



Needs assessment of young adult carers in County Durham

Carried out by:



www.barefootresearch.org.uk

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Comments from young adult carers

My mam's always been ill ... I've been caring since I was five

I have taken responsibility for the whole house, the money, the cooking, cleaning, looking after my mam, paying bills, making sure my brother gets to school, going to parent's evenings

I can't handle it when people don't take me seriously when I say I'm a full time carer ... like they think I'm lying or lazy or scrounging

Just the recognition ... it feels as if it's the most help in the world. I feel like I've been left out of the loop for so long

People don't realise how stressful it is ... doing all this and watching my mum go downhill

Comments from services for carers

They have a problem of isolation and exclusion at a very important time in their life

They are isolated from their peers, more so than the over 30s

They've had problems in school, often have self esteem issues and are very vulnerable

Normal carers don't like hanging around with carers of drug users ... there is a lot of stigma attached. Carers won't go to [drug] treatment centres and they won't go to carers centres, there is nowhere for them except here. The difficulty is convincing the council that they are carers



i Executive summary

This is a needs assessment of carers, aged between 18 and 25, commissioned by Durham County Council and NHS County Durham and Darlington. Its objective is to better understand the needs of young adult carers in order to develop new and shape existing services to support them. The study was carried out by Barefoot Research and Evaluation, an independent north east research organisation, between May and September 2010.

We found a range of different types of carers with different characteristics, all of which experience different issues and have different needs. In relation to the person cared for, we found people caring for:

- Their partner with physical disabilities
- Their partner with mental health disabilities
- Their partner with substance misuse problems
- A family member (most commonly a parent) with physical disabilities
- A family member (most commonly a parent) with mental health problems
- A family member (most commonly a parent) with substance misuse problems

It was also found that carers may care for two or more family members with disabilities, such as their parent and grandparent. In addition to caring for people with disabilities or substance misuse problems, carers were also commonly found to have additional caring duties for other family members, either siblings or children, effectively doubling their caring load.

It was clear from the research that young adult carers are resilient, strong and capable people. However, it was also clear that they experienced many hardships in addition to their caring duties, with the main difficulties being social isolation, a lack of time for themselves and financial problems. It was also apparent that young adult carers were not a homogenous group and that they could be stratified into different groups (as above). What is important about this, is that these differences need to be borne in mind when developing services.

From the findings of the research, we can make a number of statements about young adult carers in County Durham. These are:

- **Young adult carers are a hidden group because they do not present themselves at services.** There are also subsets of young adult carers who are even more hidden such as carers of people with substance misuse problems.
- **Carers do not present themselves at services for a number of reasons** including: they may not consider themselves carers; they may not be aware of services that exist for them; and the services that are available that are known about are not attractive to them.



- **Young adult carers respond to proactive, energetic and persistent outreach.** We know this because of testimonies from young adult carers who have accessed Easington carers centre services and from those who have accessed young carer services; both services were described to use such a model.
- **Recognition as a carer is a matter of great importance.** Young adult carers were greatly affected by negative perceptions reported to be held by the general public and many services. Carers often did not recognise themselves as carers until late into their caring 'career' and many only did so when a professional provided that recognition.
- **Young adult carers commonly suffer from social isolation, an absence of friends and feel that they have no independence.** The common characteristic of having very little money compounds this isolation as it means carers spend very little on themselves and they often become housebound because they lack the means to do anything, e.g. go shopping or do activities either as a family or on their own.
- **Many carers are unable to secure employment because of their caring role and must rely on state benefits to survive.** This is uncommonly carers allowance and more often Jobseekers Allowance or Income Support.
- **Experiences of school were very poor.** Although national research indicates that 28 percent of young carers have serious problems in secondary schools, we found as much as 65 percent of carers in our sample were bullied and unsupported in school.
- **Caring can often affect the health of carers, particularly mental health.** Contact with the medical profession varies from good to very poor, the latter particularly with mental health cases.

There were a series of different responses to the question of what services young adult carers would like to see on offer. These ranged from drop-ins, support groups and respite cover. The most popular response was for mutual support opportunities; somewhere where carers could go to socialise and to talk with people in a similar situation to themselves. Here suggestions included a regular monthly meeting opportunity or a drop-in. One carer reflected this by saying "*It would be good for young people to meet together, to come up with a plan about what young people would like ... at the minute, there's nothing on offer*".

There were other suggestions from many carers who said that they would like a general package of support. For example, one carer said "*general help and support, trips, to give you a break, get away from the whole thing ... somewhere someone understands you*". In a similar way, carers also felt in need of activities designed for a younger age group. One carer said "*young carers do activities, when you're 20 you're still young enough to do stuff like that*".

The reaction to the subject of respite care varied amongst the carers interviewed although most were very cautious. Carers of people with mental health problems



found the idea of respite most difficult to consider as the people they cared for were not in a position to let a 'stranger' look after them even for short periods. There were other people who cared for someone with a physical disability whose situations were so specific that no-one else could look after them. Other carers however would value some respite care, especially those that cared for a parent and younger siblings. One such carer said "*it would be nice to have someone to help [with the kids] ... even just for a short time so me and my dad can have a chance to talk on our own [about family management issues]*".

When carers were asked more broadly about what would help them in their caring duties, their responses included:

- Information, advice and guidance on finding employment
- An increased involvement, help and support from family members
- Recognition from members of the general public about their caring role.

Based on the findings of this needs assessment, we make a series of recommendations:

- **Raising awareness and public education**

These elements have the objectives of increasing the awareness of the carer themselves about what they do and creating a greater recognition both from the general public and services about the importance of what carers do. Both these aspects would raise the public profile of carers.

Recognition was considered to be very important to the majority of carers interviewed and many reported negative impacts when recognition was not given or doubt was voiced about the carers' motivations. Also, many carers interviewed felt that an important time in their life was the realisation that they were carers. This led to a moment of both self-realisation (and associated empowerment) and also the point when they could begin to consider accessing services. It was therefore felt that more needed to be done to raise awareness amongst carers about what they do and the value of that work. It was felt that such awareness raising was most effectively done through public education campaigns. For example, there were suggestions for advertising services and raising awareness amongst young adult carers through 'big and bold' approaches such as the use of advertising space on buses.

There was similarly felt to be a need to raise awareness and educate members of both the general public and general services about the role and responsibilities of carers. It was felt by carers and associated services that if services in the community were made more aware of carers, particularly young adult carers, then this would lead to an increased identification of carers. And this would hopefully eventually lead to an increased engagement with carer services.



- **Provide mutual support opportunities**

The main service gap that was identified by carers was the desire for a regular social/mutual support opportunity, either through a drop-in facility or a support group meeting. It was suggested that this could be a monthly feature which would address their isolation. There were other suggestions for a programme of activities but the support group option was the dominant suggestion. It was also reported by many of those interviewed that a support group would be a good place to start in hearing the views of young adult carers and involving them in the service development process. There were certain carers who felt that such an opportunity, if one were to exist, should include specific groups of carers, e.g. a group for carers of people with mental health problems and another for those with physical disabilities.

- **Advertise carer services better**

There was a general consensus that services for carers needed to be advertised more, particularly the Council's carers development team and also services available at carers centres. It was felt that the way these services were advertised needed to be targeted at a younger audience. One carer said "*when you're younger you tend not to look at posters or read flyers, you watch TV and listen to the radio*".

In relation to the more micro level of how services could be advertised and how carers could be notified of activities or services, letter was the most preferred method. Only a few felt email would be a suitable method of being notified and similarly text messaging. Some felt text messaging to be too personal a method (one carer said "*you get texts from your friends, not from anyone else*"), however, there were some that felt they could be notified about services via text; it was a personal preference issue.

It was felt by several carer services that the client group is often too vulnerable for new technologies, such as social networking internet sites (it was similarly felt that these vulnerabilities were also thought to be apparent with text messaging as its use in a professional context has a risk of "*blurring the boundaries*" between friend and professional). It was thought that if an internet site was to be developed with elements of social networking, it would have to be 'policed' and monitored. As a result this, it may make it too costly a proposal.

- **Allow partners and carers to do things together**

The experience of caring for a partner was considered different to other carers. It was felt that most services are targeted at either the carer or the cared for person, but not them as a unit. Indeed, it was felt that services try to split the unit up, for example, one carer said that he was offered complementary therapies that they both would have enjoyed together, similarly, she was offered sessions in a hydrotherapy pool which they could have enjoyed together but her partner could not go with her. This is an area



that the DISC project supports their clients to do, i.e. supporting young carers enjoying activities as a whole family.

- **Develop a young adult carers service**

There were unanimous calls from all adult carers centres about the need to develop a service specifically targeted at young adult carers. Indeed, such a service would address most of the above recommendations. It would also address the additional support needs of carers of people with substance misuse issues (it is unrealistic to expect Liberty From Addiction to continue to support this group with no additional support). Carers centres felt that there would need to be a minimum staff contingent of two in order to cover the county. Such a service would be able to carry out much of the awareness raising with associated agencies, provide a proactive and energetic service which would identify young adult carers and bring them into services (which would in turn produce a snowball effect of attracting further numbers) and provide a number of activities including mutual support. Indeed, this model has already successfully been implemented by DISC. We would therefore recommend that such a service be developed.

In the absence of additional investment, there are several of these recommendations that could at least partially be achieved. These include: increase awareness amongst agencies, this could partially be achieved through existing local authority channels (senior management and frontline staff meetings, communiqués, etc.); providing mutual support opportunities, through a more concerted and coordinated effort from the adult carer centre and a partial reshaping of their service; advertising adult carer services better, this could partially be achieved by targeting young adult carers by letter; and allowing young adult carers and their partners and families to be able to enjoy activities together, through reshaping existing services.

In relation to the young adult carer service, funding could be accessed from either the statutory or charitable sector, using this needs assessment as evidence.



Table of contents

		Page number
i	Executive summary	2
1.0	Introduction	8
1.1	Methodology	8
1.2	Background and context	9
1.3	Carers in County Durham	10
1.4	Strategic context	11
2.0	Findings from young adult carers	13
2.1	Types of carers	13
2.2	The experience of being a young adult carer	14
2.3	Everyday living	18
2.4	School and education	19
2.5	Employment	20
2.6	Benefits and money	20
2.7	Social life	21
2.8	Health	22
2.9	Accessing services for carers	24
2.10	Service proposals	27
3.0	Findings from professional organisations	30
3.1	Carer centre findings	30
3.2	Findings from other agencies	33
4.0	Conclusion and recommendations	35
4.1	Conclusion	35
4.2	Recommendations	37
Appendix one	Interview guide	41
Appendix two	Demographics of sample	42



1.0 Introduction

This needs assessment of carers, aged between 18 and 25, was commissioned by Durham County Council and NHS County Durham and Darlington. Its objective is to better understand the needs of young adult carers in order to develop new and shape existing services to support them.

The aim of the research is: *to gather the views of young adult carers on their experiences and ideas in relation to services that reach out to themselves and their peers; and identify the level and type of need for services for young adult carers, including analysis of existing services, in order to inform future carer commissioning activities.*

The study was carried out by Barefoot Research and Evaluation, an independent north east research organisation, between May and September 2010. For more information on the organisation, see website (address on footer).

1.1 Methodology

This study consisted of detailed semi-structured interviews and focus groups with young adult carers and associated agencies. A copy of the interview and focus group guide is presented in appendix one.

Carers were identified through a variety of means including through existing contacts at adult carer centres, young carer projects, newsletters, the carers development team in County Durham, colleges and through peer to peer contacts.

A total of 38 young adult carers were interviewed from across County Durham with a diverse range of caring responsibilities (demographic information is presented in appendix two). Such caring responsibilities included caring for:

- Partners with physical disabilities, mental health problems and drug and alcohol misuse issues
- Parents with physical disabilities and mental health problems
- Grandparents with physical disabilities and mental health problems
- Younger siblings because the original primary carer was unable to do so.

In addition to young adult carers, a series of associated agencies were interviewed about their perspectives on the needs of young adult carers. These agencies were:

- The six adult carers centres across County Durham, including Derwentside (based at Consett), Durham and Chester le Street (based at Chester-le-Street), Durham Dales Action for Carers (two centres – one based at Barnard Castle and the other at Bishop Auckland), Easington (based at Peterlee), Sedgfield (based at Newton Aycliffe). These are all independent voluntary sector organisations, although all are affiliated to the Princess Royal Trust.



- Liberty from Addiction who are a voluntary sector organisation supporting carers of people who have a substance misuse problem.
- Durham County Council's Carers Development Team.
- DISC and Barnardo's young carer support projects.
- The Primary Care Trust's Adult Carer's Support Service.

1.2 Background and context

We understand a carer to be someone who *'spends a significant proportion of their life providing unpaid support to family and potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has a mental health problem or substance misuse problems'*ⁱ.

For the purposes of this study we understand young adult carers to be: *People aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner or other relative who is disabled, has some chronic illness, mental health problem or substance misuse issue connected with a need for care, support or supervision'*ⁱⁱ.

The majority of carers belong to a hidden population and many never present themselves to services and as such their needs are not known. Those carers that do present themselves to services generally represent the tip of the iceberg. For example, Easington District has one of the highest numbers of carers in the country with an estimated 15,000 carers, although the carers centre that covers that area only has 1100 carers registered. Those carers that do present themselves to services tend to be older people: the most recent Census data shows that the age group which contains the largest number of people providing care is those in their fifties¹. We therefore know most about the needs of this group and perhaps not surprisingly most of the existing carers services in the county are targeted at this group.

However, there are certain categories of carers which are more hidden than others and young adult carers are one of those. While there is a growing body of research evidence on young carers aged under 18, there is far less research evidence on young adult carers aged 18-24ⁱⁱⁱ. We know that young adult carers have been largely ignored in research although it has been recognised that they are an important subpopulation of carers to consider because, as young adults, they are at a critical developmental stage with many having not yet solidified their life plans and choices about education, work, marriage and parenthood (although others have)^{iv}. There are also subsets of young adult carers who are even more hidden such as carers of people with substance misuse problems.

¹ There is an issue of recognition here: that older people are more likely to recognise themselves as carers and young carers less likely. This difference in recognition will skew the recorded data which increases young adult carers hidden nature.



The most recent and comprehensive research concerning young adult carers in the UK^{vi} makes a number of statements about young adult carers:

- There are 229,318 young adult carers aged 18-24 in the UK, and this is 5.3 percent of all people in that age group. One quarter of all young adult carers in the UK (56,069 people) are providing care for more than 20 hours per week and almost 27,000 of these (12 percent of the total) are providing care for more than 50 hours each week.
- Many young adult carers were unaware of what help may be available to support their relatives, how to access this and who supplies it.
- Most young adult carers experience significant financial hardships as a consequence of caring and are living in a low income family where there is physical or mental ill health, disability, and alcohol or drug misuse. There is strong evidence of poverty and social exclusion for all family members and of young adult carers using their own money to subsidise the needs of parents.
- Very few young adult carers ever use an adult carers service. Carers centres working with (older) adult carers identified a range of factors (or barriers) that made it either unfeasible or more challenging to engage with young adult carers aged 18-24.

1.3 Carers in County Durham

From the 2001 Census, we have a reasonably detailed picture of the numbers and types (in terms of caring load) of carers in County Durham. Table 1.1 shows that in 2001, there was a total of 57,225 carers in the county.

Table 1.1 Numbers of carers in County Durham

	The Dales	Derwentside	North Durham	Easington	Sedgefield	Total
General Population	85,796	85,074	141,401	93,993	87,206	493,470
Carers providing 1-19 hrs care per wk	6,107	6,023	10,312	6,473	6,188	35,103 (61%)
Carers providing 20-49 hrs care per wk	1,239	1,313	1,825	1,817	1,419	7,613 (13%)
Carers providing 50 + hrs care per wk	2,358	2,550	3,276	3,674	2,651	14,509 (25%)
Estimated carer population	9,704 (17%)	9,886 (17%)	15,413 (27%)	11,964 (21%)	10,258 (18%)	57,225 (100%)

Source: Census, 2001.

The number of carers of people with substance misuse issues is unknown and they are likely not to be captured in the above figures. We do know from the Drug and Alcohol Action Team in County Durham that there are approximately 2000 problematic drug users in County Durham and 20,000 problematic alcohol users. However, how many of these have carers is unknown but it is suspected that the figure is high.



If we compare the number of carers who are registered at one of the seven carers centres (including Liberty From Addiction) across County Durham, we see that only a small proportion of carers access services; between nine and 16 percent of the locality populations².

Table 1.2 Numbers of carers registered at a carers centre

Locality	Number of Registered Carers	Percentage of Estimated Carer Population
The Dales	1,549	16%
Derwentside	972	10%
North Durham	1,441	9%
Easington	1,256	10%
Sedgefield	1,532	15%
Liberty From Addiction	472	unknown
TOTAL	6,750	12%

Source: Joint Commissioning Strategy for Carers, 2009-13^{vii}

When we asked those carers centres how many young adult carers they had registered with them, the totals varied from zero to 100. It therefore becomes clear that most young adult carers do not access any services.

1.4 Strategic context

Durham County Council is explicit in its recognition of the importance and value of carers. For example, in its Carers Strategy, it estimates that the economic value of the contribution made by County Durham carers is £945^{viii} million per year. They also recognise that carers need more help and support, not only in being a carer but also with having a life outside of their caring role.

The strategy recognises that there are three types of carers:

1. Adult carers - adults caring for adults over the age of 18, this includes parents caring for their adult children.
2. Parent carers - parents caring for a child or young person under the age of 18 who has a disability.
3. Young carers – children or young people under the age of 18 who are caring for either another child or young person or an adult

As a result of council restructuring which separated adult and children's services, there are now separate strategies for parent carers and young carers. The Joint Commissioning Strategy focuses purely on adult carers and therefore provides the strategic framework for this needs assessment.

In the strategy, it is stated that Durham County Council and NHS County Durham will work towards to the following key principles for carers:

² The Joint Commissioning Strategy 2009-13 states that there are also approximately 2,200 carers who have voluntarily registered as a carer with the Council but many of these carers may also be registered with one of the County Durham carer centres.



- Carers will be at the centre of planning, monitoring and developing relevant services
- Carers will have timely information
- Carers will have recognition
 - of the value of their contribution to the health and well being of those they care for and for that contribution to be listened to
 - of the impact of the caring role on the carer
 - of their differing needs as individuals
 - of their needs for a range of practical and emotional support
 - of their type of caring role
 - of their expertise and skills
 - of the need to involve carers in monitoring services and the importance of taking into account their experiences in the evaluation of services
- Carers will have an informed choice
- Carers will be provided with appropriate personalised support
- Services and information will be provided on an integrated/coordinated and equitable basis within and across organisations
- The financial cost of caring will be minimised and economic well being promoted
 - By helping carers to maximise their income through practical help such as form filling
 - By ensuring access is available to timely information and advice on welfare and tax benefits, grants, entitlements, debt and money management and also other services and support to reduce carer expenditure
 - By providing appropriate support through assessments
 - By supporting carers, in conjunction with key partners such as Jobcentre Plus, in gaining and maintaining employment, which includes helping carers to access training
 - By raising awareness of local employers on carer issues and needs in the workplace

The strategy is closely aligned with the goals and objectives of the national carers strategy, *Carers at the heart of 21st century families and communities*, published in June 2008.

It is therefore clear that there is a strong and supportive policy framework for carers in County Durham.



2.0 Findings from young adult carers

This section presents the findings of our research with young adult carers in County Durham.

2.1 Types of carers

We found a range of different types of carers with different characteristics, all of which experience different issues and have different needs. In relation to the person cared for, we found people caring for:

- Their partner with physical disabilities
- Their partner with mental health disabilities
- Their partner with substance misuse problems
- A family member (most commonly a parent) with physical disabilities
- A family member (most commonly a parent) with mental health problems
- A family member (most commonly a parent) with substance misuse problems

It was also found that carers may care for two or more family members with disabilities, such as their parent and grandparent. In addition to caring for people with disabilities or substance misuse problems, carers were also commonly found to have additional caring duties for other family members, either siblings or children, effectively doubling their caring load.

These different caring situations meant that carers had different needs and experiences. To attempt to provide a flavour of such different situations, a series of comments from young adult carers are presented below:

- Caring for a partner with physical disabilities

“For those caring for their partners, it’s different for them ... I don’t want respite or to do activities, we want to enjoy things together ... everything is all about trying to separate us”.

- Caring for a partner with mental health disabilities

“When she’s bad she won’t let anyone else in the house but me, she won’t let me go out, it’s like I’m trapped”.

- Caring for a partner with substance misuse problems

“We get no respite, no allowances ... prison [for the person cared for] is our only respite”.

- Caring for a family member with physical disabilities



"I get myself ready, get my two kids ready for school, get my three year old sorted, then I've got to get someone to sit with my dad while I get them off to school ... he can't be left for a minute on his own".

- Caring for a family member with mental health problems

"I've been caring for my mam since I was six and it's become more and more, she needs me to be near now all the time, if it's not in the house, then when I'm out I can't go far in case I need to come back".

- Caring for a family member with substance misuse problems

"Once he's [the substance misuser] got his drink, the rest of the day revolves around caring for him".

2.2 The experience of being a young adult carer

The period when caring began for young adult carers varied enormously. For some, they had been caring since they were young children and for others, caring had begun relatively recently. Those with a long caring history were mostly those who cared for parents. For example, one carer said *"my mam's always been ill ... I've been caring since I was five"* and another said *"I've been caring since I was seven"*. In these cases, the caring responsibilities have increased as they have got older, as the carer becomes legally able to carry out household administration duties and as the person's disabilities and needs increase. This long history of caring shapes their experiences and for most who have cared since they were a child, they reported that they did not have a childhood. As one carer reported *"I grew up really quickly ... I'm used to being around adults"*.

The extent of the caring also varied, with some carers taking responsibility for running the entire household and others having periodic duties. To illustrate the former, one carer for their parents and siblings said, *"I have taken responsibility for the whole house, the money, the cooking, cleaning, looking after my mam, paying bills, making sure my brother gets to school, going to parent's evenings"*. Another carer of someone with substance misuse problems said *"I do absolutely everything ... when you've a partner it's supposed to be easier but it's harder"*.

To illustrate periodic duties, one carer said *"I look after my sister's kids when she's bad [who has Multiple Sclerosis]"*. However, the caring load amongst those interviewed was high with half the sample (n=19) caring in excess of 50 hours a week, with 45 percent (n=17) caring between 20 and 49 hours with the remaining five percent (n=3) less than 19 hours.

In relation to the experience of caring, all those interviewed accepted it as routine and normality and none had a negative view of their general caring. As an illustration, one carer said *"caring is something you do automatic, sometimes it's good, sometimes it's bad"*.



The experience of being a carer was significantly influenced by perceptions of the public. One carer said *"I can't handle it when people don't take me seriously when I say I'm a full time carer ... like they think I'm lying or lazy or scrounging"*. Indeed, a number of respondents (n=10) reported being called lazy as a result of not working or dropping out of education. This was also felt by the person cared for in cases where they were young. One carer reflected this by saying *"if you're young with disabilities people think that you like to depend on people ... the ambulance driver said to her 'you're just a drama queen aren't you' ... all we want is independence and mobility"*.

Carers of people with substance misuse issues were reported as being particularly affected by perceptions of the public, professionals and other carers. Liberty From Addiction, who support carers of substance misusers reported *"normal carers don't like hanging around with carers of drug users ... there is a lot of stigma attached. Carers won't go to [drug] treatment centres and they won't go to carers centres, there is nowhere for them except here. The difficulty is convincing the council that they are carers"*.

Many carers (n=20) interviewed said that they never recognised themselves as a carer, despite having duties for a prolonged period. The point of recognition was extremely important to them and this recognition was generally provided by a professional organisation. A common response was reflected by one carer who reported *"before [being in contact with the carers development team] I didn't know I was a carer ... but now I do and now I have a better understanding"*.

A number of carers (n=13) interviewed talked about the significance of recognition of their position and role as a carer. One carer said *"just being recognised as a carer is the best help, just talking to people who understand"*. Another stated *"just the recognition ... it feels as if it's the most help in the world. I feel like I've been left out of the loop for so long"*.

The carers who had accessed the DISC young carers project (see later) as under 18 year olds reported that a main benefit has been being in a place where other people understand and can empathise. One carer said *"it was all about having someone to talk to who understands"*.

Almost all carers interviewed felt isolated and most felt that no-one provided them with any support or assistance. One carer said *"we get no support from anyone, not from the carers centres or any organisation"*.

When carers were asked what they had the most difficulties with, they provided the following responses (which have been ranked in relation to frequency):

1. Lack of money/financial hardships
2. Socialising/making friends



3. Their caring duties
4. General difficulties (for example, one carer said “*finance, life, everything*”)
5. Education

Carers of people with substance misuse problems experienced a specific problem relating to the risk of death. For example, one carer said “*the worry that he might kill himself [through drug or alcohol misuse] is always at the back of your mind*”.

When questioned about the carers’ futures, there was a number of different responses. The majority of carers felt that their futures consisted of a continuation of their caring role in a similar situation as was currently experienced. There were others who had aspirations of getting more qualifications which would ultimately lead to a “*good job*”. Only a small number (two) of carers talked of a future independent from the person they currently cared for. This independence consisted of living in their own home but very close (in the same street or estate). These felt that they would not move away to work because they needed to be close to the people they cared for.

It was noted by Liberty From Addiction that futures for carers of people with substance misuse issues are commonly bleak, particularly for younger carers who are looking after parents. Such futures are bleak because of learned behaviour, substance misuse and criminality.

Case study 1: Caring for a parent with mental health disabilities

Cora is 21 and cares for her mother who has mental health problems including anxiety, depression and bipolar disorder. She has been caring for her mother since she was eight years old. Her caring duties have steadily increased over the years and now she cannot leave her mother alone. As a result of her mother’s mental health, she cannot accept any respite care as her mother would not let a stranger into the house.

Cora says is very isolated and has no friends. She has no friends from her school days as she was severely bullied because of her mother’s disability and she has few prospects of making new friends as she says she never goes out.

Cora feels her own mental health has started to be affected by her situation. She says she becomes anxious when she is outside and suffers from paranoia. She has seen a counsellor about this and has been offered medication.

She also has very little money. She says she gives her mother a part of her carer’s allowance for rent and they then pool the remainder of their combined incomes for housekeeping. She says this leaves her with £10 a week to spend on herself.

She would like opportunities to mix with young people in a similar circumstance to herself, that understand what it is like to be a carer.



Case study 2: Caring for a partner with substance misuse problems

Shona is 23 and has been caring for her partner David, for the last five years, who is addicted to heroin. They have three children, one aged eight months and a two and three year old. She says she has lost all her friends and has no contact with her or David's family as a result of his heroin use.

She says she cannot leave him alone with the children as he is unfit to parent alone. She says, "*I get no help from anyone, I do everything, it's like I have four children, not three*". She also says she lives in a constant state of worry about David's welfare. She says "*the only time when I don't worry is when he's asleep, and even then I can't relax ... when he's awake, I worry that he'll break something or sell something ... or I'll find him dead*".

She also says that he can be violent and abusive when he has withdrawals. She says, "*I have no one, people don't like me ... if it wasn't for this place [Liberty From Addiction] I don't know what I'd do*". She also said "*it's not like I'm a carer for someone who is disabled, so people don't think you're a carer, but you are*".

Case study 3: Caring for a partner physical disabilities

John is 24 years old and cares for Sarah, his 22 year old partner, who has severe physical disabilities. John started caring when Sarah became disabled just after she gave birth to her son, Jack who is now 12 months old.

Sarah is unable to walk and suffers severe pain, even during the smallest movements. The family live in the small downstairs rooms in their council house. Sarah must use a commode as she cannot access the toilet which is upstairs. They are awaiting the installation of a stair lift so they can use the upstairs area.

John spends all of his time looking after Sarah and their young son. They are not able to accept any respite care because Sarah's disabilities are so specific and cause her so much pain. John said "*touching or moving can be so painful to her ... it's only me that understands that, even her parents can't do it*".

They feel very isolated as the only time they leave the house is by ambulance for hospital appointments. Although she has a mobility scooter, she cannot use it because it causes her so much pain. Their isolation is increased as they feel that people do not believe that she is disabled and that he is her carer. She said "*the ambulance driver called me a drama queen and questioned why I needed to be fetched by ambulance*". John also said that they got derogatory comments when she used her mobility scooter. He said "*people see us and see we're young and don't believe us*".

John does not access any services offered to him by the local carers centre because he does not want to be apart from his partner. He says "*we want to enjoy things together, not apart ... everything seems to be geared to separating us, hydrotherapy for her, and I'm not allowed in the pool, relaxation for me, but she can't go ... we'd really like to enjoy things together. Maybe to go out together once a month*".



2.3 Everyday living

The experience of everyday living varied depending on the situation of the carer. However, the overriding sentiment that was expressed was one of capability and being able to manage. One carer reflected these sentiments by saying “*everyday living? It’s not hugely difficult ... you get used to it and you manage*”. However, there were a number of responses that related to the stressful nature of their lives. For example, one carer stated “*people don’t realise how stressful it is ... doing all this and watching my mum go downhill*”.

For all carers interviewed everyday living revolves around the person that is cared for. This relates to both the care of the person and also to other essential living duties such as shopping and paying bills. One carer reported “*when I go to sign on I have to take my whole family because I can’t leave her [partner]*”. For those carers with families, caring is doubled as they must look after the person cared for in addition to their other routine family duties. For example, one carer commented, “*my biggest problem is sorting everyone out. Three kids up at seven to get ready for school, then a two year old and a one year old ... I need a babysitter for my partner who can’t be left. I have no time for myself*”.

Carers of people with substance misuse problems experience a specific set of daily issues. Often they must source a supply of drugs or alcohol for their person they care for. If not, then they often experience physical and verbal abuse, as well as witnessing such abuse targeted at siblings and other family members. There may be a number of visitors (strangers) to the house, if drugs are the issue or conversely there may be high levels of isolation if alcohol is the substance misused. If the carer is caring for a parent then the house may be unkempt and dirty and there may be neglect issues if there are younger children in the household as all money goes on drugs or drink.

Time is a precious commodity and something which was reported by many carers (n=16) to be in short supply with many competing duties. One carer said “*my time is split into a million different things*” and another said “*what I would really like is to find a bit of time for myself*”.

The carer’s independence was found to be significantly restricted by their caring. For example one carer from Easington reported “*the furthest I’ve gone on my own is to Peterlee town centre, an hour’s walk away, and when I got there I had to turn around and come back [because his partner needed him]*”. Another said “*because I can’t leave her ... I can’t do many things*”.

There were many reports from carers about them planning to do things which remained as plans and were never realised. One carer stated “*I planned to go fishing, to go to the army cadets which I enjoyed when I was younger but it all comes back to the doctors, her medication and condition and she gets worse, then you fall flat on your face*”. Another said they had planned to start their own business but had never found the time to do so.



2.4 School and education

Young adult carers were asked about their experiences of school and education. Almost all carers of a parent or grandparent (n=23, but no carers of partners) had a very poor school experience due to bullying. One carer reported *“my school was normal ... I got bullied”*. Carers reported changing schools and missing significant time and often years. One carer of her mother reported *“I was hardly ever there”*. A particular note of dissatisfaction from many carers who were interviewed was from Educational Welfare Officers (EWOs). These were singled out as being unhelpful, unsympathetic and who generally made an already difficult life (from bullying and the caring responsibilities), worse. EWOs focussed on these young people because they had missed often significant time at school. For example, one carer reported *“I got bullied, picked on a lot, I had a breakdown when I was 10, I had counselling from the child psychologist, the doctors put me on medication and I had the EWO on my back ... I had no help in the home”*.

However, despite these problems, a number of carers (n=13) interviewed had achieved some significant GSCE successes in school, including carers with between two and eight GSCE passes.

Many carers (n=15) had also progressed onto college, either New College in Durham or to Bishop Auckland College, or university to do a range of qualifications from hairdressing to childcare to nursing. One carer reported, *“I finished school, went to college, got an NVQ IT qualification”*.

However, whilst many carers had achieved much success in pursuing further education, many reported problems caused by their caring and for some this meant they had to prematurely end their studies. For example, one person who cared for her mother said, *“I had a lot of trouble at college because I was missing about three days a week. I thought I could manage ... I did a hairdressing level 2 with great difficulty ... I stopped when I was 19”*. The pattern of ‘dropping out’ of education by certain carers was corroborated by carers centres, one of which reported *“there was someone doing a nurses degree who had to drop out because of her caring”*.

Generally, those carers who did pursue further education found it difficult on a range of levels, from being away from the person they cared for and the worry associated with that, to not being able to go to college because of the need to care for their family. For example, one carer of their partner with substance misuse issues said *“college has been hard because I have to leave him and I don’t know what state he’s in ... if he’s in bed it’s OK but when he’s up you don’t know what might happen so I have to be there”*.

There were a small number of carers (n=4) who said that they wanted to continue with their education but were unable to because of caring responsibilities. For example, one carer said *“I wanted to be an IT technician, I’d got it all planned,*



where I was going to go, I'd saved up ... but I couldn't [because of caring responsibilities]".

2.5 Employment

Although the experience of employment varied amongst carers, with some being able to pursue employment, for most (n=24) it was not possible because of their caring responsibilities. There were certain carers who stated that they would like to be employed but thought it was unlikely as they would need a sympathetic employer who would let them go home when required, which may be often. One carer stated "*I would need a job that I could go backwards and forwards to*".

A number of carers (n=7) reported that they have been asked to leave jobs. For example, one carer said "*I've tried being employed but I've lost four jobs ... some I've had to leave and some they've let me go ... because I've had to go home [to look after partner]*".

Those younger carers who were in full time education reported that they felt it imperative to get as many qualifications as possible in order to get as good a job as possible.

There were two carers who reported that they would like to become self employed and could devote time to their business ideas in the evening. Although both cases said they were so tired at the end of the day that this was not possible (despite having attempted it).

Most carers (n=26) however said they would be unable to work. For example, one carer said "*I can't work because I need to control her medication*" and another said "*I'd have to come back home three or four times a day, and that's just not possible with a job*".

2.6 Benefits and money

Related to the issue of employment were the issues of benefits and money. There were only six carers who were in receipt of carers allowance with others receiving a variety of income sources including Educational Maintenance Allowance, Job Seekers Allowance, Child Tax Credit, Income Support and a small number who received no benefits and lived from their partner's Disability Living Allowance.

For those on Job Seekers Allowance, there were reports of Job Centre staff knowing them well and being aware of their situations, i.e. being unable to work because of their caring duties. Many carers were not in receipt of carers allowance and instead receive Job Seekers Allowance, for which they must regularly visit their local Job Centre. Their caring responsibilities prevented them from taking most employment opportunities and most Job Centre staff were aware of this. Staff at Job Centres often knew about young adult carers as they often bring their entire family with them to sign on and are as such visible and



known. However, despite this knowledge, it was reported by carers that staff at Job Centres do not direct young adult carers to carers centres or development teams, but they may direct people to other services³. For example, one YAC reported *“when I was homeless, the people at the Job Centre were really helpful and pointed me in the direction of the homeless people, but no-one’s ever said about carers service and they all know I’m a carer”*.

Almost all carers interviewed reported that they experienced financial difficulties and this increased their hardships significantly. For example, one carer said *“I struggle with the bills and the rent ... it’s my main problem”*.

Many carers who were interviewed had different levels of financial hardship, from debt problems to generally receiving too little money. One carer said *“we do have trouble with money, we’ve had debt problems in the past and went to a debt management place ... we share our money and we just about manage ... but I have very little for myself”*. Another carer interviewed similarly pooled the family money. They said *“I get £50 carers allowance, £20 from income support ... it’s all pooled and I end up with £10 a week for myself”*.

It appeared from the interviews that this was particularly true of smaller families. For example, one larger family said *“it’s not that bad ... I don’t get carers allowance ... I’ve got five kids so I get child benefit and tax credits and my husband gets incapacity benefit”*.

The lack of money had a range of impacts from affecting diet and health (one carer said *“we eat crap food because we’ve got so little money”*) to increasing the isolation of carers. For example, one interviewee said *“it’s difficult to socialise, not only in getting the opportunity to go out but also financially ... I’ve got so little money that I couldn’t anyway”*. The lack of money was reported by many carers to stop them accessing the activities put on by adult carers centres, which although were recognised as being subsidised, were felt to be too expensive for them to afford. For example, one carer said *“it might not seem much to you but to spend £10 on a trip ... that’s all my money for myself for a whole month”*.

2.7 Social life

One of the biggest impacts of being a carer was the negative effects it had on carer’s social life, including impacts on both the carer and the person cared for. There were a series of different types of impacts which affected different types of carers in different ways. These include:

- Never having a social life: this was often experienced by those who had cared for a family member from a young age and had been bullied at school as a consequence. All carers of older family members (i.e. parents and

³ It is recognised that in principle Job Centre Plus’s have specific designated staff whose responsibility it is to cater for the employment and training needs of carers. However, clearly, in this case, more work needs to be done with frontline Job Centre Plus staff.



grandparents) that were interviewed were bullied in school because of their role as carer. These extremely negative experiences were reported to have shaped their subsequent social relations and carers were often left with no friends and little opportunities or prospects to make friends. One carer said *“people don’t want to know if you’re a carer”*. Another said *“making new friends is really difficult because when people see your other family members they back off”*.

- Isolation experienced by carers of people with mental health issues: several interviewees reported that they felt their own mental health being affected. For example, one such carer said *“I don’t like going out, I get agoraphobic because I’m so isolated”*. Another one carer said *“you feel so alone”*.
- Isolation experienced by carers of their partners: the impact was felt by both parties and there was an effective doubling of their isolation. Comments from carers of partners include: *“my social life? it’s non existent, I’ve lost every friend I have”*; *“when she got ill, she lost all of her friends ... my social life dropped dramatically”*; and *“we are completely imprisoned in this house ... we are imprisoned and isolated”*. Carers of their partners also reported the steady erosion of their friends during the progression from child to adult. For example, one carer reported *“when you’re young you have lots of friends and when you get older you expect to lose some of them and you just keep your good friends and you make others, through work or other stuff you do, but when you’re a carer, you don’t make new ones and you lose the ones you had, so you find yourself with no-one ... I don’t have friends”*.
- Isolation experienced by carers of people with substance misuse issues: carers reported losing both friends and family because of their partners’ substance misuse. One carer said *“they have all deserted me”*. This isolation is compounded by fear of authorities and them attempting to remain hidden.

It was felt by the majority (n=30) of those interviewed that they lacked the opportunity with which to meet people and make friends. Indeed, one of the main reasons that led to the formation of a carer support group in New College (see later) was because of the need by the lead individuals for friends.

There were many reports from carers about them planning to do things which remained as plans and were never realised. One carer stated *“I planned to go fishing, to go to the army cadets which I enjoyed when I was younger but it all comes back to the doctors, her medication and condition and she gets worse, then you fall flat on your face”*.

2.8 Health

Many carers (n=29) interviewed professed to be in good health. However, there were others who felt that their health had deteriorated due to their caring. This affected both mental and physical health. For example, one carer had problems with his back because of all of the lifting of his partner that he was required to do. He had asked his local carers centre if there were any available manual handling



and lifting training but they were waiting for sufficient numbers before they could run one.

Another carer who looked after her mother with mental health problems reported that she had developed mental health problems because of her caring. This carer said *"I started getting anxiety, I went to see my GP, I had some counselling and I some medication ... wasn't helpful"*. This carer felt that the counselling offered to her was too short (six weeks) and the treatments offered were not felt to be satisfactory.

There were other carers of people with mental health problems that could see an impact on their mental health. For example, one carer said *"I find it really difficult to go outside a lot ... it makes me really anxious"* and another said *"my health has suffered, I can't sleep, my stress levels are really high"*. The link between caring and ill health has been documented and Dearden and Becker (2000)^{ix} commented that in a few cases stress and depression were severe enough to lead to physical and psychological ill health.

There were other health-related issues that arose during the research. One of these related to the experience of being a carer, particularly of a partner, was heavily influenced by the situation of the cared for and their contact with the medical profession. There were a number of reports of unsatisfactory responses from the NHS about medical conditions. For example, one carer of someone who had mental health problems stated *"I never met any doctor who takes depression seriously ... it's [depression] overlooked ... one doctor said 'you shouldn't have depression at your age'"*. He continued *"we've had so many doctors and they all have different ideas, prescribe different pills, one doctor took her off pills completely, that was the worst two months of my life"*.

Other carers of those with mental health problems complained that their contact with health professionals was poor. One carer said *"if you've got mental health problems, they [medical professionals] don't talk to the carer ... they talk to her but not me. You just get a whitewash explanation, there's no explanation about the therapies or what to do if there is a crisis"*. An example of such a crisis was when this carer's partner was driving and suffered a panic attack which the carer felt helpless to deal with. He commented *"if I'd have known what to do, I could have talked her round but I had no idea"*.

However, other carers interviewed had positive experiences of health services. Many carers of parents and grandparents felt that they were always kept up-to-date with the treatment and medical outlook for the person they cared for. This started from a young age in many cases (one carer reported giving her mother insulin injections when she was eight years old) and included being fully debriefed by doctors and nurses and taking control of the cared for's medications.



2.9 Accessing services for carers

The majority of those carers interviewed (n=28) did not access any carers services, including those offered by the adult carers centres across County Durham. There were a number of reasons given for this, including:

- Carers did not feel that services on offer were relevant or appropriate for their age; for example, one carer said that they considered adult centres “*too old*” and another said “*I don't go to carers centres because the things they do don't interest me ... although I did go to Whitby on a trip with them last year because I'm a Goth and Whitby is special for Goths, but generally I don't go*”. Another carer reported “*they don't deal with our age group*”.
- A lack of awareness about what was on offer: for example, one carer said “*I've never heard of a carers centre*”.
- A lack of time to be able to engage in activities: one carer reported “*it immediately puts you behind [with your caring tasks]*”, which acts as a disincentive. Another said “*I did get the opportunity to go to an archery day through the carers development team ... I'd always wanted to try that but she had a bad turn and I couldn't go on the day, I was gutted*”.
- A reluctance to engage because of feelings of guilt (particularly felt by those caring for partners). One carer said “*you get back from relaxation or being out and she's there and you feel bad because she can't do that*”. Another said “*when you get back in it doesn't take two seconds til you're brought down again ... what's the use?*”.
- A lack of money to be able to participate in activities: for example one carer said “*the carers centres charge for stuff they do, like £15 for a trip, but I can't afford that ... the young carers stuff is free*”.

The non-uptake of services was mutually reinforced by common experiences of self-sufficiency and self-reliance, with common responses from carers being that they have never received any support in the past. For example, one carer illustrated “*I've never had any help from anyone*”. The result of this together with the points above, leads to the widely held view amongst carers that “*there's nothing really out there for [young] adult carers*”.

Carers of people with substance misuse problems experience a specific set of problems. As the carer is often responsible for sourcing drugs or buying alcohol for the user and often visits a series of off licences or engages in criminal activity (i.e. buys drugs) for the user, they wish to remain hidden from authorities. One carer said “*I can't turn to anyone for help ... I want nothing to do with the Police or Social Services*”. Indeed, as the carer will also often hide from school, social services or other authorities out of fear of prosecution or other punitive measures, particularly if they are looking after younger siblings who are in school, this compounds their hidden nature.



However, there was a small number (n=6) of young adult carers who did access services provided from an adult carers centre (Easington) and some carers (n=3) of people with substance misuse issues who accessed Liberty From Addiction.

Such services that were accessed from the adult carers centre included the activities (e.g. ten pin bowling), alternative therapies such as Raki and group lunches. From the interviews with these carers, it became apparent that although services accessed were universal (i.e. open to carers of all ages), they were attractive to a younger age group. It was also clear from the interviews that much of their engagement was due to the enthusiasm and energy of their carer support worker and their proactive and persistent outreach approach. For example, one carer said *"it takes me a long time to trust people but [name of support worker] kept on contacting me and I ended up trusting her ... she's like a friend now"*.

Whilst some of these carers were able to access all the mentioned services, some were only able to access the services when their caring allowed. However, the opportunity to do this was nonetheless highly valued, despite only accessing the services occasionally.

Carers who were interviewed who accessed the services of Liberty From Addiction were all highly appreciative. For example, one carer said *"I came to Liberty three years ago ... they have been a godsend, if it wasn't for them I don't know where I'd be now ... I have met new people, and they help me and understand"*. Another carer said *"They [Liberty] have really been there for me ... I don't feel alone like I did ... the worker comes out and sees me every week"*. Another said about the organisation *"if it wasn't for them I'd've had a nervous breakdown"*.

There were a small number (n=4) of carers interviewed who were in contact with Durham County Council's Carer Development Team who had carried out a carers assessment. Some of these found the team very helpful and others less so. Those who had had a carers assessment reported finding them very useful. They were described as being flexible and useful. One carer reported that the team were looking into providing activities through joining a local sports centre (which she could not afford to do) as she could not access routine respite (as no-one could care for her mother with mental health problem. However, all of those interviewed who were in contact with team were all appreciative of the recognition that the team gave them.

There were several carers interviewed who had accessed support from DISC when they were young carers. This support was all widely appreciated and carers had a number of very positive things to say about them. Elements of support that were particularly valued were the social networking and the practical and emotional support that was provided. For example, one 18 year old carer reported *"they helped with everything, they even came to my nan's funeral"*. There were particular reports of regret and disappointment when they had to



disengage from the project, either because they had become too old or for other reasons. One carer reported *“I did get help from DISC, they started helping me when I was 12 and they really helped me at school ... I really liked the activities but when I was 16 they said I didn’t need help anymore but I coulda done with their help”*. One carer said *“when I found out about it [DISC] I was 18 and too old ... I was gutted”*.

Of those who were aware of services available for carers, they had heard about them in a variety of ways. For example, one carer said *“I’ve been caring for 10 years but I’ve only been offered help in the last couple of months ... maybe it’s because I’m older that I’ll read posters and leaflets ... I never used to when I was younger”*. Another said *“I was told about the carers development team by Crisis [Shelter] and then seen information at the William Brown Centre in Peterlee in their carers corner”*.

In relation to the young carer services, one carer of her parents with physical disabilities had heard about the DISC young carer project from her father’s district nurse. Another had heard about DISC through her school as she was being bullied and a teacher told her about it.

There were two examples of self initiated services, through the creation of two support groups in New College and Bishop Auckland College respectively. Each of these groups has between six and 10 regular members and meets every month. The former of these had been independently initiated by two carers and supported by the college’s student support (counselling) service and the latter had been started with the help of DISC young carers project. Members of the support group at New College felt that the only support they received was the mutual support provided by the group and this support was rated as very important in their lives, particularly at critical times. As one group member said *“it’s very important depending on what’s happening in your life ... if nothing’s going on, it’s not that important but when something does happen, it’s really important”*.

It was reported by the student support service that in addition to the support group members, the student counsellors give support to around an additional 10 carers each academic year.

Despite the widespread non access of services, most of those interviewed said they would like to access appropriate services or have them available. For example, one carer said *“I would love to go to a carers centre”*. Others however stated that what would improve their lives would be more care for the people they care for (particularly those who care for their partners). For example, one carer said *“what I’d really like is more ways about supporting him [the cared for individual]”*.



2.10 Service proposals

There were a series of different responses to the question of what services young adult carers would like to see on offer. These ranged from drop-ins, support groups and respite cover.

The most popular response was for mutual support opportunities; somewhere where carers could go to socialise and to talk with people in a similar situation to themselves. Here suggestions included a regular monthly meeting opportunity or a drop-in. One carer reflected this by saying "*It would be good for young people to meet together, to come up with a plan about what young people would like ... at the minute, there's nothing on offer*". Another said "*a support group would be good*".

There were other suggestions from many carers (n=15) who said that they would like a general package of support. For example, one carer said "*general help and support, trips, to give you a break, get away from the whole thing ... somewhere someone understands you*". In a similar way, carers also felt in need of activities designed for a younger age group. One carer said "*young carers do activities, when you're 20 you're still young enough to do stuff like that*".

The reaction to the subject of respite care varied amongst the carers interviewed although most were very cautious. Carers of people with mental health problems found the idea of respite most difficult to consider as the people they cared for were not in a position to let a 'stranger' look after them even for short periods.

There were other people who cared for someone with a physical disability whose situations were so specific that no-one else could look after them. One carer said "*we don't know people, we don't trust people ... I must handle her so carefully not to cause her intense pain so other people can't do what I do*". This specialism of knowledge and intimacy with the cared for also stops help in other ways. For example, one couple with a seven month year old baby lived in a small council house, living in a small downstairs room with a bed because the she could not climb the stairs and a commode and cot. They were unwilling to let any outside person help with cooking or cleaning because of the intimacy of their situation.

Other carers however would value some respite care, especially those that cared for a parent and younger siblings. One such carer said "*it would be nice to have someone to help [with the kids] ... even just for a short time so me and my dad can have a chance to talk on our own [about family management issues]*". Another carer reported that they would like someone to help with their caring duties, especially to allow them to go to college or to go socialising.

Carers of people with substance misuse issues who also had young children said that they would appreciate respite in the form of someone looking after their children. For example, one carer said "*it would be nice if someone could take the kids for a day so I can have a break*". Although not a traditional form of respite,



such support needs to be viewed in the context of extreme isolation of these carers, with no family or other support. For example, one carer said “*I would like more support ... I never get a break*”.

When carers were asked more broadly about what would help them in their caring duties, their responses included:

- Information, advice and guidance (IAG) on finding employment
- An increased involvement, help and support from family members
- Recognition from members of the general public about their caring role



What the research tells us

Leisure and socialising

The main themes from previous studies are that young adult carers feel more restricted than other young adults in terms of their opportunities to go out, join in with activities and go away on holiday^{xxi}. Another local study^{xii} indicated that young adult carers were able to get some leisure time away from the home but they weren't using this time to keep fit and healthy because the cost of this was prohibitive to them. The authors suggested that there should be a leisure card allowing subsidised access to such facilities for carers. Whilst the emphasis is often about whether or not the carer can take a break, one study^{xiii} also raises the point that disability and illness usually restrict the whole family's ability to go out and take part in everyday activities together, which in turn affects family dynamics. Restricted income can compound this problem.

Finance

The relationship between disability, illness, caring and low income was a recurring theme in one report^{xiv}: "Virtually all the families were in receipt of welfare benefits and were outside the paid labour market. Experience of poverty and social exclusion were common" (p 32). In common with other research, our study confirms that many young adult carers aged 18-24 experience significant financial hardship as a consequence of caring and living in low income families with illness and disability^{xv}.

Young carers projects

For many, the value of young carers projects was about friendships that they developed with other carers who were able to understand, empathise and provide support for each other in a way that others, without caring responsibilities, could not. Acceptance of each other and a non-judgemental attitude was fostered within these projects:

Caring services

Many young adult carers perceived that services for adult carers were geared to much older carers. They thought that their need for support was of a different nature than older adult carers because of their life stage. They felt they had outgrown young carers social events but that they were too young for the adult carers meetings, leading to the conclusion that: "It appeared there was a need for a distinct social calendar for this age group"^{xvii} (p19).

Recognition

None of those interviewed had regarded themselves as a carer until this was defined for them by someone else, most often a health or social care professional, teacher or young carers service. For example, one participant said it was only when she received counselling at college that she became aware that she was a carer despite having lived with and supported her mother, who had mental ill health, for many years:

Higher education

For some young adult carers school was an unhappy place due to their experiences of being bullied or due to name-calling^{xviii}. On reflecting on their experiences of college, current or past, young adult carers currently attending college found it to be a more positive experience than school because of its flexibility, its adult-orientated focus and staff who were more understanding and supportive of young adults with caring roles.

Source: Becker and Becker 2008.



3.0 Findings from professional organisations

3.1 Carer centre findings

There are five adult carers centres across County Durham all of whom receive funding from Durham County Council and NHS County Durham and all are affiliated to the Princess Royal Trust. Each centre has around 10 staff, with between five and seven support coordinators who deliver services to carers. The level of service from each centre varies, with some offering respite care, others support groups and others with specialised parent carer services. In addition to these, there is also Liberty From Addiction who provide services for carers of people with substance misuse issues.

The five centres all have high caseloads, which are dominated by older carers with the number of registered young adult carers being very low (see table 3.1).

Table 3.1 Number of young adult carer registrations with carers centres

Centre	Total number of registered carers	Number of registered young adult carers
The Dales	1,549	60
Derwentside	972	1
North Durham	1,441	50
Easington	1,256	Exact figure unknown but less than 100
Sedgefield	1,532	18
Liberty From Addiction	472	30

There were two main reported reasons for the low number of registrations. Firstly, as their services are dominated by high numbers of older carers, this group forms their main business. This is due in part to a historical legacy, where carers were traditionally viewed as older people. As one carers centre manager explained, “*as a general rule, carers centres were set up for older people*”. The high numbers of older carers means that their services have been developed for them. For example, one carers centre manager said “*we are just managing with our existing caseload*”. Indeed as a result of this, it was felt “*carers centres have never needed to shape services [for other client groups] because they’ve always been so busy*”.

The other reason that was given for the low number of young adult carer registrations was the recognition by the centres that they are generally not attractive to young adults. These two reasons were summarised by one carer centre manager who said, “*we have two issues, one capacity and two we don’t focus on it*”.

There have been efforts in the recent past to attempt to attract young adult carers into adult carer centres, although they have been mostly unsuccessful. For example, there were efforts by both the young carers projects and the adult carers centres to provide a transition referral process between both services. As part of these efforts, carers in transition between children and adults were



introduced to the adult carers centres. However, the number of referrals these introductions resulted in numbered less than five over two years.

As part of this carers centre staff received training from Barnardo's (who deliver the young carers service in west Durham) around young carer transition issues, which included carers coming up to adulthood (aged around 18). However, despite the training which included approximately eight young carers who were either 18 or approaching 18, they had never received any referrals.

A text messaging service was launched in 2008 by the adult carers centres aimed at younger carers where people could text in, an email would be generated to the Durham carers centre which would be directed to the relevant carers centre and action would subsequently be taken. The service and publicity was funded through £500 contributions from each carers centre and posters were distributed mainly in GP surgeries. The numbers of referrals through this service has been small, for example one centre has received four referrals in two years, all of whom were 18. However, other centres received no referrals from this method.

As a result of the low numbers of young adult carers accessing the centres, they were unaware of the problems, issues or needs of this group. However, certain centres had some knowledge and others offered their perceptions of the issues faced by young adult carers. Carers centres said the following:

- It was felt that young adult carers require a different type of support than that which currently exists in carers centres. For example, one carers centre manager said "*young adult carers have a specific set of needs ... they have many different needs depending on who they are looking after but most want to continue with their own set of activities*". Another said young adult carers "*need a different set of activities*". Such support was thought to include one-to-one support, information, such as benefit entitlements and more young people targeted activities.
- In relation to the above, it was unanimously thought that young adult carers needed a specific resource. One reflective comment was, "*to tackle that group, you need a specialist worker*". Another issue that was raised in relation to this was the older nature of their existing support workers, with one manager saying "*our workers tend to be middle aged so we're not attractive to them [young adults]*".
- Some carers were felt to need a care facility and/or crèche but the carers centre cannot provide this facility.
- It was felt that carers experience social isolation and had a range of related vulnerabilities. Comments included: "*they have a problem of isolation and exclusion at a very important time in their life*"; "*they are isolated from their peers, more so than the over 30s*"; and "*they've had problems in school, often have self esteem issues and are very vulnerable*"



- It was also felt that they experience financial and childcare problems and experience problems with employment and education. Another said *“social care needs to be provided so they can go to education, employment and other do other things ...the provision of care to allow them to be average 18 to 25 year olds”*.
- Housing was thought to be a common problem amongst carers. One carers centre had close links with of a housing organisation due to their physical proximity. This carers centre said *“one young lad who cared for his grandma wanted his independence and to live alone and find a job but he didn’t want to leave his grandma, so he needed a house close to her. We succeeded in finding him a house next door and much of that was due to us having the housing office [Sedgefield Borough Homes] next door to ours”*. They continued *“we need housing services to recognise their [young adult carers] situations”*. Another example that was given was of a young woman who cared for her mother who suffered from psychosis, the young woman became pregnant and had to get her mother sectioned under the Mental Health Act because she was worried for the safety of her baby whilst sharing a house with her.
- Becoming Independent from the person cared for was thought in many cases to be very difficult. For example one centre manager said *“if a young adult is caring for a disabled parent, how do you make that break?”*
- It was felt that certain carers may have limited choices because of the benefits system and their role as carers, with one centre manager saying *“The majority will have been young carers. You can leave school at 16 and get carers allowance so you can become trapped by the benefits system”*.
- And finally, it was correctly thought that recognition as a carer was very important.

There were some misconceptions about young adult carers and these included the following:

- It was thought that young adult carers are under a lower caring load than older carers which means they retain a level of independence. For example, one centre commented *“young adult carers are not the sole carer ... usually there’s another adult there so they can get out and about a bit”*. Clearly there are carers which experience such situations, but this and other research has demonstrated that for many their caring load is very high.
- There were thoughts expressed that young adult carers may have difficulty in administering to the people they cared for on a more intimate level. However, this was not expressed during the research and caring was expressed as an experience or a lifestyle rather than a set of activities.
- It was also felt that young adult carers may have existing support mechanisms in place as a result of growing up in the context of other young people. One comment included, *“if you started as a young carer then you will have informal support systems ... so you wouldn’t think of coming to a group”*. There were a small number of young adult carers that either knew other



young adult carers or had created their own support groups. However, these support structures were self-created because of an absence of other support systems (e.g. friends or family). In other words, informal support structures were commonly absent, so there was an increased need for more formal support systems.

In relation to the service needs of young adult carers, there was a consensus that a targeted service was required. At best such a service would consist of dedicated workers to deliver a young adult carer service and at minimum there would be an annual focussed and coordinated initiative.

In relation to the former, a minimum requirement for a targeted service was thought to consist of two workers across County Durham. Such workers would develop links with agencies, ensure a referral routes and organise a portfolio of dedicated services. One carers centre manager said *“they need more intensive and dedicated work, one-to-one from someone who understands the system”*. It was felt that in doing so, the needs of young adult carers would be more accurately known and their profile would be raised. For example, one manager commented, *“a dedicated worker will engage people and once they do that people [carers] will tell us what they want”*.

In relation to the provision of dedicated services, it was recognised that different types of carers require different interventions, from support groups for isolated carers to intensive physical and emotional support, including help with building self esteem and confidence for very vulnerable carers.

In relation to the minimum requirement, it was felt that carers centres could focus on young adult carers at least once a year. One manager reflected the feelings of others; *“we could with a push ... the strategy group could do it with concerted effort ... but what services do we provide for them?”*. Another said *“[we] need to make sure that carer activities are appropriate”*.

3.2 Findings from other agencies

There were an additional four agencies interviewed for this needs assessment: DISC and Barnardo’s young carer projects; the Primary Care Trust’s Adult Carers Support Service; and Durham County Council’s Carers Development Team.

It is noteworthy that there has recently been a support project which has focussed on young adult carers in County Durham. Between 2002 and 2005 DISC delivered a young adult carers (16 to 25 years) service with funding from Northern Rock Foundation. The project was reported by DISC to have worked very well with a caseload of 100 each year.

The responses from adults who used to access DISC services were all extremely positive. One of the elements of DISC’s current service consists of themed



support groups, e.g. carers of parents with physical disabilities, mental health problems and specific age brackets, which are reported to work very well. DISC did report that in the past they had referred clients to the adult carers centres but they have not made any referrals in the recent past.

DISC did identify that young adult carers of people with substance misuse issues were particularly vulnerable. For example, it was noted "*carers of someone with drug and alcohol problems are radically different from other carers ... there's a lot of neglect, a lot of vulnerabilities, like adults grooming them to get at the children*". It was noted that such carers are even more under provided for and more investment is needed for this group.

The Primary Care Trust's Adult Carers Support Service noted the difficulty in gaining access to young adult carers, who they recognised as a hidden group. It was felt that it would be easier for young carers services to increase their age range from 18 to 25, than for adult carers centres to make their services more accessible to a younger audience.

The Council's Carers Development Team reported that most of the carers that they support are over 50 and the numbers of young adult carers they support is small. However, it was noted that many people (both professionals and carers) were unaware of the existence of the service and "*unless someone's putting their hand up, they're left to plod on*". In relation to the former, the team reported that previously they carried out awareness raising amongst other teams, but that ended in 2007.



4.0 Conclusion and recommendations

4.1 Conclusion

It was clear from the research that young adult carers are resilient, strong and capable people. However, it was also clear that they experienced many hardships in addition to their caring duties, with the main difficulties being social isolation, a lack of time for themselves and financial problems.

It was also apparent that young adult carers were not a homogenous group and that they could be stratified into different groups, i.e. carers of people with physical, mental and substance misuse issues and carers of partners, parents and siblings. What is important about this, is that these differences need to be borne in mind when developing services.

From the findings of the research, we can make a number of statements about young adult carers in County Durham. These are:

- **Young adult carers are a hidden group because they do not present themselves at services.** There are also subsets of young adult carers who are even more hidden such as carers of people with substance misuse problems.
- **Carers do not present themselves at services for a number of reasons** including: they may not consider themselves carers; they may not be aware of services that exist for them; and the services that are available that are known about are not attractive to them.
- **Young adult carers respond to proactive, energetic and persistent outreach.** We know this because of testimonies from young adult carers who have accessed Easington carers centre services and from those who have accessed young carer services; both services were described to use such a model.
- **Recognition as a carer is a matter of great importance.** Young adult carers were greatly affected by negative perceptions reported to be held by the general public and many services. Carers often did not recognise themselves as carers until late into their caring 'career' and many only did so when a professional provided that recognition.
- **Young adult carers commonly suffer from social isolation, an absence of friends and feel that they have no independence.** The common characteristic of having very little money compounds this isolation as it means carers spend very little on themselves and they often become housebound because they lack the means to do anything, e.g. go shopping or do activities either as a family or on their own.
- **Many carers are unable to secure employment because of their caring role and must rely on state benefits to survive.** This is uncommonly carers allowance and more often Jobseekers Allowance or Income Support.



- **Experiences of school were very poor.** Although national research indicates that 28 percent of young carers have serious problems in secondary schools, we found as much as 65 percent of carers in our sample were bullied and unsupported in school.
- **Caring can often affect the health of carers, particularly mental health.** Contact with the medical profession varies from good to very poor, the latter particularly with mental health cases.

What is also clear from the research is that Durham County Council has a supportive carer policy and has been proactive in listening to both service providers and service users. For example, in the current carers strategy, Durham County Council firmly positions itself in support of the national carers strategy and recognises the role of both the Council and other partners in supporting carers:

*The national strategy for carers called *Carers at the heart of 21st century families and communities* was published in June 2008. Its vision is “...that by 2018 carers will be recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to individual needs enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.”* The responsibility for delivering this vision is shared by central and local government, the NHS, voluntary and community sector, families and communities. Delivering the vision would mean genuine equality and recognition for carers. The strategy recognises however that improving support to the person being cared for is vital to improve the life of the carer^{xix}.

There work that has already been done by the County Council has also identified many of the needs that have been found during this needs assessment. For example, in the previous local carer strategy *Meeting the Needs of Carers 2005-2008*, it was stated that publicity and awareness raising were important issues which will be addressed as part of the strategy’s implementation. In other words and in many respects, the findings of this needs assessment and the strategic direction and willingness of Durham County Council are mutually supportive.

If we look at the national research, we also see much cross over in identification of need and service delivery proposals. The important Becker and Becker study in 2008 made a series of recommendations which included:

- Universal and specialist service providers need to be more alert to meeting the specific needs of young adult carers
- There is a need to identify and engage with young adult carers, with particular reference to agencies not traditionally associated with meeting the needs of



carers such as colleges, universities, Job Centre Plus, employers, leisure services providers and others

- Commission, design and deliver services to achieve outcomes identified in the National Carers Strategy
- Involve young adult carers in the design, development and evaluation of services
- Improve integration and joint working between services for young carers and adult carers including the transition
- Provide young adult carers with high quality information, advice and guidance including the promotion of legal rights and their right to a carer's assessment from the local authority, which is a potential gateway to services and support for carers and their family
- Adult carers services need to address the barriers that are inhibiting carers aged 18-25 from using their services and address their own lack of relevance to this group (as perceived by young adult carers)
- Identify the needs and service responses for young adult carers within each local authority carers strategy

Becker and Becker's research also contained a veiled warning about service development for young adult carers.

Providing a service for young adult carers may not be sufficient in itself unless the barriers that prevent the uptake of support services by young adult carers are addressed. Such barriers were highlighted in the study in Flintshire (Barnardo's, 2007): "*The young adult carers interviewed seemed to lack the confidence to act on signposting, do not receive information on adult services or feel that they ought to be able to cope because they are adults*" (p 38). This study found that young adult carers don't necessarily recognise themselves as carers and therefore information needs to be directed at them about this. Young adult carers and professionals may also assume that because they are adults they can cope with their responsibilities and indeed that society expects them to cope^{xx}.

The next section outlines our recommendations based on this needs assessment.

4.2 Recommendations

Based on the findings of this needs assessment, we make a series of recommendations:

- **Raising awareness and public education**
These elements have the objectives of increasing the awareness of the carer themselves about what they do and creating a greater recognition both from the



general public and services about the importance of what carers do. Both these aspects would raise the public profile of carers.

Recognition was considered to be very important to the majority of carers interviewed and many reported negative impacts when recognition was not given or doubt was voiced about the carers' motivations. Also, many carers interviewed felt that an important time in their life was the realisation that they were carers. This led to a moment of both self-realisation (and associated empowerment) and also the point when they could begin to consider accessing services.

It was therefore felt that more needed to be done to raise awareness amongst carers about what they do and the value of that work. It was felt that such awareness raising was most effectively done through public education campaigns. For example, there were suggestions for advertising services and raising awareness amongst young adult carers through 'big and bold' approaches such as the use of advertising space on buses.

There was similarly felt to be a need to raise awareness and educate members of both the general public and general services about the role and responsibilities of carers. Indeed a key motivation of those carers setting up the college support groups was to raise awareness about carers.

It was felt by carers and associated services that if services in the community were made more aware of carers, particularly young adult carers, then this would lead to an increased identification of carers. And this would hopefully eventually lead to an increased engagement with carer services.

- **Provide mutual support opportunities**

The main service gap that was identified by carers was the desire for a regular social/mutual support opportunity, either through a drop-in facility or a support group meeting. It was suggested that this could be a monthly feature which would address their isolation. There were other suggestions for a programme of activities but the support group option was the dominant suggestion. It was also reported by many of those interviewed that a support group would be a good place to start in hearing the views of young adult carers and involving them in the service development process. There were certain carers who felt that such an opportunity, if one were to exist, should include specific groups of carers, e.g. a group for carers of people with mental health problems and another for those with physical disabilities (carers of people with substance misuse problems already had support groups that they attended at Liberty From Addiction).

It should be noted that if such groups are to be developed, there needs to be associated work carried out with bringing young adult carers into the groups



to avoid Becker and Becker's (2008) warning detailed at the end of section 4.1.

- **Advertise carer services better**

There was a general consensus that services for carers needed to be advertised more, particularly the carers development team and also services available at carers centres. It was felt that the way these services were advertised needed to be targeted at a younger audience. One carer said "*when you're younger you tend not to look at posters or read flyers, you watch TV and listen to the radio*".

In relation to the more micro level of how services could be advertised and how carers could be notified of activities or services, letter was the most preferred method. Only a few felt email would be a suitable method of being notified and similarly text messaging. Some felt text messaging to be too personal a method (one carer said "*you get texts from your friends, not from anyone else*"), however, there were some that felt they could be notified about services via text; it was a personal preference issue.

It was felt by several carer services that the client group is often too vulnerable for new technologies, such as social networking internet sites (it was similarly felt that these vulnerabilities were also thought to be apparent with text messaging as its use in a professional context has a risk of "*blurring the boundaries*" between friend and professional). It was thought that if an internet site was to be developed with elements of social networking, it would have to be 'policed' and monitored. As a result this, it may make it too costly a proposal.

- **Allow partners and carers to do things together**

The experience of caring for a partner was considered different to other carers. It was felt that most services are targeted at either the carer or the cared for person, but not them as a unit. Indeed, it was felt that services try to split the unit up, for example, one carer said that he was offered complementary therapies that they both would have enjoyed together, similarly, she was offered sessions in a hydrotherapy pool which they could have enjoyed together but her partner could not go with her. This is an area that the DISC project supports their clients to do, i.e. supporting young carers enjoying activities as a whole family.

- **Develop a young adult carers service**

There were unanimous calls from all adult carers centres about the need to develop a service specifically targeted at young adult carers. Indeed, such a service would address most of the above recommendations. It would also address the additional support needs of carers of people with substance misuse issues (it is unrealistic to expect Liberty From Addiction to continue to support this group with no additional support). Carers centres felt that there



would need to be a minimum staff contingent of two in order to cover the county. Such a service would be able to carry out much of the awareness raising with associated agencies, provide a proactive and energetic service which would identify young adult carers and bring them into services (which would in turn produce a snowball effect of attracting further numbers) and provide a number of activities including mutual support. Indeed, this model has already successfully been implemented by DISC.

We would therefore recommend that such a service be developed.

In the absence of additional investment, there are several of these recommendations that could at least partially be achieved. These include: increase awareness amongst agencies, this could partially be achieved through existing local authority channels (senior management and frontline staff meetings, communiqués, etc.); providing mutual support opportunities, through a more concerted and coordinated effort from the adult carer centre and a partial reshaping of their service; advertising adult carer services better, this could partially be achieved by targeting young adult carers by letter; and allowing young adult carers and their partners and families to be able to enjoy activities together, through reshaping existing services.

In relation to the young adult carer service, funding could be accessed from either the statutory or charitable sector, using this needs assessment as evidence.



Appendix one: Interview guide

Questions for young adult carers

- What are your experiences of being a carer?
- What are the best things and the worst things?
- What are the things that are easy for you?
- What do you have time to do?
- What don't you have time to do?
- What are the things you have most trouble with?
 - Money
 - Education
 - Health
 - Employment
 - Friends/relationships/family
 - Everyday living/shopping/cooking/cleaning, etc.
- Which things have the most impact on you and those that you care for?
- What would help you the most with these things?
- Do you access any services? (what are these?)
- What is this like?
- What puts you off going to services?
- What would improve services set to help you?
- How would you like to access good services?
- What type of help would you like but is not currently available?
- How would you like to be kept updated about what's going on?

Questions for professionals

- What services do you provide?
- Are these accessed by young adult carers? (how many, per month/year)
- What do you think are the main issues associated with young adult carers?
- What do you think are their needs?
- What are the gaps in service?
- What services would you set up for this group?
- What do you think about the use of new technologies to engage with young adult carers?



Appendix two: Demographics of sample

A total of four focus groups were carried out with a total of 18 respondents. There was a total of 17 individual administered semi structured interviews and three telephone interviews.

A 1. Ages of carers in sample

Age	Number
17	2
18	7
19	4
20	6
21	2
22	3
23	5
24	5
25	4

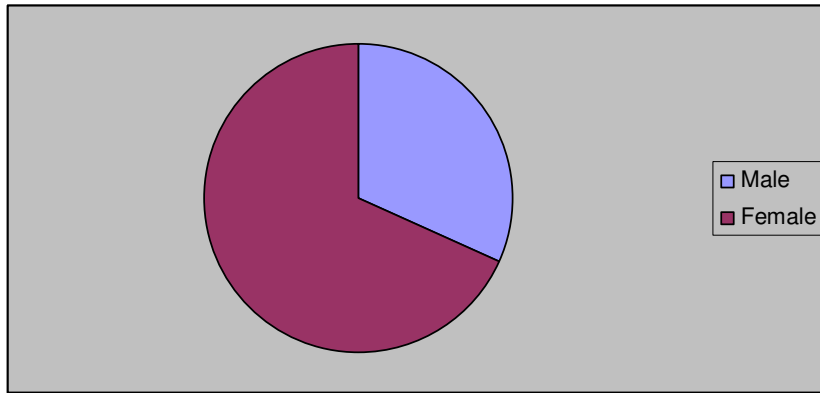
A 2. Town of residence of sample

Town of residence	Number of carers
Brancepeth	2
Chester le Street	5
Coxhoe	1
Durham	5
Easington	4
Haswell	1
Horton	1
Cassop	1
Newton Aycliffe	7
Pelton	2
Peterlee	3
Sacrison	1
Seaham	3
Shildon	2
Total	38

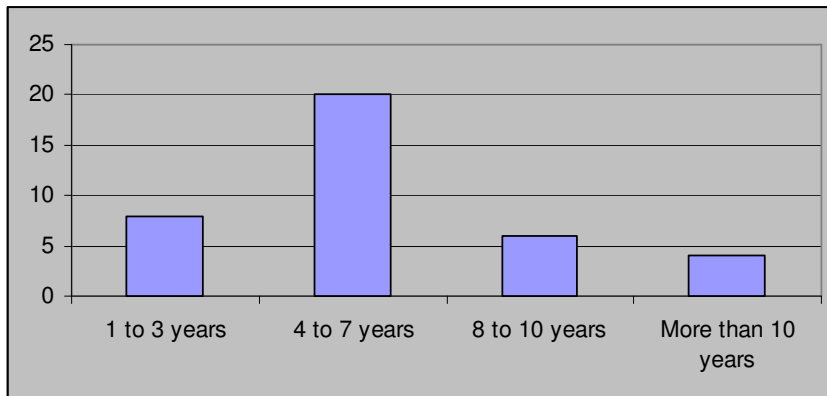
A total of 68 percent of respondents were female and 32 percent male.



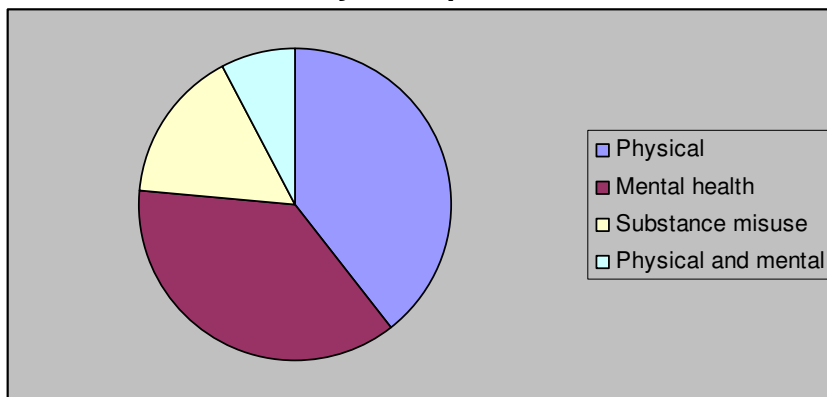
A 3. Number of females and males in sample



A 4. Duration of caring of carers in sample

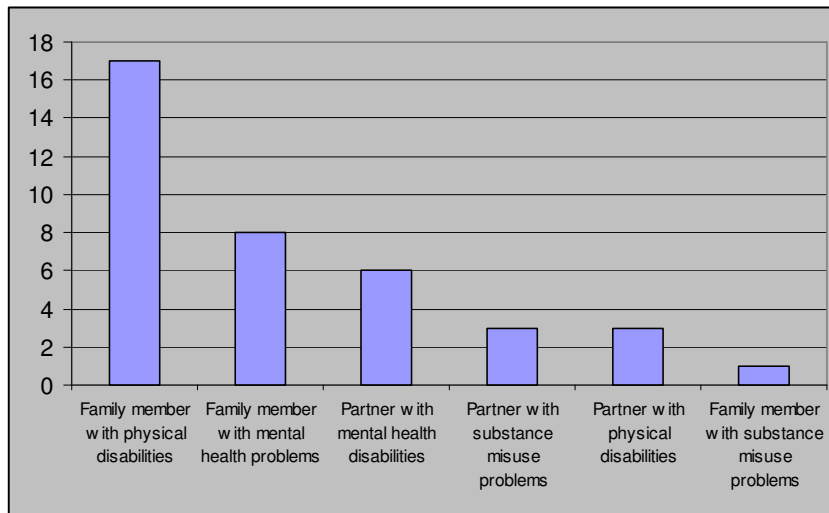


A 5. Nature of disability in the person cared for





A 6. Carers relationship to person cared for in sample



Carers assessment

A total of four people out of the sample had received a carers assessment.

Carers allowance

A total of six people out of the sample were receiving carers allowance.



Endnotes

- ⁱ Department of Health, 2008
- ⁱⁱ Adapted from Becker, F. and Becker, S. 2008 *Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24*. London: The Princess Royal Trust for Carers.
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- ^{iv} Levine, C., Hunt, G.G., Halper, D., Hart, A.Y., Lutz, J. and Gould, D.A. 2005 *Young Adult Care Givers: A first look at an unstudied population*, *American Journal of Public Health*, 95, pp. 2071-2075.
- ^v Becker and Becker, 2008.
- ^{vi} *Op. cit.*, 2008.
- ^{vii} Joint Commissioning Strategy for Carers, 2009-13, Durham County Council and NHS County Durham
- ^{viii} Carers UK, ACE National and The University of Leeds, 2007, *Valuing carers – calculating the value of unpaid care*
- ^{ix} Dearden, C. and Becker, S. 2000. *Growing Up Caring: Vulnerability and Transition to Adulthood - Young Carers' Experiences*, Youth Work Press for the Joseph Rowntree Foundation, Leicester.
- ^x Action for Young Carers (2005) *Young Carers: The Next Step Forward*, The Carers Federation Ltd (unpublished).
- ^{xi} Dearden, C. and Becker, S. (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK.
- ^{xii} Barnardos (2007) *Flintshire Young Adult Carers Research Project 2006-7* (unpublished).
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- ^{xiv} Dearden, C. and Becker, S. (2004) *Young Carers in the UK: The 2004 Report*, London: Carers UK.
- ^{xv} Yeandle, S. and Buckner, L. (2007) *Carers, Employment and Services: Time for a New Social Contract?*, Report No 6, London: University of Leeds and Carers UK.
- ^{xvi} Carers UK (2007) *Real Change, Not Short Change: Time to Deliver for Carers*, London: Carers UK.
- ^{xvii} Action for Young Carers (2005) *Young Carers: The Next Step Forward*, The Carers Federation Ltd (unpublished).
- ^{xviii} *Ibid*, 2005
- ^{xix} Joint Commissioning Strategy for Carers, 2009-13, Durham County Council and NHS County Durham, page 27.
- ^{xx} Becker and Becker, 2008, page 16.