

The Moray Council
Education and Social Care

Adult Social Care

Accommodated respite review - consultation with service users and family carers

November 2014

(Draft v2)

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1. Background

Moray Council Adult Social Care provides or commissions social care services for people with eligible care needs.

The council has a responsibility to ensure services are meeting people's assessed needs in the right way to enable them to live the life they want in the way they want.

Respite care is an essential part of the overall support for unpaid carers and those with care needs, helping to sustain the caring relationship and enabling carers to have a break from their caring role.

Moray Council provides an internal accommodated respite services and also commissions external care organisations to deliver respite in their own buildings or buildings owned by the council.

In the financial year 2012/13 the council purchased total respite capacity of 5,800 bed nights. The actual number used was 3,835.

Self-directed support (SDS), which became a requirement for all local authorities in April 2014, brings significant changes to the way the council delivers and commissions services.

SDS introduces the concept of an indicative budget to meet the cost of each individual's assessed care and support package. The individual will be supported to decide how much **control** they want over how their support is arranged and how their budget is managed. They have **choice** over the kind of services they want to spend their budget on and use to achieve their outcomes.

To be sustainable services must be the ones service users choose to directly or indirectly spend their budget on.

In August 2013 Adult Social Care embarked on a review of accommodated respite services. The review identified under-utilisation of block booked respite. Figures range from 80% of capacity purchased in older people's services to less than 50% in learning disability services.

At a meeting of the council's Health and Social Care Committee on 4th December approval was given for consultation to be undertaken with service users and carers as part of the review of accommodated respite provision.

Adult Social Care undertook a process of stakeholder engagement to obtain the views of service users and unpaid carers on current and future provision of accommodated respite.

2. Summary

Respite is a valued service with many service users and carers expressing high levels of satisfaction with the current service.

Service users welcomed the quality of care they received, the variety of activities provided and the opportunities for social interaction with friendly staff and fellow residents.

Some, however, preferred to be at home.

Views were mixed on how future respite should be provided. More than half wanted to be with people their own age, 64% wanted to be with people who have similar needs and disabilities but conversely 57% said they would prefer somewhere that allows them to mix with people of all ages and disabilities.

The primary concern of carers was that respite must be a positive experience for the person they care for, with all social and care needs being met by caring and professional staff.

For carers, respite needs to be available at the right time and in the right place. Issues were raised around allocation of respite, how flexible it was, communication and difficulties around funding and transport.

3. Consultation process

The consultation sought the views of service users who receive an accommodated respite service from an internal or external provider and the view of their unpaid carers.

Service users and unpaid carers were identified using the council's CareFirst database system.

Two versions of the questionnaire were produced – one for people who go to accommodated respite services and one for carers.

An explanatory letter, consultation questionnaire and freepost return envelope was sent out via a mail shot. A link was also provided to the on-line version of the survey.

Recipients were offered the opportunity to contact a named officer for support to complete the questionnaire.

Six focus group sessions – in Forres, Keith, Elgin (x2), Buckie and Aberlour - were held for people who use respite services and carers to put forward their views.

The consultation ran for four weeks from 5th February 2014 to 3rd March 2014.

4. Consultation survey responses – service users

A total of XXX consultation forms were sent out to service users.

- 68 responses were received giving a return rate of XX.
- Responses were split equally between men and women
- 29% (n=19) of service users were aged 75 and over; 25% (n=14) were between the ages of 65-74
- 94% (n=63) had used accommodated respite in the past; 66% (n=44) said they were likely to use it again
- 8% (n=5) had used respite in the last week; 29% (n=18) in the past week; and 63% (n=40) in the past year
- 72% (n=42) preferred the term respite to short break.

4.1 Service user group

Service users were asked to indicate which client group they identified with.

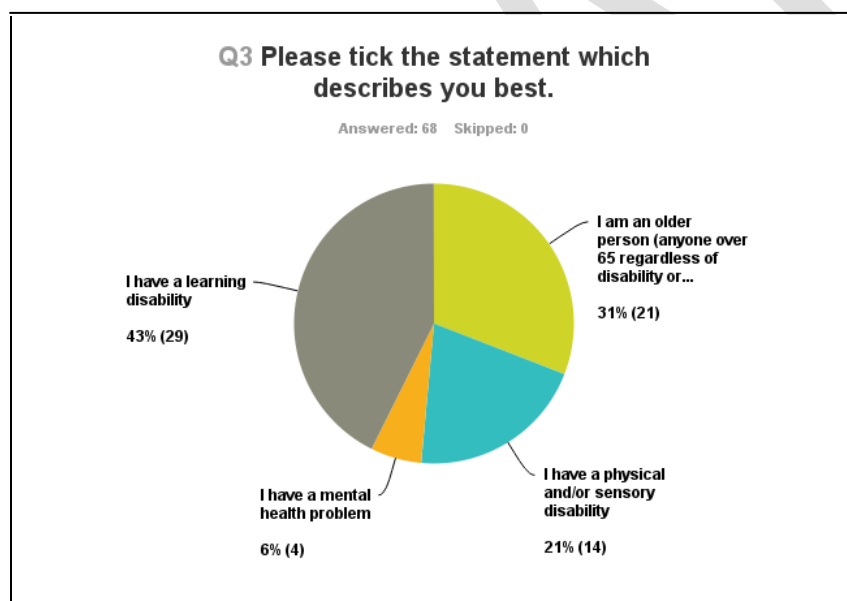


Figure 1: Service user group

Answer statistics:

- The highest number of returns, 43% (n=29), came from people with a learning disability
- 31% (n=21) were from older people

4.2 Respite facility used

Respondents were asked which respite facility they had used. Some individuals stayed at more than one facility.

Birchview, Elgin	12	The Meadows, Huntly	2
Spynie Care Home, Elgin	11	Abbeyvale, Elgin	2
Taigh Farrairs	10	Glenisla Care Home, Keith	1
Doocot View, Buckie	9	Parklands Care Home, Buckie	1
Murray Street, Elgin	6	Lythe Care Home, Cullen	1
Wakefield Care Home, Cullen	5	Andersons Care Home, Elgin	1
Speyside Care Home, Aberlour	2	Cameron Court, Forres	1
Meadowlark Care Home, Forres	2	Weston House, Keith	1

4.3 The cared for's experience of respite

Service users were asked to consider a number of questions about their experiences while in accommodated respite.

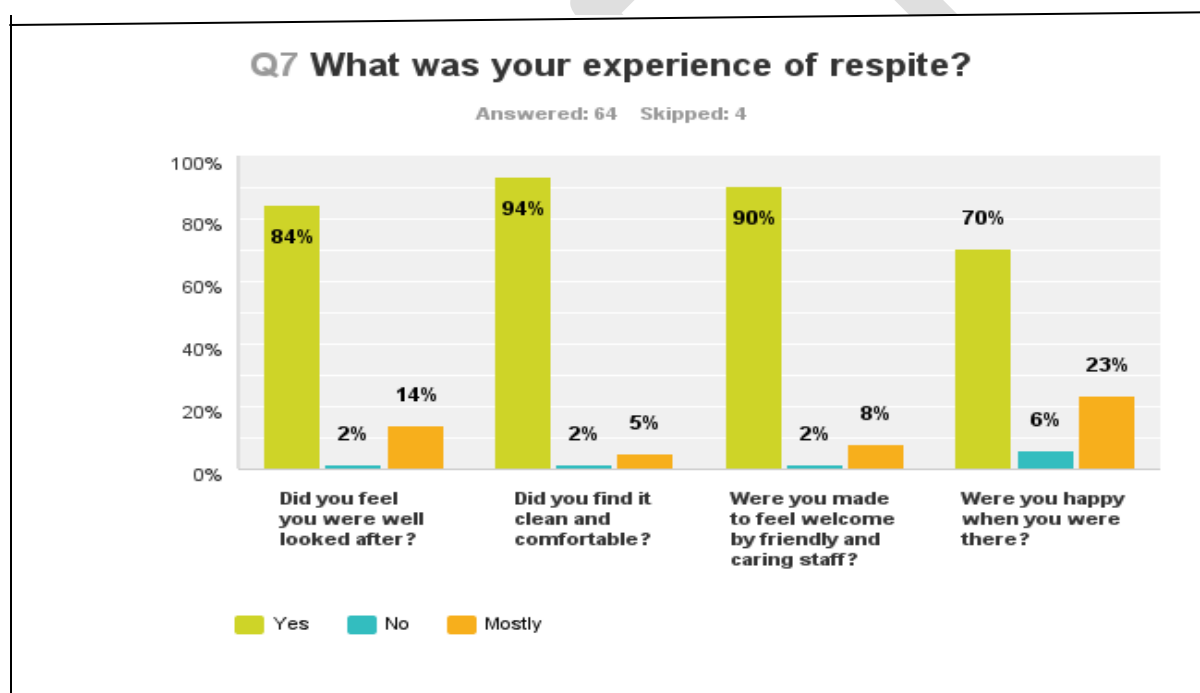


Figure 2: Experience of respite

Answer statistics:

- Each question drew a positive response from at least two-thirds of service users
- People were most satisfied with the cleanliness and comfort of the accommodation at 94% (n=59)
- 70% (n=45) were happy during their time in respite; 23% (n=15) were mostly happy; 6% (n=4) were not happy

- A text box was provided for additional comments. 26 comments were made.

Comments summary:

- Positive – quality of care; relationships with staff and other residents; quality of the environment
- Negative – preference is to be at home; suffered an accident; lost belongings; quality of the environment

The comments are given in full at **Appendix 1**.

4.4 Current respite activities

Service users were asked about the activities they took part in during their respite break. 60 comments were made.

Activities ranged from the passive to the more active both in the accommodation and out in the wider community.

Comments summary:

- nothing; resting; relaxing; reading; watching TV; crafts; board games; singing; sports; walks; cinema; shopping; going for coffee/meals.

4.5 Additional activities

Service users were asked to identify if there were any other activities they would have liked the opportunity to participate in.

24 of the 31 people who answered said no. One person said that physical activities were limited as they were in a wheelchair.

Comments summary:

- more trips out; more walking; swimming; bowling; more exercise; music; dancing; more cinema visits; more socialising with other residents; practising cookery skills.

4.6 Future respite provision

Service users were asked how to agree with statements on what was important to them with regard to future respite opportunities.

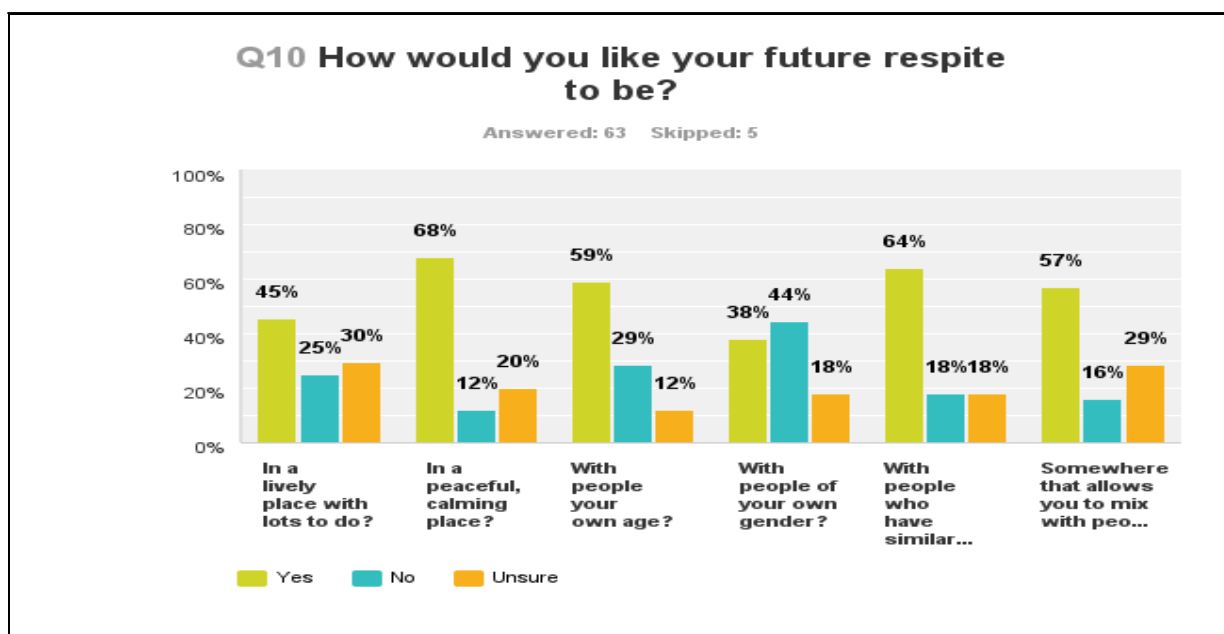


Figure 3: How would you like your future provision to be?

(The last two statements in full read: with people who have similar needs/disabilities as you; and somewhere that allows you to mix with people of all ages and disabilities).

The responses give a mixed message due to the structure of this question.

Answer statistics:

- Over two-thirds of people (68%, n=34) preferred a quieter environment; however 45% (n=20) also indicated they wanted a lively place with lots to do.
- More than half (59%, n=29) wanted to be with people their own age; 64% (n=32) wanted to be with people who had similar needs/disabilities as themselves; however 57% (n=32) also said they wanted to be somewhere that allowed them to mix with people of all ages and disabilities
- 44% (n=22) wanted their respite break to be with both men and women.

4.7 The impact of respite

Service users were asked what difference respite makes to them. 50 comments were made.

Summary of comments:

- Support for carers – gives them a break from the caring role
- Social opportunities – have fun, make friends
- Own wellbeing – feelings of enjoyment, having a rest/break

- Negative – would rather be at home.

The comments are given in full at **Appendix 2**.

4.8 What makes respite perfect for you?

Service users were asked to explain what good respite was for them. 42 people provided comments.

Summary of comments:

- Quality of service and staff – friendly, helpful and caring staff
- Location and quality of facilities – comfort, close to home, en-suite
- Activities – choice of activities to suit interest of individuals
- Social opportunities – time away from family, different company, meeting and making friends.

The comments are given in full at **Appendix 3**.

4.9 Further comments

A final text box invited any additional general remarks. 20 comments were made.

Summary of comments:

- Positive – respite gives carers a break; staff are caring; met my needs
- Negative – did not like being away from family/home; cost; incidents while in respite care, suitability of respite offered

The comments are given in full at **Appendix 4**.

5 Consultation survey responses – carers

A total of **XXX** consultation forms were sent out.

- 280 responses were received giving a return rate of **XX**.
- 80% (n=217) of responses were from women
- Just over half of carers were over the age of 65. 23% (n=64) were 75+; 28% (n=78) were aged 65-74; 25% (n=70) were in the 55-64 age group
- 60% (n=160) were retired; 23% (n= 63) were working full or part-time

- 94% (n=63) of carers indicated they had used accommodated respite in the past; 66% (n=44) said they were likely to use it again
- 55% (n=146) had never used respite services. 3% (n=9) had used respite in the last week; 14% (n=37) in the past week; and 28% (n=74) in the past year
- Of those carers who had never used allocated respite, 54% (n=71) said they did not need it; 20% (n=26) said the person they cared for did not want to go; 17% (n=23) said they did not know how to access it
- 70% (n=88) of places were partly funded by Moray Council; 19% (24) fully funded by the carer; 12% (n=15) partly funded by the council. 89% (n=55) did not use self-directed support
- 52% (n=128) of carers considered they would have a need for more respite in the future
- 52% (n=138) of carers preferred the term respite to short break.

5.1 The caring role

Carers were asked who they provided care for. They could indicate more than one person.

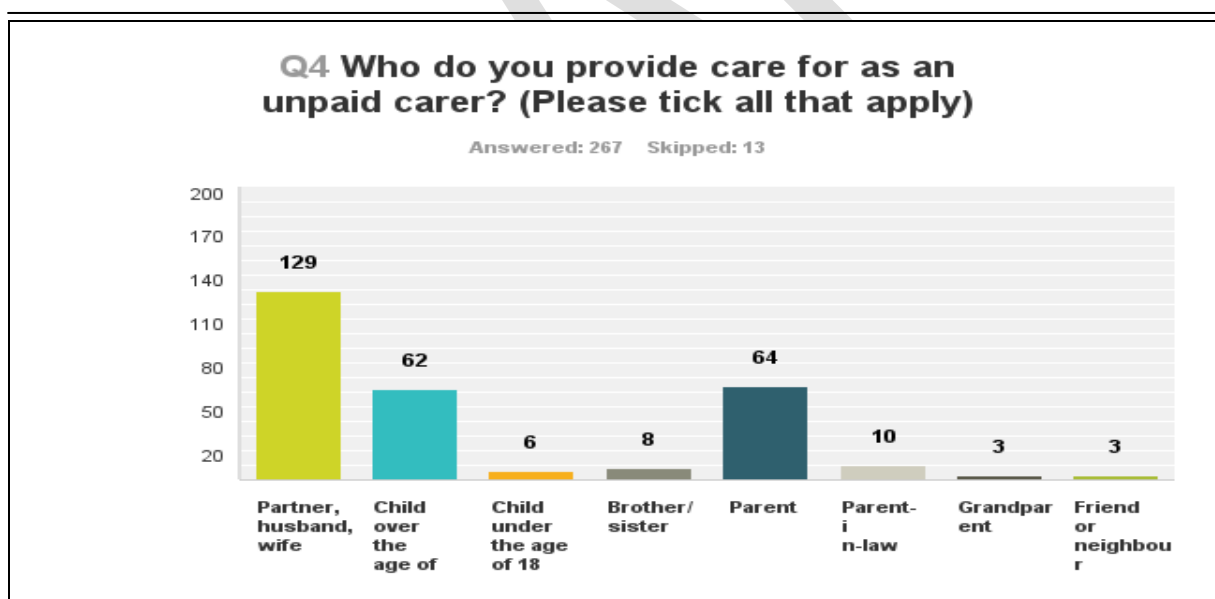


Figure 4: Who do you provide care for?

Answer statistics:

- The largest group of carers (n=129) were providing care for their spouse/partner, followed by parent (n=64) and son or daughter over the age of 18 (n=62).

5.2 Person or persons being cared for

Carers were asked which service user group the person they cared for identified with. Some people were caring for more than one person.

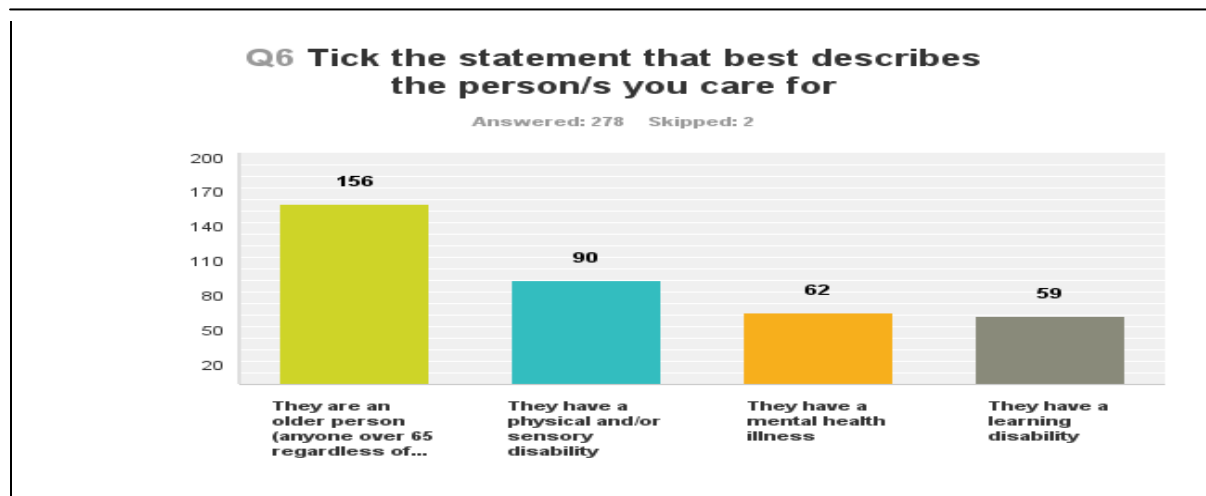


Figure 5: Person being cared for

Answer statistics:

- The highest number of carers (n=156) were those caring for an older person over the age of 65, followed by someone with a physical and/or sensory disability.

Those who responded they were caring for someone with a mental health illness may have included individual with dementia in this category rather than in older persons as the respite facilities used were mainly care homes.

5.3 Time spent providing care

Carers were asked how much time they spent providing care in an average week.

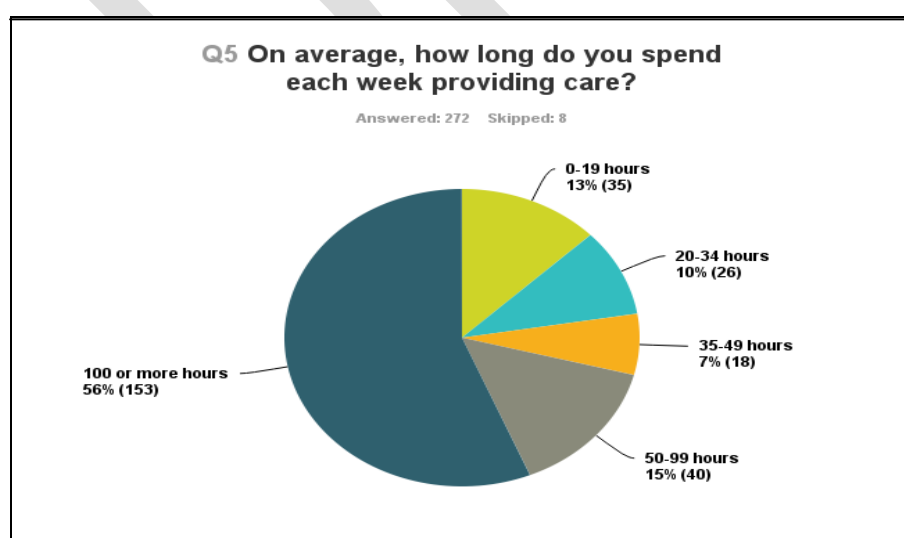


Figure 6: Time spent in the caring role

Answer statistics:

- More than half of respondents (56%, n=153) devoted 100 hours or more a week to the role of unpaid carer
- 15% (n=40) provided care for between 50-99 hours a week.

5.4 Location of respite facility

Carers were asked which respite facility they had used. In some cases this was more than one facility. 125 responses were received

Birchview, Elgin	27	Chandler's Court, Elgin	2
Spynie Care Home, Elgin	26	Alba Place, Elgin	2
Doocot View, Buckie	13	Whinnybank, Lossiemouth	2
Wakefield Care Home, Cullen	11	Speyside Care Home, Aberlour	1
Taigh Farrais, Forres	10	Parklands Care Home, Buckie	1
Murray Street, Elgin	8	Abbeyside, Elgin	1
The Meadows, Huntly	8	St Olaf's, Nairn	1
Meadowlark Care Home, Forres	7	Auchbuie, Alford	1
Glenisla Care Home, Keith	5	Struan House, Alloa	1
Abbeyvale, Elgin	4	Cameron Court, Forres	1
Lythe Care Home, Cullen	4	Weston House, Keith	1
Andersons Care Home, Elgin	3	Private accommodation	1
Shared Lives	3		

5.5 Reason for using respite

Carers were asked what their main reason was or would be for using respite. 108 carers responded, selecting all applicable answers.

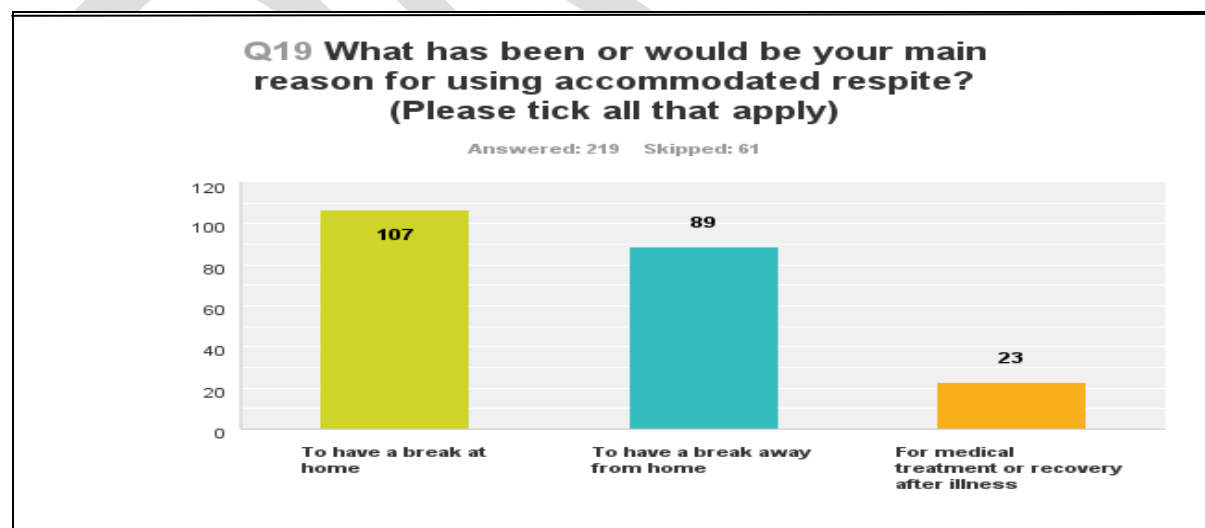


Figure 5: Reason for using respite

Answer statistics:

- The largest response (n=107) was from carers having a break at home.

A free text box was also provided for any additional responses.

Comments summary:

- Supports family relationships – allows time to be spent with other family members
- Positive experience for the cared for – provides additional opportunities for the person who receives care to socialise and take part in activities
- Unplanned care – while the carer was ill or had to go away from home.

The comments are given in full at **Appendix 5**.

5.6 Meeting the needs of carers

Carers were asked how respite meets their needs as a carer. 123 comments were made.

Comments were largely positive. Negative comments included a serious incident involving injury to a service user and lack of availability/flexibility. Carers also made use of respite for events such as attending hospital appointments or funerals rather than for a break for themselves.

Comments summary:

- A break from the caring role – at home or away, supports carer's health and wellbeing by providing opportunity to rest, more time to spend with other family members/friends
- Opportunities for the cared for – opportunities to socialise with others
- Negative – negative experience for the service user, not day care provided, not flexible enough, unable to secure dates wanted.

The comments are given in full at **Appendix 6**.

5.7 Carers feelings before and after the respite break

Carers were asked to describe how they felt before and after the person they cared for went to respite. 120 comments were made. The most common responses are listed in the following table.

Before the respite	After the respite
Tired	Refreshed
Exhausted	Rested
Frustrated	Happier
At breaking point	Better able to cope
Depressed	The same

5.8 Improving carers' experience of respite

Carers were asked to suggest ways in which their experience of respite could be improved. 84 responses were made.

A number of carers said they were satisfied with their experience of respite. Their experience of respite was linked with the experience of the person they cared for.

Comments summary:

- Funding – financial support, reduced cost
- Staff – improved staff levels and training
- An improved experience for the cared for – more stimulating activities, social opportunities, if their family member had enjoyed their time at respite
- Respite provision – increased allocation, flexibility over timings, improved booking arrangements
- Location – help with transport, closer to home
- Communication – improved information

The comments are given in full at **Appendix 7**.

5.9 Meeting the needs of the person cared for

Carers were asked to consider how current respite met the needs of the person they care for. 121 comments were made.

Comments were largely positive with carers responding that they were happy with respite and felt needs were being met. This was again linked to their cared for enjoying their time in respite.

Comments summary:

- Social opportunities – time away from home and family with staff and other residents
- Care needs met – physical needs taken care of, well looked after, professional care

- Negatives – care needs not being met, cared for not happy in respite, lack of interaction with other residents.

The comments are given in full at **Appendix 8**.

5.10 Improving the respite experience for the cared for

Carers were asked to put forward ways in which the respite experience could be improved for the person they care for. 82 comments were made.

Many carers stated they were satisfied with respite and that the experience could not be improved. Negative comments related to incidents which had taken place.

Summary of comments:

- Social activities – greater variety of activities, opportunities to be with other residents they can interact with
- Care needs – staff able to carry out tasks and meet care needs
- Flexible provision – right time, right place

The comments are given in full at **Appendix 9**

5.11 Carers who have not used respite

Carers were asked to identify their reason for not having used respite.

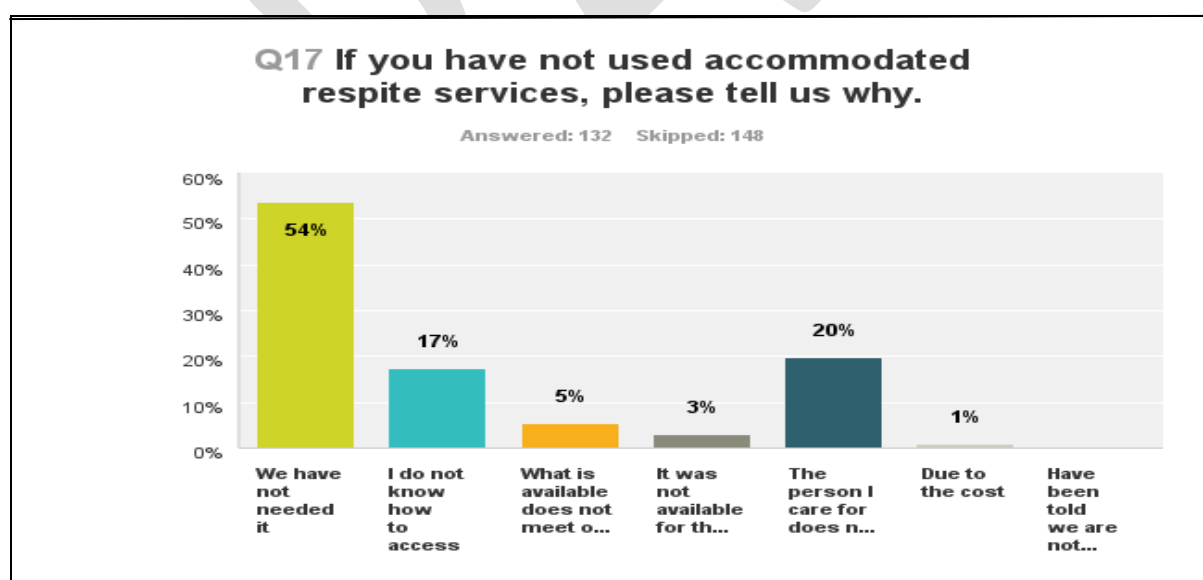


Figure 6: Reasons for not using respite

The statements in full are: we have not needed it; I do not know how to access it; what is available does not meet our needs; it was not available for the time we needed; the person I care for does not want to go; due to cost; have been told we are not eligible.

Answer statistics:

- More than half of carers (54%, n=71) who had not used respite said they did not need it
- 20% (n=26) said the person they cared for did not want to go to respite

Carers were asked to give more details. 62 comments were made.

Summary of comments:

- Not needed – alternative care provided by family members
- Wishes of cared for – cared for does not want to go to respite, carers' feelings of guilt
- Access – unsure how to access respite
- Provision – does not meet needs of the cared for

A number of carers indicated they were likely to access respite in the future as the care needs of their family member increased and their own health declined.

The comments are given in full at **Appendix 10**.

5.12 Importance of key issues for carers

Carers were asked to rate the level of importance of a number of key statements

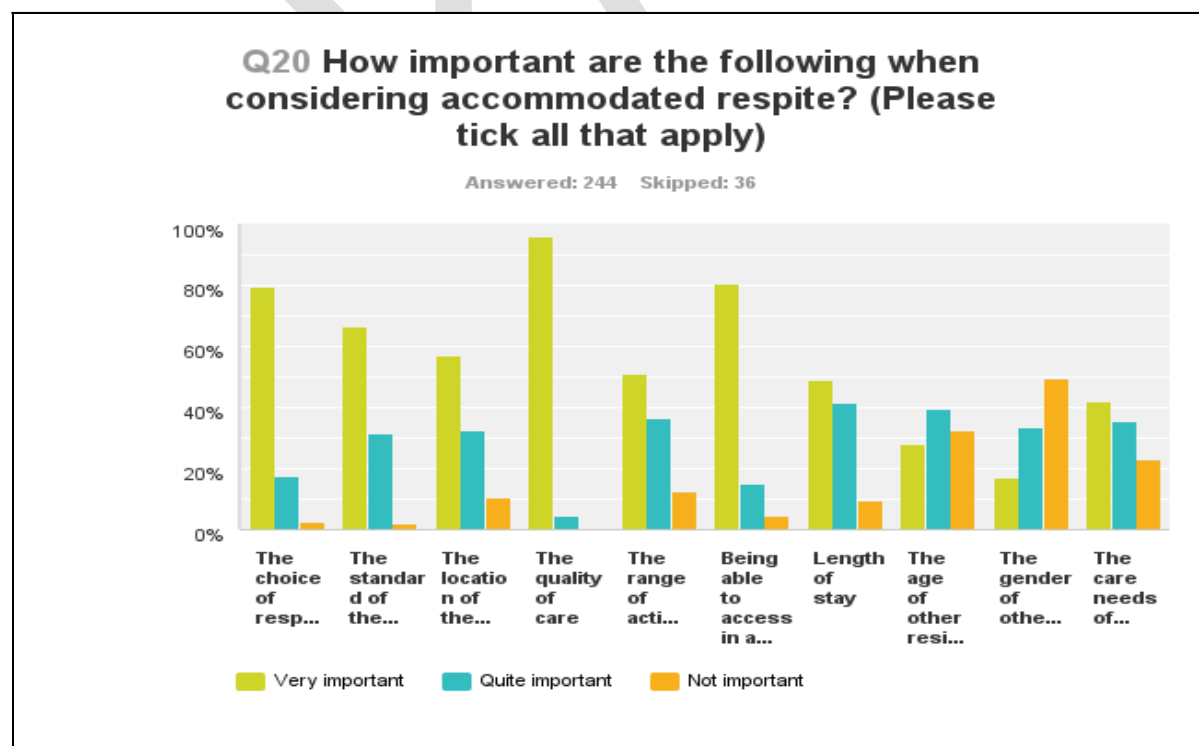


Figure 7: Importance of key issues

The statements in full are: the choice of respite accommodation; the standard of the building; the location of the building; the quality of care; the range of activities provided; being able to access in an emergency; length of stay; the age of other residents; the gender of other residents; the care needs of other residents.

Answer statistics:

- 96% (n=226) of carers felt the quality of care was very important; the choice of respite and being able to access respite in an emergency was very important to 80% (n=185, n=165) of carers
- The gender of other residents was not important to 49% (n=96) of carers.

A further 75 comments were made.

Comments summary:

- Experience of the service user – that are safe, comfortable and have had an enjoyable time
- Care needs – care needs are being by caring, professional staff as they would be at home
- Choice and flexibility – respite is available in the right way to meet the needs of the individual and at the right time and place for the carer
- Communication – carers know what is available and how to access it and have good communication with the respite care staff.

The comments are listed in full at **Appendix 11**.

5.13 Improving respite in the future

Carers were asked to put forward ways in which respite can be improved. 130 comments were made.

Many carers were satisfied with respite services. A small number had not made use of their allocation

The comments themes echoed those from the previous sections:

- Meeting the needs of the service user
- Allocation, availability, flexibility, choice
- Communication/awareness raising
- Activities/social interaction
- Funding

- Transport

The comments are given in full in **Appendix 12**.

6. Focus group meetings

In addition to the paper survey, six focus groups were held between 19th February and 3rd March 2014. Five were daytime meetings and one was held in the evening.

In total 33 people attended and almost all were carers.

The comments made during the focus groups in response to the survey questions have been included in the appendices.

APPENDIX 1: The cared for – your experience of respite

1. The cared for - your experience of respite	
Positive	Negative
<ul style="list-style-type: none"> • I would be more than happy to go back. • Excellent service, very homely. • Care was brilliant. • I appreciate the care given me at both establishments. • Service user's communication is very poor and it is hard to ascertain these answers but he is always happy to go and on his return. • Very well looked after by all the staff. • It was very comfortable. • One-on-one care - familiar surroundings. Other residents known to me - very friendly staff. • Respite for two weeks following a stay in hospital. • The friendliness of staff, very welcoming. • Home away from home • At respite I get breakfast, lunch and tea to keep me going through the day. I run a bath and staff check it is ok for me to get in before I do. • I love going to Birchview • I would like to go everyday (I love it there!) • It was nice and cosy and warm. Staff were pleasant and nice • The staff interact with the service users which makes them feel more like friends than careers 	<ul style="list-style-type: none"> • They were late with my medication sometimes. • Prefer to stay at home with family • Do need reminded to do things, have a routine for washing etc. Got scared while out shopping with shoplifter bumping into me. • Didn't like being away from home • Can't remember from one minute to the next • Please note on service user's last visit she most unfortunately suffered an accident - This has coloured her comments! • Up to a point • Lost some of my clothes! • Would like a quieter, less busy place • Bedding very poor, staff spent most time with dementia patients

APPENDIX 2: The cared for – the impact of respite

2. The cared for - impact of respite	
Theme	Comment
Support for carers	<ul style="list-style-type: none"> • It means a lot to me because it helps my husband maintain contact with his family and I remain in control of my care • Gives my carer a break and allows him to have a holiday with friends • Made me feel independent. Gave parents a break. • Gave 24 hour care after being in hospital while daughter was on holiday. • Gives my carer some time off • Feel relaxed and at ease also knowing my wife can have a break. Feel relaxed and at ease also knowing my wife can have a break. • Nothing for me - gives my daughter a break • I get a holiday there and take a break from home, my parents get a break • Not sure, but when in carer can get holiday • Gives my carer a break • It allowed my wife who is my carer to spend some time with our daughter and our grandchildren. • Gives my wife a real from caring for me
Socialising/activities	<ul style="list-style-type: none"> • Different company • Allows me to socialise with other people • Enjoy the company of carers and other residents • It allows me to mix with others and meet new people. • Meet new friends out with my family. Learning to cook • It lets me meet others of my peer group who I do not normally meet at day services • Get to try out different things with different people, and I get a rest from my mum • I meet new people • It's like a holiday, fun to meet new people, freedom from mum and dad • Fun. Like to be with friends and socialise

2. The cared for - impact of respite	
Theme	Comment
	<ul style="list-style-type: none"> • Like the change - socialising - is fun like a holiday, freedom from mum and dad • It's fun and I meet other people • Lets me have a social life with people out with my family and this is important for me • I like to see my friends • Makes me happy and enjoy the change • It gives me a chance to break normal everyday routine with little or no problems .It also gives me a chance to meet other people in similar situations
Wellbeing	<ul style="list-style-type: none"> • Calms me down. More relaxed. Less frustrated • Gives me a break. Something to look forward to • Makes me feel rested • I look at it as a little holiday when I go for Respite. Look forward to coming home again. • Gives me a break. • Helped me to get over an illness • Enjoy going. • I look forward to going there greatly. • I always enjoy my respite period at Taigh Farraiss with the friendly and caring staff who always go the extra mile in looking after residents • Enabled rest • Have only been once, and I enjoyed it. • Time away from home • Time to myself • It lets me be on my own if I want to, be away from my mum and dad for a little time to myself
Negative	<ul style="list-style-type: none"> • Not much, would rather be at home. • Removes me from my comfort zone and doesn't make me happy

APPENDIX 3: The cared for - what makes respite perfect for you?

3. The cared for - what makes respite perfect for you?	
Theme	Comment
Location and quality of respite facilities	<ul style="list-style-type: none"> • En-suite bathroom. • Comfortable room and spacious day rooms. • Single room • Familiarity of people and place • Accommodation. Location • Close to home to allow family to visit • Accommodation with no stairs to climb • Single room with en-suite bathroom. Hoist is essential in getting in and out of bed and shower chair. Facilities are a mirror of those at home. • Single rooms, good food choice, • Accommodation being right for me • Comfortable accommodation and the location of accommodation. • Not far from home. • En-suite bedroom, • Clean well maintained accommodation decent food • Being in Elgin so family can pop in and out to visit • Type of accommodation • Lovely place • The bedroom • The accommodation at Taigh Farraiss is purpose build for physical disabilities and also the size of the unit allows a more informal approach • A room with a bigger window and an interesting view would be appreciated
Activities	<ul style="list-style-type: none"> • Relaxing atmosphere. More reading. Play Nintendo DS. Watch TV (TV in own room) • Day trips not far from home • Plenty of things to do. • Musical afternoons all available at Cameron Court.

3. The cared for - what makes respite perfect for you?	
Theme	Comment
	<ul style="list-style-type: none"> • Somewhere I am able to relax and not feel under pressure but also somewhere where the staff won't allow me to just sit. • Activities, other guests, regular meal routine. • Activities for disabled, clientele of similar disabilities. • To play bingo and meet other people • The activities on offer, outings etc. • going out for meals and drinks, going shopping and to the cinema • Going shopping, football matches swimming, bowling, cinema trips and cafes. I like doing these activities with staff and my peers. • I get time to be on my own away from my family • Peace and quiet • Going to the cinema, going for hamburgers
Social opportunities	<ul style="list-style-type: none"> • Different company • Enjoy the company and the surroundings • Other guests • Meeting friends. Friendly atmosphere. • Prefer when there is a friend staying at the same time, and like the different activities • Guests to speak with • Seeing friends • Where I am staying and the other people that are staying at the same time • Other guests • The people I meet
Quality of staff and service	<ul style="list-style-type: none"> • The staff and level of care, flexibility to take items of equipment – sling etc • Good and caring staff. Good food. Flexibility when it comes to personal care. • Nice, pleasant people (staff and guests) • Quality of care and friendliness of staff • Very friendly and helpful staff. • I like Murray Street the best, the carers and other clients

3. The cared for - what makes respite perfect for you?	
Theme	Comment
	<ul style="list-style-type: none">• Nursing care• Helpful staff• Friendly and caring staff

DRAFT

APPENDIX 4: The cared for - is there anything else you want to tell us?

4. The cared for - is there anything else you want to tell us?	
Positive	Negative
<ul style="list-style-type: none"> • It is extremely important to have a facility such as Taigh Farrais close so that I can maintain contact with friends and family whilst in respite. It is also important to me that my husband gets a break from his caring role. • Wakefield is ideal for me. • Respite in Taigh Farrais gives my wife a rest and time to do other things other than caring on a full time basis. • It was fun and I enjoyed it. Would like to go more often with or without my brother. • My needs are great and my wife needs a break so respite is needed for me • What I like about respite is that the staff are friendly, caring, helpful and funny. This makes respite a welcoming, safe and protected house to be in. • People are friendly and kind • Like it the way it is • Respite is a very important part of the caring process it allows carers and the person with the disability a break and allows the person with disability to meet other like minded people. Also it elevates the health service because of there was no respite there would be a lot more people would require hospital beds both in mental health and medical wards which would cost a lot more money and time 	<ul style="list-style-type: none"> • Have had some difficulty trying to complete this pro-forma as service user has become rather agitated and distressed as she recalled her accident. Previously she enjoyed the company of her friends • Did not want to go in the first place but husband had to go into hospital for an operation. Hated being away from husband. • As I need dialysis 3x a week it is very restricting as Elgin hospital cannot always take me (no room) as the NHS will not provide the necessary staff needed to take on an "extra" all the time. This is what stops me going on "holiday" more often. It is bad. • Seats in conservatory were very comfortable, but the seats in the lounge and bedroom were not at all. Too hot for comfort • I thought that the week was rather expensive • I believe Taigh Farrais is the last respite centre in Moray. Should a decision be made to close it, I would be unable to get the same professional care at any other ad hoc establishment. This would also mean that my parents, my primary carers, would be unable to get a break. • My mother did like it but is refusing to go back because she doesn't like being away from home • Never had respite • It is unrealistic to expect service user to respond to this as she has no recollection of ever being in respite • I prefer home

APPENDIX 5: Carers - what has been or would be your main reason for using accommodated respite? Additional comment

5. Carers – what has been or would be your main reason for using accommodated respite	
Theme	Comment
Support family relationships	<ul style="list-style-type: none"> • Spend time with my son, doing activities with him when his dad gets worse and is no longer able to join in • To be able to concentrate on other members of the family e.g. children • To make sure we still have a marriage • I have elderly parents still living in their own home in Hampshire with few supports. I am only child in the UK and never know when a crisis will come
Experience of the cared for	<ul style="list-style-type: none"> • To allow my daughter to have a break with other experiences • To give clients a break, too, build up their confidence in other to help them care for them in the future when we are no longer able/here
Support wellbeing of the carer	<ul style="list-style-type: none"> • Now is needed on more regular basis to prevent illness and exhaustion • Inability to cope
Unplanned care	<ul style="list-style-type: none"> • Emergency situations • Emergency illness cover • If care could not be arranged in the home or if the type of care required changes
Other	<ul style="list-style-type: none"> • At 69 I do not know when I may need but would be nice to know help will be there if needed • Not needed at the moment, maybe when I get old • To get mum's house cleaned to get rid of fleas • I would prefer a short break of say 2 to 3 hours just now and then, not on a regular basis, just to wind down at times

APPENDIX 6: Carers - How did respite meet your needs as a carer?

6. Carers- how did respite meet your needs?	
Theme	Comment
Positive/general	<ul style="list-style-type: none"> • Satisfactory x 3 • Yes very good x 3 • Shared Care to Meadows worked well. • Excellent x 3 • Most definitely • Murray street – great • Met all my needs • Very well x2 • Fully • Adequately • Very helpful. • At the time. • In every way. • Very satisfactory, no complaints. • OK x 2 • Well • First class. • No family nearby • Respite provided when carer was in hospital • Just getting started so far it's been one tea visit and one overnight. But needs so far have been met. • All what was required
A break away from home and the caring role / supports carers health and wellbeing	<ul style="list-style-type: none"> • To go on holiday • Excellent care meant I could go away feeling confident mother was being well looked after. • Gives me a weekend to go to visit friends, do things for myself. • It allowed me to go to an award ceremony for my daughter

6. Carers- how did respite meet your needs?	
Theme	Comment
	<ul style="list-style-type: none"> • It allowed me to have a short break away from home with my friend for one week • Mainly benefits my mother - when father is able to attend respite (not on our door step) it gives her time to look after herself and have a much needed break. • Gave me a break from caring role. • Enabled me to have a holiday knowing mum was safe • It was great to have a fun break with the people I care for. • It freed up time for myself. Twice I went to Manchester to visit my house and once I went to France. In the case of the Short Break I went to a folk festival in Lossiemouth 3 days in a row. Also I needed to extend respite a week in Jan 2013 due to my sickness. • I feel that my daughter enjoys the respite very much. It has allowed me and my husband to go on a week's holiday this year. So we are very pleased. • Gave myself and my husband a long needed break. • Helps me to get away from the house for a while with my wife as family helped when we arrived. • Break from day to day routine • It gave me the chance to get away and relax with family without the constant worry. • It helps me to get a rest and to do some things by myself. • Break for Both • Gave me a break and gave daughter a bit of freedom. • Enabled me to have a break! And spend quality time with the rest of my family. • I had time to myself to socialise with friends and family • Knew mother was cared for 24 hours a day while on holiday, she was just out of hospital as I was leaving. • Care provided was excellent; I had no worries while on holiday. • Gives me a day off from caring as I am disabled myself. • Gave me two days of relief, to do as I liked, knowing he was being cared for in a safe environment. • Overnight care and accommodation whilst I went on a trip to Glasgow • Gives me a break.

6. Carers- how did respite meet your needs?	
Theme	Comment
	<ul style="list-style-type: none"> • Allowed me to go on holiday. • Gives me a break and for my grandmother but I think by the time she is back I need another one. • Very well, I knew my husband was happy to go there. • Able to have a few days away • Helped us to have a break. • Good to get away knowing my mother in law was cared for day and night. • My husband has only had positive experiences at Wakefield. This allows me to trust them with the care and not worry too much while being away. • Gave us the ability to have a short break and take our other more able son on holiday. • A relaxing 4 days knowing my husband was in caring hands. • It gave us both a break. • Gave me a break from caring. • Mum was looked after so I could have a holiday. • It gives us a break. • It enabled me to have a short break (1 week). • Enables us to have a break and try to pursue interests and studies that are not possible with a handicapped adult. • I feel my daughter enjoyed the respite very much, It has allowed my husband and I to go on a week's holiday this year so we are very pleased • I could not manage to look after my husband full time without my regular respite breaks. Essential for my well-being. • Allowed me to recharge. • Gave me much needed break and I could relax knowing he was being well looked after. • Give me a much needed rest so I could recharge my batteries as they were running out of charge. • It gave me peace of mind that my father was being looked after. • It provided a comparable alternative to the care provided at home for my wife. This is the first time we have found such an alternative.

6. Carers- how did respite meet your needs?	
Theme	Comment
	<ul style="list-style-type: none"> • A welcome rest. • Gave me a few nights of much needed rest and sleep and a chance to think of me for a change! • For me - it gave me the break I needed but from my mother it was depressing as she is mentally alert and aware of her surroundings. • It gave me time to myself and I was able to have a few days holiday. • Was able to have sleep and get head round things. • This met my needs as a carer through time for me to re-charge my batteries physically and mentally. • It was perfect for me at the time as it gave me a day to myself as I also have heart problems. • I was able to undergo needed surgery. • It gave me a break from all the responsibility that comes from looking after my daughter. • It gave me piece of mind knowing that my husband had carer and company. Also carer was provided in case of a fall. • Gave us time to relax and spend time as a family without the stress that we are placed under. • Ok, bit of a rest. • Relaxation - but still kept in contact by phone, and knowing Taigh Farrais staff would provide professional care and support. • It gave me a break from the responsibility with looking after my daughter. • Could leave my husband and have peace of mind knowing he was well cared for but most of all he enjoys going. • It allowed me to have a few nights sleep and rest • It gave me a break so that I could recharge my batteries. • A break from looking after my brother, a chance to relax. • Allowed a break. • It gave me peace of mind knowing that whilst I was in hospital my husband was being cared for. • Took care of my mother. • Gave me a break, allowed our family to go away to deal with family matters for two weeks.

6. Carers- how did respite meet your needs?	
Theme	Comment
	<ul style="list-style-type: none"> • Always good to get away and just chill out, also have someone to talk to • It gave me time to myself knowing my child will be well cared for • Gives me a break, can get to accommodation in emergency, quality of care • It was good to relax and get a break • It was good and gave me a weekend free from caring • It was an immense help to me to get Mums house cleaned • Currently goes to farm with horses and he loves it. If I go away for weekend his carer goes to school to collect him. This gives me time for myself and to recoup as he has autism and he can be up most of the night at times and I do not get much sleep • Gives me a break and my daughter is happy to go there, she goes to the shops/café's love to have her fancy piece at the café, knows a lot of people.
Opportunities for/ enjoyed by cared for	<ul style="list-style-type: none"> • Respite was so my son could have company beside me. • I knew my husband was safe and well looked after. More than that though was that he enjoyed and has used it frequently. • Birchview is very good. My son enjoys going. It gives us a break but also my son gets a break. • Gives me a break and gives son a chance at having time away to gain independence
Negative	<ul style="list-style-type: none"> • It doesn't due to a number of incidents at the above service, all of them serious resulting in our family member being disfigured but there is nowhere else. • It met our needs successfully with very kind, caring staff. However, unfortunately on service user's last visit she had quite a serious accident. • Met our needs partly. Can only be used by us at weekends, as does not provide daily care during the week. If our daughter has no planned activity i.e. Cedarwood etc. then Birchwood is of no use as no daily care during week. • For me - it gave me the break I needed but from my mother it was depressing as she is mentally alert and aware of her surroundings. • Birchview didn't, not flexible enough with open times and virtually impossible to book 2 in at once.

6. Carers- how did respite meet your needs?	
Theme	Comment
	<ul style="list-style-type: none"> • Not very well. I gave plenty of notice but on two occasions didn't get dates we needed for holidays so he stayed with relatives. • Had to attend a funeral so was not really respite. • I desperately needed respite care before I actually got it. • It was while I was ill and in hospital • It is very good when it works but I can't always get the dates that I need. • Not very well, it is too far from bus routes, getting there was very frustrating. • Yes it meets my needs at times, but when we go on holiday for a week it takes a lot of the allocated 29 days per year which I feel is not a lot. • Birchview was not ideal - times open too restrictive and very difficult to get two people in at once. Murray Street was ideal but need more than a few days at a time • It was as an experiment, but my daughter wanted home • Hassle to get and arrange. Did get respite for November but only found out at the last minute. Husband went to the Meadows, I said I didn't drive and was told to get a taxi. Spynie would have been best. My son had to take the day off work to take me and my husband to Huntly and back again on the Monday so my days of work were used to transport my husband too and from respite. • Taigh Farrais is always fully booked so it is difficult to get respite • Issues with medication at Chandler's Court, Elgin, as they did not know what a MARS sheet was.

APPENDIX 7: Carers - what would have improved your experience of respite?

7. Carers - what would have improved your experience of respite as a carer?	
Theme	Comment
Positive	<ul style="list-style-type: none"> • Nothing x 8 • Thankfully I have never had a bad experience of respite care in the 12 years that I have cared for my husband. • Alba was a brilliant place. • Very satisfied x 2 • Very pleased by the service provided • I enjoyed peace and quiet. • It was good the way it was. • It is perfect. • Nothing really, people were there if I needed anything, just to know there's someone to turn to is a massive benefit. • I was quite happy with the service provided x2 • Daughter was happy. • They cared very well for my daughter. • Was a relief to know partner was being well looked after. • Well cared for, quite happy. • Current system is satisfactory
Experience of the cared for	<ul style="list-style-type: none"> • Knowing there were activities planned during her short break. • It would have been greatly improved if the accident had not occurred. • Knowing that my father understood the need for a break, which he did not. • If there could have been other stimulating activities and companions 1:1 have to cope with the resulting depression. • If my husband has been comfortable and happy in respite. • If my husband didn't have mobile phone he still gave me verbal abuse. • If she had not "escaped" 3 times in 4 days and been bashed over the head by an elderly man causing a cut on her head

7. Carers - what would have improved your experience of respite as a carer?	
Theme	Comment
	<ul style="list-style-type: none"> • Outdoor activities and social activities. • It would be good to know who the other service users were going to be there and also what staff just so I could prepare my daughter. • My father returning home the same as he was when he went in. • Knowing that my husband was happy in the care home • If I had gone on my own. I would need assurance of my wife's care when I was away. • It took time pack mums stuff up and also was stressful for both of us getting her in as she didn't even know she was going - but I can't see how this could be improved.
Staff	<ul style="list-style-type: none"> • Having better management and team leaders whom one can trust especially to tell the truth and better communication and understanding the people's needs. • More staff in care home and "better" trained. • staff at home were quite abrupt and unhelpful. • If my own carers could have helped care for my partner I would have been more at ease knowing his routine continued with people he knows.
Provision of respite	<ul style="list-style-type: none"> • I feel that a midweek intake would be very beneficial to me as I prefer to have weekend breaks and have to use 2 weeks to incorporate a weekend break. • Perhaps a bit longer and a future break later on. • Care provided during day on weekends. • If it was easier to arrange. • Extra care. Longer weekends - Friday night to Monday night. • Flexibility of times - accommodate carers who have more than one dependant - no restrictions on where client has day service or not (Birchwood) • Not having the dates muddled and causing confusion. • Another break or perhaps for a longer spell. • Longer. • For it to be more often • Having to give 6 weeks' notice • Smaller respite all over Moray. • More flexibility of days, length of stay, ability to stay even if clients have no day service to go to

7. Carers - what would have improved your experience of respite as a carer?	
Theme	Comment
	<p>(Birchview) this place is closed more than open - a waste.</p> <ul style="list-style-type: none"> • Allowing us to book into a more local care home. • Having more choice. • The times that you have to put them in and the time of collecting as if in on Friday at 3pm and collect on Sunday at 11am only gives you one full day and 2 x 1/4 of a day but is classed as 2 days. • Having it for longer. • Be able to use it more often, he only has 29 nights a year. • An earlier intervention. • I would like it to be longer • More days available and what to do if I wanted a holiday. • Some confusion over booking dates. Resolution by council was good • The process of accessing respite care was very difficult and stressful. Moray Council could not help with respite in advance for 2 people so had to resort to private respite care. • Short breaks fund was time intensive to set up.
Information / communication	<ul style="list-style-type: none"> • Would have been helpful if some relevant information had been made available to parents at the time instead of having to search and pursue various avenues to ferret out info of importance. • Support with finding people to help clean the house, names of companies etc • It would be good to know who the other service users and staff were going to be there in advance so I could prepare my daughter. • More information and how to access it
Funding	<ul style="list-style-type: none"> • Financial support. • Not as expensive. • Having to pay less
Location of building / transport	<ul style="list-style-type: none"> • Help with transport as getting there and back with wheelchair, luggage etc. I have to rely on family who only have a small car. • Different care home • Too far from bus routes, it was very frustrating getting there. Have smaller respites all over

7. Carers - what would have improved your experience of respite as a carer?	
Theme	Comment
	<p>Moray</p> <ul style="list-style-type: none"> • Somewhere nearer home to be available • Not having to arrange the transport. • As long as service user gets Elgin his family can visit I know he is happy which makes it easier to leave him • The respite centre we used not being closed down • Help with the travel to and from respite.
Other	<ul style="list-style-type: none"> • Respite was fine but they need to take more care when doing laundry • Not losing laundry! • Administration of morning meds despite MAR sheet being provided
Neutral	<ul style="list-style-type: none"> • Don't know • Not used respite for myself yet so don't know.

APPENDIX 8: Carers - how did respite meet needs of the person you care for?

8. Carers - how did respite meet the needs of the person you care for?	
Theme	Comment
Positive	<ul style="list-style-type: none">• Perfectly x2• Excellent in every respect.• Super, they really enjoyed it.• Very well x 6• Fine.• Met all his needs• Very satisfactory. X 2• Satisfactory.• Ok• Very suitable
Social opportunities	<ul style="list-style-type: none">• My son really enjoys going to Doocot View and can't wait to pack his bags. He enjoys being with other people.• It gave him a chance to meet other people and he enjoyed this as he lives in sheltered accommodation and doesn't go out very often.• Very well - my father also needs a break from home to meet social needs etc. Refreshed him and also helps their relationship• Made her feel safe and enjoyed the company• The same as me. They had fun and relaxed.• She really loved Birchview and has asked to go back.• My daughter really enjoys going to Birchview, I think it meets her needs quite well• My wife enjoyed it, especially with me being there.• Allowed us time away from family and a break with different people• Lets her mix with others that go to services with her• My husband feels happy and safe and Wakefield• He settled well in Glen Isla.• Great he loved it and since the day care closed he's continued to go out on a Monday with the handyman from the centre which he loves.

8. Carers - how did respite meet the needs of the person you care for?	
Theme	Comment
	<ul style="list-style-type: none"> • Allowed her to have a change of environment and interact with people other than family. • My daughter spent time with people that care about her well being as much as I do but most of all she loves and looks forward to going to respite. • Happy to see old friends in staff and residents (an essential feature). • It gets him used to staying with others outside his home, should this be necessary in the future, but more importantly, helping him with independent living. • Suits her very well. Looks forward to going. Enjoys going there, gets on well with staff. • My husband does need the stimulation of being with other people; there is just the two of us at home. He enjoys watching others, badly needs to socialise. Better behaviour sometimes away from home. • Service user loves the break from everyday goings on • My daughter really enjoys going to Birchview. I think it meets her needs quite well • I think my partner was quite happy there. • She loves going to respite • Away from the normal routine, house, me. • Lets her meet different people. Good company for her. Gives her her own time and independence. • Provided a break for her also, with a change of environment and company. • Enjoyed the staff, very pleasant and friendly. • Enjoys going and meeting the staff again. Likes to go on outings which I am unable to take him on. • She was very happy there. • Gave them time away from my moods due to tiredness. • Well. She loves going. • Service user is always happy to go as he has TV in his room and can get out for his cigarette • She was excited to go and talked about it non stop • She really loved Birchview and has asked to go back • To socialise with friends and go out with them • Gives them time to them self, meet new people

8. Carers - how did respite meet the needs of the person you care for?	
Theme	Comment
	<ul style="list-style-type: none"> • Gave him a "sleepover" like his siblings • He enjoys the different company. Calms him down (for a while) • Never felt so guilty in my life about putting my father-in-law into respite. Went to Cameron court and have never felt so welcomed. Would recommend it to everyone my relief when we got back and he said "are you back already". He now goes to day care and he does sitting down exercises which has helped us. • He seemed to enjoy the break also, but glad to get back home.
Care needs met	<ul style="list-style-type: none"> • My wife is happy to return to Taigh Farrairs. I have not found any other facility that has met her needs - she remained in control and felt central to the care provided. • Mother decided not to sleep over so they picked her up at 10am every day and returned her at 7pm and Crossroads came at 8am and 8pm each day to wash/dress and apply medication to her legs (we're still waiting for a carer to carry out this process on a daily basis, been waiting for 9 months). • Carried out special requests exactly as I asked • All needs were met. • It kept her safe, amused and fed. • Everything was catered for - personal care, help with food and toileting, clothes cleaned and some outings too. • It met them well - staff caring and kind and it gave service user the opportunity to socialise with the other tenants - This was really beneficial. • They helped meet my son's needs and mine. • Took basic care of her physical needs • Staff at Andersons professionally cared for them • All needs met • It meets all their needs. • Lythe was very good with my father even though he was demanding. • Normally it meets the needs very well and staff are kind and caring and aware of the medicine and mobility problems that the client displays. • They were cared for very well. 24 hour support.

8. Carers - how did respite meet the needs of the person you care for?	
Theme	Comment
	<ul style="list-style-type: none"> • Provided familiar surroundings and familiar faces who understand his needs. Good interaction with his day to day care support also provided by Cornerstone. • Fully met his needs. • The care provided by staff at Abbesside was excellent. Food was very good; nurses/carers were attentive and met their needs. • Well looked after. • They carried out all personal physical needs of son to the way was asked and needed • Provided food and accommodation. • Staff at Andersons professionally cared for. • I felt he was well taken care of and he was quite content. He attends day care in Abbeyvale so knows all the staff. • They met her needs very well. • Meets all his needs • Huge difference to appearance and well being. She was clean, tidy and so happy having people around her • Excellent. Community carer came in to help with breakfast and medication plus helping get ready for bed, set out clean clothes for the next day. • Was good as she was just out of hospital and I was going on holiday. • Provides day care. Friendly staff. Nice meals. • Meets my son's needs but only when I ensure another male is in with him he knows and is of able needs. • Provides day care. Friendly staff. Nice meals. • Meets my son's needs but only when I ensure another male is in with him he knows and is of able needs. • Taigh Farris was brilliant. My wife can't get out of bed she has reflexology etc and she really enjoyed it
General	<ul style="list-style-type: none"> • It was the nearest and available for the time required. • Birchwood was fine IF you can get them in - bit too busy for 1 of ours. Murray Street flat - brilliant.

8. Carers - how did respite meet the needs of the person you care for?	
Theme	Comment
	<ul style="list-style-type: none"> • Was adequate gave 24 hour carer as she had just left hospital. • Not sure as he was more concerned about giving me (his wife) a break • As well as possible with available resources • Fine (she doesn't like to be away from home though) • More physio, encouragement. • First Class. • My wife was re-accommodated full time at Meadowlark with all necessary services provided • Difficult to assess as she has little memory of events. • Birchview - seemed ok but clients seem to be in and out week days. Murray Street - was brilliant as brother and sister could be in together. • Respite care helped my husband to come to terms with the fact that I alone could not do for him what the respite carers were doing for him.
Negative	<ul style="list-style-type: none"> • It doesn't due to past experiences. • While criticism of staff in the care homes is in no way intended, we felt they were unable to care for my wife's needs. • The first Shared Care was less successful due to my mother's increased dementia and anxiety. • My husband wasn't happy in Spynie. He was in his room for a week. The patients with mental problems were walking in and out of his room but after speaking to the manager his door was locked. • He was always negative, moaning not going back was always the saying • He didn't like being away from home. • Not very sure as since his stroke he can't communicate so he doesn't join in on things. • Carer felt the evenings were long. • .It did not meet the needs of my father. • Not very good. Husband did not get all his mail. Items of clothing "lost". • I didn't see mum when she was in respite. I suspect she was uncomfortable with the more decrepit patients and those needing nursing care who are clearly not in mums category. The lack of outdoor exercise would have hurt her. The extra bustle and change of food and

8. Carers - how did respite meet the needs of the person you care for?	
Theme	Comment
	<p>environment would have been good for her. She was always none the wiser when she got home and picked up the routine quickly.</p> <ul style="list-style-type: none"> • He was very confused and had to find me if I was not in sight. • Not really. • Not very well I'm afraid. He was in the room 24 hours 7 days a week, he had one shower in the week that he was there and he wasn't very happy. It made him realise how comfortable home is for him! • Taigh Farris – Used it when daughter was only 25 and they did not understand that she was not able to take part in activities outside the facility due to her condition. We are unsure about her going back again as she has ME and this makes her very tired and she cannot concentrate for very long.
Lack of interaction	<ul style="list-style-type: none"> • Physically very well, but not much interaction in care home. • He did not get as much interaction as I had hoped for. • Accommodation was fine but clientele in home were not able to communicate well. • OK physically - but she needs to be able to interact more with others - only the staff were capable. Sad but true.

APPENDIX 9: Carers - what would have improved the respite experience of the person you care for?

9. Carers - what would have improved the respite experience of the person you care for?	
Theme	Comment
Positive experience	<ul style="list-style-type: none"> • Very satisfied. • Nothing x23 • I have been happy and St Olafs Manor is perfect for my husband's disability. It is a pity there are not more respite homes like it in Moray. • Quite satisfied with care given. • Nothing as it is perfect. • I can't fault any of our care. • Nothing as they enjoyed their time at respite • None, Birchview is really good, staff are warm and friendly. • Our daughter enjoys the experience, but makes our lives hell before she goes • None really as my husband never complained and seemed to like all the staff - a home away from home! • Nothing really, although the opportunity to feedback to the social care officer immediately after respite would have been useful. • Everything ran well and smoothly • Murray Street was spot on for our 2. Birchview was too "full on for them", not as relaxing • He likes staying in both places and always knows it is just for a short time • Nothing can improve - perfect! • Great experience so can't think of anything that could have improved it. • She was very well cared for • That provided by Taigh Farrais staff is most satisfactory and should continue to be provided
Additional activities, better interactions with other residents	<ul style="list-style-type: none"> • To be amongst those he could interact with • More activities involving stimulation helping with small tasks and not just left watching television. • If he was given things to do, not enough stimulation, he seemed to spend time in his room, but he is hard to please. • More activities

9. Carers - what would have improved the respite experience of the person you care for?	
Theme	Comment
	<ul style="list-style-type: none"> • Maybe with like patients (there were some). Some outdoor trips and gardening. • More interaction with other male residents. • More activities. • More interaction and more outings. • Going out and doing more activities. Trips out for the day, limited in Elgin in what to do. • More trips out away from Forres • Perhaps hymn singing • To be with her friends she has at the day centre • Do more activities, try and set them with persons with similar needs • Try and do variety of different things while they are there. Service user needs reminded to do things, gets upset easily • To find somewhere clients had same prognosis and communicate better • More people of a similar age • Staying in care home where she goes for day care as she is familiar with the surroundings and staff. • Going in with others she goes to day services with • To find somewhere where clients had same prognosis and able to communicate better. • Having a bit of contact with other people. Unfortunately Spynie has lots of dementia patients and they were walking in and out of his room. However, the door was locked when I mentioned this to management.
Better able to meet individual's needs	<ul style="list-style-type: none"> • Having a better understanding of the person in respite about their needs and feelings. • Having more time to cope with my wife's needs. • 1:1 attention all the time • Social interaction or taken outside of his room. My husband can't use his hands as others can therefore washing, dressing, eating etc is difficult and needs more attention than care home could provide. • Caring, compassionate treatment. Ensuring hydration and medical assistance. • That staff members were quite obviously not aware of the degree of lack of mobility of client.

9. Carers - what would have improved the respite experience of the person you care for?	
Theme	Comment
	<ul style="list-style-type: none"> • Staff able to use continence products e.g. sheath and drainage bag. Husband had very sore bottom after one week. Staff advised treatment by district nurse. • Staff able to use continence products e.g. sheath and drainage bag. Husband had very sore bottom after one week. Staff advised me to get treatment from district nurse. • More staff and activities for the in care persons - no apparent physio! or activities for bed ridden. • More staff • Administration of morning meds. Staff at night on sleeping duty were warned that Dad might wake very early and be a bit disorientated. This did indeed happen. We are not sure how patient the staff were in this situation. The staff had considered phoning emergency contact number.
Funding	<ul style="list-style-type: none"> • More finance to pay for it.
Flexibility	<ul style="list-style-type: none"> • Having a shorted break if available. • Birchwood need to realise that not all clients got 5 day a week day services and need to accommodate clients 24/7 through week - everyone is after weekends. We don't mind breaks through the week days but are put off by their restrictions. This is a waste of a purpose built facility if it cannot be accessed 24/7.
General	<ul style="list-style-type: none"> • Perhaps visiting beforehand would have prepared her better. • More space. • If I had gone on holiday by myself
Negative	<ul style="list-style-type: none"> • Not going as he hated it. • Not closing down the respite centre. • He lost 1st in weight but has gained 2lb since coming home • If she hadn't escaped or been physically assaulted • Access to respite care is not available for couples - that is a double room. Also, not being able to book accommodation in advance is very stressful for carer and those you care for. Personal care allowance not available due to resorting to private care

APPENDIX 10: Carers who have not used respite

10. Carers who have not used respite	
Theme	Comment
Not needed/ been managing/alternative respite arranged	<ul style="list-style-type: none"> • My daughter comes to give me respite two or three times a year. • My sister has always been able to stay when I need a break. • I arranged for family members to stay. • The service I have is an hour break every Saturday. At the moment this is adequate. • I am from a big, close family and my brother lives at home with my mother. When he has time away from home, the rest of the family rally round and takes care of mum. • Accommodation was required when work was being done in her home. We opted for a care home as this bypassed social work department. This was a private arrangement. • We made a private arrangement while work was being carried out in her home. This was self funded. • Although we have not felt a need for my respite to date, we do feel that it may become useful in the future. • Our elder daughter stayed with him for 2 nights while I visited my father's grave. • When I go away for a few days mums friend comes to care for her. • Husband has just been diagnosed with Alzheimer's and we are managing at the moment. • At present if I have been away I have organised for friends or a neighbour to keep an eye on my mum. I have organised food etc. so there is little things she would need but I haven't been away longer than a week. • So far we have not needed respite but service user said if I had to go away for a day she would be willing to take up the offer of respite. • I am a backup legal guardian for my sister and my parents are still able to look after her. I have not felt the need the need to use service yet. • We have family members who have moved in to look after mum in an emergency. • Looked after father in law in our home Nov 13 - Jan 14. Now in his own little house. I am his main carer - I have now applied for carer's allowance. My husband also helps. • Use Crossroads as wife has been reluctant to go in to respite in the past
Cared for does not want to go/carers unsure or feels guilty	<ul style="list-style-type: none"> • The person I care for does not want to go x8 • The person I care for does not want to go. We have self directed support and use the money for short breaks to benefit us both.

10. Carers who have not used respite	
Theme	Comment
	<ul style="list-style-type: none"> • Mother preferred her own bed. • My husband is not too keen on leaving his home and therefore maybe a visit to local respite care would be a help. • Unwilling to leave husband in respite care • The man is 93 yrs of age and does not want to leave the house unless for a holiday. • I am not comfortable of the idea of leaving my wife in respite. • I would find it difficult to discuss with my mother as she might see it as "going into a care home" permanently • I need a break but find it difficult to allow someone else to support my husband therefore I have not tried to access this type of service. I would need lots of reassurance and encouragement. • My husband is not keen to go to respite care as he much prefers his own home and thinks we are managing fine as we are. • I have slept on mum's sofa for a couple of long stretches at times (4 weeks and 3 weeks after and prior to hospitalisation). She is not keen to go anywhere other than home at the moment. She has the start of dementia so this may have to change in the future if we are on holiday at our sons in Italy, hopefully not for some time yet • Feel guilty at having to put husband into respite care. • Mother refuses to go as she feels that she is going into a care home and will not get back home again
Access	<ul style="list-style-type: none"> • I do not know how to access it. Mother is starting Shared Lives. • I have never been offered respite as a carer or service user. • I do not know how to access it x5 • I once phoned short break phone number and left a message but never got a response. • It was not available for the time we needed. My wife and mum did not know about it. I am also a paid carer for my wife.
Current provision does not meet needs	<ul style="list-style-type: none"> • Nobody seemed able to put in place what was needed i.e. buddy system. • What is available does not match our needs. • Everything at home is geared to his needs. • None available for me to use as mother has mental health and drug and alcohol problems
Availability	<ul style="list-style-type: none"> • Because of my husband's illness we are not always able to predict when we will need respite care and

10. Carers who have not used respite	
Theme	Comment
	<p>have not been able to get it when needed so far.</p> <ul style="list-style-type: none"> • The dates we wanted were not available. He ended up at a relatives' on 2 occasions. • We also have child care issues
Cost	<ul style="list-style-type: none"> • When I enquired they told me it would cost about £400+, when retired the cost was too much for one week. • Due to the cost x2 • Applied to Quarriers 2013 for short break but were unsuccessful. Told to apply again in 2014.
Future use	<ul style="list-style-type: none"> • I will be 80 in March, my wife will be 76 March and she has Dementia, can't remember and gets confused but is physically able. But in the future she will need help. • Try and do as much as we can for him but it is not as easy some days, I wish he could go into respite for just short breaks to see how he settles. • I have only recently started caring for my mum. She moved to Elgin so I could look after her. I am looking into respite for this year to give me the choice, advice and right type of care for my mum. I need to know my options so I can choose what will be suitable for my mum. I also need to know costs too. • In the process of hoping to get a week in may for the first time. • I would like to use respite services this year as recently moved to Scotland and feel more settled. • This service was unknown to me, but I have a meeting in two days time. • Don't know what our need for it will be in the future • Have not discussed it with my mother, and I am going on holiday for 2 weeks in summer and usually my sister and her husband help but they are struggling to cover this. • Never had respite, have been managing and now just feel I need a week away. Husband goes to day care for nearly 2 years now in Dufftown. Used to take him with me when went away but it's getting more unmanageable now.
Other comments	<ul style="list-style-type: none"> • Recently became able to use respite after the death of a much loved pet that could not go into the kennels for the last 2 years. • Fairly new in system so not familiar with what is available. • I am a new carer for the person and have not used the service; it was used before for the last carer. • Have been told we are not eligible. My son has tourette syndrome and associated ADHD/anxiety. He

10. Carers who have not used respite	
Theme	Comment
	decided during his early teens he did not want to be treated differently to his peers. Sleep deprivation has always been our biggest problem. Respite was never offered/known about or my husband/me and other family members would have used it.

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APPENDIX 11: Carers - what else is important to you?

11. Carers - what else is important to you?	
Theme	Comment
Experience of the service user	<ul style="list-style-type: none"> • Mainly that my husband doesn't feel that he is put into an "old folks home" as he is not old and doesn't want to play bingo. • Age suitable as my son would not like to be with old people at his age (42). • That it is a small house as my husband would not go if it was an old people's home. • It is important that the service used benefits from the experience of socialising with their peers, out with their home environment. • Parent being happy. • Access to Television. Likes to smoke about 10 a day • To understand that some clients need peace and quiet not always on the go. • Not too many people in the facility at once - not everyone likes crowds, noise and "busy" times. Relaxation is a high priority with our two. • Peace and quiet. • Knowing that my husband is contented and well cared for • It is very important that everyone using these facilities feel as happy as possible. Being close to relatives and friends who can visit is very important along with having activities etc. to do if they are able to. Try to make it as much a home from home as possible. • Simply peace and quiet • Good food, helpful staff, my mum is happy and content where she is going, not confused or upset. • That he or I would be happy and settled where ever and as I don't drive to be within easy reach for me as I am also disabled. • My sister is happy with her care, feels safe, comfortable and adjusts ok to it. • That their well being is met to the best that they can do.
Safety and comfort	<ul style="list-style-type: none"> • That I know my daughter is safe. • Safety • That my mother is safe and comfortable. • Knowing she will be safe

11. Carers - what else is important to you?	
Theme	Comment
	<ul style="list-style-type: none"> • That my brother is safe. • Knowing she is safe • That they are safe and looked after • That the client be cared for safely and properly. And when medical attention is required it is accessed speedily ASAP.
Standard of care/needs are met	<ul style="list-style-type: none"> • Friendly, helpful staff - like minded articulate people. • Ratio of support staff to service users. • Knowing that staff can work with them and understand a person's needs. • That my wife receives the same care and attention that she receives at home: specifically that her pad is changed at regular intervals. • Most important is to find somewhere able to cope with my wife's needs. • The medical requirements are adhered to. • The care and understanding of his needs by respite staff. • All care homes are really under staffed and cannot give the care really needed which is a big factor and needs to be addressed. • Carers who care • The staff being aware of my husband's needs regarding getting plenty fluids. • Dignity Medical trained staff Physiotherapy • Age of staff, for us younger is good but it is also necessary to have older. • To make sure cared for are treated the same way you or me would like to be treated. • Medical staff on duty 24hrs per day. • Kind, friendly staff, good nutritious food. • The nursing care, as he is a large, heavy man and requires help with most things. • The quality of care is the most important consideration. • Friendly staff • Consistency of staffing. • The carers at Birchview are just marvelous people. • That their well being is met at all times • The carers at Birchview are just marvelous people

11. Carers - what else is important to you?	
Theme	Comment
	<ul style="list-style-type: none"> Staffed by people who are able, skilled, and knowledgeable and who want to care. That staff listen to me and take advice as to needs of my partner. Nursing care and attention. Help with washing, dressing and eating as my husband can't use his hands like other people. Friendliness towards everyone
Choice and flexibility	<ul style="list-style-type: none"> An afternoon in our home, just for me. Short trial periods before use for longer periods for example tea visits/part day visits. Can respite be covered in the persons own home in order to cause them less stress? Respite for the two of us together. Would like home visit for my mother in law. That family can visit when I am away. If my mother is in hospital, she becomes quite confused. At home she is more lucid. Local respite would be better for her. Important to have short term breaks at home, not just accommodated respite. Social opportunities needed locally for high functioning autism. Having respite accommodation for the person being cared for, which is not on our doorstep Close to the shops. Proximity - Elgin is best for us. Our limitation is availability Respite care for cared for person in own home while carer goes away That carers had someone to help with personal care in the morning, same as at home. Within travelling distance of home and in a location suitable for residents e.g. country accommodation for country people Son is now going through transitions period and we know that he will not be able to go to (current respite) for much longer and are currently exploring our options with his new social worker. I was quite surprised at what was available when he hits 19
Communication	<ul style="list-style-type: none"> That all carers know about what is available. Had we known the mental and physical exhaustion we all felt as a family (other children included) may not have been such a huge

11. Carers - what else is important to you?	
Theme	Comment
	<p>stress trigger. Care has put a massive pressure on us as a family unit.</p> <ul style="list-style-type: none"> • Ability to contact while away and be kept updated. • To be notified if there is any problems • Good communication services as needed. • Information on what is available as this service would be very useful/helpful.
Other	<ul style="list-style-type: none"> • Appreciate that it's there and found it very good. • The price of the facilities. • Bureaucrats have labeled me as a "carer" for their own facility. My wife doesn't want me to be her "carer". I used to be, but she's resentful now. That drives me further from her.

APPENDIX 12: Carers - how can respite services be improved in the future?

12. Carers- how can respite service be improved in the future?	
Theme	Comment
Satisfied with current provision	<ul style="list-style-type: none"> • Services are ok for my needs at the moment. • Happy with everything as it is. • Day care activities are excellent. • I feel it meets our needs at the moment • Spynie is great as it is • Birchview is perfect • Quite good the way it is. The staff were all so helpful and friendly and would help away in any occasion. • Ask the carers what they want. Not all the carers want the same. Lisa listened to my needs and they were met. More of the same. • By not being changed from that currently in existence. • Very good, quite happy as they are. • I am happy with the service as it is • Having used the service three or four times and been very, very impressed by the service provided from you, please continue. The holiday break with my husband was made even more special because of your work to provide carers made all the difference. • I feel it meets our needs at the moment. • The standard of care in respite services at Birchview is second to none. First class service providers. • I can't fault the service we have received so keep up the good work. • Where my sister goes at the moment is Birchview, Elgin, as she seems to enjoy it there. They do a wide range of indoor and outdoor activities and she does not appear to have any concerns when asked. • I've only recently applied for help and found a first class service - it's the patient that's difficult. • I had a very positive experience with Quarriers. That respite services are very well advertised and promoted to the very vulnerable even visiting them to explain what is available.
Allocation, availability, flexibility	<ul style="list-style-type: none"> • Capacity and availability are a problem at peak times with my bookings made well in advance there is limited opportunity to take advantage of respite.

12. Carers- how can respite service be improved in the future?	
Theme	Comment
	<ul style="list-style-type: none"> • Need to be more flexible - not sure how to do this. • More accessible to everyone and you didn't go through the social work channels. I would be better if the carer could make more of a decision as to when they need a break • More days could be allocated for when emergencies occur • Flexibility in "open times", length of stay. • Perhaps a break more often throughout the year • Present use of only weekends and this "blocks" longer breaks for others. • More allocated nights. • I feel that sometimes a shorter stay (for example, a long weekend) would suit so that they could maybe go into respite more often. • By being available when needed. As a carer for years I'm not always aware of how stressed I am but the nurses who come in seem to see this and have been wonderful. • Making sure we have enough days for all year round as this is the only time we get to our selves. • We need to know that in an emergency there is respite care available to look after mum • Guarantee of my two away each year • Notification of availability • By being more flexible with admissions • Being available when needed as carers just keep going. I understand cash is a problem and they are doing their best but with older people on the increase the situation will become worse. • Flexibility of times - open longer (Birchwood seems to be closed more than open because of the restrictions, what a waste of a facility!) Longer stays to be able to access to clients from one family at once otherwise there is no point of respite to these people. If one person can only be accommodated they still have one to care for so no respite for them at all.
Choice of provision	<ul style="list-style-type: none"> • More places in the area to be able to do respite, desperately lacking accommodation for wheelchair clients in Moray. • More of them • Choice of respite accommodation that has a high quality of care and range of activities for

12. Carers- how can respite service be improved in the future?	
Theme	Comment
	<p>service users</p> <ul style="list-style-type: none"> • I would want respite services to be provided in my own home, not for my mum to go elsewhere. I would prefer to use people who already know my mum to look after her. • Provide day care at Birchview. • More places like Taigh Farraais as they are more homely and ideal for disabled clients. • Service user attends day care at Cameron Court two days per week. I feel very strongly that his respite should be at Cameron Court, not Cullen or Huntly where they were going to put him. • A care home that she goes to for day care allowing her to go there. • More respite choice of places. • Having respite within our own locality in a smaller setting • If it was located nearer home as transport in future may be a problem. • To have more places available. • Carers need to be aware respite exists and is there when needed. • More widely available. • Allowing us to book her into the local home she goes to daycare into. • More respite beds. • More local care home - preferably the one she uses daily anyway. Day care has problems coping with her after respite and think she would be better there too. • Having "whole day personnel" available to care for the cared people in their own home to allow cover "day off" from caring to concentrate on other matters. Cared for persons would be much happier in their own home with someone else rather than "decanted" into a strange place. • As both my husband and I provide care for each other for different reasons it is vital and respite be provided for us as a couple • By offering caravan type respite. • Better choice of accommodation • Choice of care home should be chosen by the carer that is placing relative in for respite. • We have only used respite care in the home, allowing us to have holidays. This has been

12. Carers- how can respite service be improved in the future?	
Theme	Comment
	<p>excellent. If the health of my mother in law changes and we feel accommodated respite is needed flexibility would help.</p> <ul style="list-style-type: none"> • More for specific ages e.g. 25-35. More for dementia only. More for specific nursing needs like severe head injuries etc. • It would be great to have more respite services available in Moray. St Olafs is a Godsend • Parents would like to have a respite break together
Communication, awareness-raising	<ul style="list-style-type: none"> • More information on the cost. • More information please! Don't know anything about accommodated respite. These answers apply to me (the carer) as my wife cannot leave her bed. • Make information readily available and easy to apply for • That information regarding the subject should be more readily available • It would be nice after making an initial call if they would phone back and keep me informed as to whether my request has been met. As I usually have to book flights I do need to know if I can go on dates required! • My daughter doesn't speak very well, so maybe a bit more communication as to what she has done while in respite. • Short Break Bureau was brilliant but found out about it by accident. Better joined up communication between Short Break Bureau/Care Organisers/NHS/Hanover especially re MAR sheet, funding arrangements. • To let carers know what is available, where it is and the cost included • Just a simple list of what's available that all carers (registered or not) can access through their GP would have helped us. • Awareness for everyone on your list even if they are not accessing other services. • When an older person is incredibly dependent on care (family member/friend), perhaps GP Practices/NHS could flag this up for informal referral. The carer often keeps on caring to breaking point, not realising that help is available • Better communication, for example - doctors and libraries • By making people aware of this great service i.e. many people do not know that respite services is available for them to tap into when needed.

12. Carers- how can respite service be improved in the future?	
Theme	Comment
	<ul style="list-style-type: none"> • Good communication planned well in advance • Be more accessible to public so that when someone phones you they get a response from their message left on your answering machine. • Easier to understand, choice and access • I did not know how to access respite and how to bring it up with my mother
Activities, social interaction	<ul style="list-style-type: none"> • Social activities within the group • In with own friends, more activities • Need to have variety of different things to do, e.g. go to the cinema • To remember that everyone does not like to be "active" all the time, quiet and relaxation is beneficial too. • Patients who can be taken out should be as isolation can be depressing to a disabled person. • Most people watch TV in their homes anyway so it would be good not to park them in front of yet another TV in order to occupy them. How about short plays, orchestra, reading aloud, quizzes etc to stimulate the brain. Board games that require a little effort for example "Snakes and Ladders". • Would like to have lots of activities for interaction and not just sitting around. If have younger ones they might chivvy along older ones.
Surroundings, equipment	<ul style="list-style-type: none"> • Provide fold down grab rails at respite unit toilet as I had to bring toilet frame in from home. • An inspiring view of garden or sea would seriously enhance the respite stay • To make the surroundings and atmosphere like home and not like a hospital.
Meeting needs/outcomes of the service user	<ul style="list-style-type: none"> • More staff on duty and an understanding into the illnesses of each person that is in their care. I do not know that ever person is the same with each illness, but a broader spectrum is required in the care staff. • Better support • For service user - close contact on a one to one basis. • Please ensure that staff are adequately trained to deal with a wide variety of circumstances which can arise unexpectedly ensure there are sufficient staff on hand to cope. • More trained care staff in homes. Ratio of 18 rooms approx 50% bed ridden to 4 or 5 persons on duty (not enough)

12. Carers- how can respite service be improved in the future?	
Theme	Comment
	<ul style="list-style-type: none"> • Medical/nursing care available 24/7. Ensuring basic needs i.e. nutrition, hydration and personal care. Home from home support and care. • The more personal it can get, the better - but we're not complaining. • More supported accommodation which meets the needs of the variety of disabilities both medical and physical. Staff being properly trained and confident to deal with emergencies. • Moray Council has a responsibility that when they as commissioners decide which agency they will give the contract to must be able to meet the needs of the people who will use the service and also their carers. They must also listen to and act on the carers if a service continually fails Moray Council must ensure the service is not awarded anymore contracts which we, the people of Moray, pay for. The meetings i.e. focus groups, two are in Elgin one of which is 7pm-9pm. Most people are at work daytime why hasn't the 7pm-9pm time been allocated to the other towns enabling perhaps more carers to attend at that time giving them the opportunity to discuss respite services.
Finance	<ul style="list-style-type: none"> • If day service could be funded we would get a complete break • The Scottish Government established a fund to enable carers to be properly assisted to have some respite. • We have an issue when it comes to transport, I would like to have a transport in place. • Don't cut them • I think an injection of Government funds to provide more respite/short break facilities would help greatly - there just aren't enough facilities available, this puts a lot of stress on the caring organisations and carers alike • More finance • More funding. • Supporting Carers Services in the past we have been told there is no budget for carers and it is all about the cared for. •
Transport	<ul style="list-style-type: none"> • Transport issues. Cost to son - when the council take 100% of his "excess" benefits weekly • To supply transport to and from • What I found difficult was that no transport was provided. It was very difficult organising

12. Carers- how can respite service be improved in the future?	
Theme	Comment
	<p>transport as you have to do it yourself and having no car and person who can't walk without falling all the time, was very traumatic and costly is taxis are used.</p> <ul style="list-style-type: none"> • Transport could be an issue for as I do not drive
Neutral	<ul style="list-style-type: none"> • Moray seems to be going the right way and came out well in a recent survey by Audit Scotland. The rest of Scotland needs to follow Moray. • Important for my child to know he's not different. • Currently I receive respite for up to 3 hours on Thursday afternoons from a lady from Crossroads. This allows myself and daughter or sister (either of whom is here!) to go shopping or have lunch • For me: conversation is better than composition
Not used/not needed	<ul style="list-style-type: none"> • Not needed as they are adequate at present. • I have never used respite services but I would like to think that all services provided the standard of care as I think is very important. • Having never used, I cannot comment. • Not used x 12 • Having not used this service I do not know how I can improve it. On several occasions I have had to have surgery myself leaving or being unable to care or assist my wife, it would be useful to have assistance when needed. • As we haven't used any respite care we have no idea how it can be improved, perhaps being able to visit local respite homes. • I have never been told of local respite mostly because service user has a good support package which managed while I am away & service user has family to invite him to stay and the Findhorn (Foundation) courses which all give me a break.