

**A report on the respite needs of
carers of adults with a learning
disability living in the family home**

by

**Clackmannanshire Learning
Disability Carers Group**

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(Falkirk and Clackmannanshire)

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Background and introduction

The Princess Royal Trust Carers Centre was established in 1996 in Falkirk to provide information, advice and support to carers in both Falkirk and Clackmannanshire. In 1999, an office was opened in Alloa and a Carers Development Worker was employed to develop services for carers in that local authority area. In the autumn of 2004, a group of carers for adults with a learning disability in Alloa approached the Development Worker requesting a support group for themselves, which was separate from the support group which was already organised for carers in Clackmannanshire. The local authority agreed to make funding available to meet this request on the understanding that members of the group would participate in its planning groups to provide carers' input. The need for more and better respite services emerged as a major issue for the group and we were successful in securing SCARF funding to undertake an action research project.

The focus of inquiry

The overall aim of our inquiry was to examine respite provision in Clackmannanshire for carers of adults with learning disabilities living in the family home and to look at examples of good practice in other areas.

For the purpose of our study we defined respite care as short-term care that helps a family take a break from the daily routine and stress. It can be provided in the family home or in a variety of out-of-home settings and involve either time apart or time together with extra support. Respite care can vary from several hours to several weeks and be provided on a planned basis to address an assessed need, as a holiday or in emergencies. We addressed four areas:

1. Need

- *What is the extent of the need for respite services?*
- *What kind of service and in what form, are carers looking for?*

2. Experience

- *Who currently is receiving (or not receiving) respite care?*
- *For those in receipt of respite, what kind of service do they receive?*
- *How satisfied are they with the current service?*
- *How easy is it for them to access respite services?*
- *What problems have they encountered?*
- *For those not receiving respite services, why is this?*

3. Provision

- *What is the extent, nature and quality of current respite provision in Clackmannanshire?*
- *How well (or badly) does it meet the needs and aspirations of families?*

4. Good Practice

- *What should a model respite service look like?*
- *What are the essential elements?*
- *How should it operate?*

We intended to draw on the experience of our members and other Clackmannanshire carers, as well as on examples of good practice from elsewhere in Scotland to help us make suggestions for a respite service which better meets the needs and aspirations of carers in the 21st century.

Our inquiry focused on the carers of adults with learning disabilities living in the family home and resident in Clackmannanshire. Clackmannanshire Council's Social Work Service agreed to forward material from us to all such families known to them outlining our project and inviting them to participate - approximately 100 families. We also advertised the study in community and public venues and in the local press in the hope of also recruiting families not currently in receipt of social work support.

What we hope to achieve

We hope the research and findings will:

- raise the profile of our group and the people it represents with the wider Clackmannanshire public, opinion-formers in the community, and most especially with local councillors and social work officials
- give these groups a better understanding of the demands and costs of caring and the nature of the challenges which so many carers face on a daily basis
- show that we are not, as often portrayed in the media, a victimised group, but rather people with a positive outlook who are ready to do something to change our situation
- push respite higher up the political agenda
- give our members the credibility necessary to exercise an effective voice in the planning and delivery of services
- achieve a respite service that better meets the needs and aspirations of carers and improve their quality of life.

The research approach

The Scottish Community Action Research Fund gives community groups support to improve their skills and confidence to carry out their own research. SCARF was paid for by Communities Scotland, the Scottish Executive's housing and regeneration agency, and managed by the Scottish Community Development Centre. SCARF provides funding for research by community organisations to help communities get actively involved in decisions that affect them and improve their circumstances. We used a variety of methods including:

Questionnaires: Clackmannanshire Council's Social Work services agreed to forward leaflets from us to all those carers known to them, outlining our project and inviting them to participate and to assist families to complete a questionnaire seeking socio-demographic information, details of care needs and experience of respite services.

Interviews: in order to obtain more detailed information of need and experience, we carried out 11 interviews with carers using a structured interview schedule.

Case Studies: using our interview material and with permission of interviewees, we constructed short case studies to illustrate the range of need and experience.

Observations: we surveyed existing respite provision within and out with the county using a structured proforma to record relevant information and examples of good practice.

The questionnaire findings

The profile of carers who responded to the questionnaire

Questionnaires were completed by carers from 27 families out of a total of 98 families who use or have used social work services and an estimated 170 families in Clackmannanshire:

- 92% of the respondents were female
- all were over the age of 45
- half were over retirement age
- 93% of respondents had been caring for over 20 years
- 48% of respondents were retired
- 23% were in part time employment
- only one person was in full time employment
- 22% were not in paid employment and not seeking work

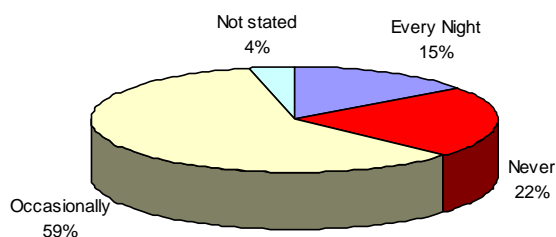
Duties undertaken by carers

Respondents were asked what kind of support and care they provide for the person(s) that they care for. Carers could tick more than one statement.

	% Respondents
Practical e.g. cooking, shopping, laundry, gardening	93%
Financial e.g. banking, bills, forms	93%
Social e.g. going out	89%
Communication e.g. speaking up for them, correspondence	85%
Emotional e.g. providing encouragement	78%
Transportation e.g. to day-care, employment, appointments	74%
Medication e.g. administering drugs, changing dressings	67%
Safety e.g. in case they harm themselves or others	67%
Personal e.g. dressing, bathing, washing, eating, using the toilet	63%
Physical e.g. walking, using stairs, getting in and out of chair/bed	26%
Other support or care needs	22%

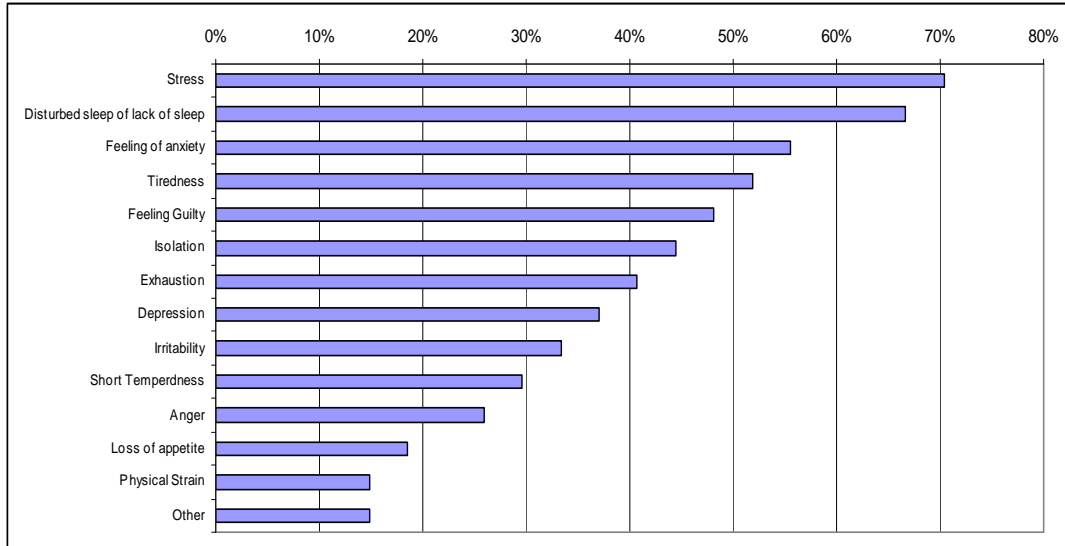
74% of respondents said they get up during the night to assist the person they care for. 45% in this category get up 1 or 2 times per night, 10% 3 or 4 times and 5% get up 4 or 5 times during the night.

% of Respondents Assisting During the Night

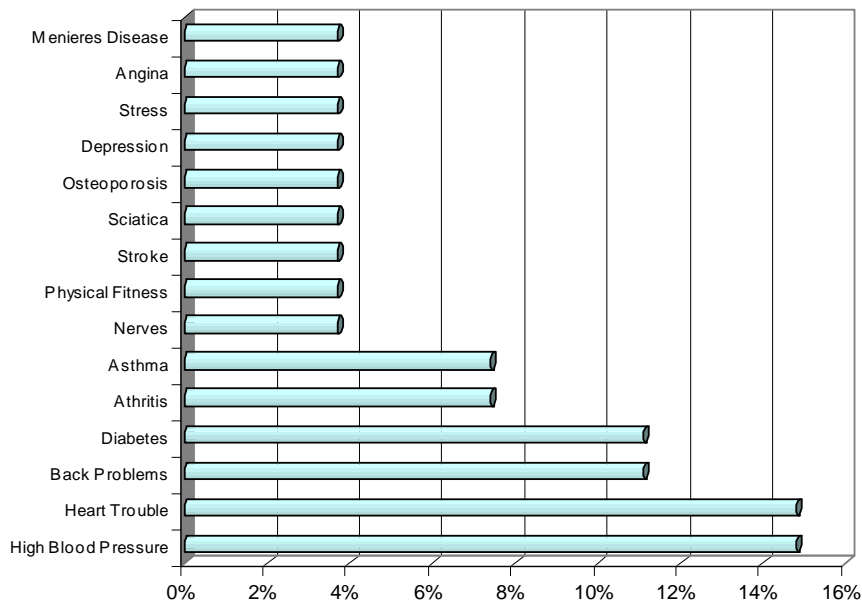


Impact of caring on carers' health

Respondents were asked to tick all that applied of a range of given symptoms they had experienced as a result of being a carer. The most common symptoms were stress (70%), lack of sleep (67%) and feelings of anxiety (56%).

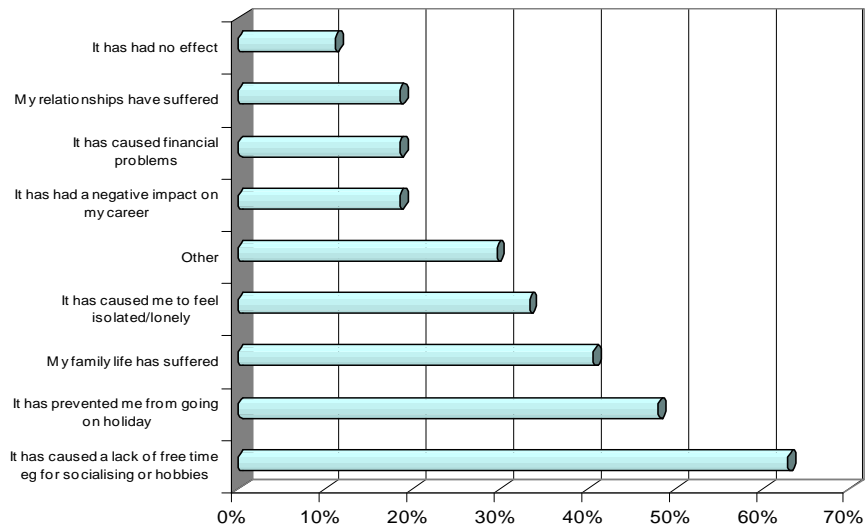


Carers health problems: 67% of respondents from Clackmannanshire reported having a health problem. The most common health problems being heart trouble, high blood pressure, diabetes and back problems. 26% of respondents said they had received treatment from their GP because their health was being affected by being a carer.



Impact of caring upon respondents social life

Only 11% of respondents surveyed from Clackmannanshire said their personal/social life had not been affected as a result of being a carer. Of the respondents who did feel their life had been affected, 67% complained of a lack of free time.



Help for carers

Respondents were asked what help they receive. Carers could tick more than one statement. Statistics show that 30% respondents receive residential breaks for the person they care for. Other types of help include, help and understanding from Community Nurse, Crossroads Care, Befriender and Local Area Co-ordinator. Of the number of respondents who received some form of help, 44% had to pay or contribute towards these services.

	% Respondents
Residential breaks for the person you care for	30%
Carers support group	26%
Other help	26%
Aids and equipment	22%
Someone to talk to	22%
Information	19%
Adaptations to your home	15%
Help with providing personal care	11%
Alternative care at home to allow you a break	11%
Help with household tasks e.g. cleaning, shopping	4%
Training e.g. moving and handling	4%
Help with nursing tasks	0%
Supported holidays	0%

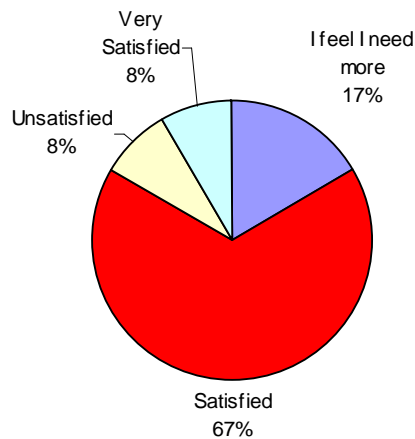
Carer breaks

Respondents were asked, if they were not currently receiving a regular break, why not? Carers were asked to tick all that apply.

	% Respondents
I've never asked for a break	52%
I've never been offered a break	37%
I don't know how to access such a break	19%
I don't feel as if I need a break	11%
The person I care for won't allow anyone else to provide care	7%
The break we were offered didn't suit our needs	7%
I can't afford to take a break from caring	4%
The person I care for can't afford the cost of respite care	0%

Of the number of respondents not receiving a regular break, 50% thought a supported holiday for the person they care for would be the most useful. 20% thought alternative care provided in the home of the person they care for would be useful.

Respondents were asked, if they currently receive a regular break from caring, how satisfied are they with the service provided. 67% respondents receiving services said they were satisfied with the services they were receiving. Only one carer was unsatisfied who felt 4-6 weeks respite wasn't enough out of 52 weeks.



About the people being cared for

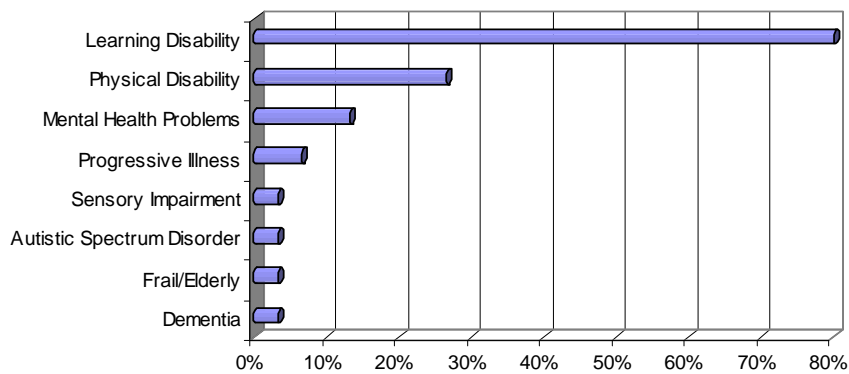
- 63% were female and 33% were male (in one case gender was not stated)
- in 84% of households, the person being cared for was a son or daughter

Age of person cared for

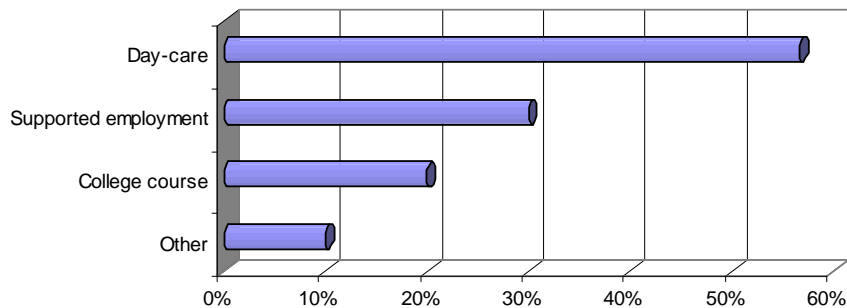
Under 18	0	0%
18-24 years	7	23%
25-34 years	7	23%
35-44 years	3	10%
45-59 years	9	30%
60-69 years	0	0%
70+ years	3	10%
Not stated	1	3%

The questionnaire findings show that adults with a learning disability very often have additional disabilities and health problems.

% Persons Cared For By Care Group



% Persons Cared For By Additional Services Received



The interview findings

The profile of carers who were interviewed

Interviewees were identified through the Carers Group, by the Local Area Co-ordinator and from responses to invitations sent out by the Alloa Centre. Twelve carers were interviewed, two of the interviewees being a couple.

- 11 interviewees were female
- 1 was male
- 3 were between the ages of 35 and 44
- 4 were between the ages of 45 and 59
- 4 were between the ages of 70 and 79
- 1 was aged 80
- 5 were the sole carers in the home
- 5 received no respite services
- 7 said they had had no choice in respite service
- 1 family had to go to Stirling for a suitable respite service
- 10 said they would use respite services / more respite services if offered

The profile of the people they cared for

- 5 were between the ages of 18 and 24
- 2 were between the ages of 25 and 34
- 2 were between the ages of 35 and 44
- 2 were between the ages of 35 and 44
- 9 attended Alloa Day Centre
- 4 attended Clackmannan College courses
- 4 attended CLiCK Learning Centre
- 2 had supported employment
- 1 attended Reachout

The case studies

From the eleven interviews, we selected four which we felt gave a personal insight into the daily pressures of caring for an adult with a learning disability, a detailed qualitative picture of the range of carers' views on respite, and carers' preferences for and requirements of respite. We present these as case studies constructed from the interview data.



1. The White House

Andrew has severe learning disabilities and epilepsy – he's 22. Sometimes the epilepsy can bring challenging behaviour and he forgets things. Andrew needs 24 hour support in everything he does and you have to reinforce everything he has learned. We just give him the support that he needs. If he gets stuck with anything we reassure him that things are going to be fine and that he can do it himself. He can never actually button up a shirt right so you have to undo the buttons and try to say to him that he has done it wrong, just little pointers. Making sure that his shoes are on the right feet. He will put the kettle on for you but then he realises after that it is your job because it's dangerous. If he wants a sandwich or something I usually put him up the other end of the kitchen with the butter and knife and the bread and whatever he is putting on it but he will tell me he can't do it himself. I say he can and I leave him and just watch from a distance. He will make toast but nothing with the cooker. He has tried but he has put boiled eggs in the chip pan before! It's some kind of liquid you see. He can use the microwave. He knows everything is roughly two minutes and that it says how long on the box, so that's good. If he has a seizure during the night, we have to get up, shower and change him. That's usually a two man job so there would be two of us up. We are trying to get him to the next step where he can be on his own but living with support. That's our next aim.

Andrew goes out on a Saturday with Crossroads. We have 3 hours one Saturday and 6 hours the next Saturday where Andrew goes out to the pub. He loves darts and things like that so the pub is the place to go. It is really good as they include him in everything. Then he will go shopping and other things that he wants to do. It's good for me as I get a rest on a Saturday. Crossroads have the run of my house and they know where everything is. It's like having another member of the family coming in. I have a team that consists of 3 people for a Saturday but if he is going into respite I have a bigger team. I know who the people are each time and some become like another mum and they are really good with him. The newer members have a lot to learn but they will get there!

We get 8 chances of respite per year. Andrew goes away on a Friday at 6pm and I get him back on a Sunday at 6pm. So I actually get the full weekend. It's really nice. Being in the house himself lets him do what he wants to do. He is being totally included in things and being asked where he wants to go. I think that gives him so much confidence as a person. He calls it the White House and he is a totally different guy there to what he is at home. He will put the washing machine on, he will dry the dishes, but when he comes home and I say "Go and dry the dishes", he says "no, that's your job." So it's not only to give us a rest, it's actually helping Andrew. I think

he thrives being in the flat. For that couple of days it's like "I'll do that". He is going out more, going shopping more he has got the concept of being independent and what it is like to be an adult. And then it kind of fades out.

It's like the first step of Andrew living by himself with support which is reassuring because if anything happens to us, we know that he has the structure there, he has the basics. But I think a lot of the older carers are frightened that they are letting themselves down, that it means they not coping or they feel guilty about using respite services. But if anything happens to them their loved one is going to be unprepared. I would hate to see that for Andrew personally, I would like to see him settled before anything happened to me, so I have peace of mind. You have to think about the future when you will not be there for them.

Respite helps the rest of the family because for that weekend life is stress free! You can recharge your batteries and, I know it sounds terrible, you can actually be a proper human being, you are not a prisoner. Even going down to the shop for a paper it's a nightmare if Andrew's here to get him ready to walk 100 yards. I can just go grab my purse, out the door, and basically have freedom. When Andrew comes home from the centre, that's you, you're a prisoner, because he doesn't want to go out he wants to live in his own little environment. Having that weekend just to say I can open the door and go where I want, it's like getting back in society again, like having a life again, go out and socialise and be yourself. If you want to go shopping you can go shopping, you don't have to rush back, it's like all boundaries are lifted. For that weekend it is fantastic! We go for family lunches without Andrew so that my other son gets some attention and time, and we can spend time just saying "How are you?" without Andrew trying to interrupt. For that weekend we are a family unit, and we know he is fine and well cared for.

We used to have respite once a month, then because there was so much demand for respite on the Council, the Head of Services decided that if we cut it down to 8 times a year, it meant other people would get the service too. Which I have no objection to but when you get it for 12 then all of a sudden you are getting 8 you think what are they going to do next? All my friends knew that it was once a month and everyone could work out my respite. People used to plan outings around Andrew's respite, without even telling us, and knew that I could come because Andrew was away. So I had a social life. I would like to see more respite, I would like to see more units so people could actually use it more. The funding for units is limited, and let's face it, the problem is only going to get worse. We really have to be aware of this just now and be prepared for the next 30 or 40 years coming up.



2. A Lovely Day Out

I'm 80 and Morag will be 55 next month. I just have to call her in the mornings and she gets up, she showers herself - I just supervise. She will ask me "what should I put on today?" I cook her meals though. She is afraid she would burn herself. She can't go out on her own. At night, I don't have to supervise, she'll get ready for bed, if

she needs clean pyjamas, she will bring the dirty ones through and she puts them in the wash place. And she knows the drawers where things are kept. All her night clothes are in one drawer, underwear's in another, tops in another. So she picks what ones she wants to put on. She doesn't go out in the evening. She seldom sits with me to watch television because she likes other programs. She likes anything funny. She's got loads of videos, funny ones. She knows by the pictures on the covers which ones they are. She can't read the name but she knows if she looks at the picture. She could play the part in some of the films, specially *Gone with the Wind*. Morag goes to the Alloa Centre and she likes bowling. I got sent a letter saying they were going to write down what she did every day. Two or three of them has this problem, they can't communicate with parents when they go home because they forget. She has her note book for the centre but there is never anything written in it. On the days she is not at the Alloa Centre I usually take her out.

I knew about respite but I didn't pursue it when my husband was alive because we used to go out everyday with him. We have respite once a month at Torbrex, St Ninian's. Morag's Social Worker arranged it. He sent me a list and said they had arranged for respite once a month and I've got all the dates there. Torbrex is the only place she can go really. Morag gets there in time for tea on the Friday. I give her some pocket money. I tell whoever's in charge and they take her down to Somerfield at the end of the road and she usually buys a comic. Not that she can read it, she gets something with all the pictures in it. One time she went to a Karaoke. I don't know how respite affects Morag because she won't talk about it. She never takes the initiative you have to ask her all the time. And she has a very short memory. I don't know how she performs there. I don't get any feedback.

When Morag is at Torbrex, I get a lovely day out with my friend. We take the bus to Edinburgh. Get off in Princes Street, take another bus down to Leith and there is a big shopping mall there and you can look down on the Britannia yacht and then we come back up to Edinburgh and have tea in Jenners. We have just started doing that, we have been twice already, but we are going to go elsewhere. Respite gives me a break and it gets Morag used to being away from me.

If I had more respite I might be able to plan a few days holiday away. I would like there to be more respite in Clackmannanshire, a nice place, where you would feel happy that they are there. That's well supervised.



3. The Golden Wedding

Amanda does all her washing and dressing herself - she showers every morning, she has got her routine - and she goes off to the Centre. There is the odd thing her mum needs to remind her about, maybe speak to her about what she is wearing but on the whole she gets herself sorted. Say, have you got a jacket with you? Sometimes she would walk out, wouldn't she, without her raincoat and not think what the weather's like. We just oversee, make sure she does everything she needs to do and gets there. She is pretty good at knowing she goes away at 9 o'clock to the Centre.

We've been up at Tillicoultry this morning with her. They have moved the venue and we are concerned about her crossing that road. She wants to go on the bus, and we want her to go on the bus to help her independence. But we are concerned about her crossing the road so we are trying to do something about it.

Amanda uses the Alloa Centre four and a half days a week – she is not there all the time, she goes off from there to do various things. Her programme is that on a Monday she goes to the toning tables, there's about four of them goes down to the toning tables. Have their lunch, go to the library for computing and then go back to the Centre. But she is really only back at the Centre for about an hour. On a Tuesday she's got her supported employment in the morning but she goes to the Centre when she is finished that. She is at the Centre on a Wednesday and she's got CLiCK for computers. She goes swimming on a Thursday morning and she has drama on a Friday.

We've never, ever had any respite. Never, never. We are actually getting a break in August. A week in August, it was our Golden Wedding in July. And she is going to live with our son for a week. Very nice. She is quite happy going to stay with him - we've got grandchildren you see.

How does it affect us not having a break? You just take it as that's your lot and just get on with it. I did push for respite when a social worker interviewed us. And it was supposed to be arranged to get something up and running but I've never heard a cheep since. I brought it up at one of her reviews but what I was looking for originally was a befriender. It was to be looked into after Amanda's hip operation at Christmas but I haven't pushed it, to be quite honest with you.

Our idea of respite is a befriender really, somebody to take her away from us and give her a break from us. For her sake more than us. She has no social activities other than with us. All her social activities stopped and there is nothing now. Amanda is at her happiest amongst her peers. She loves to be with her friends of the same level. And they don't get the opportunity do they? Not now, not since the Society folded. That was the one that provided the social side.

If respite was available we would use it a little now because we are getting older – we are in our 70s now. Yes, age has got a lot to do with it. And I've got a lot of health problems which means it's really my wife who is dealing with both of us.



4. A Kind of Solace

I'm 48 and I look after my daughter Laura who is 23. My husband helps of course. And her granny has her 3 hours on a Saturday and 3 hours on a Sunday. I dress Laura for quickness. She washes herself though. You go through to get a towel and half the towels are in the washing. I give her her medicine because she would take the full packet. I make her meals but she is able to eat it herself. She needs supervision going out because she has no road sense.

In the evenings at home, she's got her own leather recliner, she got a DVD she's got CD's, she's got magazines, she's got her stuffed toys. She has a little wander about the house, she comes through and sits with us, then she goes back in the hall, but it's murder trying to get her to bed. At 11 o'clock she goes to her bed. She can put her own pyjamas on. The reason I know she can put her pyjamas on is there was one night I was tired and I was watching something and I turned round and said to go and put her own pyjamas on, and she went and did it. And the look on her face, "Uh oh, what have I done here!" So she can dress herself, put her pyjamas on, put her shoes on, she can do the hoovering, dry the dishes, and I'm trying to get her to make her bed.

If we're going out for the day, and we are going to Falkirk, we don't tell her beforehand. We slowly take her to the car, put her in, put her seat belt on, pick her gran up, then go to Falkirk. Because if we tell her beforehand, she shouts, screams, bites herself, kicks herself, and we end up staying in the house. She likes to go to Matalan to buy stuff, and I like going to Matalan, I like getting out for a run in the car. That's what we do.

Laura goes to the Alloa Centre 2 days a week. We tried 3 but, it just didn't work. They were having more problems on the third day than they were having the rest of the time. When she is not at the Alloa Centre Laura likes helping me in the house with the housework and she watches her DVD's, she reads papers. She puts the recycling in the box, helps me tidy up, does the hoovering, dusting, dishes, she really tries to help in the house.

There are days where I'm tired. But, you get a kind of solace when she comes up and sits next to you and cuddles in to you and says "I love you Mum" and you say "I love you too". Most of the time I'm alright because if I don't feel right I just tidy up my house and make sure everything's fine and his dinner is in the fridge if he's coming in, see if Laura needs anything. She can help herself to water, she can go to the toilet herself, she can do a lot of things for herself. If she is needing me I'm there for her. But, she's not bad, she's got her good days and her bad days. But I'm not too bad.

There are days I've been ill but you've just got to get up and get on with it. That's why I get the flu jag every year because it actually does help. One day last week, I felt just like yuck. And I felt like going back to my bed, but I couldn't because I've got Laura. And it was a beautiful day outside, you couldn't have got a nicer day, I just couldn't get myself moving. I just sat in the living room and Laura came through and I made her dinner and I was like slow motion all day. But, I got there in the end.

I've not got respite at the minute – I've never had respite. I am willing to try it but my husband is not willing at the minute. And Laura says a very definite 'no'! Because she doesn't want anybody else coming in the house. And for her to go to a respite place the problem is getting her from A to B. It's alright once she is there but it's getting her there. We tried somebody, a care worker to take her to the Alloa Centre and take her various places but she just wasn't having it. She started crying for me, she was jittery and upset so they just brought her home. And in the end they came to the door and said it would be the last day, that they weren't making enough money out of it. But,

respite's a question at the minute. I'm wanting it, I'm definitely wanting it. It would be nice for her to mix with other people. But she's not at that stage yet. She doesn't want to leave the house, she doesn't want to leave me. And you will know yourself, when they dig their heels in, you can't budge them!

My idea of respite is Laura wanting to go there with her friends. And then I would know that I've done the right thing and I brought her up the right way. And just to give me a bit of breathing space sometimes and me and her dad some time together because we've never had any time since we got married. It would help me. I would be more relaxed and maybe be healthier. I would be a little bit worried, but it would really benefit me, and it would benefit Laura. What I would want from respite is for Laura to think, "Yes, this is interesting" or think, "Well, if I can do this, what else can I do? Where else can I go, who else can I meet? ". Does that sound silly? That's what I want for her. I want her to help me pack, eventually, put her stuff in a case, and I want her to say, "Bye Mummy see you tomorrow." I know it's an awful lot to ask.

There's not enough respite. All the carers should have respite, even if it's just to go and get their hair done, or go down the town for two hours, or maybe just wanting to sit with their feet up without somebody having the screaming ab-dabs. Every carer should be entitled to time to themselves.

Other interview findings

(a) Experiences of respite

For most families we interviewed who had a respite service, respite was a weekend their son or daughter spent at a respite house from teatime on Friday until teatime on Sunday, supported by care workers, while the rest of the family had a break. The frequency varied between once a month to once every eight weeks. In every interview, the carer stressed that respite has to be a good experience for the cared for person too:

- ❖ *I wouldn't want him to be just sitting in a flat – he should be out doing things and enjoying himself.*
- ❖ *Someone taking my son for a long weekend with no worries about who he is with or what he is doing. Knowing he is being cared for.*
- ❖ *Taking her out for the day with other young people like herself.*
- ❖ *A full week with her friend so they can do silly girly things together.*
- ❖ *Weekends on a regular basis, not just one offs, because it gives you peace of mind knowing that it is coming up.*

The respite facilities mentioned were Hillcrest Drive and Marchside Court in Clackmannanshire and Torbrev in Stirling.

One family no longer had residential respite but did have a carer coming to take their daughter out every Friday evening:

I get a break with Crossroads on a Friday evening for 4 hours when a care worker comes in. I feel it's more of a befriending service for my daughter because the care worker takes her to the pictures or bowling. It lets her socialise with people her own age. Because they don't get a chance to meet, they've not got the opportunity to meet out with the Centres that they go to. To meet people their own age.

The reasons why carers did not have respite included:

- Not assessed as in priority need for respite
- Shortage of respite resources
- Parent felt respite was not helpful or appropriate at that time
- Not wanted or accepted by the cared for person
- Family still awaiting a response from social services
- Parent did not know about respite services for carers

Helen was in her 70s caring for her daughter Clare who was in her 40s and has epilepsy. They spent only one day a week apart from each other when Clare went to the Alloa Centre and Helen went to the Stoke Club at the Whins. Helen told us:

You see, I had a stroke a few years back and of course that has kind of limited me getting out and about. I try to go out most days with her, you know, even if it is just up the road and back again, but of course I find it difficult walking because it was my right side you see. We are so much together. It is difficult

being under each other feet all the time. I'm not very young myself, but you hear a lot of old people going for respite, but apart from that I don't know anything about respite. A little break would be nice! I think it would do us good. As I say, I thought it was more for older people. She sometimes spends the weekend with her sister. It's only from a Friday to a Sunday but she doesn't like to go. She is crying when she leaves me but when she comes back she is glad that she has been away.

Clare was present during the interview and offered her own comments:

Well, I think sometimes, Mum's had enough and I'm just wanting to go somewhere else with somebody else but I just can't.

(b) Costs

We asked if the cost of respite was an issue for families but only three families felt it was:

❖ *They say to me, right she has got to pay for her food, buses, her trains whatever else she needs to do. And they calculate it will be around 40 to 50 for the day. £50 I've got to send in. Well she came home with about £16 or £17 for the last respite. I find it disgusting. We even have to pay per mile to be in the car.*

❖ *Not for me, but I could see it being an issue for some people though because if you want to do things. I mean, she goes away there with quite a lot of money and she does spend it and if you didn't have the money to give them well, what would they do? They would end up sitting in the flat probably.*

Another carer who does not have respite said:

I think it would be. I don't think it's fair that we should be charged, this is a facility we need and I think I would kind of object to that.

(c) The effect on carers of having or not having respite

Interviewees who have respite were able to articulate clearly the benefits of having a break from caring:

❖ *When the care worker comes to take my daughter out my husband and I can have decent conversation and some peace.*

❖ *It lets me recharge my batteries. I don't have to constantly worry about him having seizure and I get a good sound sleep.*

❖ *I can do what I want to do and I can sort of please myself. I'm not seeing to someone else. Get up in the morning and have a cup of coffee. Usually, as soon as my feet hit the floor she is there. When she comes home from respite I'm feeling refreshed.*

❖ *I sit on my backside and do nothing for three days!*

The effect of not having respite was described also:

❖ *I mean I can cope with a lot but my husband has had heart problems and he gets really badly stressed out with it. The effect of not having respite is increased stress.*

❖ *We get fed up getting on to her, and we shouldn't be getting on to her - it's not her fault. It's just a matter of the condition that she has. But you can tolerate it if you get a break, you cannot tolerate it if you are not getting a break. It's difficult to talk to her.*

❖ *It affects your health because you are not sleeping right – because you worry. And not enough sleep makes you short tempered.*

(d) The effect on the cared for person of having respite

The importance and benefits of respite for their sons and daughters was the priority for the interviewees:

❖ *She comes back more chilled. She tells me all that she has done, where she has been. And things she has been able to do herself. She goes and orders her Chinese meal herself and pays for it. She knows to ask them for a receipt.*

❖ *It gives him freedom to do what he wants to do when he wants to do it*

❖ *She enjoys it and comes back in a better mood.*

❖ *I'd like her to be able to socialise on her own and have weekends away and have some fun for a change. Get used to being with her peers more and get better at relating to them.*

❖ *He comes back happy. He has been with one of his peers all weekend because two of them go at once to the respite house. Sometimes he comes back tired because he has been up talking all night! And he has missed me and he comes back quite happy to see me and that lasts for a couple of days.*

❖ *When she comes back, she is pleased to see Mum and Dad, and happy to be back in the home environment. I usually find that she is quiet and calmed down. I think it obviously gives her the chance to think when she has been away on the respite, what it is not to have her Mum and Dad around about her all the time. And then she is meeting other company when she is out, different company, not just stuck with her Mum and Dad.*

❖ *I think respite would be helpful for my son because it would teach him he has got to do things for himself and not to rely on his mother and father to*

do everything for him. A care worker won't do what we do for him He can do it, but he just doesn't do it because we are his Mum and Dad. He will do it for the care worker though.

(e) Levels of satisfaction with the respite service

We asked the interviewees how satisfied they were with the respite service they have:

- ❖ *Consistency of care workers. That is one sore point, she has had 6 different care workers in just 3 respites. And even she says she wants the same care worker. The problem with different care workers is that I've got to stay in the house for them to come at tea-time to meet me. And I only get the chance to meet them for about half an hour and then they are looking after my daughter which I'm not happy about. Because I want consistency, they say it's not really feasible. And I say "No it is, that's your job!" If they are care workers, that is their job. I can understand when people are off ill, sick etc., I'm not stupid, but when it comes to consistency it's a must for these kids to thrive and to be comfortable with the people they are with. Meeting somebody for half an hour doesn't tell you whether they are any good or not, no matter how nice they are.*
- ❖ *He used to get 12 a year, one weekend a month, but then the respite flat got very busy and we had to cut it back to 8 weekend a year, but I am wondering if they will cut it back more come April when the new year starts.*
- ❖ *More of it, we need loads more of it. More social interaction for people with learning disabilities I think.*
- ❖ *We need more help for carers. And the cost of respite. That seriously needs discussed.*
- ❖ *They need more places for respite. Having 3 beds for young adults with learning disabilities is not good enough.*
- ❖ *They need to advertise it more to other carers to let them know. Finding out by word of mouth, it shouldn't be the way you find out.*
- ❖ *It would help if people knew more about respite. Knew what respite was. If there was maybe a leaflet sent out from the Alloa Centre or from the Social Workers letting people know that they can get respite. Not everyone knows and unless you shout your mouth off yourself you don't know anything about it.*

Conclusions

The overall aim of our inquiry was to examine experience of respite provision in Clackmannanshire for carers of adults with learning disabilities living in the family home and to look at examples of good practice in other areas. Our intention was to draw on the experience of our members and other Clackmannanshire carers, as well as on examples of good practice from elsewhere in Scotland to help us make suggestions for a respite service which better meets the needs and aspirations of carers in the 21st century.

Our research has highlighted a huge reliance on families to care for adults with learning disabilities in Clackmannanshire with a common thread through the interviews of lack of support for carers. We have highlighted how important respite is for the wellbeing of carers and to prevent illness. But carers made the point again and again that their priority was feeling confident their loved one is being looked after well. Our research has also highlighted a need for better support for families to encourage independence and develop skills for independent living. We found that respite is very beneficial for the personal development and growing independence of adults with learning disabilities who will do more for themselves outside the family home and have an opportunity to explore their own potential.

The Scottish Government has issued its draft guidance on respite care planning for consultation, its main purpose being to help local service planners improve respite provision in line with the overall principles of supporting self-care and working with carers as partners in care, by:

- improving respite planning
- shifting the balance towards preventative support and
- personalising support to improve outcomes both for carers and people with care needs.

The Scottish Government Budget Statement for 2007 includes a commitment to “significantly extend respite and other carer support”. We therefore hope that the launch of our report will assist local elected members to plan and make budget decisions on respite.

1. Information, entitlement and access to services

It was alarming to find people in a fairly small sample who were not aware of respite opportunities and had never been offered respite. Getting information to families at the time they need it is not a simple task, but having no information leaflet on respite for carers of adults with learning disabilities is not acceptable. Entitlement depends on assessment but general guidelines should be available (see appendix 1.) Having no discreet budget means that families have no sense of fair entitlement to respite, limiting their capacity to collaborate with services to make best use of the budget. Clackmannanshire Learning Disability Carers Group requests that:

- ***Robust and regular systems be established to make relevant information about services available to carers of adults with learning disabilities.***
- ***Accessible leaflets about respite in Clackmannanshire be made available.***

2. Improving current services

Clackmannanshire Learning Disability Carers Group suggest that carers are reluctant to complain about the service they have in case they lose it. This may be reflected in

the questionnaire findings. The main concerns voiced by carers about respite services during the interviews was lack of consistency of care workers and poor communication in preparing for, and after, a respite break. The case studies demonstrate the vast knowledge and skills carers have. More emphasis should be given to the task of briefing care workers about the person they are looking after. Carers lack awareness of and access to systems to evaluate the experience of respite, to voice concerns or make suggestions. Consistency is extremely important for people with learning disability. One bad day with a poorly prepared care worker or an unsuitable facility can result in the person with a learning disability refusing to go back to a respite house. The bad experience can therefore impact on the health and wellbeing of the person with learning disabilities and the carer long after the event. To improve services, Clackmannanshire Learning Disability Carers Group requests:

- *More dialogue between the person with learning disabilities, carers and providers about the type of respite service needed*
- *Better communication between carers and agencies providing care workers*
- *More life skills for people while on respite breaks*
- *Better matching of people to share the respite flat*
- *That people should not have to share a bedroom*
- *An exchange system to swap weekends*
- *Systems to evaluate the experience of respite, voice concerns and make suggestions be offered to carers and made more available.*

3. Establishing more and better respite services

While there are improvements to be made to the resources we currently have, we recognise that greater investment is needed to support adults with learning disabilities and their carers adequately. Some carers found little consistency or continuity of care teams due to a rapid turnover in care workers and voiced concerns that agencies are not providing a service they feel confident about because of this. Clackmannanshire Learning Disability Carers Group requests that Clackmannanshire Council invests in:

- *Better pay, conditions and staff training to achieve continuity and higher standards in care workers*
- *More purpose built accessible respite provision in Clackmannanshire (see appendix 2) to increase the frequency and availability of respite in Clackmannanshire*
- *More variety of respite, not just within Clackmannanshire (see appendix 2).*

Finally to add value to the respite experience:

- *Greater emphasis on using respite to work on person centred plans and life skills for independent living with adults with learning disabilities.*

Appendix 1: Current respite provision in Clackmannanshire

Joanne Aitken, Service Manager Adult Assessment, Services to People,
Clackmannanshire Council (4/10/07)

1) What is the referral/assessment process for respite in Clackmannanshire?

The need for respite will be highlighted during assessment or review carried out by the community care worker. We generally look at the need for carer respite as the highest priority, not to be confused with client's need for a holiday.

2) An update on and details of the respite houses in Clacks.

There are three houses in use at present. Hillcrest Drive, a one bedroom house suitable for wheelchair users, Marchside Court a two bedroom house suitable for non disabled people, and Ochil Court a one bedroom house, suitable for wheelchair users.

3) What is the financial cost?

The rents and maintenance costs vary per house according to usage. Support costs are high as support workers are paid for per hour. If a person needs one to one support for a week the cost could be as high as £2100 per week. Different clients need different levels of support and different support agencies have different costs.

4) Is there a limit to the number of weeks available to service users/carers?

The current standard is 4 weeks although some clients have more.

5) How are bookings for respite dates administered by the Social Work Department?

Clients, carers and worker should determine together what dates they want and the worker will then seek to find a respite service for those dates. This becomes more complex when families choose to have respite over weekends only. The calendar quickly fills up and is over subscribed at weekends but the resources can be empty mid week.

6) Details of other services that provide respite e.g. sitting services, befriending etc.

Respite can be offered in the client's own home although this has not proved popular. Day care is used as respite, some people have asked for a direct payment and others use residential care. A few families have used activity centres.

7) The budget for respite

There is no separate budget for respite and costs for this service are subject to budget availability as are all other services. This is why there are limits to the number of weeks available for respite and why it varies from year to year. The budget is an aggregate budget which deals with all community care client groups of which people with learning difficulties make up approximately 7%. Of the spent budget people with a learning disability incur approximately 20% of expenditure.

Appendix 2: Visits to existing respite providers

Visit to Birchwood Perth & Kinross LA Resource (7/12/06)

1) Describe your respite resource?

Birchwood is a 4 bedded respite unit which offers respite to adults with a learning disability. Birchwood is situated in Perthshire and is a Local Authority resource. Staffing levels are in line with standards set out by the Care Commission.

2) What kind of information do you request about an individuals needs?

All referrals for the service are made via the local Social Work Department. A Pre Admission assessment is completed by care staff where full details of personal care needs, medication, likes/dislikes are ascertained. A member of the Birchwood staff team is identified as the Link Worker to the individual and their family/carer.

3) Describe your process of introducing a person to your respite facility

Following the pre admission assessment home visit plans are put in place for an introduction to the resource e.g. tea time visit etc. There is no time limit to this process and it is dependant on how well the individual settles.

4) How regular is respite offered?

A maximum of 8 weeks would be offered – this is dependent on need.

5) Are you able to provide emergency respite?

Emergency respite is made a priority and the unit would endeavour to try to accommodate requests where able.

6) What period of time is respite offered?

Carers put in requests for specific dates and the unit tries to accommodate where possible. Week days and/or weekend respite can be offered. Some individuals may have a 2 week period of respite in the year.

7) What kind of recreational activities are on offer during the respite visit?

There are various indoor activities available in the unit e.g. cooking, arts and crafts, board games, DVDs etc. Staff endeavour to ensure that individuals access community resources – most popular one being to go to the pub!

8) What issues are taken into account when offering respite dates to make the experience a positive one?

Staff try to find out who people are friendly with so it can be arranged for them to come at the same time. Also try to ascertain where conflicts are to avoid these.

9) What kind of feedback is given to carers after the period of respite?

Contact is maintained between families/carers and the Link Worker who can feedback on any pertinent issues.

Some service users have respite diaries where information can be logged. In addition reviews are held twice a year which gives opportunity to have contact with carers and to be involved in the care planning process.

Visit to 'The Meadows' (19.01.07)

1) Describe your respite resource?

The Meadows is managed by PSS Scotland which is a social care charity and is an accredited provider with 6 Local Authorities in Scotland. The Meadows is a specially adapted bungalow which is available to support adults who have learning disabilities and also physical disabilities to have a short break in a community setting. The bungalow is situated in Larbert. The bungalow is a 4 bedded unit and the staffing levels are 2 staff to 3 service users.

2) What kind of information do you request about an individuals needs?

Information is received from the Social Work Department; in addition a full assessment is carried out by staff from the Meadows to assess an individuals needs relating to personal care, medication, likes/dislikes etc.

3) Describe your process of introducing a person to your respite facility?

A programme of initial visits is organised to introduce a person to the Meadows. This period of introduction can be as long or short as necessary depending on the individual and how well they settle.

4) How regular is respite offered?

The Meadows endeavours to meet requests that are made for respite; there is no limit to what respite a person may receive in the year- if there is availability and funds are in place respite will be offered.

5) Are you able to provide emergency respite?

The Meadows has one bed that is designated for emergency respite only.

6) What period of time is respite offered?

Respite can be offered from an overnight basis to a period of 3/4 weeks at a time.

7) What kind of recreational activities are on offer during the respite visit?

The Meadows has mini buses which are used to access all recreational services available in the community. Staff endeavour to plan activities based around individual needs and likes/ dislikes.

8) What issues are taken into account when offering respite dates to make the experience a positive one?

Where possible a balance is tried to be achieved when offering individuals respite to ensure that friendships, similar interests are taken into account.

*What kind of feedback is given to carers after the period of respite?
Contact is made with families to give feedback. In addition an evaluation form is sent out for carers to complete to give an opportunity to raise any issues.*

Ludgate Local Authority Resource visited on 9/02/07

1) Describe your respite resource?

Ludgate is a Local Authority Resource situated in Alloa Clackmannanshire. Ludgate provides a day care service and respite service for service users who are over 60's and whose care needs are related to physical disability, mental health, and dementia. The respite accommodation consists of an 11 bedded unit all of which have en suite facilities.

Staffing levels are 1 to 5 services users during the day and 1 to 10 service users during the night.

The unit operates within the regulations set out by the Care Commission.

2) What kind of information do you request about an individual's needs e.g. personal care needs, medication, likes/dislikes etc?

Information is received via the assessment completed by the Community Care Worker from the Social Work Department.

3) Describe your process of introducing a person to your respite facility?

The service user would have a key worker who would help with the process of introduction to respite. Initial visits are organised and respite planned thereafter.

4) How regular is respite offered?

The respite offered is dependent on the need identified. Respite could be a period of 1 overnight, weekend or a 2 week period. A rolling programme of respite is usually put in place with a there being a maximum of 8 weeks offered in the year.

5) Are you able to provide emergency respite?

The unit will endeavour to meet any emergency respite

6) What kind of recreational activities are on offer during the respite visit?

Indoor activities are available within the unit e.g. games, arts and craft, cookery activities. The unit also has access to a mini bus which enables recreational activities in the community to be organised.

7) What kind of feedback is given to carers after the period of respite?

After a period of respite a report is completed which is passed to the family/carer. In addition verbal feedback is given with regards to how the respite progressed.