. This equates to three hours Friday evening @ €4.20 per hour (€12.60)) and 12 hours Saturday (€50.40) and 12 hours Sunday (€50.40) and one hour Monday (€4.20) and three sleepovers (€90). The total for example D is €207.60.

Plan two (Residential with Host Family)

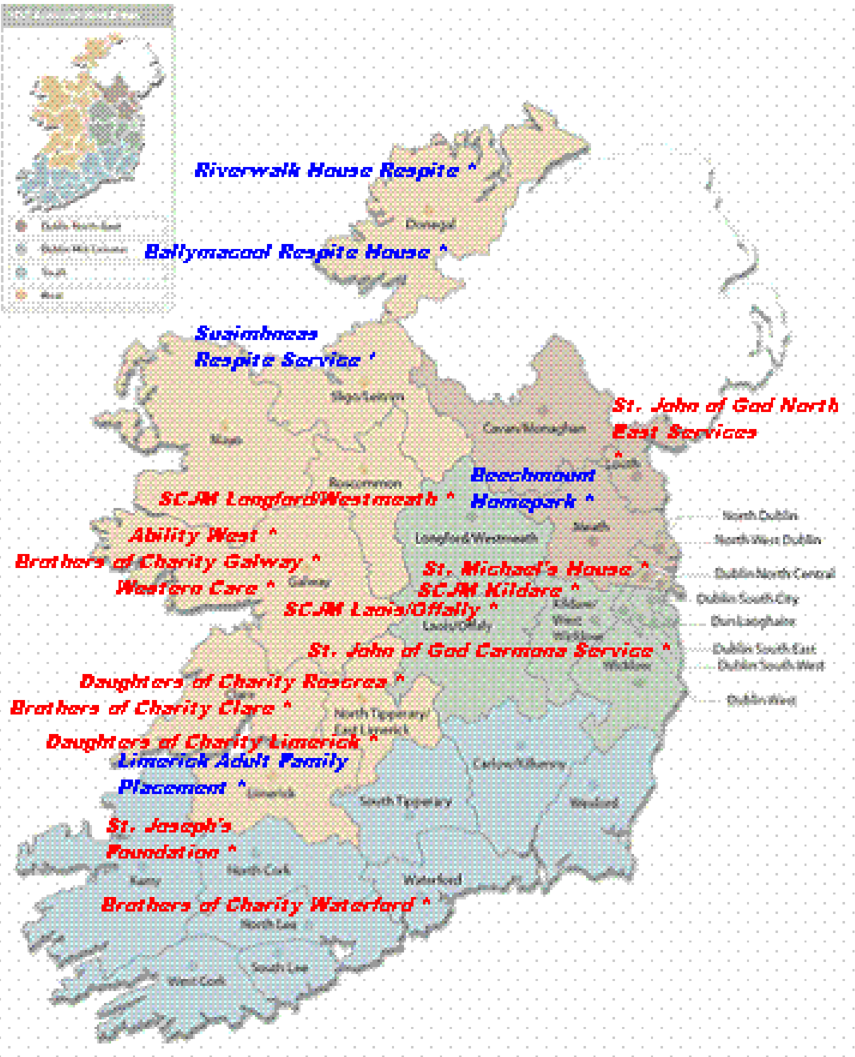
This is based on the foster payment rate of €352 per week. The proposal is predicated on service user giving a contribution of €84 per week from their Disability Allowance. This contribution is the average contribution paid by the service user. The remaining funding requirement is provided by the HSE. This equates to €268 per week. The total annual cost to the HSE is €13,936 per year. The overall payment to the host family is €18,304, comprising €13,936 from the HSE and €4,368 contribution from the service user. The recommended rates must also include any retainer fee paid to host.

The above rates are the recommended rates that should be paid to host families. If clients have high support needs, additional funding may be paid subject to the agreement of the local HSE Disability Manager and appropriate validation in relation to assessment of need.

The recommended rates must also include any retainer fee paid to host.

The payments outlined above are payments to host families only and do not include staffing, once off, non-pay or organisational costs.

Appendix IV: List of Service Providers that participated in Mapping Exercise



HSE Dublin Mid-Leinster

Sisters of Charity of Jesus & Mary (Longford/Westmeath)
Sisters of Charity of Jesus & Mary (Kildare)
St. John of Gods, Dun Laoighaire (Carmona House)
Sisters of Charity of Jesus & Mary (Laois/Offaly)
Daughters of Charity Services (Roscrea)

HSE West

Ability West
Brothers of Charity (Clare)
Western Care
Donegal (Riverwalk) (Statutory)
Limerick (Adult Family Placement) (Statutory)
Bothers of Charity (Galway)
Daughter of Charity Services (Lisnagry)
Donegal (Ballymacool) (Statutory)
Sligo (Suaimhneas) (Statutory)

HSE Dublin North East

St. Michaels House
Meath (Beechmount, Navan) (Statutory)
St. John of Gods (Dublin North East)

HSE South

Brothers of Charity (Waterford)
St. Joseph's Foundation (HSE South + West)

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