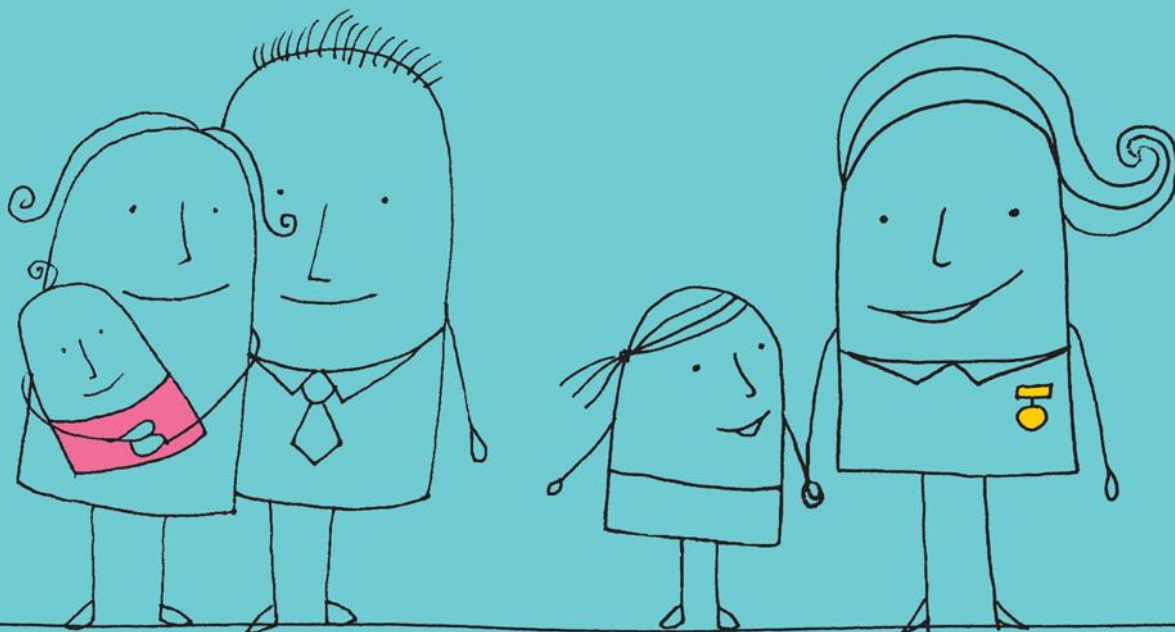


## Patient and Client Council

# Respite (short breaks)

The views of people with a learning disability, parents, carers and family members; and families and carers of people with Dementia

August 2011



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## Foreword

As parents and carers of adults with a learning disability and members of the Bamford Monitoring Group, we are delighted to have been invited to write this foreword.

We extend our congratulations to everyone who contributed to this excellent report, which provides a comprehensive cross section of opinions and aspirations of those who avail of respite services, and those of their carers.

The report identifies the positive and negative aspects of the provision of what is clearly considered to be an **essential service** and provides an insight as to how it can be improved in the future. There is also evidence that access to the service can often depend on where you live, which is unacceptable.

The needs of those who access respite are often complex and varied. It is crucial that these needs, together with the reasonable wishes/choices of those who use it, must be catered for if the service is to derive maximum benefit from the available funding.

Clearly the need for respite greatly outstrips the resources currently being allocated to it, despite the huge benefits it provides for the most vulnerable members of our society and those who care for them. As one carer stated quite simply, *"it's a life line... helping to keep me sane"*. Failure to adequately provide for person centred respite in the future will not only further disadvantage those who use it but is likely to put increased pressure on other aspects of the health and social care budget. It is therefore in everyone's interests to ensure that this vital service is adequately and intelligently funded in the long term.

We commend this report to you. It provides a valid and honest assessment of the value and pros and cons of current respite provision. More importantly, it issues a

challenge to the Minister, Executive, Assembly and service providers to not only provide all necessary funding but take action to ensure that it fairly meets the complex needs of the disadvantaged people who rely on their support.

Sandra Harris and Brian Sinnamon,  
Bamford Monitoring Group members

## Summary

The purpose of this report is to give people with a learning disability and the parents, carers and family members of people with a learning disability and dementia the opportunity to share their experiences of short breaks (referred to throughout this report as respite) and to determine what changes they have seen in the provision of respite.

**417** people completed a regional respite (short breaks) survey. **316** took part in 'Our Stories' events for people with a learning disability, parents and carers at which respite was one of the main topics for discussion.

The clear message coming from parents, carers and families of people with a learning disability and dementia is that **respite is an essential service**.

Most people agree that respite, **if** and **when** they can access it, is a good service. However, across Northern Ireland people feel that the respite service could be improved with **greater availability** and **more respite facilities** in their local area.

People are aware that respite allocation is limited because demand is high and resources stretched. When asked if respite (short breaks) have changed over the last 5 years the most frequent response from parents, carers and family members across Northern Ireland was that things have '**stayed the same**'. However, in the Northern and Western Trust areas some people believe that this is very much a local issue, that there is a shortage of respite facilities in their area and no budget locally to provide extra places. The majority of those living in the Northern and Western Trust areas feel that they have not received sufficient respite over the past 12 months.

There are a number of areas where parents and carers across Northern Ireland said that respite services could be further improved.

People would like more respite options and more alternatives to residential or nursing home accommodation. Again, parents and carers living in the Northern and Western Trust areas feel that there is a distinct lack of respite options available to them locally;

People need more information on the respite (short breaks) available in their area and advice on how to access it;

People need more information on and support when accessing a Carers Assessment and Direct Payments. **42%** of parents, carers and family members said that they **had never heard of a Carers' Assessment** and some of those who have had an assessment carried out are unsure that it had made any difference to their respite provision;

Some parents and carers feel that the respite (short break) service could be more flexible, especially in relation to advance bookings and late confirmation of dates and respite allowance for emergency or short-term breaks;

Transport to and from respite (short breaks) was an issue for some family members and carers living in rural areas;

Most people caring for a relative with dementia voiced some reservations about the respite they received, if indeed they had received any. They felt that only a limited number of facilities could meet the needs of someone with dementia;

It is clear from this report that parents, carers and family members of people with a learning disability and dementia really value respite and that this service is of utmost importance to them and to the person they care for.

## **1.0 Background and Purpose**

### **1.1 The Patient and Client Council**

The Patient and Client Council provides a powerful, independent voice for people. It has four main duties. They are to:

- listen and act on people's views;
- encourage people to get involved;
- help people make a complaint; and,
- promote advice and information.

### **1.2 The Bamford Monitoring Group**

In 2002 the Department of Health, Social Services and Public Safety (DHSSPS) carried out an independent review of mental health and learning disability law, policy and service provision. It was called the Bamford Review of Mental Health and Learning Disability, now known as the 'Bamford Review'.

Between June 2005 and August 2007 the review produced a series of 10 reports that made over 700 recommendations to improve mental health and learning disability services. It represented a far reaching vision for reform and modernisation of mental health and learning disability services in Northern Ireland. The Equal Lives report (DHSSPS, 2005) focused on reviewing policy and services for people with a learning disability.

In October 2009, the DHSSPS published the report 'Delivering the Bamford Vision: The response of Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability. Action plan 2009 – 2011' (DHSSPS, 2009). This sets out the specific actions that Government Departments and their agencies are committed



to take during the period 2009-2011 to improve mental health and learning disability in line with the Bamford Review recommendations.

The Bamford Monitoring Group has been set up by the Patient and Client Council to monitor how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability are affecting people and communities.

The role of the group is to find out from people with mental health needs, learning disabilities, parents, carers, family members and communities whether these changes are making a positive difference to them.

We want to know if people have experienced any changes to services in their area, if so what has been the effect of the changes on their health and wellbeing. We aim to make sure that the voice of people who have mental health needs, learning disabilities, families and carers is heard and acted upon.

The Bamford Monitoring Project Team of the Patient and Client Council carried out the field work for this project, information about the team is in Appendix 1.

### **1.3 What do we mean by ‘Respite (short breaks)’?**

Respite can mean different things to different people, but it is generally understood to be any sort of help and support that enables a person caring for somebody else to get a break. As part of the respite (short breaks) survey, people were asked to tell us what they considered respite (short breaks) to be, and further detail is outlined in this report.

However, within Health and Social Care, respite (short breaks) are defined as:

- *short-term, temporary relief to those who are caring for others, it is any activity or service of limited duration designed to provide a break for a dependent person and their carer/family from the usual routine;*

- *the activity or service can be provided on a planned or emergency basis to meet the needs of either the dependent person or the carer and to sustain the carer in their caring role;*
- *the distinctive feature of respite care is that it provides time-limited breaks for families and other unpaid care givers in order to support and maintain the primary care giving relationship;*
- *respite (short breaks) also provide a positive experience for both parties in order to enhance the quality of their lives and to support their relationship.*

Whilst this definition recognises that respite should benefit both service user and carer it does not allow for individual service users to initiate respite. For example, in the case of a service user who is also a care, the Bamford Monitoring Group are of the opinion that this does not accommodate the complexity of real lives and “cannot” see people wearing two hats.”

#### **1.4 What is the purpose of ‘Respite (Short Breaks)’ report?**

The purpose of this report is to present the views and experiences of people with a learning disability, as well as carers and family members of people with a learning disability and dementia, in relation to respite (short breaks). The aims were to:

- provide the opportunity for people to voice their opinions regarding respite (short breaks) in Northern Ireland;
- determine what changes people have seen to the provision of respite (short breaks);
- identify concerns regarding respite (short breaks) available;
- produce a report based on what people said, their views and experiences;
- use the findings in the report to advise policy and decision makers, if and how changes to respite (short breaks) are being realised and making a positive difference in the lives of people, and to parents, carers and family members.

Delivering the Bamford Vision (DHSSPS, 2009) made a commitment to developing respite services to support people with a learning disability, dementia and their families in Northern Ireland.

The Department of Health, Social Services and Public Safety made £3.2m available to invest in an additional 200 new or enhanced Learning Disability respite packages over the period 2008 – 2011 to benefit at least 800 people, including children, young people and adults (baseline 2007 / 2008). However, this was subsequently revised and reduced to provide 125 respite packages<sup>1</sup>.

The aspiration for respite services for people with a learning disability and their families is to “move away from traditional respite to the delivery of a more flexible and responsive service, taking full advantage of Direct Payments, self-directed support and other innovative forms of respite” (DHSSPS, 2009, P.121).

***‘support for individuals with a learning disability and their carers and families by the provision of short breaks and respite opportunities’ (Learning disability)***

***‘improve regional information on provision of respite care’ (Learning disability)***

***‘improve respite care for people with dementia’ (Dementia)***

*Source: (DHSSPS, 2009)*

The Department of Health, Social Services and Public Safety also made £0.6m available to invest in 2,000 additional respite places per year, for people with dementia by March 2011 (baseline 2007 / 2008). Again, this was subsequently revised and reduced to provide 1,200 respite places.<sup>2</sup>

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<sup>1</sup> Learning Disability; 1 respite ‘package’ is equivalent to 13 weeks or 2184 hours of residential care or 728 hours domiciliary care.

<sup>2</sup> Dementia; 1 respite ‘place’ is 1 week residential (168 hours), or equivalent in domiciliary care.

This report is necessary as it gives the views and experiences of people with a learning disability, and the family members and carers of people with dementia as **evidence** to determine:

- **if**, and **how** respite (short breaks) are changing; and
- whether people have noticed an improvement in respite (short breaks) availability (in line with the standards outlined above).

## 2.0 Our Approach

In order to find out what people think about respite (short breaks) the Bamford Monitoring Group took two approaches.

A regional respite (short breaks) survey was used to capture people’s views. Also ‘Our Stories’ events were held to bring people with a learning disability, parents, carers and family members together to discuss hot topics, such as respite. This included a conference in November 2010 and a series of nine regional workshops hosted throughout March 2011 across Northern Ireland.

In total, **417** people completed the respite (short breaks) survey and **316** took part in Our Stories events.

**Table 1: Respite (short break) survey responses (Total = 417)**

|                               | <b>Mental Health</b> | <b>Learning Disability</b> | <b>Dementia</b> |
|-------------------------------|----------------------|----------------------------|-----------------|
| <b>Family/Carer</b>           | 5                    | 258                        | 17              |
| <b>Individual<sup>3</sup></b> | 5                    | -                          | -               |
| <b>Easy Access</b>            | -                    | 132                        | -               |

---

<sup>3</sup> A number of family and carers completed ‘Individual’ survey on behalf of their relative and a number of people with a learning disability filled out an ‘Individual’ survey instead of the ‘Easy Access’ survey. Their answers have been incorporated into the appropriate sections of the report, and the figures in Table 1 adjusted accordingly.

## 2.1 Respite (Short Breaks) Survey

Bamford Monitoring Group members developed the questions and designed the respite survey. It was planned that the survey be aimed at individuals and family members / carers of people with a learning disability, mental health needs and dementia. Therefore, three separate versions of the survey were created to accommodate the needs of all groups, and thus allow everyone to share their views. Versions of the survey made available are as follows (copies of each are available at [www.patientclientcouncil.hscni.net](http://www.patientclientcouncil.hscni.net)):

- Family member and carer survey;
- Individual survey; and
- Easy access survey (for people with a learning disability).

The respite survey was circulated widely through voluntary and community contacts and networks, Health and Social Care Trust contacts and facilities, the Patient and Client Council membership scheme and the Patient and Client Council website. It should be noted that this survey was circulated through health and social care trust adult learning disabilities services only and did not specifically target children services. Although some parents and carers of children with disabilities have responded.

However, response to the survey was particularly limited from people with mental health needs, and from family members and carers of people with mental health needs and dementia.

For this reason, this paper reports only on the responses of people in relation to **learning disability** and **dementia**. Further work will be necessary to reach greater numbers of people with mental health needs, and family members and carers of people with mental health needs. It is also necessary to continue the work to gather the views and experiences of family members and carers of people with dementia, to strengthen this voice.

## 2.2 'Our Stories' conference and workshops

The Bamford Monitoring Group hosted a conference in November 2010 called 'Our Stories'. This conference was attended by 120 people with a learning disability, parents, carers, family members and people involved in supporting adults with a learning disability. During the conference, people with a learning disability, parents, carers and family members embraced the opportunity to speak out about several key issues including respite (short breaks).

Following the success of the conference, the Bamford Monitoring Group took the decision to reach out to people in their local areas. The team went on the road and hosted a series of nine 'Our Stories' regional workshops in various locations across Northern Ireland. Locations were chosen to be close to where people live.

The 'Our Stories' regional workshop were attended by 196 people and were particularly important in reaching parents, carers and family members of people with a learning disability. Details of the nine workshops are provided below; attendance across these varied greatly.

In total, **316 people** with a learning disability, parents, carers, family members and people involved in supporting adults with a learning disability attended 'Our Stories' events.

### 3.0 Our Findings

Findings from the respite survey are presented with numbers, percentages and weightings to quantify the numbers of people who raised specific issues. All of the diagrams presented throughout this report refer to results from the respite (short breaks) survey.

It was not always been possible to present the feedback provided as part of the small group discussions at 'Our Stories' events in this way. These comments have been integrated into the relevant sections of the survey results presented below. Additional comments posted on 'word walls' at the Our Stories events are in Appendix 3.

Therefore, in the discussion of findings readers should use the following as a general guide to the frequency with which people expressed a particular view:

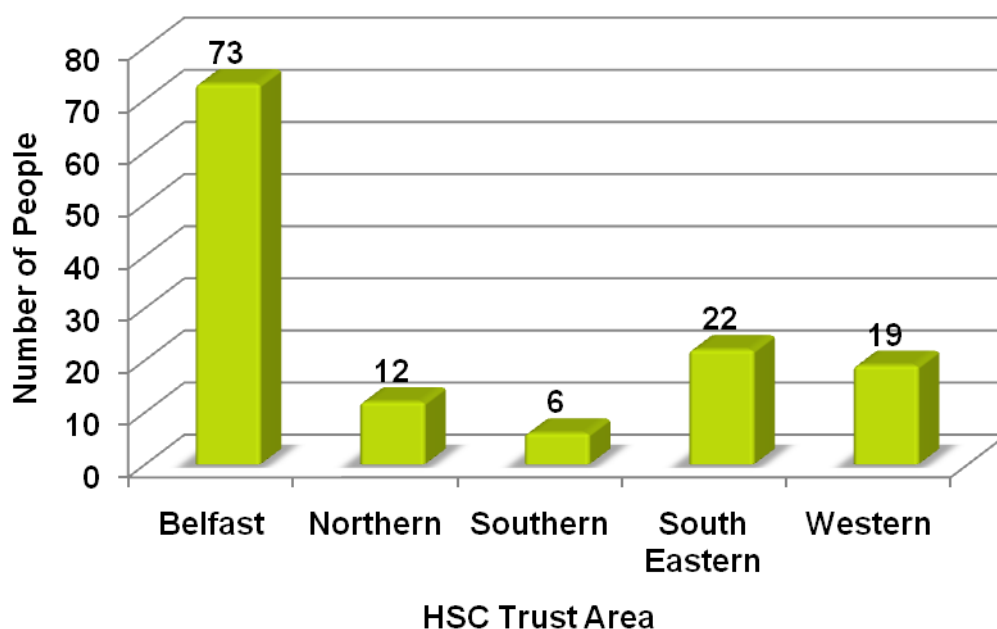
| <b>WHEN WE SAY:</b> | <b>WE MEAN:</b> |
|---------------------|-----------------|
| "few"               | = 10 % or less  |
| "some"              | = 11 – 25 %     |
| "many"              | = 26 – 50 %     |
| "the majority"      | = 51 – 75 %     |
| "most"              | = 75% +         |

### 3.1 What people with a learning disability said

This section gives feedback about what people with a learning disability said about respite (short breaks). **132 people with a learning disability** answered the respite (short breaks) survey, an equal number of men and women responded.

People told us where they live, and we have shown this information by Health and Social Care Trust area:

**Figure 1: Where people live by HSC Trust area**



#### **What do you think respite (short breaks) are?**

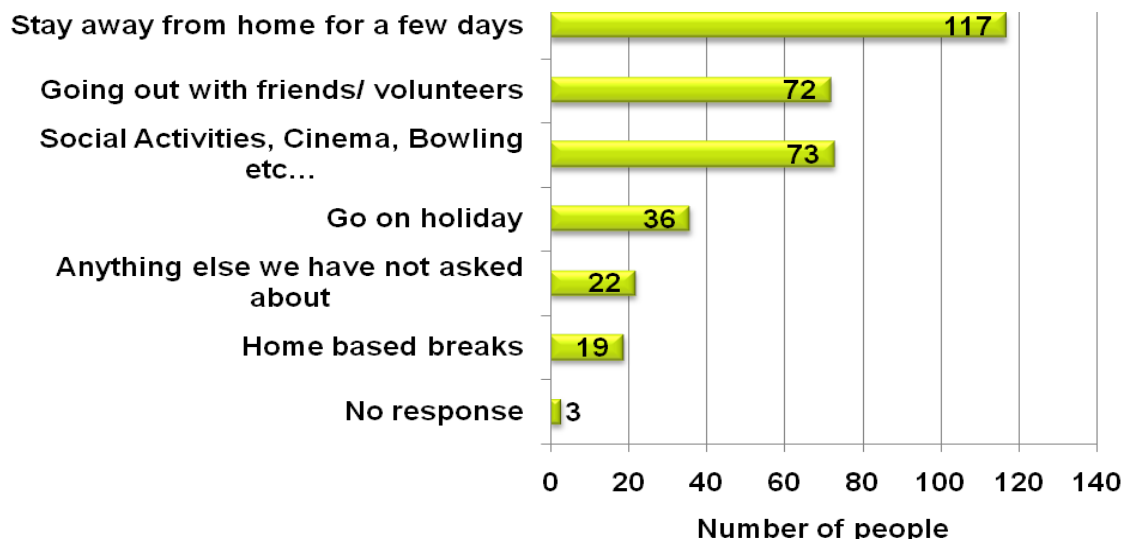
Most people said that respite was a short holiday, time away from home, “*time to relax*”. For others it was a change from their normal routine, “*a change of scenery*”. Most people agreed that respite was also a break for the family so that parents and carers could have a rest “*it gives mummy a wee break*”, “*it gives mum and dad a chill out time*”. Most felt that respite offered a mix of both, “*a break for my family and fun for me*”.

Many people said that respite meant “*getting out*” and taking part in social activities like going for meals, to the cinema, shopping, swimming, bus trips and going out with



friends. Some said that respite was an overnight stay at someone else’s house and a few said that they stayed with other family members. Many people felt that respite was time spent having fun with friends, a chance to meet new people and time to get the batteries recharged, “a place to try and get life into perspective”. A few people could not define what respite was but went on to talk about their respite experiences in the rest of the survey.

**Figure 2: What people do for respite (short breaks?)**

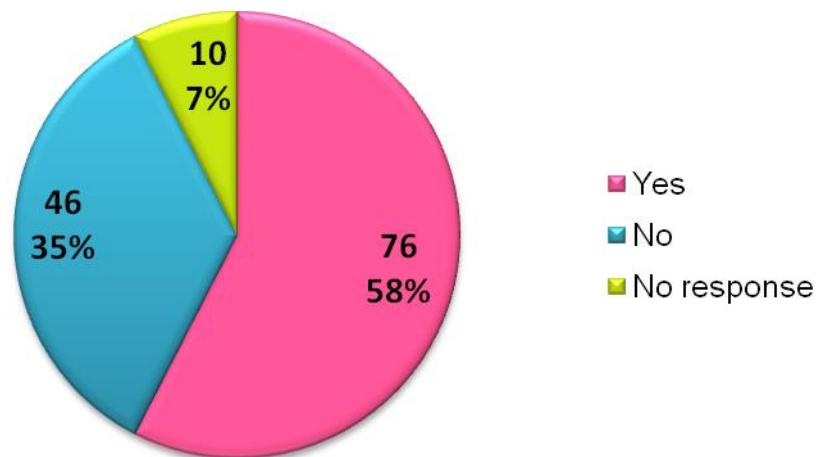


(Note: people could select more than one option)

**Choice...**

The majority of people (58%) said that they had choice in what they did for respite:

**Figure 3: Do you get to choose what things you do for respite (short breaks)?**



A few people felt they could not make their own decisions about respite, as one person said *“long term respite is decided for me – I am told when I am going to the respite unit”*.

A few people said they would like a bit more choice of respite; people wanted to be able to choose from a selection of places to go for respite, to have more choice over who they stay with, to be able to pick their own room, to have more options at meal times and more access for people in wheelchairs with mobility problems.

### **Respite (short breaks) are GOOD because?**

The majority of people said they enjoyed respite, *“it makes me happy”*, *“it gives me a break among friends”*, and it is a *“home from home”*. Many said that they liked everything about respite.

Many people talked about the personal benefits of respite, *“this is a time for me”*. They felt that it was good to get a break from routine and a welcome change of scene, *“it gives me a break from everything”*, *“I like a wee break to get my head showered”*. People said that respite provides a *“safe setting”*, *“takes away my worries”* and *“lifts the mind”*; one person felt that respite gave them a *“new perspective on my home life”*.

Many people also felt that respite was good because it gave their families a break, *“it gives my family a break as they look after me 24/7”*. One person said more about this, *“the carers who look after and care for people with a learning disability are very grateful for the short breaks as it enables them to have a more relaxing few days. It helps a lot”*. Some said it was good to give their families and carers a chance to recharge their batteries.

Most people talked about the different activities they like to do when on a respite break such as getting out on trips, going to the cinema, shopping, going for walks, swimming, cycling, eating out, watching football, going for a drink with friends, *“it gets you out away from the four walls”*. Other people said they like respite because it *“takes you out”*. One person said of respite *“I think it’s great”*; he liked his carers

making him cups of tea, trips out with the other people on respite and the fact that he still got to do his normal activities when he was on respite during the week.

A few people felt that respite helps build confidence and a sense of independence; one person said they liked going on holiday without their parents and another shared that *"I feel like an adult without mum and dad"*.

Most thought that respite was good because they got to spend time with friends and meet new people. Many said they like the *"craic"* at respite, spending time with old friends and meeting some new ones. One person said they are happy when it is all girls on a respite placement, *"we have girlie nights"*. Some people liked respite better when friends from the day centre were there at the same time, while others said they liked to stay in another person's house and spend time with different friends. A few people said that when they were on respite they liked that they were not told what to do.

Many said that they liked the supportive and friendly staff and host families who cared for them at respite. Some explained that they liked the respite staff because they take you out on activities, help you to settle in and let you stay up late. A few people said they enjoyed this time with other carers, *"staff are always funny and kind"*. Being looked after well by respite carers was important to people, especially as they are fully dependent on others for their daily needs.

### **I do not like respite (short breaks) because...**

Most people said there was nothing bad about respite but a few people had issues and concerns.

Some people said that they can miss home, family and friends, especially if it is a long respite break. A few people said that they can get bored at respite and would like to do more activities there. Two people did not like missing out on their normal day activities, such as the day centre, when they were at respite.

A few people said that they sometimes find it difficult to get along with others when at respite. Some added that they did not like having to share a room when at respite. A few felt that there were too many people at their placement; it was too noisy and sometimes other people could misbehave.

One person explained why he did not like respite and had decided not to go back. He felt that he had no choice over where he went for respite because his carer made that decision for him and when he was at respite he did not like staff making his tea, he preferred to do this himself. They never went on holidays and any trips they did take were to places near his house so they did not feel like a break. A few other people agreed that they had no choice over activities at respite; they just had to do what everyone else wanted.

Another person explained why he no longer went on respite; he hated his previous placement because no one spoke to him and he felt that because it was in a residential facility the staff did not have time for the people who were only there on respite.

A few other people mentioned problems with respite staff; individuals felt that respite staff were always busy which meant outings were short, respite was sometimes understaffed so their needs were not always met and staff were always telling them what to do when on respite.

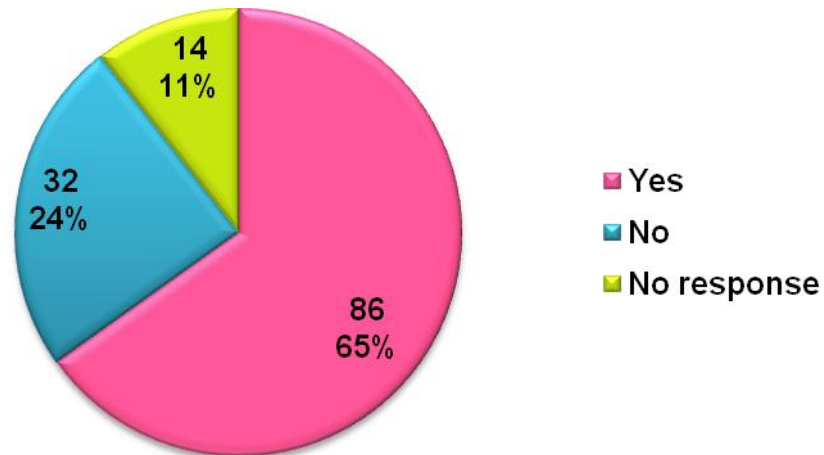
People talked about other things they did not like about respite; breaks were too short, respite was a holiday so they did not want to do chores when there and change could be difficult. One person said that they do not get to go on holidays because they were in residential accommodation and another said they no longer get respite breaks because their family cannot afford it.

## **Daily Routine**

We asked people if they were able to do their normal activities when at respite. The majority (65%) said that they missed doing the things they normally did each day. One person said that they spend too much time in their room when at respite and

they are not able to attend the clubs they normally go to each day. They said they were bored at respite and would like to do more activities when on a break.

**Figure 4: Do you miss doing things you normally do when you are at respite (short breaks)?**

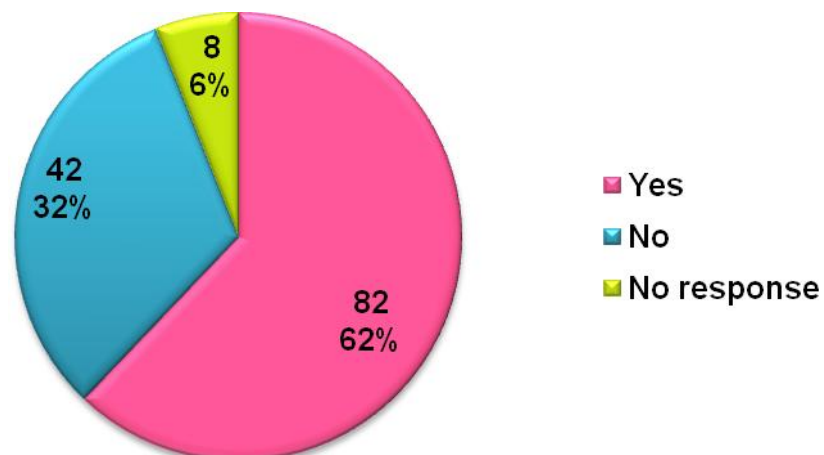


A few people said that transport to respite could be a problem, especially transport to and from the day centre when on respite. One person added that lack of transport meant lack of choice. Another person said that it was their own choice to take a “complete break” when at respite and not do the things they normally do during the week.

### Going to respite (short breaks)

We asked people if they had a say if they went to respite. The majority (62%) agreed that they did.

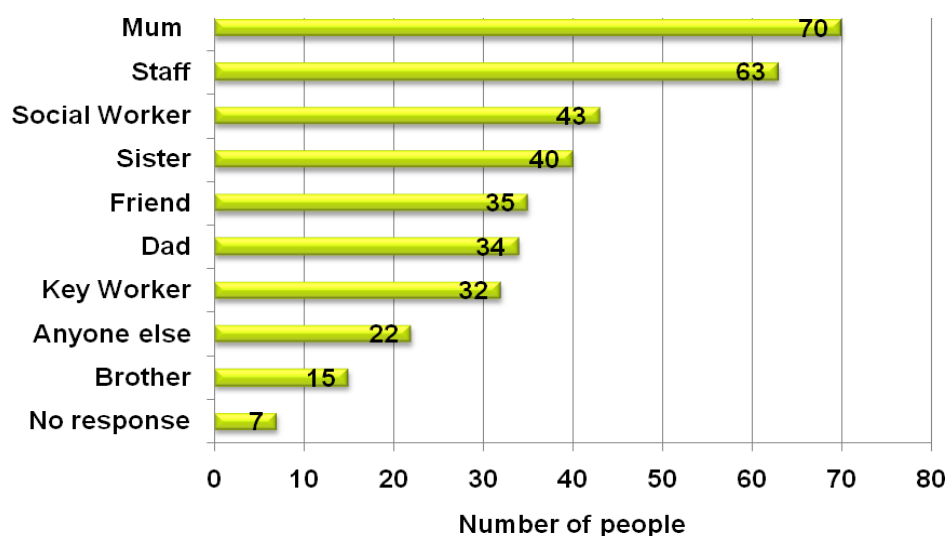
**Figure 5: Do you have a say if you go to respite (short breaks)?**



## Is there anyone you can talk to if you are NOT happy with respite (short breaks)?

The majority of people (86%) said that there was someone they could talk to if they were not happy with respite. Most people said that they would talk to their mum, staff or a social worker if they were not happy. In addition to the options given, people said that they would talk to their grandmother, cousin, sister-in-law and step-mum if they were not happy.

**Figure 6: Who do you talk to if you are NOT happy with respite (short breaks)?**



(Note: people could select more than one option)

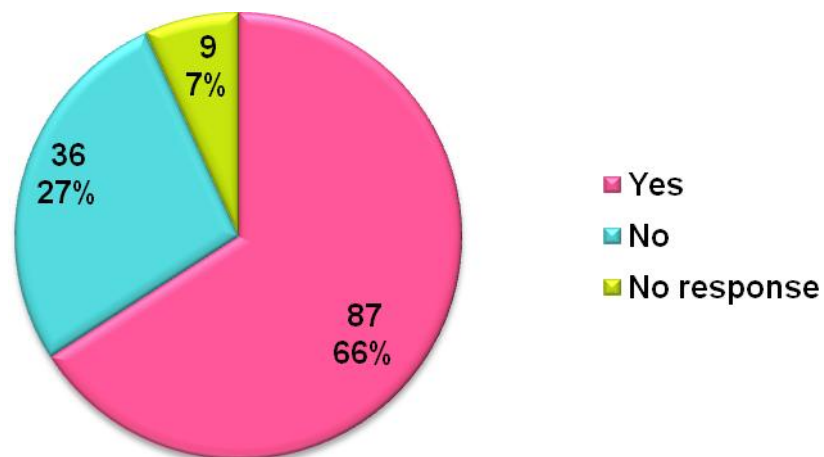
## What would you change about respite (short breaks)?

The majority of people said that there was nothing they would change about respite and a few said that they would like to go more often, *“I don’t want respite changed, I just want more breaks”*.

Some people said that they would like more activities at respite such as football, swimming, walks and outings. Some would like to go on longer breaks.

A few people said they would like to go on more holidays, have more relaxation time and to go out with their friends more when at respite.

**Figure 7: Would you like more respite?**



A few people felt that there were not enough respite places available. One person thought that respite availability was very limited and that it was difficult to get a bed in an emergency. Another person agreed there was a shortage of respite beds, *“I was in respite once for a week, I enjoyed it and I would like to go back but the social worker said no more available”*.

A few people had concerns about getting respite on the dates they wanted; they said they were just given random dates and felt it was difficult to get weekend placements. A few said that they did not like their current respite placement at all and would like to change. One person who used to have a respite placement would like it to start up again.

### **Is there anything else you would like to tell us?**

Many people wanted to add that they really enjoyed respite because it is fun, it gets you out of the house and you can spend time with friends. One person said that they would like their current respite placement to continue because *“my family and I both benefit from the break”*. Some people added that they like their respite carers and look forward to going, *“I have been at respite since I was three years old. I love going. I go every Saturday”*.

A few people agreed that they like making their own decisions at respite. Two people said that they were upset when they first went to respite but after a few hours

they settled down and began to enjoy it. One person said that they used to go on respite and felt it helped them prepare for a move into supported living.

A few people talked about their positive experiences of respite. One person explained that she lives in the community with her fiancé and goes to respite once a week so that they can get a break separately, *“it helps ease the pressure a bit”*. She said that she likes the company at respite and feels a bit more isolated at home, *“I think the respite is good”*.

Another person admitted that she was sceptical the first time she used the service because the respite placement was in a residential facility where people live full-time, she felt like she was *“stepping in their house”*. She enjoys it now *“once you get used to it – it’s something new, it’s a change”*. However she still felt it would better if respite was separate from where people live. A group who go for respite breaks in an old residential facility agreed; they believed that the service had improved since the people who used to live there had moved into supported living. They now find it quieter and are pleased to have their own room.

One person talked about how much they liked their new respite unit, but they did complain that they never get to see their social worker about respite. This person felt that staff sometimes do not listen when you say you are unhappy with respite; in their old respite placement they did not get to go to the day centre and had no say in when they had respite but felt they could not talk to staff about this. Another person said that the Share the Care scheme was good but the placement was too far away from home.

However, a few people raised issues with respite. One person said that they would like more respite at evenings or weekends so they can spend the night in their own home. They did not want anymore overnight stays because they found respite too noisy and did not like having to do the same things as everyone else.

A few people said that they did not like the place where they went for respite. One person said they go for a week each time to a local hostel; they would prefer to have



respite in a different setting but have been told that any alternatives are for two week placements only which they feel is too long. They said that the placement was very noisy at night, they do not get a proper rest and wake up early in the morning. One person felt that their respite placement was not suitable for them, *“I am not happy with the respite placement I go to because of the people they have in at the same time as me who are less able”*.

### **3.2 What family members and carers of people with a learning disability said**

This section gives feedback about what parents, carers and family members of people with a learning disability said about respite (short breaks). **258 family members and carers** of people with a learning disability answered the respite (short breaks) survey; this is what they told us about themselves:

- **The majority of people (84%) said they cared for one person**, the remaining said they cared for two or more people;
- **Most people (94%) said the person they care for lives in the family home;**

In the Northern, Southern and Western Health and Social Care Trust areas the majority of people indicated that they spent more than 12 hours each day carrying out one to one care for their relative. The remaining respondents said that they spent 1 – 12 hours in a caring role. While most people in the Belfast and South Eastern Trust areas also spent more than 12 hours each day caring for their relative, many others said that they spent 9 – 12 hours providing one to one care.

#### **Tell us about your relatives' care needs**

Parents, carers and families took a lot of time to tell us about the care needs of their relatives. Of the 258 people who responded 30% stated that their relative needed “constant” supervision or 24/7 care. However, it was clear from the remaining comments that many more people require a high level of supervision from their carers as an inability to assess or determine common dangers and a range of challenging behaviours meant their relative was always vulnerable.

61% of people said that their relative needed complete assistance with the activities of daily living such as washing, dressing, cooking, eating, toileting and continence care. In addition to helping with personal care needs, 30% people said their relative had problems with communication, such as speech, hearing or visual impairment

and 29% people said their relative had a physical disability which meant they also had to provide assistance with mobility, walking and going up and down stairs.

21% people looked after relatives with additional medical conditions such as epilepsy, diabetes, heart and kidney conditions. A few people added that they had to supervise medication, provide practical help such as shopping, housework and financial guidance and help to transport their relative to day activities and social events.

Parents, carers and families also spent a lot time caring for their relative's emotional needs; they were there to listen, motivate, reassure, counsel and offer guidance.

***“We cater for every need.”***

***“I am so proud of my son but he will always need supervision.”***

***“[Our son] wants constant attention in short breaks of 1-2 minutes ... we have a forty-three year old man and a six month old baby in one.”***

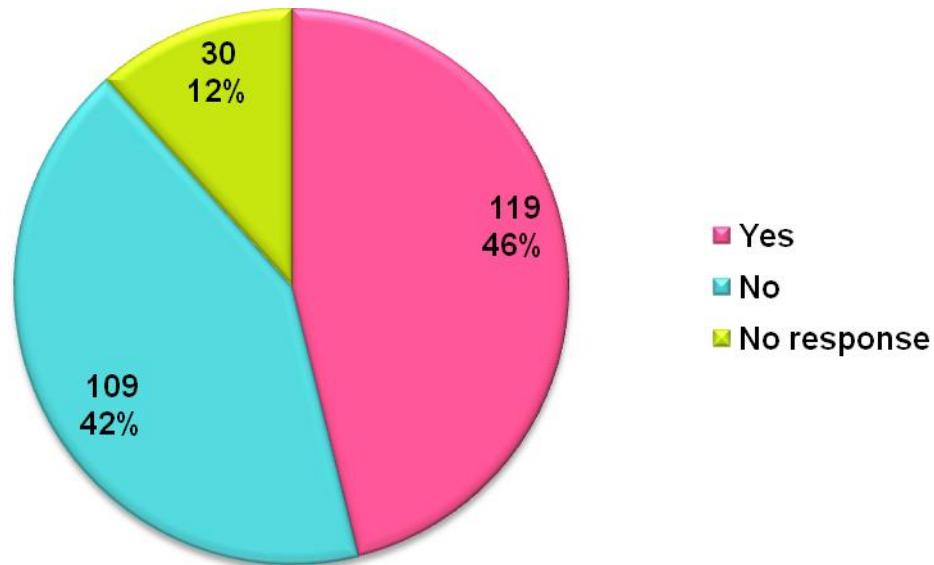
## **Carers Assessment**

Families and carers who indicated that they had heard of a Carers Assessment ranged from 39% of people in the Southern Trust area to 55% of those in the Northern Trust area, with the percentage of people in the remaining Trust areas falling between the two. People in each area commented further on this process.

Some people said that having a Carers Assessment was a positive experience and felt that the outcome had changed their situation for the better. Many of those who responded positively talked about the help they received from either a social worker or a community nurse; they felt that they had been talked through the process and

that the carer's needs and worries had been taken into account. One person added that it was a long but in-depth assessment that covered every aspect of their needs.

**Figure 8: Have you heard of a 'Carers Assessment'?**



However, some people felt that the Carers Assessment was difficult to access, especially as carers had to request one personally because it was not automatically offered to families. People said that they had repeatedly asked their social worker for a Carers Assessment; one added that they had waited seven years for one to be carried out.

A few people raised the question of qualification; two people said that they did not qualify for the assessment because they were over 65 years old, one person suggested that they could not have one carried out because they worked for the local Health and Social Care Trust and another felt that they had not been offered an assessment because of the nature of their daughter's needs.

A few people said that they found the process of having a Carers Assessment carried out quite daunting. People felt that the assessment took too long, that many of the questions were repeated and that the whole experience was quite stressful. Two people agreed that the Carers Assessment was quite an emotional experience as it was the first time they confronted the true extent of their caring role.

**Even though some people felt that the assessment itself was good, they were unsure if the process made any improvement to their respite provision.**

A few felt that while their needs were recognised by the social worker carrying out the assessment, they were offered little in the way of practical help. As one person explained, while the Carers Assessment itself was satisfactory, what a person needs and what they can get within adult services was not the same.

Some people were in no doubt that the Carers Assessment had made little difference to their situation. This was especially true in the Southern Trust area where most people said that after their Carers Assessment was carried out they were told that their needs could not be met due to a lack of resources; as one person explained, four years after they first requested a Carers Assessment from their social worker the outcome was “*unmet needs*”. Some people across the other Trust areas agreed that despite being assessed as in need of respite, lack of funding and resources meant that little or no respite was made available. A few people felt that the Carers Assessment involved a lot of paperwork with no end product; individuals described it as a “*pointless paper exercise*” and “*keeping the bookwork in order*”. One person said that the Carers Assessment was a “*waste of time*”; it may serve as a record of a family’s care needs but there were no resources or services available to put the recommendations into action.

The majority of people who indicated that they had not had a Carers Assessment said that they did not know why this was. Some people said that they did not actually know what a Carers Assessment was or if it was available to them. One parent added that they had never heard of a Carers Assessment despite having two social workers, one for each child they care for.

A few individuals raised issues of access; one parent said that since their son moved into Adult Services he no longer had a social worker to advise them on this process and another said they were advised that the Carers Assessment involved a lot of paperwork and would make little difference to their situation.

A few people said that they had not actually requested a Carers Assessment because they felt that their needs were currently being met. One person said that they chose not to have a Carers Assessment carried out because they felt that the process would be too intrusive.

### **How do you define Respite (Short Breaks)?**

The majority of parents, carers and families defined respite as a break from the caring role, time to rest, relax and recharge the batteries – a life line for parents and carers. Some carers added that respite allowed them to spend time alone with other members of the family.

Many also said that respite was a break for the person being cared for and a chance for them to spend time outside their normal living space. Some added that it offered their relative the chance to socialise with others and experience new things within a secure environment.

A few people felt that respite was preparation for the future, a chance for their relatives to become more independent and to grow accustomed to others providing for their needs. Some people just identified respite as a break in general, be that overnight, for a few days or a weekend. A few people felt that respite was a service that could be used in emergency.

***“A short time for me to re-charge and an excellent opportunity for my son to go on “holiday” as he calls it”***

***“Something for us both to look forward to”***

***“A rest for carers, to be a normal couple, have a life again”***

***“In our family, respite care is more for the benefit of our son, to give him somewhere different to go, meet new people, become less reliant”***

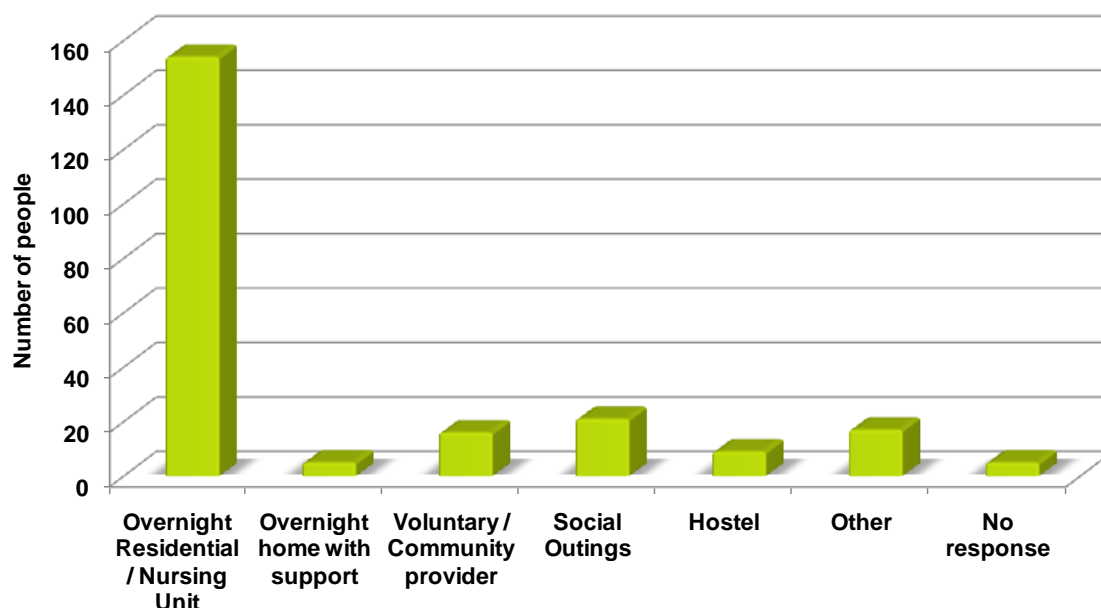
***“Respite for me is absolutely vital. It gives me the chance to recharge my batteries, catch up on some sleep deprivation, see family, friends, have a holiday that would otherwise be impossible. As the sole carer the respite gives us both the opportunity to get a much needed break from each other”***

***“To have a normal life outside the disabled bubble”***

***“At times they are a life saver”***

Most people (68%) said that their relative went to an ‘overnight residential / nursing unit’ for respite (short breaks), followed by social outings (9%):

**Figure 9: Types of respite (short breaks) accessed**



Many people had positive things to say about their experiences of respite. They said that respite was an excellent service which provided a necessary break for both them and the relative they care for; one person added, *“I would find life very difficult if I could not avail of respite”*.

Some people said that respite breaks in residential accommodation had worked well for them. This was especially true in the Southern Trust area, where many said that

local residential units provided a high standard of care and were well staffed; one parent described the respite unit as a “*home from home*” for their son.

A few people said that short breaks with host families were particularly good; they felt that the home environment allowed relationships to develop beyond that of a residential placement and that their relative was often made to feel like part of the family. Two people in the Belfast Trust area said that their relative really enjoyed social outings through Caring Breaks.

However, people did raise some concerns with the respite service. Some people found the service too inflexible, especially getting suitable dates or weekend placements, and others felt that there was not enough availability. Some people also questioned the range of respite options available and felt that there should be more alternatives to residential or nursing home accommodation. For example, one person said that overnight support within the family home sounded like a great service but they had only ever been offered residential respite placements.

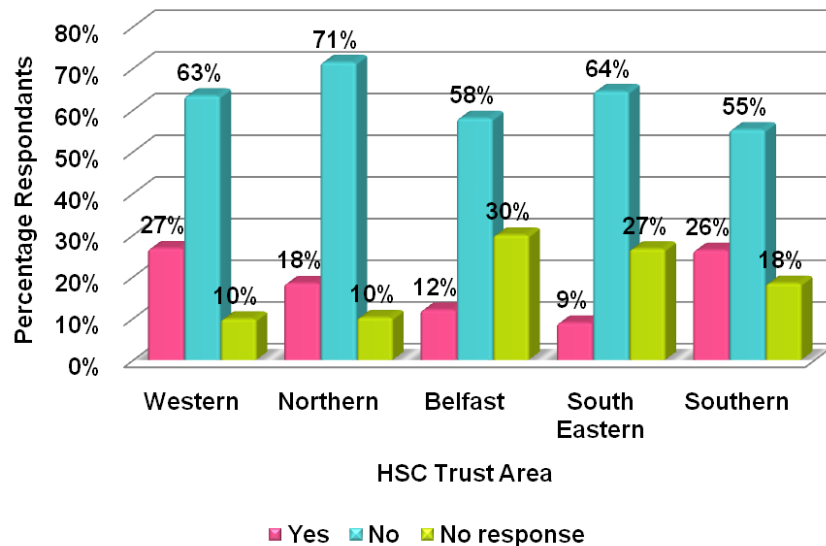
A few people said that their relative did not like to stay overnight in a residential setting. Others had reservations about the standard of care available in residential units; individuals shared that residential or nursing homes could be understaffed with little one to one care and that they often failed to provide for people with more complex needs. Another parent felt that the level of care at the residential facility their daughter used had fallen in recent years as there were no longer enough resources to meet demand.

### **Do you use Direct Payments to access respite (short breaks)?**

There was some variation in the percentage of respondents within each Trust area who said that they use Direct Payments to access respite. 27% of people in both the Western and Southern Trust areas said they use Direct Payments to access respite, compared to 12% in the Belfast and 9% South Eastern Trust areas. 18% of respondents in the Northern Trust area said that they use Direct Payments.



**Figure 10: Use of Direct Payments by HSC Trust area**



However, the observations of those who commented further on the system of Direct Payments were similar no matter which area they lived.

- **At least one person from each Trust area said that they had no idea what Direct Payments were or how they work – lack of information.**

The ways in which people used Direct Payments were also similar. Many people indicated that they use them to pay for holiday and weekend breaks, social outings and overnight breaks. Some said that they use payments to provide day activities or a sitting service for their relative. For example, one parent said that the payments allow their son 4 hours of social time with another carer each week, another said that they cover week long respite breaks for their daughter and one person uses Direct Payments to pay for domiciliary care.

- **Access to Direct Payments was said to be problematic.**

Some people raised the issue of accessing Direct Payments. A few said that they would like to get respite through Direct Payments but had never been offered this

service. One person said that they had been told after their Carers Assessment that Direct Payments were not available to them and another said that they had applied for this service more than six months ago but were still awaiting a response. Two people agreed that accessing Direct Payments involved a lot of paperwork, was “*tedious*” to manage and gave the carer more work to do; however one added that it was worth the effort so that their son could avail of 6 hours of respite each week.

One person said that Direct Payments works well for them at present as it offers their daughter the opportunity to go out and have fun doing something she enjoys while they as carers get a break. However, they also recognised that Direct Payments were extremely difficult and time consuming to set up and having gone through the process once would not do so a second time. One person felt that the system of Direct Payments was too complicated for the older carer to understand.

- **Beneficial aspect of Direct Payments is the ability to CHOOSE and have control.**

A few people did say that they use Direct Payments regularly; one added that it was useful to be able to personally choose their relative’s carer and another felt that they could not do without Direct Payments. A parent at an Our Stories workshop felt that Direct Payments arranged through a Carers Assessment were very beneficial to their daughter and they felt that this method of accessing respite gave those involved much more control.

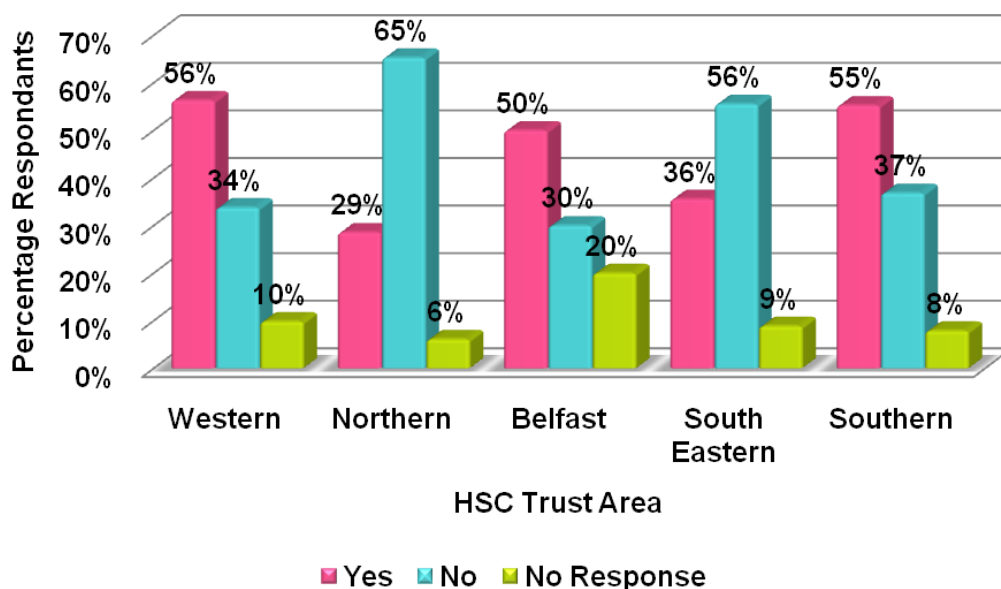
A few people agreed that after they were offered Direct Payments, they only used it occasionally or found that it was difficult to use the payments in the way they would like. For example, one person found it very difficult for people to employ a stand-in carer using Direct Payments because applicants could not be police checked or vetted and family members could not be used. They felt that this was particularly frustrating as people with a learning disability often find it difficult to deal with change or relate to new people so respite with unfamiliar staff in strange surroundings was not possible.

## Who helps you to access respite (short breaks)?

The majority of people said that their social worker or key worker helped them to access respite. Some people identified the community nurse as someone who helped them to access this service. A few people referred to their care co-ordinator or respite co-ordinator.

## Were you offered a choice of respite (short breaks) options?

Figure 11: Were you offered a choice of respite options?



Some people commented on the respite options available in their area. Most people in the Northern Trust area felt that respite options were very limited. One person said that they simply had to take what respite was offered to them and another said that if the local residential home was not suitable they had to find their own alternative. A few people felt that the only respite facility available in their area did not suit the needs of the person they cared for but said they were asked to use it anyway. Another person added that there was only one respite facility for children in the area.

Most people in the South Eastern Trust area who made further comment said that there were few options locally that suited the needs of their relative. A few people felt that choice was limited more generally. One person said that there would be more options if they looked outside the local area but their relative preferred to go on respite close to home and familiar faces.

Response was more varied from people in the Western Trust area. Many people did feel that respite facilities were limited and they had very few options locally. One person suggested that provision for children's respite was particularly poor and explained that they had to travel up to 160 miles to access a placement for their child. However, some people did say that they had discussed different respite options and were happy with the choice in their area.

In the Belfast and Southern Trust areas most people who commented further felt that they were offered a choice of respite options and that their respite preferences were accommodated where possible. However, a few people felt that their options were restricted because few places could provide for their relative's needs and one person added that there should be more respite places for people with behavioural issues. One carer explained that their relative was autistic and would not even consider using respite. Other parents agreed that there should be a respite facility that specifically provides for autistic adults.

- **People recognise that high demand for respite places imposes a limit on choice.** As a result, some also felt they had little choice when it came to dates or duration of respite breaks.

### **Frequency, Flexibility and Duration**

While some people in all Trust areas said that their current respite did meet their needs and those of the person they care for, many people identified issues with flexibility, frequency and duration of respite breaks.

**Flexibility** - Many people felt that the respite service was too inflexible and as a result failed to meet their needs or the needs of the person they care for. Much of

this inflexibility was in regards to respite dates. People said that they had to work around whatever dates they were offered, once dates were set it was difficult to change them, late confirmation of dates made it difficult for families to organise their own holiday and it could be difficult to book dates so far in advance. Individuals also felt that the days and times of arrival and departure from respite were too rigid, transport could be unreliable and that there was a shortage of overnight breaks. A few people also said that the lack of available emergency respite could prove difficult.

**Frequency** - Some people said that, while they were happy with the service, they felt that the frequency of respite breaks did not meet their needs or those of the person they care for. A few people added that as they were getting older they required more respite to help them to cope with the caring role but this need had not been met. One parent said that they care for two sons but is only allocated enough respite to provide for one and another felt that respite breaks were so infrequent and irregular that when they were offered it proved unsettling for their relative. A few people living in the Northern Trust area felt that there had been a recent reduction in the number of respite breaks they receive; one person referred to this as a “*drastic*” reduction.

**Duration** - A few people said that they would like longer respite breaks but the inflexibility of providers and a high demand for placements made this difficult. Others added that longer breaks would better suit their needs as it would allow time for the rest of the family to go on a holiday.

***“Respite depends on what if anything is available NOT what the person needs”***

***“Respite appears to suit the provider rather than the person availing of it”***

***“Respite has to be flexible otherwise it does not deal with the issues it is intended to address”.***

However, some people felt that their current respite was a good service that did meet the needs of the person they care for. Individuals said that respite was an excellent service, great in an emergency and somewhere for their relative to take part in activities that they could not provide at home; one person described respite as “a *lifeline*”. One person added that the respite facility they use was flexible, but recognised that they had to be accommodating too.

***“Excellent service. Top quality care. Small scale accommodation which suits my son who needs one to one care but is undemanding”***

***“I have excellent respite and we are very grateful and thankful to have such good people who have integrated [our son] into their life also”***

### **If the current respite (short break) is not suitable, have you been offered an alternative?**

Many of those who responded in the Belfast, Southern, South Eastern and Western Trust areas said that they had been offered alternative respite if a placement proved unsuitable. The exception to this was the Northern Trust area, where considerably fewer respondents felt that this was the case.

Most people in the Northern Trust area who commented further said that they had not been offered any suitable alternative because respite places and resources were limited. A few added that people are expected to take what respite they were offered, otherwise they get nothing.

A few people in the Western and Southern Trust areas agreed that they had not been offered alternative respite because there were no suitable alternatives in the area or any other options that had been offered were too far away to access.

***“There is nothing else on offer, this is the land time forgot and people accept it”***

Most people in the South Eastern Trust area felt that alternatives could be negotiated and that the respite service would try to accommodate them if possible.

### **When organising respite (short breaks) how far in advance do you have to book?**

In the Southern (38%), South Eastern (38%) and Belfast Trust (61%) areas most people who responded said that they usually book respite 6 to 12 months in advance. Of the remaining respondents, some said that they book respite 2 to 6 months in advance and a few said that they only book 1 to 6 weeks ahead. In the Belfast Trust area a few people indicated that they have a regular arrangement with their respite provider so do not have to book respite, one person said that their carer was very flexible and another said that their respite provider does not require advance booking.

However, in the South Eastern, Southern and Western Trust areas around 20% of people said that they do not actually book respite but were allocated dates by their social worker, a respite panel or by the respite provider they currently use.

Most people in the in Western Trust area indicated that they have to book respite 2 to 6 months in advance and some said that they had to book 6 to 12 months ahead. Response was similar in the Northern Trust area. A few people added that even if you do book respite months in advance you are not guaranteed the dates you requested. Some people in the Northern Trust also said that they do not book respite but are offered dates by their social worker.

In the five Health and Social Care Trust areas, many people who did use a respite booking service felt that it was good, organised and worked well for them. Some added that staff were polite, helpful and accommodating and usually provided for the

dates requested. A few people felt that the booking service worked particularly well if they were booking directly with the respite provider. One person in the Southern Trust area said that this method, being responsible for booking their own dates, was much preferable to the previous system of booking respite through a social worker.

However, some people felt that there could be some improvement in the service. Several issues with the respite booking service were raised across all Trust areas:

- **Many people felt that the booking service was too inflexible; especially as there was little allowance for emergencies or short-notice requests.**

Some people said that it was difficult to get the dates requested, especially for longer breaks, and once dates were allocated they could not be changed. A few people in the Western Trust area felt that the booking process could be slow and that it was often difficult to get in touch with the social worker.

- **Many people also had difficulties with advance bookings.**

Some people said they found it difficult to plan so far in advance. They felt it was unrealistic to expect people to know up to a year in advance what dates they needed, especially as it was difficult to account for special occasions or emergencies. A few people said that they have had to cancel respite in the past because it had to be reserved so far in advance. One person in the South Eastern Trust area suggested a that a more casual “drop in” centre that their relative could occasionally access few hours respite at short notice would be a useful service.

- **Late confirmation of respite dates; makes it difficult to plan ahead.**

Some people said that, despite booking months ahead, dates were only confirmed a few weeks in advance of the respite break which made it difficult for people to make their own plans. People said that confirmation at short-notice meant that it was often too late for them to arrange holidays for the rest of the family. One person suggested that it would be helpful to have a more organised rota for families and



carers to plan around. A few people added that the respite billing system was badly organised and that they often had to wait months to receive a bill which made organising finances more difficult. People said that respite providers had to realise the carer's need for planning; they wanted quicker confirmation of dates and more time to plan.

The response of a few people in the Northern, Southern and South Eastern Trust areas was "*what booking service?!*" They felt that they had no facility for booking respite, which made planning for respite breaks impossible. One person said that the booking service that did exist was not a fair system; they felt that respite dates were not allocated on a needs basis but that "*those who shout loudest*" seemed to get the most.

### **How accessible are respite (short breaks)?**

Most people said that in terms of location and transport respite was very accessible. This response was particularly high in the Belfast Trust area, where no one felt that their respite placement was difficult to access. However, outside the Belfast area, some people did raise concerns with transport to respite.

Almost a quarter of people in the Northern Trust area felt that respite was either difficult or very difficult to access. A few people in the Southern, South Eastern and Western Trust areas also stated that respite in their area was very difficult to access.

A few people said that due to a lack of transport provision they had to take their relative to respite placements which were often a considerable distance from home. One parent said that without transport between home, day care and respite, a 3 day respite break would be reduced by 30%. Another parent had already experienced this; the bus would transport their son to respite but not his overnight bag, they had to leave this off the first evening and then collect him early on the third morning which reduced their "weekend" break to one full day. A few other people also mentioned that the school bus would take their relative to respite but not their belongings, so they had to leave the bag to respite themselves, turning what was supposed to be a "break" into an inconvenience. A seemingly small issue like

transport can have much larger implications for families and carers; for example if transport between respite and the day centre was removed then either the respite unit would have to provide the necessary stimulation for those missing out on day activities or their relative would no longer be able to avail of this service. They suggested that proposed cuts do not take account of the “*real life*” of carers and their relatives.

A few people added that while transport to respite was provided, travel costs were not covered.

### **Does your relative have access to their usual day activities when on respite (short breaks)?**

Most people said that their relative continued to have access to their usual day activities when on respite. One person added that the respite facility their relative attends is very good in ensuring that this is the case and even organises extra social activities and outings. Many said that this was possible because transport to and from respite was provided. A few people wanted to emphasise how important it was for their relative to have a normal routine when on respite.

***“Yes that is why we prefer local respite and would recommend that local respite for clients from the immediate surrounding area be of primary importance”***

***“This is good as my brother needs routine in his day. Being able to attend his local adult centre when on respite is crucial”***

However, some people said that distance and a lack of transport meant that their relative did not have access to their normal activities when on respite. Some explained that their relative would not get to keep to their normal routines if they did not collect them from respite and leave him them again once the activity was over. A few people said that their relative did occasionally miss out on day activities when on

respite, especially as transport could prove unreliable. A few others said that their relative was not always able to attend social evenings or church when on respite.

***“I feel this is a very big minus that she can’t access day care and this leads to boredom”***

### **If you care for more than one person in the family how do you find coordinating respite (short breaks)?**

A few people talked about co-ordinating respite for more than one family member. Most emphasised the importance of organising respite breaks for both relatives at the same time so that they could get a proper break. A few people felt they were fortunate in this regard because their respite provider always tried to accommodate both relatives a once. However, some said that they had not found a respite provider who could co-ordinate breaks.

***“You have to think how you are going to divide yourself”***

Some individuals talked about the extra challenges involved in caring for more than one relative. One parent explained that her son’s respite break was the only occasion she had time to focus on her brother and the rest of her family, especially as the relationship between the two relatives she cared for was strained. One person questioned why she could only claim Carer’s Allowance for one of her two adult sons despite being the sole carer for both; she added that respite breaks or holiday leave should be a standard addition to every individual’s care package. Another person agreed that the fact that she is caring for two people, her partner and her daughter, is not taken into account when she is being allocated respite. She said that arranging respite for her partner was not problematic as there were several places that could provide for him, but organising respite for her daughter was more difficult. As a result she never got a break on her own; her partner only goes to

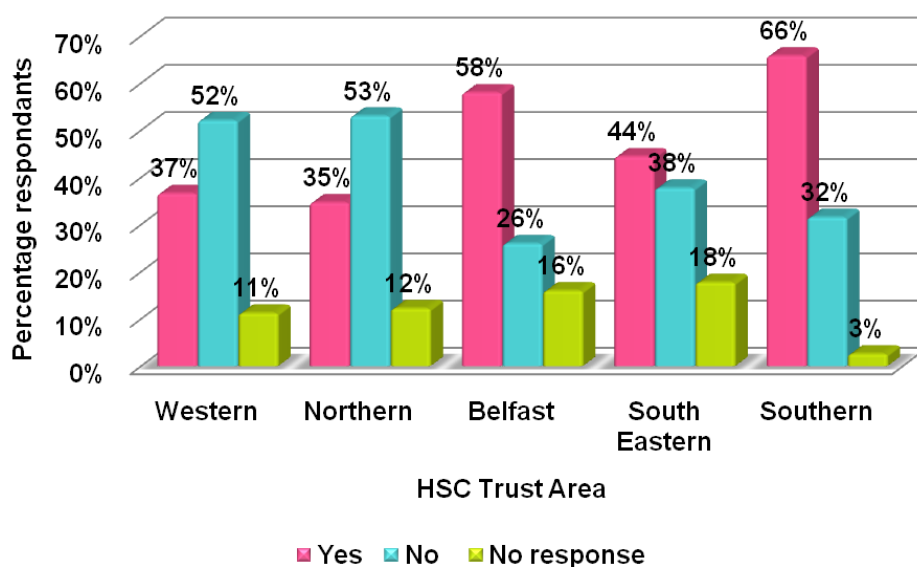
respite when she takes her daughter on holiday as she can not manage both relatives on holiday at one time.

One parent talked about the transition period between Child and Adult Services. They explained that one son was now going into adult services while the other was still in children’s services but it was proving difficult to accommodate both at the same time when it came to respite breaks. They felt that this situation needed to be addressed because if two relatives could not have respite at the same time then it would not be a break for the families and carers. Another parent agreed that it was difficult when one son went on respite because his brother, who was not entitled to respite, always wanted to go with him.

A few people shared their concerns about caring for young children and elderly parents as well as a relative with a learning disability; they felt that they often had to be in various places at one time and found it difficult to cope with little outside support.

**Do you feel as a carer that you have had sufficient respite (short breaks), over the last 12 months?**

**Figure 12: Have you had sufficient Respite over the past 12 months?**



People in the Northern and Western Trust areas were more likely to say that they had **NOT** received sufficient respite breaks over the past 12 months. Response was mixed in the South Eastern Trust area. However, people in the Belfast and Southern Trust areas were more positive; more than twice the number of respondents said they had received sufficient respite.

Across Northern Ireland people are aware that respite is limited because demand is high and resources stretched. However, in the Northern and Western Trust areas a few people felt that this was very much a local issue, that there was a shortage of respite facilities in their area and no budget locally to provide extra places. This may account for the fact that more people in these areas felt they did not receive sufficient respite.

***“We are very grateful for the respite we receive, a little more would be good but we know a lot of people need the service as much as we do”***

Some people explained why they felt that, as carers, they had not had enough respite over the past 12 months. Many said that while they appreciate the respite they currently receive they would like to avail of this service more often. Some people simply felt that they had not been given enough breaks and a few said that they had not received any respite at all over the past 12 months.

Some said that the respite breaks they did receive were not long enough to allow for a proper rest or a holiday. A few people added that they would like respite at the weekend in order to get a more valuable break, even if this was just for a few hours. Two people said that they would like to progress to overnight respite stays but this had not been accommodated.

Some people felt that the respite they received did not meet their current needs. For example, some people said that over the past 12 months their circumstances had changed but they had not been reassessed or offered additional support. A few

people said that advancing age and ill health meant that the caring role was becoming more difficult and that under these circumstances more respite was needed. One person added that they were also disabled and found it increasingly difficult to care for their relative with such little respite. Another parent believed that they were being discriminated against because they cared for two children but did not receive any extra respite.

***“As my son gets older and stronger and more difficult to manage, we become older and weaker and less able to manage. No account has been taken of this fact.”***

***“My sister’s needs changed on 3 occasions in the last year, now she has been referred for a wheelchair, my life is more restricted. I feel the Trust has let myself as a carer down. I am disillusioned ... there is no money and no facilities”***

A few individuals explained why they felt that the respite they received was not sufficient; one explained that they actually work more during their relative’s occasional respite breaks because it was a rare chance to get things done rather than to rest. One person said that they had no family support so respite was the only break they had from caring and another parent in a similar position felt that respite was particularly necessary over the summer months when their child was off school.

***“As a carer you have not just the person with special needs, you have the rest of the family and yourself, to look after, the house which needs cleaning, shopping needs done and so on. There are a lot of responsibilities. My need always comes last. So there are a lot of things that need attention and never enough of me to split.”***

## **How is your respite (short break) funded?**

Most people said that their respite was funded by the local Health and Social Care Trust or Social Services. 35 people said that they make a contribution to respite and the rest is funded by the Health and Social Care Trust. 3 people said that their respite provider was a charitable organisation that was financed through fundraising. 15 people wanted to emphasise that they personally pay for their relative to go on respite breaks and receive no financial help.

## **Positives about your current respite (short breaks)**

The most common response from parents and carers was that their current respite provided a good standard of care for their relative in a caring, safe and secure environment. Many people added that their relative enjoyed going on respite because it was a break away from home and a chance to mix with other people in familiar and friendly surroundings.

A few people added that they liked that their relative could still go to day activities, work placements and social events when at respite as a complete break from routine was not always welcome. One person felt that respite was good future planning for their relative as they would not always be able to live at home with their family and another said that respite had made them feel more confident in their child's ability to cope without them always there.

***“It’s good to know that my son is being looked after in a safe environment and that he is happy there”***

***“Friendly, caring, staff, unit is beautiful and welcoming, my son always enjoys his stay there and I always feel relaxed when he is there as I know he is well cared for and has a happy and rewarding stay”***

***“My relative looks forward to going. He is well cared for there and I can relax. It is close by, he gets to carry out his usual daily routine. It’s***

***exciting for him, to see others he likes. He needs the change and the breaks. The staff are competent and friendly. The home is cosy and comfortable. It makes my relative smile”***

Many people praised the knowledgeable, committed and caring staff that look after their relatives when they are on respite. A few added that feedback from staff on their relative’s time at respite was particularly reassuring.

Some people felt that respite with host families was a particularly positive experience; they praised the dedicated hosts who created a loving environment for their family member and another said that their son felt more at ease because he was staying in a house rather than an institution. A few people liked the small respite units their relative attends; they felt these were more homely, had a family atmosphere and felt less “*institutionalised*”; as one person added it was more like going for a sleepover with friends.

***“It is a home from home and staff are caring and professional”***

***“Staff in these facilities are exceptional – ensures that respite stays are a good experience”***

### **Any areas in which you think the respite (short breaks) could be improved?**

Across Northern Ireland many people said that the respite service would be improved with **greater availability** and **more respite facilities in their local area**. In the Northern and Western Trust areas some people felt that there was a lack of uniformity within the Trust area and that some areas fell particularly short of respite places.



A few people felt that they would like more social activities and outings for their relative when on respite; one person observed that their local respite facility could feel a bit institutional and another questioned if their relative was “*only sitting there to be minded*”. Two parents agreed they would like respite staff to provide more information on what their relative did while on respite, particularly if they have problems with communication; one suggested that this could be presented in the form of a respite diary.

Some people would like to have a greater variety of respite options. Individuals said that they would like to see more respite within the home, more units for adults with severe learning disabilities and complex medical needs, more respite with host families and better pay for those who do volunteer, a befriending service that provides respite for a few hours each week and smaller respite units which feel more like a home away from home.

Some people also raised issues about the type of respite facilities available in the Western Trust area. A few felt that large nursing home accommodation was not the answer; one person said that when their young relative returned from respite in an elderly nursing home their “*spirit was broken*”, they had been left sitting there with little to do and felt trapped.

- **More information about respite available and how to access it.**

A few people felt that there should be more information on respite entitlement and availability and more support for parents, families and carers trying to avail of this service. One person said that respite services should be better advertised so that people knew what was available. Two people felt that the Carers Assessment should be easier to access and that health professionals should be know about and offer this service.

A few people raised concerns about staff levels at their local respite facility. Two people felt that their relative could be better supervised when at respite and that

respite staff should be more experienced and better qualified. One person said that respite staff often change so it would be useful if they wore visible identification.

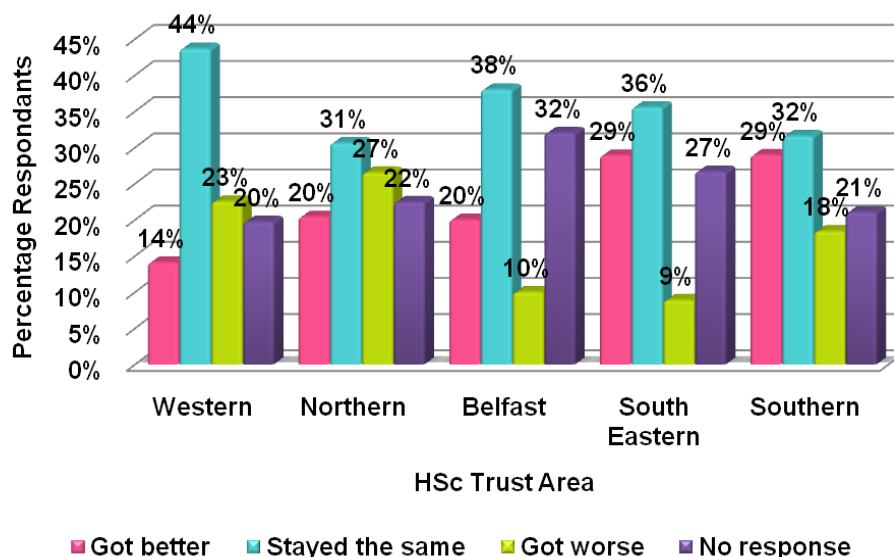
A few people felt that the transition from respite in Children’s to Adult Services could be improved. One parent said that their son was soon to turn 18 and they “dread” losing the 3 overnight breaks they receive monthly because available respite in adult services was virtually non-existent. Another parent agreed, suggesting that transition to adult services should be raised to 21 years. One parent added that there should be more co-ordination between the two services in order to accommodate respite breaks for those who care for more than one relative.

Ten people wanted to add that there was nothing they would change about respite; half of those were living within the Belfast Trust area.

### Overall have respite (short breaks) changed over the last 5 years?

We asked people if they had noticed any change in their respite over the last 5 years.

Figure 13: Overall has respite (short breaks) changed over the last 5 years?



In the Western Trust area a few people felt that respite had improved in recent years; one felt that this was because a respite co-ordinator had taken over from the social

worker and another explained that their relative could now access the day centre when on a break. One parent felt that respite had improved since their relative started going to cottage units for breaks rather than a hospital setting. Some said that the quality of the service and the standard of care provided had remained constant over the past 5 years. However, many people felt that there was less respite available now than 5 years ago. For example, one person said that their relative had been attending the same respite facility for almost ten years and had recently had their allowance reduced from once every 6 weeks to once every 12 weeks. One person added that their local respite facility had changed its client base over recent years which meant it was no longer suitable and another carer said that their relative was still going to respite in a nursing home environment where elderly people reside. A few people said that staffing levels were poor at respite facilities; there was no new recruitment and some staff members were not fully trained. One person said they were disappointed that there were still no services in their local area.

Some people in the South Eastern Trust area felt that respite had improved over the last 5 years. A few people said that they now receive more respite breaks; one person felt that their respite facility had improved and another said that their relative has more outings since the respite provider got access to transport. However, a few people felt that respite had changed for the worse over the last 5 years due to an increasingly inflexible booking system and a reduction in the amount of respite received. In one case, an individual's respite allocation had been reduced from 62 to 18 days a year without any change in the circumstances of the family involved. Some said that they had not noticed any change in the respite service over the past 5 years.

Most people in the Northern Trust area felt that the amount of respite they receive had decreased over the last 5 years. Some people identified this as the result of no new respite places being made available in the area despite a large increase in the number of families in need of the service. A few people said that less frequent respite had made their lives more difficult and stressful; one parent said that their respite allowance was so drastically reduced in recent years that they had to leave

work to become a full-time carer. One parent felt that respite provision had declined since their relative moved from Child to Adult Services; they felt that there was less funding and poorer facilities for adults with a learning disability. In contrast, another parent felt that their situation had improved with the move into Adult Services, especially since their son had found a respite unit that suited his needs. A few other people agreed that respite services had improved over the past 5 years. One person said that the respite service their relative attends was modern and well-equipped and another felt that respite procedures and practices had improved in recent years.

Many people in the Southern Trust area felt that there had been no change in respite services over the last 5 years and that their relative had received consistently good care. Some people believed that respite had improved in the last 5 years; one person indicated that respite breaks had become more frequent, another said they could now access a local respite unit so their relative could keep to their daily routine and a third person said that nursing staff at a respite facility could now care for their relative with complex needs. However, a few felt that respite had become more difficult to access and less available over the past 5 years. One person added that the respite situation declined when their relative moved from child to adult services.

Some people in the Belfast Trust area said that the standard of respite care their relative received had been consistently good over the last five years. Some felt that things had improved. Individuals who noticed an improvement explained that they now had more overnight breaks each month, that staff had worked with their relative to ensure that he settled at respite and that their current respite provider was always on hand to offer extra help when needed. Only a few felt that the respite service was not as good as it had been five years ago; they said that the booking system was more inflexible, their relative no longer has access to evening care and transport issues cut short their weekend breaks.

## **Any other comments?**

### **Respite is an Essential Service – We Need More**

Across Northern Ireland people wanted to emphasise that respite is an essential service. People talked about the demands of the caring role and the mental and physical benefits of respite. However, many people felt that the number of respite facilities in their area was inadequate and that the number of respite places fell far short of demand. They were concerned about future respite provision due to financial cutbacks and an ever increasing demand for the service. People did recognise that the current budget was inadequate and could not meet the assessed respite need of families. Some added that they understood that their present respite allocation might be reduced in order to give other families and carers their share, but felt that if the service was cut it would be less effective and would no longer benefit anyone.

***“Overall the allocation of respite in certain areas is inadequate. There aren’t enough beds available.”***

***“Short breaks are an absolute necessity. The only change I would like to see is that there are more breaks available. It helps to keep us all sane”***

***“More than ever we see the need for respite to continue in good mental and physical health in order to care for a relative. Those who hold the purse strings do not see this and fall short in respite provision.”***

***“Respite is the only light in the tunnel which keeps us going. We would not change our son despite his needs and demands but we would like the professionals to swap places, walk in our shoes and get real! If our respite situation worsens then we know our son cannot remain with us at home and a permanent residential place will have to be found. This is much more costly in the long run”***

## **Emotional Experience**

Most people agreed that respite, if and when they can access it, is a good service. However, some parents, carers and families felt that there were emotional barriers to cross when sending a relative on respite and using this service could often involve a certain amount of guilt. People said that they did not really think of themselves as carers, just as a parent doing their job.

As one parent who rejected respite for a long time because they did not want to send their child away explained, *“I’m a mommy”*. She now recognises that respite offers her the opportunity to focus on her other children. Others agreed that availing of respite could be traumatic for families because, to them, it implied they could not care for their relative without help. For one person, the only way to get past this feeling was the belief that respite was of benefit their relative. Another parent said that it helped that their respite placement offers variety, familiar faces, preparation for the future and, above all, their daughter *“has a ball”* at respite.

## **Future Planning**

A few parents agreed that respite and independence go hand in hand and that short breaks should be aimed at preparing people with a learning disability for independent living outside the family; as one parent said when it works well, is an excellent stepping stone to future supported living. One parent felt that there should be a respite introduction scheme for people with autism who find the process stressful; they felt that lack of respite now might make it more difficult for the person to adapt to new environments in the future. Some people voiced their concerns about growing older and finding the caring role more physically and mentally challenging as a result. They felt that more respite would help to ease this process and aid in future planning.

***“As parents get older, and their sons and daughters get older too, we like many others have concerns and worries about how seriously the Trusts are planning for the ever increasing demand for respite services and the need to provide more residential places and facilities to meet this”***

## **Transition to Adult Services**

Some people raised concerns about respite provision within Adult Services. Parents were worried that their child would receive fewer respite breaks, or none at all, once they reached 18 years old; as one parent said, *“now that my son is an adult I feel that we don’t exist.”*

One parent questioned the practicality of moving their son from a respite facility after it had taken years for him to become comfortable and familiar with staff and surroundings just because he had turned 18; they felt this would be highly unsettling for their son. Some people said that age appropriate respite was very important; one parent suggested that it would be good to have a facility specifically for young adults so that they could mix with people of similar age.

One parent talked about caring for two relatives who fell between the two services; one son was in the process of moving into Adult Services while the other remained in Children’s Services. The lack of co-ordination and communication between the two teams made it difficult for her to organise respite for both sons at once; she described their situation as *“a family torn apart in the middle”*.

## **More Information**

Many people felt that information about respite could be communicated better. A few people said that they had not heard of respite breaks before taking part in this survey. One person suggested that getting respite was a case of *“who you know not what you know”*. A few people said they felt that getting access to respite very much depended on the social worker. At the Our Stories conference three people who had never been offered respite for their relatives said that they had little or no contact with their social worker. People also wanted more information on how respite provision was allocated.

***“[Respite] operates around social worker as a unique point of reference – no social worker – no short breaks – no direct payments – NO INFO”***

### **Respite Carers / Staff**

Some people also wanted to say that they were grateful to the staff that cared for their relative when at respite, “*these carers are our lifeline at times*”. However, a few added that more respite places were needed and they feared that due to the current financial climate the service would be cut back rather than expanded.

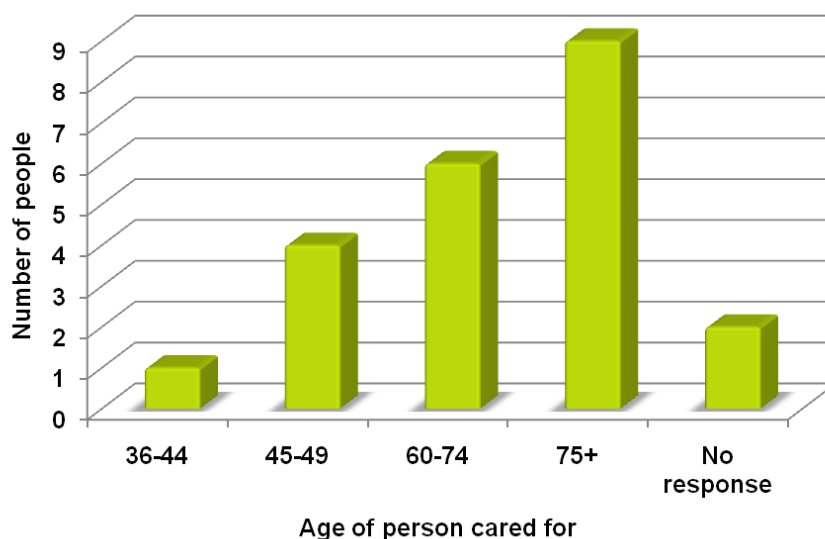
***“Carers do an amazing job caring with little or no reward ... The quality of respite is so important where clients feel safe and welcome and their needs are individually catered for. In our experience this has been so. So well done and thank you”***



### 3.3 What family members and carers of people with dementia said

This section gives feedback about what carers and family members of people with a dementia said about respite (short breaks). **17 people** answered the respite (short breaks) survey. The following chart illustrates the age range of people they cared for:

**Figure 19: What age is the person you care for?**



#### **How many hours, on a daily basis, do you spend carrying out direct one to one care for this person?**

The majority of people said that they spent more than 12 hours each day caring for their relative with dementia who lived at home with them. Only four people said that they spent less than 12 hours in the caring role each day.

#### **Tell us about your relatives care needs**

The families and carers of 17 people with dementia told us about their relatives care needs. A few people stated that their relative needed constant or 24/7 care; however it was clear that most people required a high level of supervision as they could become confused or forgetful when carrying out basic tasks.

Most people said that their relative needed assistance with personal care such as hygiene, dressing, cooking, toileting and continence care and activities such as eating, washing and taking medication had to be closely monitored. In addition to assisting with personal care, some people indicated that they had to provide practical help with mobility, transport to and from medical appointments, housework, financial and legal assistance. A few people said that their relative had additional medical conditions such as Parkinson's disease. Some people talked about providing for their relative's emotional needs as their dementia often caused them to feel confused, frightened or overwhelmed and families and carers had to comfort and reassure.

### **Have you heard of a Carers Assessment?**

Many people said that the Carers Assessment was an in depth assessment which discussed every aspect of the needs of those involved. However a few added that, despite this, they were unsure if it had made any difference to their respite provision. As one person said, the Carers Assessment itself was "*great*" but in the end their needs could not be implemented. One person just felt that the Carers Assessment was a "*waste of time*" as there were no available resources to meet the assessed needs of families and carers. One person described the Carers Assessment as an emotional experience because it was the first time they realised just how long they had cared for their relatives.

Of those who said they had not had a Carers Assessment, most people agreed that they did not know why this was the case. One person added they had described their situation to a sympathetic social worker on the phone but this was never followed up with a visit or the offer of a Carers Assessment. One person said they had been told why they could not have Carers Assessment but did not disclose this information and another said that they were not registered as a carer so could not avail of this service.

### **How do you define Respite (Short Breaks)?**

Most people said that respite was a break for carers and the rest of the family, a break from the routine of caring and a time to recharge batteries.

***“A way of building up energy to support your loved one”***

***“1-2 weeks where a vulnerable adult can avail of holistic care to enable family to have a break”***

Many people defined respite as a break in general, whether in suitable residential or nursing care or short breaks within the home. Some felt that that respite was necessary for both carer and the person being cared for. One person described respite as preparation for the future when their relative has to go into a care home.

One person said that their idea of respite was a sitting service for a few hours each week within the family home so that the carer could get a break; however they felt that this was something that their relative would really dislike.

### **Tell us a bit about the respite (short breaks)**

Only one person said that respite provided an excellent break for their relative. Most people had reservations about the respite they received. A few felt that a limited number of respite facilities could meet the needs of someone with dementia; for example one person felt that the nursing home their relative was allocated was understaffed and provided little one-to-one care and another said that the only available respite accommodation was not suitable as they often had to visit their relative when away from home to settle him. Another person added that, beyond overnight residential accommodation, there was little choice for people with dementia in terms of respite. One person felt that respite did not meet the needs of the carer because it had to be paid for privately. A few people said that they only used respite in an emergency or when they were really desperate for a break.

## **Do you use Direct Payments to access respite (short breaks)? If yes how is this used?**

Two people said that they used Direct Payments to access respite and both indicated that they use this to provide holidays and weekend breaks for their relative. One person who did not use Direct Payments felt that that the system was much too complicated for the older carer and questioned where carers and families find people to employ through Direct Payments.

## **Who helps you to access respite (short breaks)?**

Most people said that their social worker helps them to access respite. A few people identified the community nurse, one person the doctor and another person the Alzheimer's Outreach Worker as people who help them to access this service.

## **Were you offered a choice of respite (short breaks) options?**

Most people felt that that people with dementia had little choice of respite options. Only two people said they did have options.

***“Put dementia and disability together and you fit in nowhere”***

## **Do you feel the current respite (short breaks), meets the needs of you and the person(s) you care for?**

One person said that their respite was excellent and did meet their needs and those of the person they care for. However, most families and carers identified issues with frequency, flexibility and duration of breaks which meant that their current respite did not meet their needs.

Some people believed that they did not get enough respite breaks. One person said that this was due to a lack of reliable funding to provide respite beds. Another person said that they often had to go into hospital and these occasions were counted

as respite, but they felt that these “breaks” did not meet their needs as a carer. One person suggested that a certain number of beds in every nursing home should be reserved for respite.

A few people felt that no one cared that their current respite did not meet their needs. One person said that they could not find a suitable respite facility for their relative but “no one cared as there are no funds”. Another person agreed. “I am very stressed and have no help”.

Everyone who felt that their current respite was not suitable said that they had not been offered an alternative.

### **When organising respite (short breaks) how far in advance do you have to book?**

Only half of respondents said that they actually book respite in advance. Of these, most said that they book 2 to 6 months before the break and a few said that they book between 6 and 12 months in advance. Four people said they were not able to book respite but were just offered whatever dates were available, although one person felt that this system worked well for them. A few people responded that they were unsure how far in advance they have to book respite.

Those who did avail of a booking service for respite raised some issues. One person agreed that the respite booking service was just another unwanted pressure in the life of a carer. Another person felt that there was nothing in place for emergency breaks as all reservations were made so far in advance. One person said that when they were booking respite through their social worker the response was always the same, “because of cutbacks we can’t offer you the respite you need”.

More than a third of all respondents said that they had no knowledge of any booking service for respite. One person added that it was impossible for families to plan as respite could not be booked and that this was just an additional stress on the carer.

### How accessible is respite (short breaks)?

Many people responded that, in terms of distance travelled, transport and cost, respite was either very or somewhat accessible. Some people did indicate that respite was difficult to access but a few of those were not referring to issues like distance and travel but rather their ability to access this service more generally.

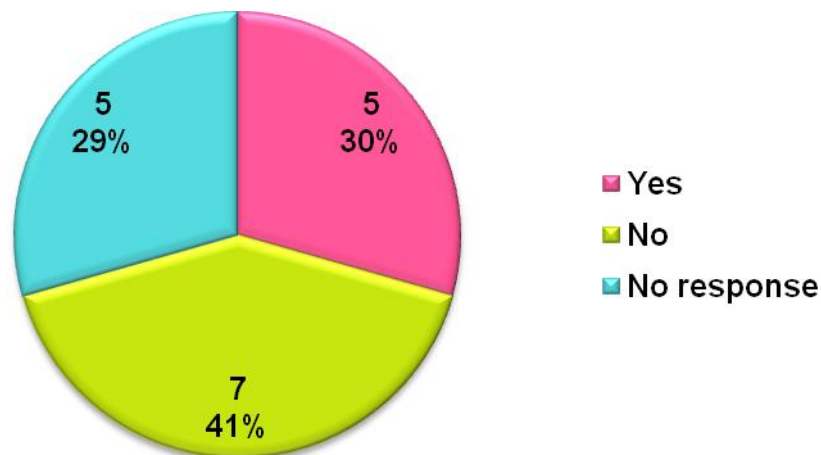
### Does your relative have access to their usual day activities when on respite (short breaks)?

Half of those who responded said that their relative did have access to their usual day activities when on respite. The other half said that this was not the case, although a few added that their relative no longer takes part in any day activities.

### Do you feel as a carer that you have had sufficient respite (short breaks), over the last 12 months?

Some people who felt that they had not received sufficient respite over the last 12 months commented further. Many said that their breaks were not frequent enough; some felt that there was no money to provide extra respite places, while others said that there were not enough suitable facilities in their local area. One person said that they had received no overnight care in more than a year, as the last time they had respite their relative had to leave early because the care home was not suitably equipped. One person repeated that they had never been offered respite by anybody within the Health Service.

Figure 20: Do you feel you have had sufficient respite



## **Positives about your current respite (short breaks)**

Some people said that their relative enjoyed going on respite. They were happy that their relative was in a safe and familiar environment and were well-cared for by competent staff. Some people also said that respite gave them, as carers, the opportunity to have quality time to themselves to rest and relax.

***“Able to go out without having to plan. To go to bed at night and have a full nights sleep. No having to organise somebody to come in while I can go out. Just to be able to run a bath and have a soak without having to rush. Able to go to the cinema or out for a meal with a friend”***

However, a few people said that they could not think of anything positive to say about their current respite; one person explained further *“I wish after 6 years I could say something positive but funding cuts and talking shop do not make it any better for these poor adults who normally love life”*.

## **Any areas in which you think the respite (short breaks) could be improved?**

Most people said that more information on the respite service was essential. One person suggested that social workers should actually visit carers at home to talk to them about the different types of respite available. Two people said that, as they had never even been made aware of respite, clear and accessible information would be the first step to improving the service. One person just responded that, *“having some would be good”*.

## **Overall have respite (short breaks) changed over the last 5 years?**

Only a few people responded to this question. One person said that the last time they were offered respite was four years ago, despite being 82 years old and struggling to care for their husband full time. Two people said that they did not know if respite had changed over the last 5 years because they had never received any.

## **Any other comments**

Many people wanted to reiterate that they do not receive any respite. A few said that they were really struggling in their current role as carer and had received no help or no advice or information on respite services. One person felt that it was “*totally unacceptable*” that no one within the Health and Social Care Trust had even mentioned that respite might be available to them and their mother. Another person said they now realise “*how little the Trust cares*” about their situation, as long as they do not complain.

A few people added that they were now elderly themselves and had their own health issues which made it even more difficult to care for their relative. A few others wanted to highlight the fact that the needs of the people they care for increase over time. They felt that as their relative’s condition deteriorates they will need more respite and more specialised care.

A few people thought that many available respite facilities were not equipped for dementia patients as they did not provide the level of supervision required.



## 4.0 Conclusions

The clear message from people with a learning disability, family members and carers of people with a learning disability and dementia is that respite and short breaks are **essential**.

Family members, parents and carers have taken great time to explain in their own words how difficult they would find life if they did not have respite (short breaks) available to them. It is a “*life line*” giving families the time to rest, relax and “*recharge the batteries*”. People with a learning disability also enjoy and value respite.

Many people across Northern Ireland praised the caring staff who look after their relatives on respite (short breaks). However, they said that respite (short breaks) would be improved with **greater availability** and **more local respite facilities** in their area.

We asked family members and carers if respite (short breaks) have changed in the last 5 years. Overall, the most frequent response from family members and carers of people with a learning disability is that respite have ‘**stayed the same**’. In Northern and Western areas the second most frequent response to this question was that respite (short breaks) have ‘**got worse**’, and in all other areas the second most frequent response was that they have ‘**got better**’. People in the Northern and Western areas were also more likely to say that they had **NOT** received sufficient respite over the past 12 months.

A further study will be required to capture the views and experiences in relation to mental health and dementia respite services.

There are several key themes emerging from the feedback:

- Many family members and carers are **unaware of Carers Assessments**. Of those who have had a Carers Assessment, some are still **unsure** if having a

Carers Assessment has made an improvement to their respite (short break) provision;

- Family members and carers require more **information about Carers Assessments** and how to access one;
- There is a **lack of information** about **Direct Payments**, and some difficulty in accessing them;
- General information on respite availability and process for accessing it needs to be clearer;
- Many people have said that the respite (short break) booking service was good, organised and worked well for them. However, improvements could still be made in flexibility around advanced bookings and confirmation of dates;
- Most people said that respite was very accessible. Although transport to and from respite (short breaks) appears to be an issue for some in more rural areas;
- Whilst there are fewer families caring for more than one person, the specific issues facing such families are particularly challenging. There appears to be a lack of co-ordination and communication between children and adult services to accommodate the needs of these families;
- Some parents and carers are worried about the transition of their children to adult services, as they are concerned that their son / daughter would receive fewer respite (short breaks) in adult services;
- Most people with a learning disability said there was nothing bad about respite (short breaks) and they would not change anything, except that they would like **more breaks**.

## 5.0 Recommendations

In addition to a further study in relation to mental health and dementia respite services, the Bamford Monitoring Group recommends that the following actions are taken to address the issues raised in this report:

- The Department of Health, Social Services and Public Safety should further develop and expand the provision of flexible respite (short break) services regionally.
- The Department of Health, Social Services and Public Safety should facilitate easier access to Direct Payments for respite (short breaks).
- The Department of Health, Social Services and Public Safety should develop new regional information regarding Direct Payments and Carers Assessments which is accessible and available to all.
- The Health and Social Care Board should continue to influence the uptake of Direct Payments and Carers Assessments regionally, by setting challenging targets for the next commissioning period and closely monitoring achievement of these.
- Health and Social Care Trusts should provide clear information about respite (short breaks) and the process for booking for people in their area. This should include details about family contribution towards the payment of respite (short breaks).
- Health and Social Care Trusts should ensure that all families in their area are informed about and offered the opportunity to access Direct Payments and Carers Assessments.
- Health and Social Care Trusts should ensure that there is greater co-ordination and communication between children's and adult services to

accommodate respite (short breaks) for families who care for more than one relative.

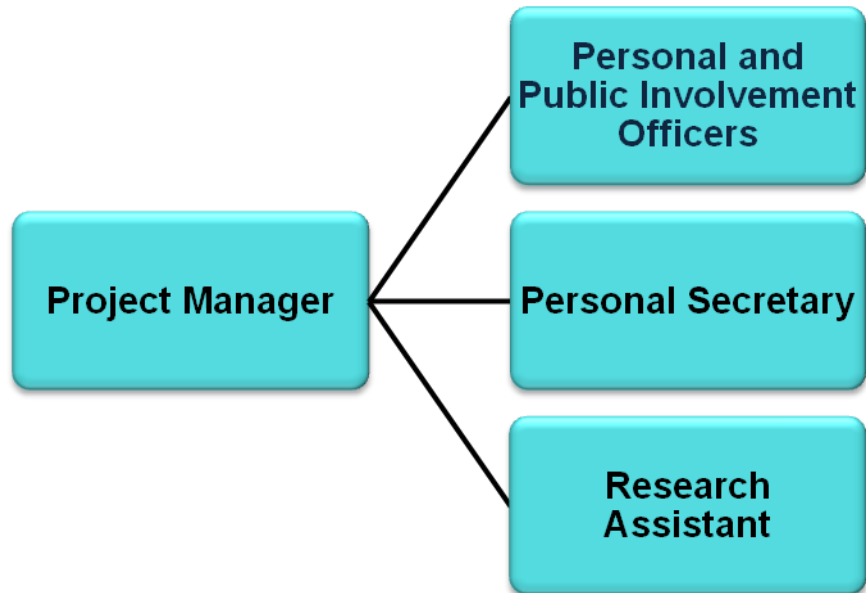
## **6.0 References**

**DHSSPS (2009) Delivering the Bamford Vision: The response of Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability. Action plan 2009 – 2011.** Belfast: DHSSPS (October 2009).

**DHSSPS (2005) Equal Lives: Review of Policy and Services for People With a Learning Disability in Northern Ireland.** Belfast: DHSSPS (September 2005).

## Appendix 1 – Bamford Monitoring Project Team

The structure of the Bamford Monitoring Group Project Team is as follows:



# Need more respite

*Downs Syndrome and Dementia. What's available if anything? The forgotten ones* More respite for

people living at home **More respite facilities – imperative for the good health, physical and mental health of carers. This is an urgent need!** *Respite*

*that provides adults with stimulating experiences* **What**

**Respite?** *People that don't have a family still need a break* It gives me a break to get time for my other kids

**Carers need care too!** *I am not*

happy because of the people they have in at the same time as me (less able) and I don't get to places all the time *Respite services should be for short periods as well as weekends etc. 1 evening a week and go home to*

*her own house afterwards* **Give**

**people a break** *People should not have to fight for support. I would like to go on respite as this is something I don't do* *More weekends putting people with disabilities first* **Why is there not enough respite beds for people?**

Long term respite is decided for me – I am told when I am going to the respite unit

**Suitable facilities for respite**

*More family based respite opportunities and more information about Share the Care*

**Need more respite for adults with learning disability and Dementia and other dual diagnosis**

*Is a ski-trip a respite option? 😊* Enjoy having privacy and independence

**More respite facilities and funding opportunities**

*A lot of money wasted in the health service* Lack of support for carers

**It is very important for carers to get a rest**

*Better training for staff on learning disability communication techniques*

**Good fun** *Still have own freedom as at home*

Concern that services will be maintained against a background of cuts

Doing activities together, going away together **Good**

**choice of things to do in respite** *For younger people with learning disabilities and autism if we are going to have 'share the care' will there always be other options open like "after school clubs" which may be more appropriate or a*

*parent may feel more comfortable with* **I think respite is very important for people to have a rest or go on holiday**





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