



Exploring the Experiences of Users of Disability Respite Services in Ireland

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List of abbreviations

These are listed in the order in which they appear in the report

1. NDA - National Disability Authority
2. HSE - Health Service Executive
3. ID - Intellectual Disability
4. NIDD - National Intellectual Disability Database
5. CHO - Community Health Organisations
6. NPSDD - The National Physical and Sensory Disability Database
7. MS - Multiple Sclerosis
8. ABI - Acquired Brain Injury
9. NICE - National Institute for Health and Care Excellence
10. USB - Universal Serial Bus
11. GDPR - General Data Protection Regulation
12. EU - European Union
13. HIQA - Health Information and Quality Authority

Executive Summary

Access to respite services has arisen as an issue in Ireland, due to the absence of a national policy, limited service hours available which can vary depending on where someone is living, and the impact this can have on persons with disabilities and their carers. The literature on disability respite services is largely focused on the impact it has on primary carers and family members. The experiences of persons with disabilities using respite services has been poorly explored and documented.

The NDA, therefore, has commissioned research in order to gather the views of adults with disabilities of respite provision in Ireland. There are two main elements to this research project:

- A literature review on the experience of persons with disabilities in relation to respite
- Information gathered from adults with disabilities with access to respite services around the country

This research has provided an opportunity for persons with disabilities to have their experiences of respite documented.

The literature review

The literature review looked at the available evidence between 2008 and 2018. It set out to analyse the relevant evidence, in national and international literature, in relation to user's experience of disability respite services. It became clear early on in the review that there were a limited number of papers on the views of persons with disabilities, and therefore the review was expanded to also include the views of children and adolescents, and of parents and carers. In total, 35 articles were included in the review.

The findings of the literature review highlighted the importance of respite provision as part of a community-based model of service provision and as an element on a continuum of support. The importance of person-centred supports in respite services was also noted. Many authors advocated for responsive, flexible, individualised supports that delivered positive outcomes for persons with disabilities. The value of engaging persons with disabilities and their family members in the design and development of respite services was also highlighted.

Users of disability respite services noted the positive aspects of respite to include a break for the person and/or their family leading to a reduction in the person and/or family member's stress levels, social opportunities, a chance for independence and skill development. Overall, it was felt that respite usually provided an enjoyable experience for the user with engagement in new and favoured activities.

The factors that contributed to a positive experience of respite included adequate qualified staff with the rights skills and attitudes, a pleasant physical environment, person-centred supports, and respite options with strong community connections.

The literature suggests that negative aspects of respite may include experiencing negative emotions such as anger, guilt, homesickness, and negative interactions with staff and other respite users. It was also noted that respite services may not always be sensitive to cultural and religious beliefs and may not meet the needs of diverse cultural groups.

A number of barriers and challenges were identified by adult users and parents/carers. These include a lack of access to respite services and funding, and a lack of accessible information. It was also suggested that respite services may not have the capacity to support individuals with complex needs.

Gathering information from users of disability respite services

Over 40 individuals with intellectual (some also had autism), physical, and sensory disabilities participated in this research. Information was gathered through focus groups and semi-structured interviews. Participants were users of traditional respite services (usually overnight in a respite house or centre) and/or alternative respite services (daybreak, weekend and evening groups). These were provided primarily by three large service providers. The research also included persons with disabilities for whom respite is available but who choose not to use it, and persons seeking to access respite services.

The analysis of the data focused on identifying themes and sub-themes that would allow policy and practice recommendations around respite to be developed.

The findings

The findings from this research project were broadly consistent with those of the literature review. Overall, the majority of participants were extremely positive about respite. There was no significant difference between the experiences of those using traditional or alternative models.

The positive aspects of respite

There were high levels of satisfaction with many aspects of respite services such as the comfort of bedrooms and other personal spaces, the opportunities provided for privacy, the food provided during respite visits and the general facilities in respite houses and centres.

Almost all participants reported being happy in respite with very few experiencing homesickness. Participants did not mention any negative emotions in association with respite stays but commented on their feelings and need for emotional support when respite was over. They noted a few difficulties settling back home, particularly after longer respite breaks.

Many participants talked about the importance of getting some time for themselves away from the regular pressures of life. They talked about respite being ‘good for their well-being’. A significant number of participants noted the importance of ‘peace and quiet’.

Some young adults with intellectual disabilities considered respite to be a break away from their family and a chance to be more independent. Many participants said they used respite to give their family members/carers a break, in particular, their mothers. Others noted the importance of family members having the opportunity to do regular things.

Several participants said they used respite for social reasons - for company and to build relationships. They explained that respite afforded them the opportunity to meet new people, meet old friends, or spend time with their current group of friends.

Almost all participants expressed the view that respite should be an enjoyable experience, with a strong focus on ‘fun’. The majority of participants wanted to spend their time at respite engaged in interesting and meaningful activities. Most wanted to get out and about as much as possible, in particular, participants enjoyed day trips and eating out in restaurants.

Participants emphasised that the activities on offer must be relevant, age appropriate, and delivered on an individual or small group basis. Most participants were not particularly concerned with learning new skills during respite. Many did not want to think about their personal goals, social roles, educational programmes or other things associated with their day service when at respite.

Factors that contribute to a positive experience of respite

Most participants were overwhelmingly positive about the staff that supported them at respite. Some of the language used to describe staff includes helpful, unbelievable, excellent, trustworthy, professional, obliging, lovely, fun, friendly and polite. Participants were not unduly concerned about the continuity of staffing as long as all staff were ‘good at their job’.

One of the strongest and most emotive topics to emerge during the research was that of compatible groupings for respite. Some participants had very clear views on who they would like to attend respite with and expressed a preference to go to respite with friends or persons they knew and liked. Others were open to an element of ‘surprise’ and happy to ‘get on with whoever is there’. Some individuals with intellectual disability expressed a strong preference to attend respite services with persons of the same gender. They saw respite as an opportunity for ‘girl time’ or ‘a lads day out’. One older person, using an alternative respite service, suggested that a group of women had more shared interests which made deciding what to do easier. Several participants suggested that groups of similar ages work best too.

A small number of participants expressed a preference to attend respite with persons with similar disability types and similar lived experiences. This was

particularly important to some individuals with acquired disabilities. A few participants with physical and sensory disabilities explained that they would prefer not to share respite settings with persons with intellectual disabilities. Some participants voiced their concerns about sharing respite services with persons with behaviour support needs. This arose primarily during interviews with participants with intellectual disabilities.

One factor that contributes to a positive engagement with respite services is the provision of accessible information. Participants suggested that they get most of their information face to face from managers, day service staff and other users of respite. Participants welcomed the opportunity to visit respite groups, houses and centres before taking up a place. They benefited from meeting staff and other users in advance.

The negative aspects of respite

Four participants in this study had been offered a respite place but refused to take it up as they did not want to be away from their families. One person, offered a traditional respite service, did not want to spend more time in a disability service.

Although participants were very complimentary about staff in general, a few individuals had experienced negative interactions with staff. A very small number of participants felt that staff could be rude or disrespectful at times. They disliked being told what to do by staff and disagreed with the rules of the house or service. A small number of participants expressed concerns about the levels of staffing in respite houses and centres. They believed that more staff would allow for a more person-centred approach, with increased choice and less 'group thinking'. Participants were aware that some activities required staff to work flexible hours, for example, concerts, sports events, long distance trips. Levels of flexibility varied from one centre or organisation to another.

Participants liked the rural location of some of the respite houses and centres. They did however identify the problems associated with this including accessibility and transport. Public transport was very limited in some areas and so users were reliant on transport provided by the respite centre. In some cases, there was only one bus or car available, or the wheelchair spaces were limited. In addition, not all staff were qualified or insured to drive. Participants highlighted that some centres were located a short distance from villages and towns. However, the lack of safe, accessible paths and pedestrian facilities made it impossible to get into the local community to use facilities such as the shop, church or pub.

The barriers and challenges to respite use

Respite services are limited, and participants reported waiting more than two years from the point of referral for a respite service. Some participants were transitioning to adult services and this also caused delays in respite provision.

About half of participants were happy with the frequency of the respite they received. The remainder would like an enhanced service with more sessions/visits or longer stays.

Some participants seemed resigned to the fact that they had little choice in the type of respite they received, or in the frequency of their respite service. Some had little awareness of their right to complain about a service or lack of service. Many participants using traditional respite services had little knowledge or understanding of alternative forms of respite.

Participants with intellectual disabilities reported that much of the information in relation to respite is shared initially with their family, and that much of the decision making in relation to respite lies with their family members. Some reported that letters in relation to respite are addressed/sent to their family member and not to them personally. Participants highlighted that the most useful information on respite came through discussions with keyworkers, managers and users of the service. They said they received very little accessible information on respite services.

Participants from all three participating organisations reported that they had little or no input at organisational level in relation to the design, development or provision of respite services. Very few were asked formally for their ideas when it came to respite planning. Several explained that they completed a feedback form after their respite visits. They were unsure if this information had an influence beyond the local level.

Only one group talked about advocating for a respite service. This group explained that they had written and spoken to service managers about the respite they wanted. Some were using the person-centred planning process to identify deficits in their service provision. They were supported by staff in their day service to do this.

The respite services on offer to participants were often inflexible. Most participants perceived that social workers and managers made all the decisions in relation to the models of respite on offer and the frequency available. There was a sense amongst participants that they had no influence over systems and processes within organisations.

Conclusions and recommendations

The themes which emerged from the information gathering are broadly consistent with the findings of the literature review. Participants, across ages and disability types, shared many of the experiences, concerns and opinions of the adults, adolescents and family members in previous studies. Overall, participants were very satisfied with their respite services and rated the quality highly.

A number of specific recommendations arose from the data:

- Respite services work best when person-centred. They should be flexible to accommodate individual needs and circumstances, and to support personal choices and preferences.
- Persons with disabilities need accessible information on respite services. The information provided should include respite models, local service information, service funding and allocation, policies and procedures. Information should

include face to face meetings, opportunities for visits and experiential learning, easy to read information, videos etc.

- Service providers should engage with persons with disabilities, as well as their families, in relation to respite provision. In particular, service providers should consider the importance of compatible groupings and look at ways to engage with persons using respite services on this issue.
- Persons with disabilities should have the chance to influence the design and delivery of respite services if they wish. They may need specific supports to advocate for the respite services they need and want. Some individuals have limited lived experience of respite models and services and may find it hard to understand what a different service could look like.
- Transitions between child and adult services should be easier to navigate.
- Service providers should carefully consider the accessibility of respite centres to local community facilities. They need to be mindful of the transport needs of those using the service.

In addition, there were a number of general recommendations:

- It would be helpful if approaches to respite provision could be underpinned by a national policy for respite in disability services as part of a community-based model of service provision and as an element on a continuum of support.
- Although this study found little difference between people's views of traditional versus alternative respite, there was a strong sense that many people had only ever been exposed to traditional respite and didn't know that other possibilities exist. There is room for the expansion of alternative forms of respite, preferably with the design and development of these having a strong input from service users.
- A number of new models for respite provision are emerging in Ireland that were not covered in this report. These include supported hotel stays and in-home respite. These new models have been met with mixed reactions from persons with disabilities. Further research will be required to examine the effectiveness of these models and the experiences of those using them. It will be important to ensure that hotels are built using universal design principals to increase the stock of hotels that are accessible.
- Although there were some good examples of person-centred supports in the findings, the group nature of respite services tempered the person-centred aspect somewhat. There needs to be a balance between respite services that are truly person-centred but also give people opportunities for social contact and spending time with friends.
- With the introduction of personalised budgets in Ireland, it is important to consider how respite could be funded in the future, and how funding arrangements might support the development of quality respite services.

I. Introduction

I.1. Aims of the research

The purpose of this research was to gather the views of adults with disabilities of respite provision in Ireland. Over 40 individuals with intellectual (some also had autism), physical, and sensory disabilities participated in this research project.

Information was gathered through focus groups and semi-structured interviews. The research also includes persons with disabilities for whom respite is available but who choose not to use it, and persons seeking to access respite services.

Respite is a topical issue currently, due to the limited and patchy nature of the service in Ireland (Hourigan, Fanagan & Kelly, 2018), and the sense that there are carers in crisis due to lack of access to respite. There is a lack of empirical evidence in relation to the value of respite services despite the fact that it has been offered in a number of disability services in Ireland over a long period of time, and at considerable cost.

Respite services for persons with a disability are largely seen as providing a break for the primary carer. This break allows them to recharge their batteries and ultimately to cope better with their caring responsibilities. The literature on disability respite services is largely focused on the impact it has on primary carers and family members (Radcliffe & Turk, 2007; Wilkie & Barr, 2008; Robertson et al., 2011; Coll & Scully, 2011; Nankervis et al., 2011; Ryan, 2011; Southby, 2018). The experiences of persons with disabilities using respite services has been poorly explored and documented. There is very little evidence of persons with disabilities participating in the design and development of respite services despite the literature suggesting this is best practice.

Chan (2008) proposes that:

“The fundamental tenet in contemporary service provision is for persons with disabilities to participate in the decisions that affect their lives, including decisions about support services.”

In light of the absence of a national respite policy for disability services in Ireland, it is timely to document the experiences of adults with disabilities in Ireland of respite.

There are two main elements to this research project:

- A literature review on the experience of persons with disabilities in relation to respite
- Information gathering from adults with disabilities with access to respite services around the country.

1.2. Definition of respite

Respite services are considered internationally to be one of the main supports offered to persons with disabilities and their families (Power, 2008; Chan et al. 2012; Pullin & McKenzie, 2017)

Definitions of respite are varied and constantly evolving.

The National Disability Authority (NDA) in 2004 described respite as:

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

Van Exel et al. (2006) define respite as:

“A generic term for different types of interventions aimed at providing support and relief to informal carers by (temporarily) easing the burden of the care giving task, with the objective to increase or restore the carer’s ability to bear this load”

Respite services can also be viewed as a means to limit the need for out-of-home placement and to keep families together (Chesson & Westwood 2004, Power 2008, Nankervis et al 2011).

Jeon, Brodaty, and Chesterton (2005) highlighted four dimensions of respite care:

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

As models of respite provision have developed, the definition has broadened to encompass the possible benefits for service users (McConkey & McCullough, 2006; Merriman & Canavan, 2007). Cramer and Carlin (2008) note that the term ‘respite care’ implies a negative experience and burden of care for the family. They believe that ‘short-break’ is more in keeping with the social model of disability and allows for a positive experience for the carer and person with a disability.

Mansell & Wilson (2009) highlight the need for a ‘clear and shared’ understanding of the term ‘respite’. A definition is required which is agreed and understood by persons with disabilities, families/carers and professionals.

In this study, respite or short breaks are broadly divided into two main categories:

1. Traditional respite – usually overnight in a specific respite house or service
2. Alternative respite – this may or may not include overnight, but can include host families, day-break services, clubs, one-on-one respite in or out of home, holiday or summer camp respite

Most participants in this study had experience of traditional respite in designated respite houses or centres, and in residential settings. Some participants had experience of alternative forms of respite such as day-break services, weekend and evening groups. A small number had experienced host family respite in the past but were no longer availing of this. Host family respite generally involves a person with a disability going to stay with an individual or family in their home. This is on a planned basis, and may be for an afternoon or evening, overnight, for a weekend, or longer.

1.3. The demand for respite in disability services in Ireland

There is currently no national policy on respite services and persons with disabilities have no right to respite. As respite services are largely led by voluntary service providers or purchased by the Health Service Executive (HSE) from voluntary or private service providers, policies around respite have developed at organisational level and are limited by the scale and scope of that organisation's activities and capacities. This contributes to regional variations throughout the country and raises questions of inequality of respite distribution. The transition from child/adolescent to adult respite services is not seamless and respite services available at age 17 may no longer be available at aged 18.

One of the most reliable sources of data on services for persons with disabilities in Ireland comes from the National Disability Databases.

There were 28,388 people registered on the National Intellectual Disability Database (NIDD) at the end of December 2017. Of these, 69% lived at home with parents, siblings, relatives or foster parents. The Annual Report of the NIDD committee (Hourigan, Fanagan & Kelly, 2018) notes that:

“The majority of adults with intellectual disability continue to live with their families with the aid of additional support services. As their caregivers age, a wide range of additional services such as respite are required for people who wish to continue to live as independently as possible. Between 2016 and 2017 there was a decrease in respite provision”

Only traditional overnight respite is measured in the Database. To capture anything else would require a standardised definition of respite. In 2016, a total of 4,385 people received respite services around the country, with a median of 17 nights received (Doyle, Hourigan & Fanagan, 2017). In 2017, a total of 4,104 people received respite services, with a median of 18 nights received nationally. This is approximately 14% of the 28,388 people registered on the NIDD at the end of December 2017.

There were marked differences between CHO (Community Health Organisations) areas in the amount of respite received. In 2017, the median number of nights received in CHO1 was 13. By comparison, the median number of nights in CHO2 was 36 and in CHO3 was 24.

The National Physical and Sensory Disability Database (NPSDD) reported 20,676 registrations in 2017 (Doyle & Carew 2017). Of these, 70% were aged 18 years or over. The majority of people (84%) lived with family members. The Annual Report highlighted that only 8% of individuals availed of one or more planned respite services. The types of respite most commonly used and required were holiday respite placement and planned residential respite with high support.

1.4. Legislative and Policy context

A number of legislative and policy developments are important in the context of the role of respite services in Ireland. These reflect a move towards a person-centred approach to supports, designed to ensure that persons with disabilities have choice and control in how they live their lives, where they live, what they do and when, and how they can participate in the community alongside everyone else. These developments are key to the development of community-based supports, including respite supports, and to a drive for the provision of high-quality services and supports.

They include a National Disability Inclusion Strategy¹ which is a cross governmental strategy to implement a range of actions to progress equality for persons with disabilities. The Strategy can support the implementation of many requirements of the United Nations Convention on the Rights of Persons with Disabilities².

A Value for Money review³, conducted in 2012, led to a process of transformation of disability services in Ireland, including policies on decongregation⁴, transforming traditional day service models⁵ and considering a policy for personalised budgets⁶.

The Assisted Decision-Making (Capacity) Act 2015 was signed into law on the 30th December 2015 and when fully commenced will support a person's right to make their own decisions and to access legally recognised supports to do this. This is an important development for persons with disabilities across many areas of life including decisions regarding choice of services.

¹ The National Disability Inclusion Strategy 2016 - 2020: Department of Justice and Equality, 2017

² United Nations Convention on the Rights of Persons with Disabilities (UNCRPD): United Nations, 2006

³ Value for Money and Policy Review of Disability Services in Ireland: Department of Health, July 2012

⁴ Time to Move On from Congregated Settings – A Strategy for Community Inclusion: HSE, 2011

⁵ Transforming Lives, Supporting Person-Centred Disability Services - Progress Report: HSE, 2016

⁶ Towards Personalised Budgets for People with a Disability in Ireland - Report of the Task Force on Personalised Budgets: Department of Health, 2018

The Health Information and Quality Authority (HIQA) has responsibility for developing and monitoring standards, as well as monitoring compliance with regulations by disability residential services. HIQA's National Standards for Residential Services for Adults and Children with disabilities⁷ impacts on respite services. The Standards 'outline to providers what they must do to ensure safe and effective care is provided to people living in, or using, residential and residential respite services'.

1.5. Purpose of the research

This research will inform any development of a national respite policy for disability services in Ireland. The analysis of the data focused on identifying themes and sub-themes that would allow policy and practice recommendations around respite to be developed.

This research is an opportunity for persons with disabilities to have their voices heard and their experiences documented on the subject of respite. The primary audience are policy makers and providers of respite services. The research will provide helpful information to disability services at local and national levels in terms of design and delivery of services. The findings will also be of interest to users of respite services, primary carers and families of persons with disabilities, and the disability research community.

1.6. The structure of the report

Chapter 1 of this report outlines the context and background to the research project. Chapter 2 summarises the literature review undertaken. Chapter 3 describes the methodology used to carry out the research. Chapter 4 focuses on the main findings from the research. Chapter 5 outlines the main conclusions and recommendations and identifies areas for future exploration.

⁷ National Standards for Residential Services for Adults and Children with disabilities: HIQA, May 2013

2. Literature Review

2.1. Aims of the literature review

The literature review set out to analyse the key evidence, in national and international literature, in relation to user's experience of disability respite services. The focus of the review was on the views of adults with disabilities, 18 years or older, accessing or with the potential to access respite services. The review included a range of disability types including intellectual, physical, sensory, autism, and mental health. It became clear early on in the review that there were a limited number of papers on this topic and therefore the review was expanded to also include the views of children and adolescents, and of parents and carers.

The research evidence contributed to the development of a topic guide (Appendix I) and research questions for the information gathering element of the research project. The aims of the literature review were to:

- critically review the available evidence between 2008 and 2018
- note key recommendations for respite service provision in disability services
- identify key elements in the reported experiences and views of respite of adults with disabilities, children and adolescents with disabilities, and family members/carers

2.2. Methodology

A number of steps were taken to ensure a thorough review of the evidence.

1. Electronic literature searches were conducted through relevant databases- PsycInfo, CINAHL, and Medline. A combination of key words and variations were used in the search. These included 'respite', 'short breaks', 'residential support', 'disability', 'adult', 'perceptions', 'experience'.
2. A number of manual bibliographic searches supplemented the electronic searches.
3. The reference list of each item included in the review was checked to see if any relevant publications were missed.
4. Searches were also conducted in search engines such as Google and Google Scholar.

Relevant articles were reviewed against inclusion criteria. Studies were included:

1. If they were published in English between 2008 and 2018
2. If the full text was available from a credible source
3. If they reported information on the experiences of/impact of respite provision for adults with disabilities

4. If they reported information on the experiences of/impact of respite provision for adolescents with disabilities (a number of studies focussed on children but included adolescents up to 19 years of age)
5. If they presented information on social or organisational approaches and policies, which may impact respite or residential support provision, and in particular the experiences of users of disability respite service

A number of studies were also included which:

1. Reported information on the experiences of/impact of respite provision on family members/carers of persons with a range of disability types.
2. Evaluated, mapped or reviewed current respite provision and needs in Ireland
3. Explored general social and healthcare supports for persons with specific disabilities such as Multiple Sclerosis (MS), where there was a focus on the perspectives of persons with disabilities

The literature search generated over 200 potentially relevant sources. These were primarily academic publications, along with government publications, policy documents and organisational reports. The abstracts of these sources were reviewed, and their relevance assessed. If there was not sufficient detail in the abstract to determine relevance, then the full text was read.

In total, 35 articles met the criteria for inclusion - see Table 2.1 for a breakdown. The full source of each article was reviewed, and the relevant data coded, extracted and collated under a number of different headings and themes. Each article was attributed only to one main category despite the fact that some studies gathered information from different groups of participants.

The majority of papers came from the United Kingdom, Ireland and Australia. There were also papers from United States of America, Canada and Japan.

2.2.1. The literature on the experiences of adults users of disability respite services

The literature on the experiences of adult users of disability respite services is extremely limited. This literature review identified seven studies which focused on or included the perspectives of adults with disabilities. Some looked at the experiences of persons with disabilities of respite services specifically, whilst others explored their views on health and social care services generally. Some findings from these generic studies are very relevant to the provision of respite services.

Of the seven studies included in this review, two explored the views of adults with MS, two looked at the experiences of adults with mild to moderate intellectual disabilities, one focused on the views of adults with acquired brain injury (ABI), one on the experiences of adults with physical disability, and one on the views of adults with mental health difficulties.

Only one study identified in this review, Mullan et al., 2011, compared the views of adults with disabilities and carers in relation to respite services.

2.2.2. The literature on the experiences of children and adolescents with disabilities using respite services

Five studies, included in this review, looked at the opinions of children and adolescents using respite services. The studies included children and adolescents with intellectual disabilities, autism spectrum disorders, and physical disability. Their views were gathered primarily through observation and interviews.

There has been significant debate about the impact of respite on children and young people with disabilities, with concerns expressed that some children may suffer distress, and that there may be a conflict of interest between the needs of the child and the needs of the family. Generally, studies of respite services for children have gathered the views of parents, carers and/or teachers. A number of authors note the problems associated with proxy or third-party reports (Radcliffe & Turk, 2007; Chapman, 2013; Spruin et al., 2017), with significant differences reported in the comparison of opinions and priorities.

2.2.3 The literature on the experiences of parents and carers of persons using disability respite services

Twelve studies, exploring the experiences of parents and carers of respite services, were examined as part of this literature review. Four focussed on the views of parents and carers of both children and adults with intellectual disabilities. Three looked at the views of parents and carers of children and adolescents with intellectual disabilities. One explored the views of parents and carers of young adults with intellectual disabilities.

One focussed on adolescents with a range of disabilities including autism, intellectual and physical. Two focused on ageing and dementia and one on spinal cord injuries.

Table 2.1. Breakdown of articles included in the literature review

Primary focus of the article or data extracted	Type of disability	Number of articles found
Perceptions of adults with disabilities on respite provision	Brain Injury, Physical Disability, Intellectual Disability, Multiple Sclerosis, Mental Health Difficulties	7
Perceptions of children and adolescents with disabilities on respite provision	Autism, Intellectual Disability, Physical Disability	5
Views of parents/carers on respite provision	Intellectual Disability, Challenging Behaviour, Dementia, Spinal Cord Injury	12
Mapping of respite provision in Ireland	Physical and Sensory Disability, Intellectual Disability	3
Identification and evaluation of models of respite provision in Ireland and internationally	Intellectual Disability, Physical and Sensory Disability, Autism,	4
Policy approaches and recommendations in relation to residential supports and respite provision	Dementia, Intellectual Disability	4

2.3. Findings in relation to social policy and practice

2.3.1. Respite provision in a community-based model of service provision

There have been major changes in social and disability policy over the past twenty years. In particular, there has been a move towards the provision of more individualised and community-based services for persons with disabilities. Quin & Redmond (1999) explain that:

“The ideal of community care is that people with intellectual disability would live a full and inclusive life nurtured by those around them”

Residential supports, including respite, are particularly important as persons with disabilities are living longer and many are living with their families. Chan et al. (2012) highlight that:

“The social model of disability emphasizes the shared role of the family and the state in caring for people with disabilities”

2.3.2. Respite as an element on a continuum of support

Internationally, respite is seen as a practical means of support to families. It can help build resilience and promote health and well-being. Chan et al. (2012) describe respite as ‘a buffer against the demands of caring for a person with a disability and families’ needs to fulfil their responsibilities’.

Some studies suggest that respite should be viewed along a continuum of support services (Merriman & Canavan, 2007; Chan et al., 2012). Persons with disabilities and

their families are seen as ‘partners’ in this process with respite building on family resources and social networks (Brown, 2007).

Merriman & Canavan (2007) emphasise that respite should not be viewed as an ‘isolated episode’ in a family’s life, but rather as part of an integrated, responsive model of service provision. Support should be viewed as a positive experience for the carer and the person with a disability.

2.3.3. The importance of person-centred supports in respite services

Some studies offer important learning on the influence of specific attitudes, policies and approaches on respite services, for example, organisational culture and person-centredness. It is widely accepted that respite services can benefit persons with disabilities, encouraging independence and facilitating social engagement (Wilkie and Barr, 2008; Nankervis et al., 2011; Cobigo et al., 2014). Respite should be tailored to the needs of the individual and not the state (Southby, 2018). It must be grounded in a ‘needs led philosophy’, adopt a person-centred approach, and reflect the personal goals of the individual (Wodehouse and McGill, 2009).

Person-centredness is core to the provision of quality supports to persons with disabilities. The limitations of a ‘one size fits all’ approach to residential supports, including respite, are highlighted (Crawford, 2008; Hole, 2015).

Kirkley et al. (2011) note ‘the importance of flexible and responsive respite care for people with dementia’. Their paper on the impact of organisational culture on the delivery of person-centred care in services providing respite and short breaks for people with dementia, identifies a number of key themes. These include understanding of person-centred care, attitudes of key managers and staff to service provision, service priorities, valuing staff and a solution focussed approach.

2.3.4. Funding respite services

A number of authors suggest that if care is provided within the family, there are significant social and economic benefits for government (Jeon et al., 2007; Post, 2007). However, many studies report an unmet need for respite and a lack of co-ordinated funding. Power (2009) describes an ‘implementation gap between political rhetoric regarding service provision and largely cosmetic on the ground services’.

Southby (2018) describes the advantages and limitations of ‘consumer directed care’. This is where persons with disabilities and their carers control their own budget and make choices about the services they use. In contrast, Chan (2008) advocates for funding flexibility and portability so resources can be used ‘in a way that best suits the needs of the person and his or her carer, giving them more control instead of relying on service providers’. This would allow persons with disabilities and their families to harness natural, informal supports in familiar environments. Flexible funding also allows families to bank respite hours and plan for times when they might need it most.

2.3.5. Principles of best practice in the design and provision of respite services

There have been numerous studies exploring housing supports and models of residential provision for persons with disabilities. Many of the values and principles recommended in these studies are relevant to the area of respite. Key recommendations include community-based services, flexible models of support, individualised approaches and outcomes focussed supports (Crawford, 2008, Cocks et al., 2014, Hole et al., 2015).

Merriman & Canavan (2007) identify the need for respite services to be provided on a rights basis. They suggest that there should be a single point of access to respite services in a given administrative area. Respite services should be age appropriate and develop as the person develops. They should have clear goals, which are regularly and systematically reviewed to ensure achievement.

In addition, it is important to note the importance of designing services, including residential and respite services, in consultation with experts by experience; persons with disabilities and their families, that have experienced first-hand the benefits and limitations of services, and the supports and barriers to accessing them (NICE, 2018). Respite services should be designed to facilitate the service user to build relationships in their community.

2.4. The reported experiences of users of disability respite services

The experiences of the adults, children, adolescents, parents and carers, participating in the studies, are summarised below. They are organised under four key headings, each with its own themes:

- The positive aspects of respite
- Factors that contribute to a positive experience of respite
- The negative aspects of respite
- The barriers and challenges to respite

Overall, the reported experiences of respite are mostly positive. No specific type of respite emerges as the most desired or as providing the best outcomes for the user. Preferences tend to be based on individual needs and on lived experiences.

2.4.1. The positive aspects of respite

Both users of respite and family members express high levels of satisfaction with respite services, when they receive them. There is a strong consensus across the literature on the positive aspects of respite. There is also strong agreement on the factors that influence respite use.

All users agree that respite should be a ‘fun’, ‘enjoyable’ experience. Adults with disabilities are seeking person-centred respite services which offer a break to and from family and carers, provide social opportunities and enhance community participation. Children and adolescents focus on the ‘here and now’, and on the

tangible aspects of their experiences – activities, menus, comfort, relationships. All users of respite identify that the skills and attitudes of staff are important to them. Parents and carers are seeking respite services that offer high quality care and provide a safe and enjoyable experience for the individual.

2.4.1.1. The needs of parents and carers

Chan (2008) identified that persons with acquired brain injury ‘considered the stress level and needs of carers and/or family members’ as one of the most important factors to influence respite use. Other relevant factors included managing unexpected situations such as sudden family illness, or the poor health of carer, spouse or family member.

Mullan et al. (2011) found that 71% of persons with MS surveyed said their main reason for using respite was to give their carer a break. Approximately two-thirds of carers said that their main reason for using respite was to relieve stress.

Generally, in the literature, persons with physical and sensory disabilities were more likely to recognise the stress and health needs of their carers than persons with intellectual disabilities.

Parents and carers consistently talk about the need for ‘a rest’, ‘relaxation’, ‘a chance to go on holiday’, ‘a chance to spend time with other family members’ (Radcliffe & Turk, 2007; Robertson et al., 2011; Ryan, 2011; Southby, 2018). They noted that respite gave them time to engage in their own hobbies (Wilkie & Barr, 2008; Ryan, 2011; Southby, 2018). The literature suggests that there may be a ‘reduced likelihood of relinquishing care of the person with a disability to an out-of-home placement’ when regular respite is available to a person and their family (Wilkie & Barr, 2008; Mansell & Wilson, 2009; Power, 2009; Nankervis et al., 2011).

2.4.1.2. Supporting independence

Dawson & Liddicoat (2009) emphasised ‘the importance of respite for parents, but also for adult children with disabilities’:

“For example, a camper, while laughing, responded to a question about what they gain from camp by stating, “Getting away from home...getting away from family.” Another camper stated, “At first I didn’t want to be here, but it gave me peace.” He followed up by stating, “and, to not have my mom around for two weeks.”

In particular, adolescents and young adults talked about needing a break from their carer or experience outside their family (Dawson & Liddicoat, 2009; Mullan et al., 2011; Hamilton et al. 2017).

Parents and carers noted that respite is an opportunity for the person with a disability to tolerate change, to become more confident and independent, and to develop skills such as social, behavioural, communication or life skills (Robertson et al., 2011; Coll & Scully, 2011; Welch et al., 2014; Spruin et al., 2017).

Improved well-being is noted by users and by parents/carers as a key benefit of respite (Dawson & Liddicoat, 2009; Mullan et al., 2011; Hamilton et al. 2017; Spruin et al., 2017).

2.4.1.3. Building relationships

There was strong agreement from all stakeholders that respite provides an opportunity to make new friends, to maintain relationships with peers, to build social networks, and to reduce isolation and exclusion (Dawson & Liddicoat, 2009; Preece & Jordan, 2009; Robertson et al., 2011; Hamilton et al. 2017). Children and adolescents commented on the benefits of team games and group activities (Preece & Jordan, 2009; Spruin et al., 2017).

2.4.1.4. Engagement in activities

Again, there was consensus amongst stakeholders that respite encouraged persons with disabilities to participate in a range of leisure activities (Dawson & Liddicoat, 2009). Children and adolescents reported that there is a wide range of activities on offer at respite, with opportunities to try new activities and to engage in favourite activities such as day trips (Preece & Jordan, 2009; Radcliffe & Turk, 2007; Robertson et al. 2011; Spruin et al., 2017).

2.4.2. Factors that contribute to a positive experience of respite

2.4.2.1. Staffing

Adult users of respite and parents/carers stressed the importance of adequate qualified staff with the right skills and attitudes. This contributes to the development of positive relationships between the respite users and those supporting them (Chan, 2008; McConkey et al., 2011; Phillipson et al., 2013; Stirling et al., 2014; Methley et al., 2017; Southby, 2018). Some adults with disabilities noted the importance of continuity of care from one staff member or provider (Methley et al., 2017). Parents and carers highlighted the importance of trusting partnerships between the service providers, staff, parents, and the person with a disability (Coll & Scully, 2011; Ryan, 2011; Stirling et al., 2014).

2.4.2.2. The physical environment

There was agreement that the service should be a 'home away from home' (Chan 2008; Dawson & Liddicoat, 2009). The provision of single rooms was important to some individuals.

2.4.2.3. Community connections

Some adults with disabilities felt that a respite service should offer them a chance to be part of a community (Dawson & Liddicoat, 2009; Hamilton et al. 2017). Some adults with disabilities would like respite services close to home (Chan, 2008).

Families and carers suggested that respite services should be in convenient, accessible locations with community connections (Robertson et al., 2011; Phillipson et al., 2013).

2.4.2.4. Person-centred supports

All stakeholders noted the importance of person-centred supports which offer choice in how a person can spend time during respite (Chan, 2008; McConkey et al., 2011; Mullan et al., 2011; Methley, 2017; Nicholson et al., 2019).

Both adult users and parents/carers described the need for flexible services (Chan, 2008; Methley et al., 2017; Gillieatt et al., 2018). They highlighted the importance of having emergency beds or funds readily available when needed (Chan, 2008; Mullan et al., 2011).

They also requested a range of respite options – both family and community-based services, provided as part of a continuum of support (Chan, 2008; Coll & Scully, 2011; McConkey et al., 2011; Nankervis et al., 2011, Gillieatt et al., 2018). A number of authors report that parents ‘felt an overnight stay was necessary for a break to be considered respite’ (Mansell & Wilson, 2009; Robertson et al., 2011). Southby (2018) suggests that with parents/carers ‘non-residential respite was not viewed as positively and did not have the same appeal as residential respite’. Non-residential respite is also viewed by carers as unreliable; support workers may be unavailable for such a short time or move on to other roles. Residential respite settings “feel more stable”.

2.4.3 The negative aspects of respite

2.4.3.1. The emotional aspects of respite

Some adult users experienced emotions such as feeling angry at needing respite (Mullan et al., 2011). Family members and carers talked about feelings of guilt, embarrassment or anxiety (Wilkie & Barr, 2008; Robertson et al., 2010; Ryan, 2011; Stirling et al., 2014). They noted some emotional changes in the person with a disability, for example, behaviour or sleep difficulties before or after a respite stay, mood changes, anxiety (Radcliffe & Turk, 2007). Privacy issues for the family with in-home respite were also an issue (Robertson et al., 2011, Welch et al., 2014).

Some children and adolescents reported that they disliked being away from home and suffered ‘homesickness’. Some had a poor understanding of why they were in respite and described feeling that they were being punished. There could be a negative association with their family needing a break (Radcliffe & Turk, 2007; Preece & Jordan, 2009; Robertson et al., 2011).

Some children and adolescents said that their respite experience was boring and that they did not like the food on offer during the break (Radcliffe & Turk, 2007).

2.4.3.2. Relationships with staff

Adult users of respite also reported some negative interactions with staff and health professionals (Methley et al., 2017). Parents and carers highlighted that a high staff turnover can impact on the quality of care received (Wodehouse & McGill, 2009; Robertson et al., 2011).

Children and adolescents said they sometimes disliked the staff working with them in respite, and they were not keen on staff discipline, for example, telling them what to do, being angry with them (Radcliffe & Turk, 2007; Preece & Jordan, 2009; Robertson et al., 2011).

2.4.3.3. Relationships with other respite users

Family members and carers identified compatible groupings as a key part of a person-centred respite services. Children and adolescents explained that they disliked the behaviour of some other children in respite – hitting, biting, screaming, (Radcliffe & Turk, 2007; Preece & Jordan, 2009; Robertson et al., 2011). Some found the sensory aspects of the respite centre and being away from home difficult, for example dealing with noise (Preece & Jordan, 2009).

2.4.3.4. Responding to spiritual and cultural needs

Both adult users of respite and family members suggested that respite services are not always sensitive to cultural and religious beliefs and may not meet the needs of diverse cultural groups. They suggest a lack of understanding and respect for ethnic and cultural differences (Chan, 2008; Robertson et al., 2011; Phillipson et al., 2013).

2.4.6 The barriers and challenges to respite

There were a number of barriers and challenges identified by adult users and parents/carers. Generally, children did not comment specifically on barriers, speaking more about their positive and negative experiences.

2.4.6.1. A lack of access to respite services and funding

There is a significant lack of access to respite, with insufficient levels of support and funding available (Chan, 2008; Gillieatt et al., 2018).

In particular, participants in the studies noted inflexible supports, delays in provision or long waiting lists, restricted or unreliable services, inequality of respite distribution, lack of home-based respite services (Chan, 2008; Wodehouse & McGill, 2009; Caples & Sweeney, 2010; Robertson et al., 2011; Coll & Scully, 2011; McConkey et al., 2011; Anderson et al., 2013; Spruin et al., 2017; Pullin & McKenzie, 2017; Southby, 2018).

Spruin et al. (2017) noted that the adolescents in their study emphasised the need for better transitions between child and adolescent/adult respite services. Poorly coordinated transitions between child and adult services were also noted by parents/carers (Wodehouse & McGill, 2009; Coll & Scully, 2011; McConkey et al., 2011).

Parents and carers were concerned about a lack of access to emergency respite supports (Gillieatt et al., 2018). They also highlighted a dearth of informal supports from their wider family and community (Caples & Sweeney, 2010).

Pullin & McKenzie (2017) suggest that:

“Long-term family carers supporting a person with a significant disability have a need for practical and lifestyle assistance, including formal respite from familial and/or caregiving responsibilities. They would appreciate regular respite from their active support role, and occasional practical assistance with childcare, domestic and home maintenance activities”.

Across the three groups, participants requested additional funding for resources (buildings and staff), different activities and longer breaks.

2.4.6.2. A lack of accessible information

Both adult users and family members described the challenges in sourcing accurate, appropriate information on the respite services and supports available to them (Wodehouse & McGill, 2009; Coll & Scully, 2011; McPherson et al., 2014; Pullin & McKenzie, 2017; Southby, 2018). This made it more difficult to navigate services and to ‘stay in the loop’. They felt that there is a lack of accessible information for persons using services (Chan, 2008; Methley et al., 2017; Hamilton et al. 2017).

Participants in the study by Methley et al. (2017) noted that the decision making on health and social supports, of both persons with disabilities and professionals, ‘is influenced by knowledge and awareness of local healthcare and community services’.

2.4.6.3. Meeting complex support needs

Adult users and parents/carers explained that respite services may be inappropriate, inadequate, or difficult to access for persons with specific disabilities such as autism, behaviours that challenge or complex support needs (Chan, 2008; Wodehouse & McGill, 2009; McConkey et al., 2011; Gillieatt et al., 2018; Southby, 2018).

Some parents/carers felt there was a lack of professional understanding and support in relation to their respite needs (Wodehouse & McGill, 2009; McConkey et al., 2011; Pullin & McKenzie, 2017).

Others felt that respite services are only available to those with the most complex needs. Hamilton et al. (2017) identified that ‘access to care services have become limited to people with critical or substantial need over recent years, there exists a growing number of people who have limited opportunities both of entering the mainstream social spaces and of accessing care’.

2.5. Summary

In general the literature review found that there were more positive than negative views of respite services among both service users and parents and carers.

3. Methodology

This is a qualitative research study. Information was gathered primarily through focus groups and semi-structured interviews. Some additional information was also gathered through informal discussions with service providers and clinicians. There was a strong focus throughout the process on adherence to best practice in consulting with people with disabilities, and the maintenance of ethical standards.

3.1. Sampling

A convenience sampling method was used to recruit participants. At the outset of the project, a sample size of at least 40 individuals was agreed. It was also agreed that ethical approval would be required from all participating organisations. The research team identified disability service providers around the country that offered respite services and had a research ethics process in place. These providers operated in different geographical locations providing traditional or alternative models of respite, or both. Research ethics applications were submitted to three service providers and approval was granted. Two of the service providers selected provided residential, day and respite services. One provided day and respite services.

3.2. Participant profile

Participants in this study were adults with disabilities. We sought to recruit individuals that could give their own experience of respite services. We did not use proxies to relay experiences on someone's behalf.

Table 3.1 below gives a breakdown of the number of participants from each service provider.

Table 3.1 Number of participants from each participating service provider

Service	Number of participants
Provider 1	14
Provider 2	13
Provider 3	14
Total	41

Table 3.2 gives a breakdown of the participant's current engagement with respite services.

Table 3.2 Profile of participants – engagement with respite services

Status	Number of participants
Users of respite services	29
Seeking respite services (on a waiting list) *	8
Refusing to use respite services when a place offered	4

*Three participants were transitioning from children's respite services to adult services

Four participants in the study received respite services from one of the three identified service providers and also from an outside agency. They spoke about their experiences with both providers during the interviews and focus groups.

Table 3.3 shows the age and gender of participants.

Table 3.3 Age Range of Participants

Age range	Male	Female	Total number of participants
18 to 35	9	12	21
35 to 50	6	4	10
50 to 65	3	3	6
Over 65	2	2	4
Total	20	21	41

Ten participants lived in rural settings and the remainder in urban. The majority of participants lived at home with their family. One participant lived in a residential setting, one participant lived in a nursing home and two participants lived independently.

Almost all participants attended a day service on either a full or part-time basis. Eight participants mentioned that they had a part-time job. It was not clear if this was paid employment or voluntary work. Some participants talked about their involvement in clubs, Special Olympics and community groups.

The main disabilities among the participants were intellectual disabilities, autism, and physical and sensory disabilities (including acquired brain injury) – see Table 3.4.

Table 3.4 Participants - primary disability

Disability type	Number of participants
Mild to Moderate Intellectual Disability	23
Autism and Intellectual Disability	5
Physical and Sensory Disability	13

Most participants in this study had experience of traditional or alternative respite, or a combination of the two (Table 3.5). For participants in this study, alternative respite consisted of small groups operating in the late afternoon/evening or on Saturdays, with the reported frequency varying from once a week or fortnight to once a month.

There were different types of traditional respite:

- Overnight in a designated respite house - the reported frequency varied considerably from one night a week to three weekends a year
- Overnight in a respite bed in a residential house - the reported frequency varied from one weekend a month to six times a year
- A short break in a respite centre - this tended to be from Monday to Saturday, up to four times a year

Some participants accessed both traditional and alternative respite services. A small number of participants reported that they had experienced host family respite in the past but could no longer access this. Host family respite generally involves a person with a disability going to stay with an individual or family in their home. This is on a planned basis, and may be for an afternoon or evening, overnight, for a weekend, or longer.

Traditional and alternative models of respite differed primarily in that one offered overnight stays and one did not. Those using traditional respite talked about activities based in the house/centre such as watching TV and DVDs, art and craft activities and household tasks such as cooking. In addition, they also participated in outings and day trips. Alternative respite, in small groups, often centred around a specific trip, event or activity – usually chosen by the group. The day trips and activities undertaken by those in traditional and alternative respite settings were very similar. Some alternative respite groups had access to a base where they could spend time and plan their session. Other groups met in a central community location and spent the time out and about. Alternative respite groups were often organised to accommodate persons of a similar age or gender, or with similar interests.

Eight participants were on a waiting list for respite. Three of the eight were school leavers, waiting on an adult respite service. Two of these had experience of using children’s respite services. The discussions with these participants centred primarily around what they would like from a respite service.

Table 3.5 Number of participants using or waiting for different models of respite provision

Model	Number of participants
Traditional respite centre / short break	26
Alternative respite	6
Both traditional and alternative	5
Refusing a respite service	4

Participants welcomed the opportunity to share their experiences and to voice their opinions on respite provision. The majority of participants communicated verbally, however visual information was provided, where necessary, to support discussions. Three participants used non-verbal methods of communication to express their views – one used sign (Lámh), one photographs, and one a communication book. A small number of individuals requested support from familiar staff members during the interviews or focus groups. The staff member did not respond on the person’s behalf but clarified information where necessary and supported the individual to interact confidently with the researcher. Some individuals asked the staff member to leave once they felt comfortable. The presence of a staff member did not deter other group members from commenting or appear to unduly influence their contributions. In most cases, supporters only sat in on a portion of the interview or focus group.

3.3. Recruitment and Consent

The research team worked with a small consultation group of persons with disabilities to develop an information leaflet and consent checklist. These were available in Easy to Read and Plain English formats (Appendices 2,3,4,5). They were designed to support individuals to give informed consent to participating in the project. The information explained that participation would not affect present or future service provision. It also stated that it is okay to say 'no' to participation and that each person should make their own decision about taking part.

A staff member was identified in each participating organisation to act as contact person and to lead out on the recruitment of participants. The lead researcher spoke to each contact person at length to explain the nature of the research and the recruitment process. The contact persons were reminded of the rights of participants. The researcher did not make contact with participants prior to the interview/focus group, unless the participant initiated this. The contact person provided the introductory information to potential participants and supported them to engage with the consent process and materials. This person knew potential participants well and invited those who she felt would be able to consent and participate to be involved. A very small number of individuals were put forward by staff or family members to participate but were not considered appropriate by the contact person or research team – this was mainly due to the need for a proxy to participate on their behalf. A number of family members requested to participate but were not included. This was because the intent of project was to focus on recipients of respite, and this rationale was explained fully to the family members concerned.

Participants were given the opportunity to ask questions and to contact the lead researcher or NDA if they wished. They were given a minimum of one week to consider the information and to decide if they wished to participate.

Researchers started from a presumption of capacity and sought to obtain consent directly from each participant. Proxy consent was not accepted. Consent was considered an ongoing process. Researchers considered the assessment of staff members, their own observations and interactions with the participant, and any other relevant information in determining capacity to consent. The consent checklist was reviewed on the day of the interviews and focus groups.

The researcher sought relevant information on supports that participants might need during the process, for example communication, medical or behavioural supports.

The research team were aware of the possible risks of inconvenience in participating and the potential disclosure of a safeguarding issue during the interviews and took steps to reduce these. This included providing breaks, cue cards etc. The researcher also sought the name of a person responsible for safeguarding in each service provider prior to interviews and focus groups. No safeguarding incidents were disclosed to the researchers.

3.4. Information gathering

Following completion of the literature review, a topic guide was prepared with a set of research questions (see Appendix 5).

Participants were given the choice to take part in an individual interview or focus group. The number of participants in each focus group was decided in conjunction with the contact person. Twenty-three individuals participated in six focus groups. Eighteen individuals opted to take part in an individual interview.

The interviews and focus groups took place in venues and at times that best suited participants, for example in day services or respite centres. The lead researcher carried out the interviews and focus groups. A note taker was also present for the focus groups and for some individual interviews.

At the start of the focus group, the researcher reviewed the consent materials and answered any questions which participants had. Participants were given the option to change their mind at this point, but all gave consent. The researcher summarised the key points at the end of each interview/focus group and gave participants time to respond and clarify information.

The data collected consisted of audio recordings, written notes and verbatim transcripts, memory-based analysis, symbols and pictures.

3.5. Data management and analysis

All data from the project is stored securely as per NDA and ACE research data protection and storage policies.

The research team sought to minimise the personal data collected and to reduce opportunities for data linking and inference in this report.

The names of participants or service providers, or any other identifiers are not used in this report or in any material disseminated in relation to this project. Codes were used for participants and service providers during the data analysis. The coding information was stored separate to the data and destroyed once analysis was complete. Transcripts were prepared by a research assistant and double checked by the lead researcher to ensure no identifying information was present. Audio recordings were deleted once written transcripts were complete.

The data was organised and coded manually using Braun & Clark's (2006) six-step framework for thematic analysis. Those carrying out the analysis were very familiar with the data from the interviews and focus groups. The data was coded by both the lead researcher and a research assistant. Open coding was used. Broad semantic themes and sub-themes were identified, organised and developed with a focus on those that would allow policy and practice recommendations around respite to be developed.

4. The Findings

Overall the majority of participants were extremely positive about respite.

Those with physical and sensory disabilities viewed respite as a holiday or short break, rather than a regular support. This was in contrast to those with intellectual disabilities or autism, many of whom saw respite as part of their everyday supports.

There was no significant difference between the experiences of those using traditional or alternative models of respite. The main factor seemed to be personal choice in relation to overnight stays. Some participants were very opposed to staying over, whilst others considered an overnight stay to be an essential part of their respite experience.

There was no difference between the views of men and women. There were some small variations in the opinions of older and younger adults. These will be addressed within the themes and sub-themes below.

Participants from rural areas were more concerned with transport than those from urban areas. Some also explained that they had less access to amenities in rural areas and so really valued the opportunity to try different activities at respite.

The main themes that emerged from the data are presented below. They are organised under the same headings as the findings from the literature review:

- The positive aspects of respite
- Factors that contribute to a positive experience of respite
- The negative aspects of respite
- The barriers and challenges to respite use

4.1. The positive aspects of respite

4.1.1. High levels of satisfaction with respite services

There were high levels of satisfaction with many aspects of respite services such as the comfort of bedrooms and other personal spaces, the opportunities provided for privacy, the food provided during respite visits and the general facilities in respite houses and centres. They felt that their care and medical needs were very well met during respite (both alternative and traditional).

“I love it...it is just great”

“I look forward to coming here, it makes my life worth living”

“I can't wait for it”

“Respite is so good... you do so many different things”

Almost all participants reported settling in easily to respite and being happy there. Very few users of overnight respite experienced homesickness or loneliness beyond

the first visit or two. Participants commented that shorter gaps between respite helps to reduce feelings of anxiety and homesickness.

“At the start you might be a small bit homesick, but I got used to it over time”

“It can be a small bit strange until you get used to it”

“I don’t miss home...not at all ... at W [name of respite house] home is the furthest thing from your mind”

Participants did not mention any negative emotions in association with respite stays but commented on their feelings and need for emotional support when respite was over. They noted a few difficulties settling back home, particularly after longer respite breaks.

“You get to know the house, get to know the people, like the neighbours... so when you go home you find it hard to settle down”

“I find it depressing really when I get home, because it’s exactly the same thing again do you know”

“I miss being there yeah, but I’d be looking forward to the next time”

“Like a holiday, sad when it is over”

“I hate going home, the day is short, and I am sad to go home”

Users of both traditional and alternative respite described feeling tired afterwards.

“You get a bit tired after it, but I got over it”

“I am wrecked cos I am so busy...I go to bed when I get home”

4.1.2. Time and space for myself

Many participants talked about the importance of getting some time for themselves away from the regular pressures of life. This was a particular feature in the focus groups and interviews with persons with physical and sensory disabilities. It was most relevant to those using respite overnight and for longer breaks.

Participants talked about respite being ‘good for their well-being’, ‘a change of scenery’, ‘a holiday’, ‘a break from the same places and things’, and ‘a chance to relax’.

“You need time for yourself, you really need it”

A significant number of participants noted the importance of ‘peace and quiet’.

“It’s quiet in respite...no noise or traffic”

“I love the quiet room they have there. I think it’s a nice place to just go in and sit down, close the door and just have me time”

“For me it’s probably the calmest place around for me at the moment. It’s a place for me just to recharge the batteries”

“Quiet, peaceful, you just relax and take it easy...quiet time, relax, it’s gorgeous, no pressure”

4.1.3. A break away from family

Most participants said their families were very supportive of them using a respite service. Some had to negotiate with their families and reassure them at the outset.

“...my parents were hesitant, but I pushed and said I wanted to go. My mam kept rejecting it, but I said that I was going, and she allowed me to make up my mind after that, she could see what I was thinking. She was very hesitant to start out but it’s grand now”

A number of participants with intellectual disabilities considered respite to be a break away from their family and a chance to be more independent. This was particularly common in the discussions with young adults.

“I go for the freedom and to get away from your parents for a while”

“yeah stand on your own two feet”

“see I’m kinda...I’m always with my parents all the time and I kinda like to get my own space and actually get to do my own thing”

“I get a break from my brothers”

Some participants explained that after this break, they looked forward to spending time with their families again.

“When I go, they look forward to seeing me again”

“I’m glad to get out of home and then I’m glad to get back home”

4.1.4. A break for family members

Many participants said they used respite to give their family members/carers a break, in particular, mothers. Some explained that their parents were ageing, and they were concerned for their health. A few reported using respite in crisis situations, such as when a family member is ill.

“It’s a break for our parents. They all be cranky isn’t that right and need a break”

“I was with my parents 24/7 when they were still alive, and I felt I needed a break for myself and for themselves”

“Get a break for my Mam for herself...my Mam needs a break for herself, she needs a break from me”

Others noted the importance of family members having the opportunity to do regular things.

“It’s a chance for them to go on holidays”

“My Mam can work when I go to respite”

“They get to do the things they can’t do when they are looking after me”

One person highlighted the challenges when there is only one family member or carer available to support a person with a disability.

“If I had a bigger family then I wouldn’t need respite cos I could be with different people in my family and not just the same person”

4.1.5. Opportunity to make and maintain friendships

Several participants said they used respite for social reasons - for company and to build relationships. They explained that respite afforded them the opportunity to meet new people, meet old friends, or spend time with their current group of friends.

“My favourite part of respite is making friends”

“Definitely, there’s one person in particular who I would not have met if it weren’t for respite, and we have a close relationship now

“When I go there, I make new friends, so it’s lovely. Sometimes I see the others that I know already”

“I would like to go to respite to hang out with people and go places with people”

In particular, participants said they enjoyed watching TV and movies with others, eating meals with others, and going out with friends to the pub, cinema or to concerts.

Young adults, waiting on a respite service, suggested that a respite group could allow them to maintain contact with their school friends. They attend different adult day services and so have lost contact.

4.1.6. Respite is fun

Almost all participants expressed the view that respite should be an enjoyable experience, with a strong focus on ‘fun’.

“It’s fun really”

“Great craic, great fun”

“Having a laugh is a very important part of it”

Again, the ‘holiday’ or ‘break’ theme dominated, and participants reported really valuing the opportunity to ‘let their hair down’, ‘chill out’, ‘enjoy myself’.

4.1.7. An opportunity to engage in activities and to try new things

The majority of participants wanted to spend their time at respite engaged in interesting and meaningful activities. They valued some time in a respite house or centre, but most wanted to get out and about as much as possible. Participants reported engaging in a wide range of activities and using many community facilities.

“I never get a chance for myself to do anything at home...and I only want to get on with new people I just feel like I don’t get to do what I want to do cause

basically I'm trying to say really...I like to go out for tea or coffee or to go to the pub for maybe one or two drinks and that...and I never get that at home at all"
(*user of traditional respite*)

Activities undertaken during respite included going on trips, out to eat, to the cinema or concerts, going for walks.⁸ There seemed to be an emphasis on group activities rather than individual ones. This was largely a function of staffing but was an issue for some individuals. Other participants, by comparison, explained that they enjoyed the company and the group nature of the activities.

In particular, participants enjoyed day trips and eating out in restaurants. Some also enjoyed the occasional take away or meal in a fast food restaurant, explaining that they may not be 'allowed' to do this at home.

4.1.7.1. Personal choice

Participants emphasised that the activities on offer must be relevant, age appropriate, and delivered on an individual or small group basis. They should be based on the wishes of those using the service. There was an acceptance that some compromises might be needed to ensure everyone had a good time.

Almost all participants stated that they made the decisions in relation to the schedule and the activities undertaken during their respite session. Most described using a plan at the start of the session/visit. Each person could input their choices and the plan was available to check back on at a later stage.

"We have a meeting on Monday where we decide what goes on and when"

"We would decide ourselves ...sometimes we would vote to decide...we always had a plan B if it didn't work out"

In one centre, participants felt that staff decided the agenda and plan. They reported that staff determined which activities would be undertaken outside of the house. This would not be in line with person-centred planning.

4.1.7.2. Building skills and developing independence

Most participants were not particularly concerned with learning new skills during respite. Many did not want to think about their personal goals, social roles, educational programmes or other things associated with their day service when at respite.

"It's a chance for a complete break from everything for a week"

⁸ List of activities that participants reported engaging in during respite - trips to places of cultural or historical interest; pub; cinema; bowling; concerts and shows; shopping; visiting local amenities such as parks, beaches, churches, hotels; eating out; going for coffee, walks, using public transport such as train or bus, knitting, listening to music, watching TV and DVDs, beauty treatments such as nails, go-karting, rock climbing, escape rooms, jigsaws, art and craft, sports activities such as boxing or swimming.

The majority of participants with physical and sensory disabilities did not attend their day service whilst at respite. Most participants with intellectual disabilities and/or autism continued to avail of their day service when they were using traditional respite services during the week.

The young adults using alternative respite services explained that they had more opportunity than at home with their parents, to practise skills in relation to using public transport, independent travel, money management, shopping and personal care. For example, they reported that parents might drive them to places rather than encourage them to use public transport or might provide more prompting and support with personal care. The researchers observed that at respite, some participants seemed to build on skills learnt in adult day services, for example, managing their own money, cooking meals.

Some users of traditional services reported being more independent in managing their money, helping with the cooking and housework, managing their own personal care, doing their own laundry, making their own packed lunch, and shopping.

“In respite, they [staff] kind of make you do it. At home my Mam does it”

“I am independent both at home and at respite. I want to stay that way”

Other participants were content to allow staff to ‘do most of the work’, and to ‘take away the pressure and stress’.

4.1.8. A pleasant environment

Participants were positive in their comments on the general environment of respite centres and houses. Generally, the locations were considered to be very good.

“It’s in a nice place”

“The views are lovely”

“On a good day it’s so nice that I could be in Spain...the trees, the view, everything”

“It is purpose-built so anything I need is there”

Some participants from urban areas valued the opportunity to spend time in a more rural setting. Others requested respite in a rural setting.

“I would like respite away from A [name of city] ...somewhere in the country...that would be a lovely break...maybe even a hotel would be fine”

4.1.8.1. A comfortable and homely place

Participants using traditional respite services described the physical environment as ‘homely’, ‘warm’, ‘relaxing’, ‘comfortable’, ‘gorgeous’.

“I love the house, absolutely love it. I love going there”

“It’s a home away from home”

“It’s a very relaxing place”

Some explained that they felt very safe in the respite house or centre. Others described how the homely environment helped them to relax and to sleep well. They talked about going home ‘refreshed’ and ‘ready to go again’.

One respite setting was described by participants as ‘hot and stuffy’. In this setting, participants said they did not sleep well and felt more homesick.

“In X [name of centre] you would be sick and miss your own bed you would”

4.2. Factors that contribute to a positive experience of respite

4.2.1. Relationships with staff

Most participants were overwhelmingly positive about the staff that supported them at respite. Some of the language used to describe staff includes helpful, unbelievable, excellent, trustworthy, professional, obliging, lovely, fun, friendly and polite.

Participants emphasised the importance of staff that ‘listen’, ‘care’, ‘are kind’, ‘are empathetic’ and ‘have a sense of humour’.

“I found them helpful...they were always there if you were feeling down”

“...kindness and goodness goes a long way and I get that there”

“I think they’re just very nice and I really appreciate that. Anything we ask them to do, they do it...no bother at all”

“It’s about the house but it’s also about the staff, and it’s about the way the staff make you feel. For me, I’ve always gotten positives from the staff”

Participants were not unduly concerned about the continuity of staffing as long as all staff were ‘good at their job’. Many said they were happy to ‘see new faces’. However, some did point out the advantages of having staff that ‘know you well, understand your needs and know where you are coming from’.

Participants reported mixed experiences in that some staff stayed for a long time and were very familiar, whilst others changed a lot. They did not always know which staff would be on duty during their respite session or stay. This was not a cause for concern.

4.2.2. Compatible groupings

One of the strongest and most emotive topics to emerge during the research was that of compatible groupings for respite.

Building friendships was one of the main reasons that people identified for using respite services. However, some participants had very clear views on who they would like to attend respite with. Several participants expressed a preference to go to respite with friends or persons they knew and liked. Others were open to an element of ‘surprise’ and happy to ‘get on with whoever is there’.

“I like to have a say in who I go with and spend my time with...that is important for me”

“I want to go with my friends”

“The group is a very big thing for me...people I know...that the group works”

“Well, I’m happy to go with whoever’s down there really. On respite here or anywhere you go, you’re always going to get people that you don’t quite gel with but because there are always six people, there’s always someone to get on with.”

Some participants were able to meet with a manager, discuss their preferences, request respite with particular friends, give their input into potential respite groupings, or meet other users in advance of respite stays. In other organisations or centres, participants had no input whatsoever.

The reported practice in relation to the sharing of information about those using respite varied considerably. Participants in one service reported that the recent General Data Protection Regulation (GDPR) has changed the information they receive prior to a respite stay. GDPR is a new set of rules designed to give European Union (EU) citizens more control over their personal data. As a result of this legislation participants reported that they can no longer be given any details about the other people attending respite.

“The other thing is that you don’t know who else is in the group, who else stays in the house”

“Well I think the older system was way better because you knew who you were going down with. Now since this new thing came in, it’s a bit strange. I actually like to know who I’ll be with... do you know what I mean? It’s a bit strange, you can’t be told in advance who else is going”

In other services, a list of those attending respite at different times was made available. Some participants had also consented to sharing their contact details with other respite users so they could communicate with each other between respite sessions.

4.2.2.1. Same gender groups

Some individuals with intellectual disability expressed a strong preference to attend respite services with persons of the same gender. They saw respite as an opportunity for ‘girl time’ or ‘a lads day out’.

“I like it with all my girls together...men...stop it...go away with that now...don’t bring that up”

“All lads is definitely best”

Some female participants explained that they were ‘uncomfortable’ with a male in the respite house at the same time, and so had stopped using the respite service.

“I used to but not anymore cos of the boy. I feel uncomfortable with a boy in there. I feel more confident with the girls...if he wasn’t there now, I would go back”

One older person, using an alternative respite service, suggested that a group of women had more shared interests which made deciding what to do easier. This individual, along with several other participants, suggested that groups of similar ages work best too.

One group of female participants suggested that it would be easier to cope with a mixed group if the male users were known to them, for example, attended the same day service.

Other participants were open to mixed gender groups.

“I don’t mind girls or boys...both is fine. I have two brothers, so I am an expert on boys”

“All boys is really great but if a girl wants to come...well you could say no...but I think I won’t mind”

4.2.2.2. Groups of persons with similar lived experiences

A small number of participants expressed a preference to attend respite with persons with similar disability types and similar lived experiences. This was particularly important to some individuals with acquired disabilities.

“I would prefer to be with other people like me...someone my own age who had an accident too...I don’t like waiting to see who will be here... I like someone I can compare notes with and have something in common with...that would do wonders for me”

A few participants with physical and sensory disabilities explained that they would prefer not to share respite settings with persons with intellectual disabilities.

“I have nothing against people. I just think our needs are different”

4.2.2.3. Persons with behaviour that challenges

Some participants voiced their concerns about sharing respite services with persons with behaviour support needs. This arose primarily during interviews with participants with intellectual disabilities.

“I like to be with good people that don’t cause trouble”

“I don’t want to be with a person that curses or calls names”

“I don’t want to go if there is fighting and shouting...that happens sometimes...I don’t like it”

One participant described how the behaviour of another person disturbed them during a respite stay.

“One person was up at night and was noisy...I was in the next room and was disturbed. I didn’t get any sleep”

Some participants highlighted that an incident of challenging behaviour can result in a ‘poor atmosphere’. One participant explained that ‘everyone is stressed and upset’.

4.2.3. Planning ahead and the provision of supports

One factor that contributes to a positive engagement with respite services is the provision of accessible information. Participants suggested that they get most of their information face to face from managers, day service staff and other users of respite.

“I got a lot of feedback from people who’d been there before me. In fact, all the feedback that I got from people who had been using the service before me was all positive”

Participants welcomed the opportunity to visit respite groups, houses and centres before taking up a place. They benefited from meeting staff and other users in advance. Some reported attending for coffee, open days, trial visits etc. They felt this was very reassuring and helped reduce any anxieties they or their family might have.

4.3. The negative aspects of respite

Four participants in this study had been offered a respite place but refused to take it up. Their reasons were clear – they did not want to be away from their families and preferred their own space. One person, offered a traditional respite service, did not want to spend more time in a disability service.

“...because I want to stay at home with Mam”

“I don’t like to have a break from Mam...no sleepovers”

“I want to stay as part of my family”

“I like just chilling out at home”

“I don’t want to do more disability stuff...prefer to do my own thing”

Most users of respite were extremely satisfied with their service. However, all were asked to identify any changes they would make if they had the opportunity. The responses to this question generated a number of themes relating to the negative aspects of respite.

4.3.1. Staff attitudes and expectations

Although participants were very complimentary about staff in general, a few individuals had experienced negative interactions with staff. A very small number of participants felt that staff could be rude or disrespectful at times. They disliked being told what to do by staff.

“I like staff to listen to me, I don’t like it when they give out to me”

One participant commented on the quality of relationships between staff, explaining:

“It is hard for us if they are angry between themselves...not getting on about something”

Sometimes participants did not agree with the policies and rules in a respite house or centre. They explained that in one location, staff determined the routine in the

centre, including bedtimes for persons using the service. These individuals accessed two different respite services and noted the contrast between them.

“The difference between them [two respite services] is that if I wanted to stay up late, for example, the latest at X [name of respite service] is 12, but the other house, [W], allows me to be up as late as I want”

“The reins are a bit looser in W [name of centre] ...you have more freedom”

“I hate the other place [X]...I am not comfortable there at all”

Two participants expressed the view that staff in respite services can restrict a person’s independence. One individual wanted to go out alone when at respite but was not allowed to for safety reasons.

“When I was out in Y [name of other respite house] I didn’t like it the last time because if I wanted to go for out for tea on my own, they wouldn’t allow me”

Another participant was frustrated when staff intervened during a shopping trip.

“I found that they didn’t let you be independent...you have to say it to them...I wanted to use the escalator in the shopping centre on my own... they said I had to use the lift with everyone else...I am able to use the escalator...I am used to it...I want to stay as independent as I am now and not be treated like everyone in the group”

One group mentioned that there could be difficulties with communication if staff have poor English.

“I do get on with other people but say if there’s a staff member...say if they’re speaking Spanish...I’d feel really nervous then cause I don’t speak Spanish. I need them to speak my language”

“I feel the same. I need to understand them, and they need to understand me”

4.3.2. Staffing levels

A small number of participants expressed concerns about the levels of staffing in respite houses and centres. They believed that more staff would allow for a more person-centred approach, with increased choice and less ‘group thinking’.

Participants were aware that some activities required staff to work flexible hours, for example, concerts, sports events, long distance trips. Levels of flexibility varied from one centre or organisation to another.

4.3.3. Transport and accessibility

Participants liked the rural location of some of the respite houses and centres. They did however identify the problems associated with this including accessibility and transport.

Public transport was very limited in some areas and so users were reliant on transport provided by the respite centre. In some cases, there was only one bus or

car available, or the wheelchair spaces were limited. In addition, not all staff were qualified or insured to drive.

“If the bus is not available, we cannot go out”

“We need more vehicles and more staff that can drive...sometimes you have to rush back so someone else can get out”

“There’s only one bus...it is a problem...it’s limiting...you are stuck in the house ...if the bus is gone you stay here”

Participants highlighted that some centres were located a short distance from villages and towns. However, the lack of safe, accessible paths and pedestrian facilities made it impossible to get into the local community to use facilities such as the shop, church or pub. Participants could not leave the centre without staff support due to road safety and accessibility issues.

“It would be great if we had a few things close by like a pub or coffee shop. Somewhere you could pop out to on your own if you wanted”

“The thing is if I wanted to go for a walk or anything around the town, they have to bring myself in because the roads are too dangerous, that main road is...there’s quite a few accidents on it”

4.4. The barriers and challenges to respite use

4.4.1. Lack of access to services

Respite services are limited, and participants reported waiting more than two years from the point of referral for a respite service. Some explained that respite services in their area had been reduced due to funding issues. In some cases, a respite bed had been removed from a residential house on the advice of the Health Information and Quality Authority (HIQA). Other participants reported that respite beds were taken up by individuals in crisis or by those who had complex support needs such as autism or profound disabilities. A shortage of residential places was given as one reason for people ‘blocking respite beds’.

“My Mam wants me to go to the respite house, but I can’t get in yet”

“We used to have another place to go but they had to take that bed away. Now there isn’t enough space for everyone that wants to go to respite”

Some participants were transitioning to adult services and this also caused delays in respite provision. These individuals explained that they had to join another waiting list for adult respite services.

“I had a group when I was in school. Now I am an adult, so I have outgrown that, but I have to wait again”

About half of participants were happy with the frequency of the respite they received. The remainder would like an enhanced service with more sessions/visits or longer stays.

“I’d like to go to respite more. If it was there, I’d love it”

“I’d stay as long as they would keep me”

One participant voiced concern about the equity of service provision, explaining that they received no explanation as to why some individuals received respite regularly and some did not.

“Another problem is that when I looked at the list, I found the exact same person going again...same people going nearly every month...no-one explains why different people get different respite...I would like to know cos I would like to go more”

Some participants seemed resigned to the fact that they had little choice in the type of respite they received, or in the frequency of their respite service. Some had little awareness of their right to complain about a service or lack of service. Others were disillusioned having fought for services in the past with little outcome. Many participants using traditional respite services had little knowledge or understanding of alternative forms of respite.

“I just fall into line”

“I’ll go whenever B [name of manager] asks me to go...he’s the boss”

“I just do what I am told...go when I am told...I don’t ask questions”

“I suppose I would like to try a different house, but no-one has ever asked me about that. I don’t know about any other kind of respite”

4.4.2. Lack of accessible information on respite services

There were significant differences between the experiences of adults with intellectual disabilities and those with physical and sensory disabilities, when it came to the provision of information on respite services.

Participants with intellectual disabilities reported that much of the information in relation to respite is shared initially with their family, and that much of the decision making in relation to respite lies with their family members. Some explained that their family member linked directly with a social worker or manager to request and arrange their respite visits. Some reported that letters in relation to respite are addressed/sent to their family member and not to them personally.

“The information and choice is with my parents...they decide if they want me to go”

“I go when I am told to”

“My social worker talks to my Mam about respite but not to me. She knows about it, but I don’t...she rings my mam but not me”

“I think someone else decides not me...I think my family does...the social worker checks with me about how I am getting on”

A small number of participants with an intellectual disability said that they made an independent choice to use respite. For many, the decision was made by or with their parents.

Participants also highlighted that the most useful information on respite came through discussions with keyworkers, managers and users of the service. They said they received very little accessible information on respite services. Participants said they should get more information on:

- The respite services available to them and what it can offer
- The different models of respite provision
- Rationale for the services offered and the frequency
- The dates and times of their respite service
- The other individuals using respite at the same time
- A contact person for information on the respite service and to share feedback and ideas

4.4.3. Lack of user involvement in respite service planning

Participants from all three participating organisations reported that they had little or no input at organisational level in relation to the design, development or provision of respite services. Very few were asked formally for their ideas when it came to respite planning. Some participants did say that the local managers of respite services often sought their feedback informally and asked about their experiences. Several explained that they completed a feedback form after their respite visits. They were unsure if this information had an influence beyond the local level.

A small group of participants explained that in one respite location, a survey was completed in the presence of staff. This made it difficult to answer questions honestly.

“At the start of the year you’re asked to do a survey and there are some questions to be mindful and wary of in how you answer them. One question could be are you happy or not happy with the organisation... You can choose to fill it out in W [name of centre] on your own, but you have to do it in X [name of centre] with a staff member present”

Only one group talked about advocating for a respite service. This group of young adults had recently transitioned from children’s services to adult services, and so were on a waiting list again for respite. This group explained that they had written and spoken to service managers about the respite they wanted. Some were using the person-centred planning process to identify deficits in their service provision. They were supported by staff in their day service to do this.

4.4.4. Inflexible models and supports

The respite services on offer to participants were often inflexible. Most participants perceived that social workers and managers made all the decisions in relation to the models of respite on offer and the frequency available.

Participants with physical and sensory disabilities felt they had some control over the dates and times of their respite stays. They said that their centre worked hard to accommodate their preferences for dates during the year. They expressed a preference for a booking system so they could request weeks well in advance, rather than waiting on weeks to be offered to them.

“I usually get the offer a few weeks in advance, so I have time to say I can’t take this week. They try and change it for me if they can, but it depends on availability. I don’t like turning down offers but unfortunately there are times when I have to”

Participants with intellectual disabilities had little knowledge of booking systems and offers as these were communicated mainly to family members.

Some participants talked about ‘being able to access respite when you need it’. A small number mentioned the need to request and access respite at short notice. Examples of ‘needing respite’ included when the person with a disability needed a break, when carers were ill or stressed, or when there were family tensions.

Overall, there was a sense amongst participants that they had little or no influence over the systems and processes within organisations.

5. Conclusions and Recommendations

5.1. Discussion

The themes which emerged from the data are broadly consistent with the findings of the literature review. Participants, across ages and disability types, shared many of the experiences, concerns and opinions of the adults, adolescents and family members in previous studies. There were very few differences between the experiences of users of traditional and alternative respite services.

Overall, participants were very satisfied with their respite services and rated the quality highly. In particular, they spoke positively about the homely environment, the range of activities on offer, the opportunities for friendships, the relationships with staff, and the sense of 'fun'.

Similar to the findings of the literature review, many participants were conscious of the needs of their carers recognizing that they need a break from them. The literature found that persons with physical and sensory disabilities were more aware of their carer's need for a break than persons with ID. This was also evident in this study.

Participants in this study, as in the literature review, also valued the opportunity for a break for themselves to 'relax' and 'recharge'. Although many participants welcomed a break from their family, they did not express a desire to have a break from colleagues in their day service. Whilst participants liked to meet new people, they still enjoyed the company of familiar friends and colleagues.

Concurring with the studies in the literature review, participants identified information on respite services as a key area for change. In addition, participants in this study, expressed concerns in relation to accessibility and transport.

In the literature review, participants described the negative feelings that they may associate with respite, for example, guilt or anger. Most participants in this study said they did not experience any negative emotions during respite. Some explained that tiredness or sadness (to be leaving respite) were the main emotions they felt after their visit or session.

Despite strong themes emerging from the literature review in relation to independence and skill development, most participants in this study prioritised having a 'good time' at respite. Several adults reported deliberately avoiding contact with their everyday lives in order to experience a 'real break'. Some were also very content to allow staff to 'do the hard work', again to enable them to have a break. It is important to note that often family members, staff, service providers and policy makers may place an emphasis on factors such as independence, goal setting, skill development or community engagement. It is important to ascertain if these aspects of respite are actually a priority for adult users; there were very mixed views in this study.

Participants described using different community services and locations during their respite sessions or visits, but interactions with community members appeared somewhat limited. Most respite centres and services were not provided in the person's own community and therefore opportunities to develop regular social roles were restricted. Chan (2008) found that persons with disabilities wanted their respite services closer to home. Parents and carers requested locations with community connections (Robertson et al., 2011; Phillipson et al., 2013). Despite these factors emerging as important in the literature review, several participants in this study requested respite away from their own community, for example, in rural settings or in a different city.

Although the literature found that users of respite wanted a range of models and options, this was not the case in this study where most participants were not aware of options beyond their traditional respite service. Those using alternative services did not specifically raise the issue of having options as being important. Participants did not tend to advocate or lobby for respite services. They reported having little involvement in service design and delivery. Some had little understanding of the funding arrangements for respite, or the rationale behind service prioritisation and allocation. There is a need for capacity building to support people to participate more effectively in service planning and design. If individuals have never experienced true choice and control, it can be difficult for them to identify what they want or need from services and supports, such as respite.

Some participants said they would like more access to respite but the frequency of respite did not appear to influence the outcome for the individual using the service. Several participants did note however that a long gap between respite stays can increase homesickness. Participants were aware that there is a demand for respite which is unmet. They talked about the need to 'share services' and 'take your turn'. Those on waiting lists would like a quicker response and access to services, and to be able to move from children's to adult services more easily. This is in keeping with the findings of the literature review.

Some aspects of person-centredness were evident in the information on respite services provided by participants. However, there still seems to be a focus on the 'group', and it could be challenging to meet individual needs and support personal goals within the resources described by participants. In the literature review, parents and carers expressed concern about compatible groupings for respite. Children and adolescents talked about their dislike for the behaviour of some other children. Compatible groupings emerged as a key theme and emotive issue for the adult users in this study. Several participants voiced their preferences in relation to groupings in both traditional and alternative respite services, for example, sharing respite with persons of similar age and disability type, not sharing respite places with persons with behaviours that challenge.

The topic of personalised budgets was raised by some authors and noted in the literature review. This topic was not brought up by participants in this study. This

may be because personalised budgets are a new concept to many persons with disabilities in Ireland and are not within the lived experience of the majority of participants.

The literature suggested that the cultural and spiritual needs of individuals were often not met in respite settings. This was not a finding from this study, but it should be noted that the group was quite homogenous.

5.2. Recommendations

A number of specific recommendations arose from the data. These are listed below.

5.2.1. Recommendations arising from the data

- Respite services work best when person-centred. They should be flexible to accommodate individual needs and circumstances, and to support personal choices and preferences. The research found that sometimes what a service provider thought a person needed, for example, building independence was not what the person wanted, for example, a break away from everything.
- Persons with disabilities need accessible information on respite services. The information provided should include respite models, local service information, service funding and allocation, policies and procedures. Information should include face to face meetings, opportunities for visits and experiential learning, easy to read information, videos etc.
- Service providers should engage with persons with disabilities, as well as their families, in relation to respite provision. In particular, service providers should consider the importance of compatible groupings and look at ways to engage with persons using respite services on this issue.
- Persons with disabilities should have the chance to influence the design and delivery of respite services if they wish. They may need specific supports to advocate for the respite services they need and want. Some individuals have limited lived experience of respite models and services and may find it hard to understand what a different service could look like.
- Transitions between child and adult services should be easier to navigate.
- Service providers should carefully consider the accessibility of respite centres to local community facilities. They need to be mindful of the transport needs of those using the service.

5.2.2. General recommendations

- It would be helpful if approaches to respite provision could be underpinned by a national policy for respite in disability services as part of a community-based model of service provision and as an element on a continuum of support.
- Although this study found little difference between people's views of traditional versus alternative respite, there was a strong sense that many people had only ever been exposed to traditional respite and didn't know that

other possibilities exist. There is room for the expansion of alternative forms of respite, preferably with the design and development of these having a strong input from service users.

- A number of new models for respite provision are emerging in Ireland that were not covered in this report. These include supported hotel stays and in-home respite. These new models have been met with mixed reactions from persons with disabilities. Further research will be required to examine the effectiveness of these models and the experiences of those using them. It will be important to ensure that hotels are built using universal design principals to increase the stock of hotels that are accessible.
- Although there were some good examples of person-centred supports in the findings, the group nature of respite services tempered the person-centred aspect somewhat. There needs to be a balance between respite services that are truly person-centred but also give people opportunities for social contact and spending time with friends.
- With the introduction of personalised budgets in Ireland, it is important to consider how respite could be accessed and funded in the future, and how funding arrangements might support the development of quality respite services.

5.3. Limitations of this study and areas for further exploration

Only service providers with an operating research ethics committee were approached to participate in this study. This tended to exclude smaller organisations, and this selection bias may have impacted on the study if the users of smaller organisations had different views from those of bigger organisations. There may also have been some selection bias due to the participants self-selecting following an invitation by a contact person in each organisation. Despite this, we feel we achieved a fair representation of users of traditional and alternative respite services in the study who provided a breadth of both positive and negative comments. We could not include persons with autism without an ID as there was no respite centre for persons with autism with an associated ethics committee. This is a potential area for further research.

Persons with severe and profound disabilities and those with complex behaviour support needs were not included in this research. At the time the research proposal was being developed there were many changes in the research consent landscape with the introduction of the Health Research Regulations 2018 (SI 314) and the establishment of the Consent Declaration Committee (CDC). As it is rarely possible to get explicit consent from this group of people, and because there was still some uncertainty around the application of the regulations and the working of the CDC, it was decided early in the design process to exclude this group. There was also a concern that if this group was included, because their views would most likely be given by a third party, such as a parent or carer, they may not be a true reflection of the person's views. Further research with this group of people is strongly recommended.

Family members also requested to participate in the study. It may be relevant to explore their views in a future study. The literature review identified that more research is need on the views of children and adolescents.

Not all types of respite were included in this study. There appears to be a limited range of respite services on offer in Ireland. This, in combination with a lack of research ethics committees in disability services, restricted the types of respite explored in this study. In addition, some groups using alternative models of respite, were approached to take part in the research, but declined to engage.

It would be helpful in the future to include participants engaging with other models of respite, such as 'home share' or 'host family' schemes, which although not widely used, tend to be more individualised than other forms of respite.

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7. Appendices

Appendix I: Topic Guide / Research Questions:

1. Tell me about your respite service
(building/location/staffing/transport/activities)
2. Did you get any information about respite services?
3. Do you know about different types of respite?
4. Why did you decide to use/not to use respite?
5. Did you need / Have you been given any support to help you get used to the idea of respite / think about using respite?
6. What supports would help you to use respite?
7. What things would stop you from using respite?
8. Did you get to choose your respite service / Have any other choices been offered to you?
9. Who decides when you go to respite?
10. How often do you go to respite? Are you satisfied with this?
11. Who do you go to respite with? Do you have any say in this?
12. What is your relationship with the staff in the respite service? Do they change often?
13. What are the good things about your respite service?
14. What are the things you would like to change about your respite service?
15. Who decides how you spend your time during respite?
16. Do you get the chance to try any new activities or to learn anything new at respite?
17. Do you get a chance to meet new friends or to catch up with old friends?
18. Do you spend any time in your community during respite?
19. Do you miss home when you go to respite?
20. How do you feel after respite (when you get back home)? Do you get any supports after respite if you need them?
21. Do you think your parents/carers miss you when you are at respite? / What do you think your parents/carers think of respite?
22. Does the organisation give you a say in how respite services are put together and run?

Appendix 2 – Consent materials – Easy to Read information leaflet

Appendix 3 – Consent materials – Plain English information leaflet

Appendix 4 – Easy to Read consent checklist

Appendix 5 – Plain English consent checklist

For the above appendices please see separate attachments.