

# Towards Seamless Support

**An inquiry into service provision and the transition experiences of young adult carers in Dundee**



## **Acknowledgements**

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**Gill Ryan  
Dundee Carers Centre  
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The report can be accessed at: [www.dundecarerscentre.org.uk/research](http://www.dundecarerscentre.org.uk/research)

**Carer:** someone of any age who provides unpaid support to family or friends who could not manage without this help due to illness, disability, mental ill-health or a substance misuse problem.

*Princess Royal Trust for Carers ([www.carers.org](http://www.carers.org))*

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## **Introduction**

Research indicates that carers are vulnerable to social exclusion due to factors such as poverty and isolation (Howard 2001, Barnes 2006). Young adult carers have been identified as being at particular risk of becoming 'NEET' – not in education, employment or training (Scottish Executive 2006). Carers centres have an important role in addressing these issues through 1:1 support, group work, social activities, welfare rights and lifelong learning opportunities.

However, Becker & Becker have identified that few young adult carers engage with adult services as they are “self-conscious of the wide gap between themselves and other carers” (2008, p67). This is evident in Dundee Carers Centre, which provides support services for young and adult carers, including the Upbeet project for young adult carers at risk of becoming Neet. Few of these young adults make the transition to adult services and the Centre engages only a small number of people who become carers between the ages of 18-30.

However, we know these carers exist: Census 2001 revealed 230,000 young adults aged 18-24 providing unpaid family care in the UK (Becker & Becker 2008, p1). A recent report by the BBC (2010) suggests that these numbers are significantly under-reported. Young carers may continue to care after the age of 18 and other young adults may become carers after this age, for example if they have a disabled child, a partner with a mental health or addiction issue, or a parent who falls ill. Young adult carers have to cope with the same transitions as others in their age group, but their experiences can be complicated by the demands of their caring role (Scottish Government 2010; Becker & Becker 2008).

Frank (2007 p9) argues that “the needs of young carers have fallen between the growing gap that separates adults’ and children’s services”. This transition may be exacerbated by differing definitions of ‘youth’ and ‘adult’; statutory children’s services end at 18, as do many young carers projects, while the

Upbeet project ends at 21, yet Youthlink (2009) defines the age range for youth work as 11-25. The recent national strategy 'Getting it right for young carers' recommends that young and adult carers services consider ways in which to provide "seamless services" (Scottish Government, 2010 p95).

This inquiry set out to investigate this identified gap in service provision, and how best to provide 'seamless support' for this group of carers. Its original objectives were to:

- Investigate existing provision for carers aged 18-30 in Dundee
- Explore engaged and non-engaged young adult carers' perceptions of existing support services
- Identify the expressed support needs of this group of carers
- Evaluate transition services for young adult carers

However, due to a limited response, the scope and scale of the inquiry had to change to reflect the data received. In addition to a review of the literature and analysis of the 13 questionnaires received, the key themes of transition and young adulthood, and the impact of poverty and social exclusion on young adult carers' experiences of these, will be explored qualitatively with a small sample of young adult carers and a support worker. This inquiry will also make recommendations on how 'seamless' support may be provided in a way which will meaningfully engage with young adult carers.

## **Carers in the literature**

While Becker & Becker have described young adult carers as “invisible” in the literature (2008 p10), there is a substantial body of research on the wider carer population (both young and adult) from which to draw. Though caring has always been part of the cycle of family life (Barnes 2006), it was only in the 1980s that the work of carers began to be recognised in policy and research (Cavaye 2006). The first national carers strategies were developed in 1999 (DoH 1999 / Scottish Executive 1999) and recently revised, with the first dedicated national young carers strategy published this year (Scottish Government, 2010).

Initial research on carers' lives focused on 'caring as a problem', and an image of hero / martyr became apparent in the literature, the media and policy statements (Barnes 2006, p111). This idealisation of carers came at the expense of the people they cared for, and there was conflict between those advocating for carers rights and the disability rights movement, whose members resented being perceived as a 'burden' (Stalker 2003 p27). This was exacerbated when the work of young carers began to be investigated in the early 1990s. Becker and Aldridge, whose pioneering work *Children who Care* (1993) put young carers on the policy agenda, fell foul of disability rights advocates who perceived their children's rights approach to be an attack on the parenting skills and independence of disabled people. Whether or not this was an accurate critique of the work, which Aldridge and Becker (1996) refuted, it is likely that the debate helped shape the 'family support approach' now evidenced in most young carers projects, including that of the Dundee Carers Centre. This approach works with the whole family to alleviate the responsibilities of the young carer while ensuring the support needs of parents are met (Frank & McLarnon 2008).

It could be argued that the young adult carers agenda is at the stage that young carers issues were in the early 1990s, with the first substantive work to focus on their experiences published in 2008 (Becker and Becker). Prior to this, 'young adult caregivers have been almost totally ignored in research'

(Levine et al 2005). Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24 (2008) is the landmark piece of research into the experiences of young adult carers. This inquiry differs significantly in that its remit is broader in terms of age (18-35) and encompasses those who may have commenced caring after the age of 24. However, Becker & Becker recognise that there is little available research on younger adult carers and their literature review draws from research on both young carers and adult carers. This has been a useful source for summarising what is known in the literature about this group, specifically in regard to the themes of poverty, educational attainment, social inclusion and transition to be explored in this review.

Howard (2001) and Barnes (2006) link caring to the broader issues of poverty and social inclusion. These themes have informed the development of this inquiry's questionnaire and interview schedule. Barnes suggests that the work of caring is undervalued by society as a result of its gendered nature, with women being more likely than men to care for a family member (2006, p152). This is reflected in Dearden & Becker's (2004) finding that gender differences among young adult carers begins to emerge between 16 and 18. Barnes argues that, as an inevitable part of life, caring should be valued and advocates an "ethic of care" (2006, p177) which transforms it from an "individual, private problem" to one of social justice. Conversely, the discourse of the current UK government would appear to suggest that carers fit well with the 'Big Society' agenda; facilitating a smaller role for the state by taking private responsibility for family members' care needs. Caring would appear to exemplify the feminist truism "the personal is political".

In *Paying the Price: carers, poverty and social exclusion* (2001), Howard presents "overwhelming evidence associating caring with financial hardship" (p14). However, the information on benefits is substantially outdated due to the previous UK government's attempts at addressing inequality through tax credits and benefits, and the effects of the first National Carers Strategies (1999). This is not to argue that poverty and social exclusion have been

eliminated; a recent survey by the Princess Royal Trust for Carers (2010) suggests there is still a strong link between caring and poverty. Howard hypothesises a link between social class and caring; as those on low incomes are more likely to have poor health, consequently there are more carers from lower socio-economic groups (2001, p12). This is reflected in Dearden and Becker (2000), which found that most young carers taking part in the study come from lone parent families, that none of their parents who were ill or disabled were working, and virtually all were in receipt of benefits (p32); factors that can predispose people to social exclusion. A recurring theme in the literature would appear to be that “illness, disability and poverty tend to go hand in hand” (p28).

Another key theme in the literature is that of transition. Much government policy concerned with young adults focuses on the transition from education to work. In *Getting it Right for Young Carers*, the first national young carers strategy, eight of the nine action points relating to young adult carers are concerned with education, employment and training (Scottish Govt 2010 pp 73-79). *More Choices More Chances* recognises young adult carers as being particularly at risk of becoming Neet (Scottish Executive, 2006). Indeed, my own inquiry on young adult carers focused on their experiences of the barriers they faced to education, employment and training (Ryan, 2010). This reflects Dearden & Becker’s finding that young adult carers may be “less available for work and more likely to have fewer and lower educational qualifications” (2000, p25). As this would appear to impact on young adult carers’ life chances and make them more vulnerable to social exclusion, it could be argued that this is an area on which support should be focused. However, Furlong (2010) suggests that, for today’s young adults, transitions “are less likely to involve a linear movement from education to work and independent living” (p1). Additionally, Howard (Chapter 4, 2001) suggests that the nature of caring means that there is not one but many transitions with different challenges which may be made over the “caring career” (p45). Heinz (2010) advocates a “life course approach” which acknowledges that borders between life phases such as youth and adulthood have become “fuzzy”. He argues

that “social origin, education and opportunity structures” are more likely than age to determine when young people make the transition to work (p5). Becker’s work would appear to reflect this, noting that for young adult carers these transitions can be complicated by guilt at leaving the family home, and those they care for, and financial pressures (Becker & Becker 2008; Dearden & Becker 2004, 2000). Indeed, the Scottish Government recognises that “at a time when their peers are leaving school and making plans ... older young carers often have to deal with demands, responsibilities and emotional challenges that influence their choices and limit their future opportunities” (2010, p74).

With such complex experiences of transition, it could be concluded that young adult carers will have higher support needs than others in that age group, but evidence suggests that they are not accessing it. Frank (2007) suggests that they fall between the cracks of children’s and adult services. Anecdotally, young carers workers note that the age of 17 is when the ‘grey area’ of support is entered, when children’s services are reluctant to engage with someone so soon to no longer be their responsibility and adult services being unobtainable or unsuitable for their needs. Though not specifically focused on young adults, Cavaye (2006) looks at those carers who do not receive or make use of formal support services, often termed ‘hidden’ or ‘invisible’, and why some are reluctant or unable to access support (p17). She notes that there have been few studies on non-users of services (p19). Conversely, Flanagan & Hancock (2010) suggest that it is not necessarily the non-engaged person who is ‘hard to reach’, but the services that fail to engage them (p4). This theme is explored further in the findings of this inquiry.

## Methodology Discussion

This inquiry could be said to employ a 'mixed methods' approach as it utilises clear quantitative data from questionnaires as well as giving the participants 'voice' to express their experiences and concerns using qualitative, semi-structured interviews. Denscombe suggests this approach can be regarded as a 'third research paradigm' (2010, p134). Becker is an advocate of this approach, claiming that "a complete picture could not be generated by any one method alone" (Becker et al, 2006 p3).

Quantitative data alone "fails to give holistic vision of the bigger picture and decontextualises the small parts on which it focuses" (Denscombe 2010, p132) and there was evidence of this in my analysis of the questionnaire data. Flanagan and Hancock (2010) suggest qualitative methods are "well placed to explore sensitive and relatively poorly understood aspects of social life" (p3); making them particularly suited to social research. It could also be argued that qualitative methods are in keeping with the 'person-centred' approach of my practice setting. Becker and Becker (2008) suggest that utilising both quantitative and qualitative data allows researchers to "piece together a fuller picture of the experiences and needs of young adult carers" (p9).

Initially, data was obtained from Dundee Carers Centre's database which identified current and previous users of the Centre's services in the age group. While attempts were made to contact all of these by email, post or telephone, only one previous client participated and four current users took part. In addition, a list of support agencies in Dundee which work with carers or with children or adults who may require care was compiled. This was to identify carers engaged with other services and also to reach 'non-engaged' carers through the person they care for; for example parents of disabled children who are engaged with a service for their child, or partners of people with a mental health issue, illness or addiction, who engage with support services for this reason.

A questionnaire was decided on as a 'first contact' with carers not currently engaged with the Centre as it was felt that a tick-box survey would be more likely to generate a response than a request for an interview. This was distributed widely to other organisations in Dundee. However, the response rate was lower than expected and only seven questionnaires were received from carers outside the Centre. Many of the agencies contacted reported having few or no clients in this age group. This reflects the literature (Becker and Becker, Cavaye, Flanagan and Hancock) that carers of this age group are less likely than other groups to engage with support services. While those who could identify potential participants were supportive and happy to distribute the questionnaire to them, this did not generate much response. An interesting theme which emerged was that some agencies reported having people engaged with them who met this criteria but that they had never identified them as 'carers'.

While the data generated from this small sample (n=13) proved useful, it did not give a clear picture of carers' experiences of services. Despite the low response rate, the spread of responses; from those engaged in the Centre, non-engaged and engaged with other agencies provided sufficient data for analysis. Some of the limitations discussed in my analysis are: confusion about the age tick boxes which meant this data was not useable; inconsistent responses about finances, sources of support, and training; and lack of context on the age and nature of transition. As such, it failed to adequately capture experiences of transition. To address this, interviews and/or a focus group were planned to add a qualitative element to the data.

A further issue was that, of 13 responses received, only three had consented to participate in a focus group or interview, and only two (both female) were eventually interviewed. In addition, an Upbeet key worker was interviewed on her observations of working with this age group. The interviews were semi-structured, elaborating on the themes in the questionnaire. While this gave me some qualitative data from which to quote, it is acknowledged that these are illustrative rather than representative of the cohort.

## Discussion and analysis of findings

While questionnaires were distributed widely among service providers in Dundee, only seven were received from outside Dundee Carers Centre. Six were completed by current or previous users of the Centre's services. As 13 questionnaires were received in all, n=13 for the presentation of the data below, except in the case of multiple choice question (where indicated). Of the responses received, six were anonymous, and five provided contact details in addition to their name. However, only three consented to be interviewed or take part in a focus group, as a result of which the methodology had to be revised. Two of these (both current service users under 21) were subsequently interviewed, and an Upbeet key worker also shared her observations of working with this client group, providing some qualitative data to complement the quantitative data obtained from the questionnaire, as presented and discussed in this chapter.

**Note:**

The quotes used to illustrate this chapter have been assigned codes to preserve the anonymity of their source. The young adult carers interviewed are referred to as Interviewee A (IA) and Interviewee B (IB). The Upbeet worker has been abbreviated to UW.

### ***Profile of respondents***

The gender profile of respondents was 4:9 in favour of female carers. This reflects the gendered nature of caring evidenced in the literature (Dearden & Becker 2004, Barnes 2006). Statistics from Carers UK (2009) reveal that women are more likely to become carers than men (58%:42%).

Unfortunately, the questionnaires produced no useable data on the age of respondents as a result of a design flaw. Three separate questions were asked relating to age; current 'age', 'age caring started' and 'age left school or further education'. As the data was analysed, it became increasingly apparent from the consistency of the answers that this had proved confusing for respondents. Only one filled in current age, but all had ticked one of the age groups listed on the next line, which related to 'age started caring'. Given the layout, these could easily be assumed to relate to the 'age' above them (see Appendix A). As such, the data for both questions is likely to be inaccurate.

### **Education**

Of more significance to the themes to be explored in this inquiry, the 'age left education' yielded more responses. However, five left this unanswered. Of those who responded, four were still in further or higher education and four had left school. One of these did not give an age; one had left at the age of 12; one at 16 and one at 26. Unfortunately, no conclusions can be drawn from such an incomplete sample though the literature would suggest (Becker and Becker 2008; Scottish Government 2006, 2010a; Ryan 2010) that poor educational attainment affects young adult carers disproportionately.

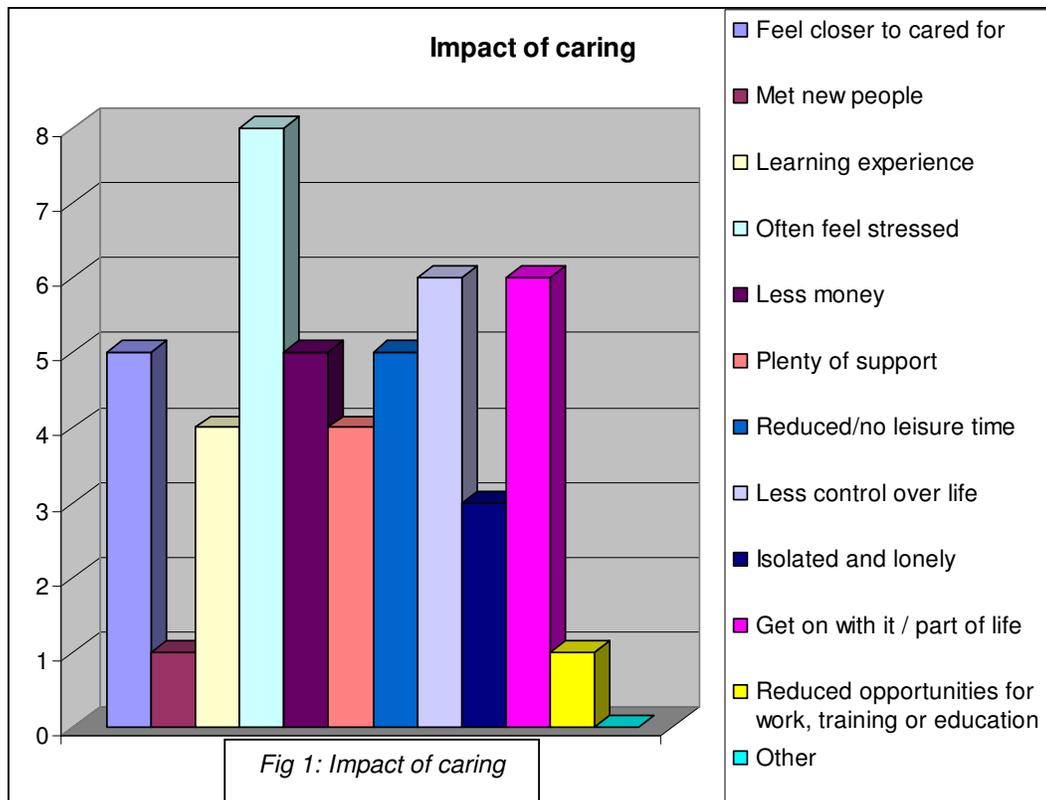
*"I started caring at 12 year old. I was never there [at school] after that" IB*

*"he [young adult carer] gave up college so he could claim housing benefit... when a family member had to go into disabled accommodation" UW*

### **Impact of caring**

Most respondents ticked a variety of answers, indicating mixed feelings towards their caring role and reflecting the nature of the caring experience which, as Barnes (2006) suggests, can have both positive and negative aspects (fig 1). A significant number (8 of 13) stated that they 'often feel stressed', which would suggest a need for stress management training though this was not reflected in a subsequent question on training. Other significant responses were that nearly half (6 of 13) felt they had less control over their lives, while the same number saw caring as a part of their lives and they 'just get on with it'. Five respondents felt that caring had brought them closer to the person they cared for while a similar number responded that they had less or no time for a social life or holidays (leisure time).

Surprisingly, only five reported that they had less money as a result of caring, which would appear to contradict the literature which links caring to poverty (Howard 2001, Becker and Becker 2008). This theme is explored further in the next question. Only one respondent reported fewer opportunities for work, training or education as a result of their caring role, contradicting the responses to a subsequent question on this theme.



### ***Financial impact of caring***

Eight respondents reported 'no difference' in their financial situation since they started caring. Only one felt they were much worse off and three were slightly worse off (one ticked 'don't know'). This would appear to contradict the literature and recent studies which suggest that caring has a negative effect on people's finances (PRTC 2010, Howard 2001). However, the consistency of the response may suggest that the young adults began caring before they were old enough to work or receive benefits and so their situation has not changed; they perhaps do not remember their family finances as being any different. Another factor to be noted may be the socio-economic circumstances of the family; Dearden and Becker (2004) found that the majority of young adult carers came from single parent families, where no adult was working and benefits were the only source of income. Unlike older adults who may have to give up work when they begin caring later in life, young adult carers who have grown up caring may never have experienced any other lifestyle.

Unfortunately, these findings cannot be linked to the age at which respondents began caring due to the design flaw in the questionnaire identified previously. Those interviewed both suggested that money was a significant issue and both their families were in receipt of benefits.

*“the disability allowance, you’ve got to wait for that to go through then we applied for carers allowance which takes umpteen whatever after that” IB*

The Upbeet worker expressed frustration with the benefits system, which can be a barrier to young adult carers accessing education and employment.

*“they tend not to want to go to college or don’t want to go and work because it’ll impact on their parents’ income” UW*

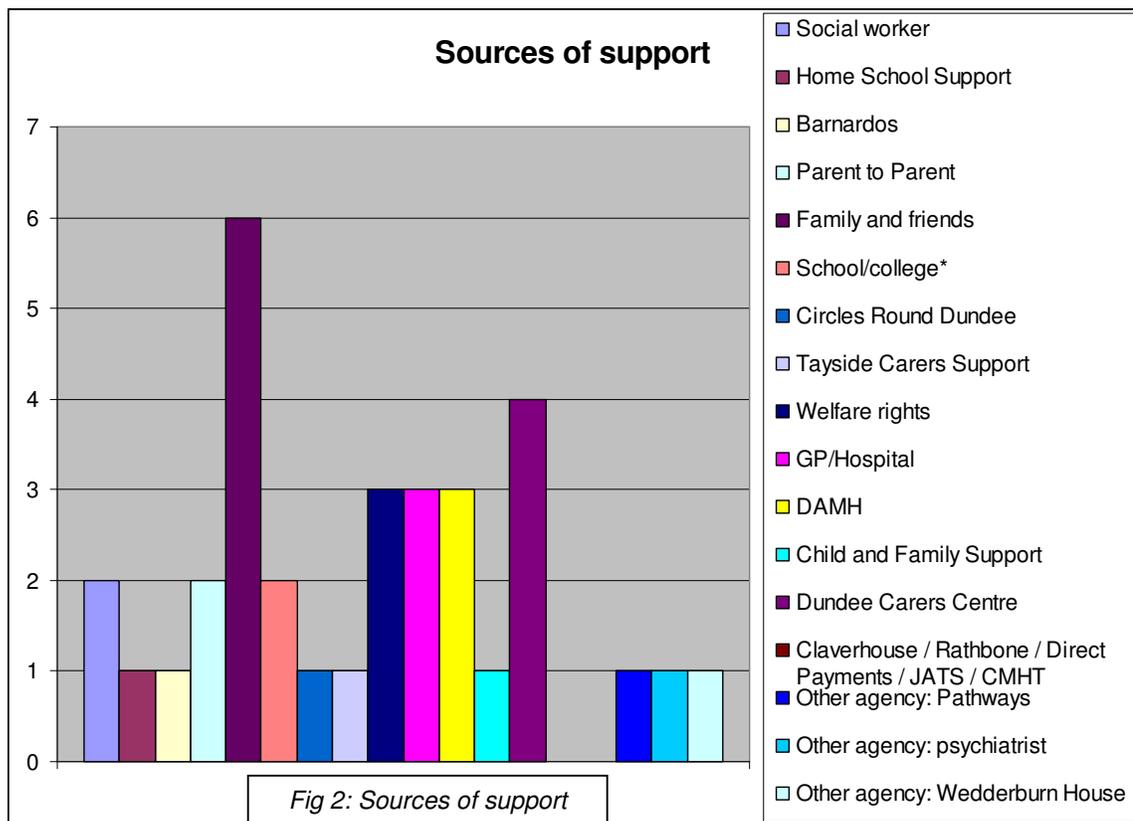
### ***Caring and employment***

When asked how caring had affected their ability to work, three stated that they had never worked due to their caring role, which would reflect the findings related to finances. However, three had given up work to care full-time and a further four had reduced work hours in order to care. The limitations of a quantitative questionnaire mean that this data cannot be explored fully; we have no way of knowing whether these jobs were full-time or part-time, permanent or casual. None reported being in work and having to take time off to care. Two suggested they would like to work but needed training (2), confidence (1) or flexible hours (1). Respite was not identified as an issue limiting their ability to work. One interviewee reported having to give up work due to her caring role but expressed a wish to work part-time.

*“I had to leave my job when I did have one all because of my caring role... I left because it all got too much. I’ve got to get a part-time one this time cos that was 40 hour a week” IB*

## Sources of support

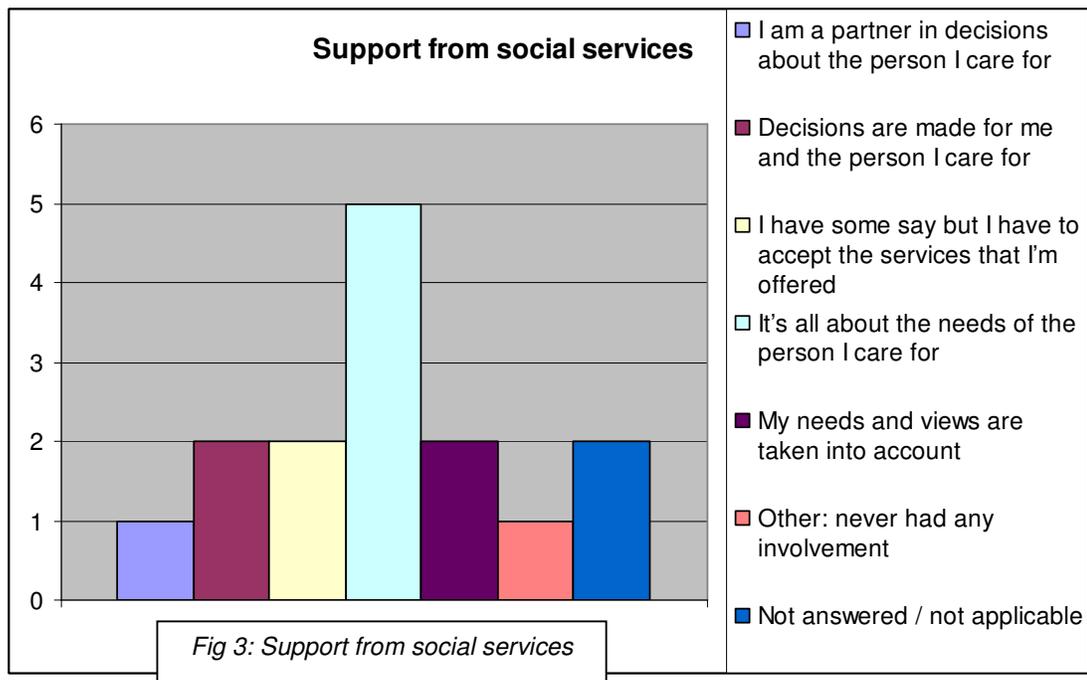
Respondents were presented with a list of statutory and voluntary support services in Dundee and asked to tick as many as they had received support from (fig 2). As might be expected from a group of carers which may be considered 'hard to reach' (Flanagan & Hancock 2010, Cavaye 2006), the primary source of support was family and friends (6 of 13). Only two received support from social services though this may reflect their perception of support for their caring role rather than involvement, as all but three responded to a subsequent question on social services. Four reported receiving support from Dundee Carers Centre, which doesn't tally with a subsequent question on the Centre, though there may be confusion among those engaged with the Young Carers or Upbeet projects who may not recognise the Centre as such. Confusingly, one respondent who claimed to have received support from the Centre answered 'never used Centre services' to a subsequent question.



\* Dundee College (1)

*"I can just speak to 'em and get it off my shoulders" IB (on support from Upbeet)*

Asked specifically about their perceptions of social services, more than a third (5 of 13) felt 'it's all about the needs of the person I care for' (fig 3). Only one felt they were a partner in the decisions about the person they care for. Two felt that their needs and views were taken into account; two that they had some say but had to accept the services offered; and two that decisions "are made for me and the person I care for". Barnes (2006) advocates an alternative 'ethic of care' which acknowledges that "care giving and receiving are part of the same process" (p177) and recognises the needs and rights of both the carer and the person they care for. Only one reported no involvement with social services though two did not respond. One respondent ticked more than one.



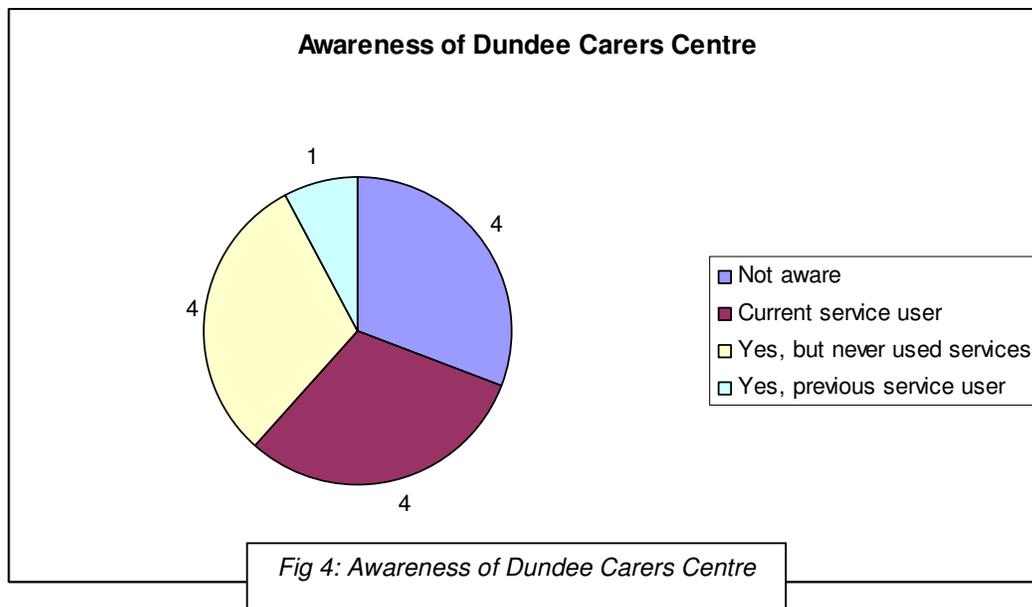
A strong distrust of social services was evident in both interviews, and this was confirmed by the Upbeet worker.

*“we don’t like social services cos it’s been too much hassle when I was younger apparently, cos I’ve been told social workers are not very nice people” IA*

*“some have got a fear they’re going to open a can of worms for the rest of the family” UW*

Asked about their awareness of the services of Dundee Carers Centre, four (of 13) responded they were not aware (fig 4). An equal number stated that they were aware of but had never used the Centre’s services (4); and that they currently used the service. Only one of respondents specified which of the services they used; the Upbeet project.

*“at school I had like one of the support workers, and they didn’t want to leave me with nothing after I left school so we looked it up on websites and somehow we just found Upbeet” IA*



### ***Experiences of transition***

As only four of the respondents were Upbeet participants, the following question was not applicable to the other nine respondents. When asked 'if you were in the Young Carers Project / Upbeet, did you use the Centre's services after age 21?', four respondents ticked 'no'. In each case this is likely to be because they have not yet reached 21. Unfortunately, given the small sample, it is not possible to capture the experiences of transition within the Centre's services from this inquiry. However, interrogation of the Centre's database reveals that very few Upbeet or YCP participants have made this transition to adult services. While some effort was made to involve those who have made the transition, and former service users who have not, none agreed to participate in this study. Interestingly, both the young adult carers interviewed expressed an interest in continuing to engage post-21, though neither was aware of other services offered by the Centre.

*"I didn't know there was anything after Upbeet" IA*

As the first interviewee revealed her work as a volunteer with the project, this was explored further with the other interviewee, who expressed enthusiasm.

*"It's like helping people that are going through the same as you. I would do that, it would be quite good to do actually" IB*

Again, because of the aforementioned design flaw we were unable to capture data on the age respondents began caring so it is difficult to know if the nine people who did not respond to the following question did so because it was not applicable to them or for other reasons. Only one clarified their reason for not responding: she had just become a carer. When asked 'If you started caring as a young carer, how is your experience different now you are an adult?' one responded that 'professionals (social services, GP, Job Centre) treat me with more respect'. One respondent missed out on benefits. Two reported that there was less support for them when they turned 18 / 21. This answer reveals a further design flaw – I had anticipated that respondents

would delete 18 or 21 as appropriate. As neither did so, it is difficult to determine whether they are referring to the transition from child to adult social services (18) or Upbeet/Carers Centre (21). This is an acknowledged limitation of the questionnaire as a method of data gathering; it provides little context (Denscombe 2010, p132) and anonymous respondents cannot be contacted in order to clarify or elaborate on the data provided.

However, the interviews provided an opportunity to explore this question further. One participant reported an abrupt transition from children's service at the age of 16.

*"they dinnae even bother whatsoever. It's like being with your mate all night and then they just go away and leave you. And then you just never hear from them, they never help you again" IB*

The Upbeet worker felt strongly that the ages of 16/17 were "a total grey area" for a lot of services in Dundee. She also expressed the opinion that, after 21, young adult carers were unlikely to engage with the Centre's adult services despite requiring ongoing support.

*"the ones that are most vulnerable will go back into their caring role and stay isolated" UW*

### **What young adult carers want**

When asked 'what do you think would make the biggest difference to your life as a carer?' most respondents ticked a variety of answers (fig 5). More than half (7 of 13) said 'more money', which could reflect the socio-economic circumstances of the family, rather than the caring role specifically. However, it is known that 'disability, illness and poverty go hand in hand' (Dearden and Becker 2004) as households with a disabled member are more likely to live in poverty (Disability Alliance 2004), but Howard (2001) also suggests that illness and disability affect poorer households disproportionately.

*"I think we [carers and disabled people] should be given more benefits and everything because the government gives everyone else money who shouldn't need it" IA*

*"I've had this dream since I were younger that I won 50 million on the lottery"  
IB*

Five respondents would like support from professionals (GP, social work, agencies), while three ticked 'support from family'. Three related answers were 'time to myself' (5 of 13), respite / breaks (4 of 13), social activities (3 of 13) and regular holidays (3 of 13), though one respondent noted that these holidays would be 'as a family'. These responses may reveal a recognised need for regular breaks from the caring role, as identified in the national carers strategies and others (Scottish Government 2010b, NHS Tayside 2007).

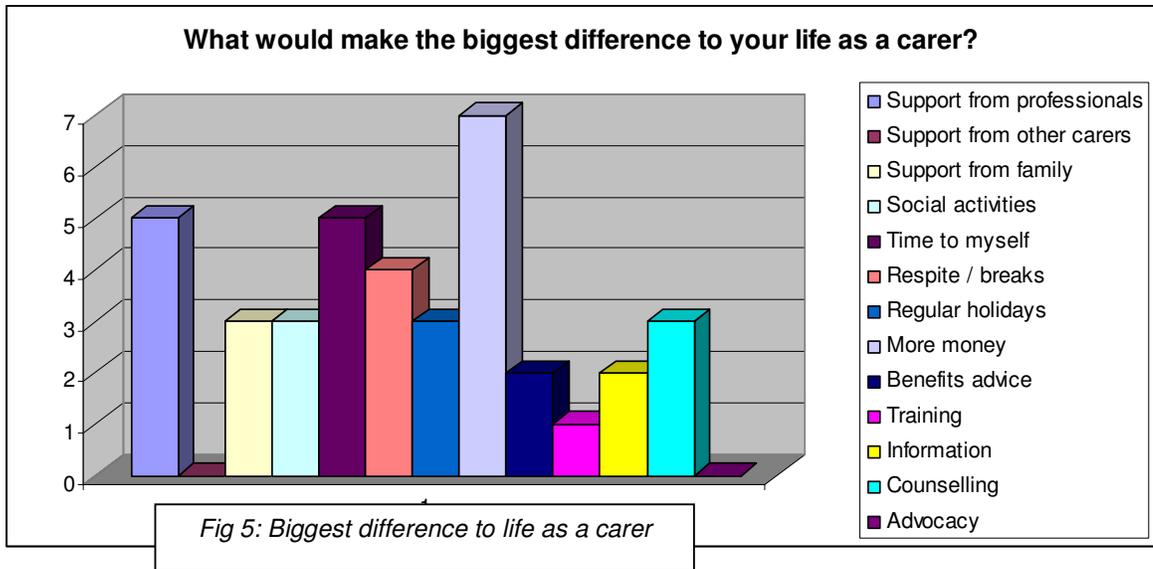
*"Just to get a break, go somewhere to get a break from caring" IA*

*"she needs someone to be with her all the time and I just cannae do it. It's too much for me." IB*

However, the need for 'time to myself' could reflect the age group as much as the caring role. It is interesting to note that no respondent identified peer support from other carers as a need, despite three identifying themselves as 'isolated and lonely' in a previous question on the impact of caring. However, both interviewees expressed a strong wish for peer support.

*"it's good getting to know like other people and know that you're not the only person that does, you get to meet other people in the same situation" IA*

*"it's people like that [friends] that sometimes you need cos it helps a lot" IB*



Though no respondent ticked ‘advocacy’, the Upbeet worker suggested that this is an important part of her role in supporting young adult carers, particularly in dealing with social services. It may be the case that participants, indeed the public in general, do not recognise the term ‘advocacy’ the way it is used by professionals.

*“they feel a lot more confident and safer when they’ve got you even sitting in the same room with them” UW*

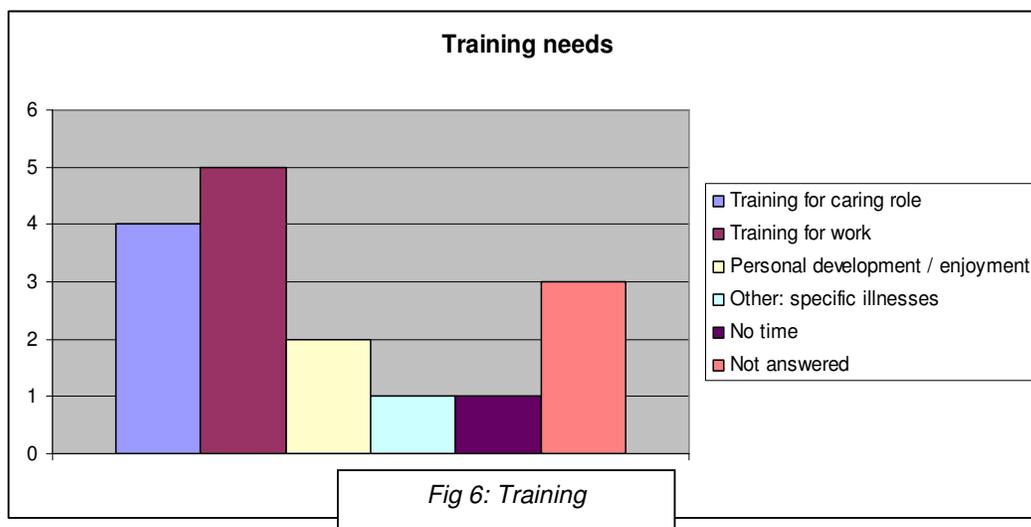
When asked what sort of services they would like the Centre to offer, in addition to practical support with their caring role and respite opportunities previously mentioned, both interviewees expressed interest in a range of activities, such as groups and outings with other young adult carers.

*“fun things to do, as long as there’s always something” IB*

Only one respondent identified training as a need, though the following question specifically on training revealed a stronger demand than this.

## Training

Training is often identified in policy documents and funding criteria as a central need for carers (Scottish Government 2010b, NHS Tayside 2007). This comes from the imperative to protect carers' own health and wellbeing and to support them to be able to continue in their caring role, by learning safe lifting techniques, first aid and stress management. Less than a third of respondents (4 of 13) stated that they would like to access this type of training (fig 6). This may be because the demands of their caring role limit their ability to participate, as noted by one respondent to this question. It may also reflect the gap between the popular image of carers as caring for someone with a physical illness or disability, and the reality of many carers lives, where the heaviest demands of caring may be emotional rather than physical, for example if they care for someone with mental health or addiction issues.



The five respondents who would like to access work-related training tally closely with the number of Upbeet participants (4) who took part in the survey. As the project's focus is young adult carers who are Neet, participants may be actively looking to improve their job skills, which would not generally be the case with the adult service. A strong focus of government policy has been on employability and getting carers into the workforce (Scottish Government 2010a, 2006).

However, young adult carers face significant barriers to employment, as explored in my previous inquiry, such as “poor school attendance, early school leaving and lack of confidence” (Ryan 2010, p11). These were reflected by the Upbeet worker’s assertion that:

*“it’s a long process to get a young person to feel even confident enough to fill in an application form” UW*

She also suggested that young adult carers who had participated in recent training provided by the Centre’s adult service had found the delivery “boring”, and were used to sessions being more informal and fun.

Only two respondents to the questionnaire would access training for their own personal development or enjoyment, while one would like training on specific illnesses, such as autism and physical disabilities. Note: while ten participants responded to this question, two of these ticked more than one type of training.

### ***Internet and social media***

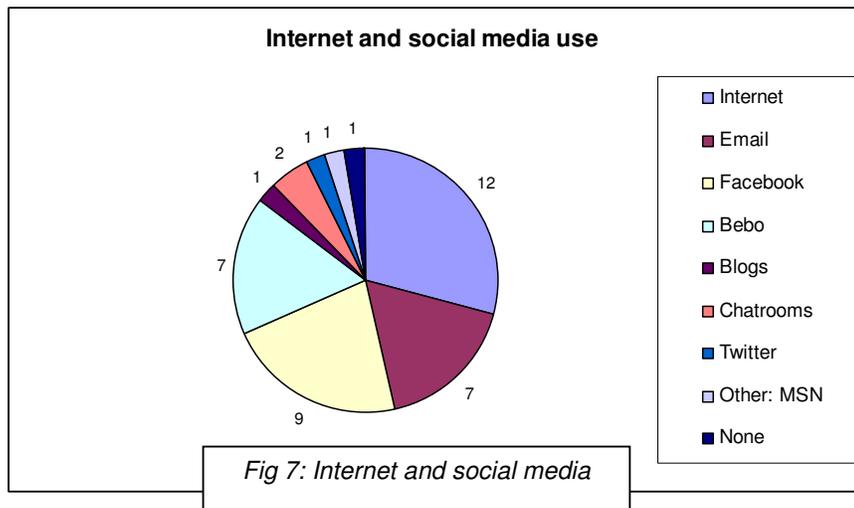
Reflecting the age group, all but one respondent had internet access (fig 7). People born after 1980 are considered to be ‘digital natives’ who are technologically fluent and likely to have high internet use (Abbot-Chapman & Robertson, 2010 p243). Concerns about a ‘digital divide’ evident in earlier literature which linked social disadvantage and limited internet access (Blackburn et al, 2004), have been significantly eroded through internet-enabled mobile phones, which could be said to have ‘democratised’ internet use. It has also had an impact on how and when young adults use the internet.

*“Facebook is where I spend most of my time” IB*

Three quarters of respondents with internet access reported using Facebook (9 of 12), while seven use Bebo and only one uses Twitter. This suggests that the Centre has chosen an appropriate social media tool to reach this age group, having launched a Facebook page in October 2010 as part of its developing social media strategy.

Indeed, Collins and Burn (2010, p285) suggest that social media in particular is an important source of peer support for young adults. This was explored further in the interviews and both young adult carers expressed interest in using Facebook as a support tool. This was also popular with the Upbeet worker.

*“social media would definitely be the way to go because my young people do not answer a phone call”*



### Summary

Overall, inconsistency in questionnaire responses reflects the limited nature of this method of data collection. Many of the responses concur with what is known from the literature on caring in general and young adult carers in particular, however there were some themes which warranted further investigation and these informed the interview schedule; notably experiences of transition, which yielded a richer insight into young adult carers' lives. Interviewees were also asked for their feedback on how best to engage them after the aged of 21. Despite being offered the opportunity, none of the questionnaire respondents provided additional comments so the two interviews with young adult carers were the only source of qualitative data. The observations of an Upbeet worker leant an additional perspective to the inquiry. However, the low response rate and small sample of young adult carers is acknowledged.

## **Conclusion and Recommendations**

This inquiry set out to investigate a gap in service provision identified in the literature and in my own practice setting, exploring the imperative to provide 'seamless' support for young adult carers, who are at risk of 'falling through the gaps' between youth and adult services (Frank 2007, Becker & Becker 2008, Scottish Government 2010). Despite a lower than anticipated response rate, the literature relating to this group of carers, quantitative data from the questionnaires, together with the small sample of interviewees and the perspective of a support worker, give some insight into young adult carers' experiences of support services and transition. Drawing on the findings of this small-scale inquiry, this concluding chapter will make recommendations on how 'seamless services' for young adult carers may be delivered.

It is evident from the literature that young adults are no longer expected to make a single transition between education and employment (Furlong 2010) and that the nature of caring means that these transitions are complicated further for young adult carers (Becker & Becker 2008; Dearden & Becker 2004, 2000). In particular, carers may enter and leave the workforce according to the changing demands of their caring role. The benefits system can make transitions into and out of education more difficult for young adult carers as their choices may impact on the family's finances, putting them at further risk of poverty and social exclusion. This suggests that they may have greater need for support and information, such as welfare rights, at these times or other periods of crisis in their caring career. Heinz (2010, p11) advocates a 'life course' approach to help young adults navigate these different life phases and this could be seen as an overarching recommendation for service providers working with young adult carers, diminishing the arbitrary boundaries between youth and adult services and facilitating 'seamless' support.

Specifically in the case of Dundee Carers Centre, this 'life course' approach could facilitate the transition between the young carers service, Upbeet and the adult service, while recognising the series of 'transitions' which

characterise the caring career. A 'life course' model as outlined above could take the form of a 'partnership' which would see the adult service 'reaching down' and/or the Upbeet service 'reaching up' (Becker & Becker 2008, p61). It could be argued that 'reaching up' may be more appropriate as the needs, transitions and experiences of this age group are so distinct from that of older adults. This may involve the expansion of Upbeet's remit beyond the age of 21 and include those not at risk of becoming Neet, or the development of a complementary programme to engage young adult carers specifically. This acknowledges the need identified in this inquiry for respite opportunities, group activities and peer support for this age group which they perceive as 'fun' and taking place at times compatible with their lifestyle.

A key principle of youth work is to 'build from where they are at' (Youthlink 2009). The findings of this inquiry would suggest that Facebook is where they are at. The extent of young adult carers' usage of and enthusiasm for social media suggests its potential beyond the Centre's current presence. The Centre should investigate the use of social media as a tool for engaging and supporting younger adult carers, through online peer support, 1:1 support, and potentially an out-of-hours service. This could also engage other so-called 'hard to reach' clients such as disabled people, BME carers and those isolated by their caring role. At a time when funding for the voluntary sector is increasingly precarious yet the demand for its services remains strong, this could represent an innovative and cost-effective method for expanding the reach of the service without a corresponding increase in resources.

Flanagan and Hancock (2010) assert that it may be the service rather than the client group which can be considered 'hard to reach'. Young adult carers are more likely to engage with a service which meets their expressed needs. These recommendations are intended to assist Dundee Carers Centre and others to develop 'seamless' support services which will meaningfully engage this group.

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# Dundee Carers Survey

Dundee Carer Centre is carrying out a survey of carers aged 20-35 in Dundee. Thanks for taking the time to fill in this form. Your feedback will help us to plan services that meet your needs.

## Am I a carer?

If you look after a family member or friend who couldn't manage without your help because they are ill, disabled, or have mental health or addiction issues, then you are a 'carer'. A carer is not paid to look after someone else.

## What's this survey about?

We support carers of all ages, from 8 to 80+, but we've noticed that very few carers aged between 20 and 35 use our services. We know there are carers in this age group – young carers who have grown up but still care for their mum or dad, parents with a disabled child, people living with a partner with addiction issues... If this is you, we would like to hear from you.

Maybe you don't know what services are out there, or you are just focused on the needs of the person you care for. Maybe the services that are there don't appeal to you, or seem to be aimed at older people. What you tell us will help us to plan services that suit you.

## If you need help filling in this form

Although the form looks long, it shouldn't take more than a few minutes as it is mainly tick boxes. If you prefer, you can do it over the phone instead of in writing. Please call Gill Ryan from Dundee Carers Centre on 01382 200 422 or ask a support worker from the agency that gave it you.

## What happens to the information I give you?

You don't have to give us your name, so everything you say is anonymous. All the information we collect is confidential and we will not use your name or anything that could identify you. We will use the information to help us plan services, and will share it with other carers organisations to help them meet your needs too. It will also form part of a student research project for Dundee University.

Later on we may do focus groups and interviews to give you a chance to share your views. If you'd like to take part in this, please add contact details at the end of the form.

**For more information, please contact Gill Ryan at Dundee Carers Centre on (01382) 200 422.**

## About you

**Are you:** Male  Female 
**Age:**

**What age did you start caring?** Under 16  16-20  21-25  26-30  30+

**Who do you care for?** Child  Parent  Partner  Other family  Friend

**Age you left school or further education:** \_\_\_\_\_

## About your caring role

**How would you describe the impact of caring on your life?** (✓ as many as you like)

I feel closer to the person I care for	<input type="checkbox"/>	I have less/no time for a social life or holidays	<input type="checkbox"/>
I have met new people	<input type="checkbox"/>	I have less control over my life	<input type="checkbox"/>
It has been a learning experience	<input type="checkbox"/>	I sometimes feel isolated and lonely	<input type="checkbox"/>
I often feel stressed	<input type="checkbox"/>	I just get on with it, it's part of my life	<input type="checkbox"/>
I have less money	<input type="checkbox"/>	Reduced opportunities for work, training or	
I get plenty of support	<input type="checkbox"/>	education	<input type="checkbox"/>
Other (please tell us)			

**How has caring affected your finances?**

Much worse off since I started caring	<input type="checkbox"/>	Slightly worse off	<input type="checkbox"/>	No difference	<input type="checkbox"/>
Slightly better off	<input type="checkbox"/>	Much better off	<input type="checkbox"/>	Explain	_____

**How has your caring role affected your ability to work?**

Never worked due to caring role	<input type="checkbox"/>	Gave up work to care full-time	<input type="checkbox"/>
Reduced work hours to care	<input type="checkbox"/>	Often have to take time off	<input type="checkbox"/>
I'd like to work but I need:		Respite <input type="checkbox"/>	Training <input type="checkbox"/>
		Confidence <input type="checkbox"/>	Flexible hours <input type="checkbox"/>

## Where you get support

**Have you received support from any of the following:** (✓ as many as you like)

Social worker	<input type="checkbox"/>	School/college	<input type="checkbox"/>	GP/Hospital	<input type="checkbox"/>	Comm. Mental Health Team	<input type="checkbox"/>
Home School Support	<input type="checkbox"/>	Direct Payments	<input type="checkbox"/>	JATS team	<input type="checkbox"/>	Child and Family Support	<input type="checkbox"/>
Barnardos	<input type="checkbox"/>	Circles Round Dundee	<input type="checkbox"/>	DAMH	<input type="checkbox"/>	Dundee Carers Centre	<input type="checkbox"/>
Parent to Parent	<input type="checkbox"/>	Tayside Carers Support	<input type="checkbox"/>	Rathbone	<input type="checkbox"/>	Claverhouse	<input type="checkbox"/>
Family and friends	<input type="checkbox"/>	Welfare rights	<input type="checkbox"/>	Other agency:	_____		

**In relation to social services, do you feel that:**

I am a partner in decisions about the person I care for	<input type="checkbox"/>
Decisions are made for me and the person I care for	<input type="checkbox"/>
I have some say but I have to accept the services that I'm offered	<input type="checkbox"/>
It's all about the needs of the person I care for	<input type="checkbox"/>
My needs and views are taken into account	<input type="checkbox"/>
Other (please tell us)	<input type="checkbox"/>

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**Are you aware of Dundee Carers Centre, Young Carers Project or Upbeet (Princess Royal Trust)?**

No	<input type="checkbox"/>	Yes, but never used their services	<input type="checkbox"/>	
Yes, I use their services	<input type="checkbox"/>	Yes, I have used services in the past	<input type="checkbox"/>	Which service?

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**If you were in the Young Carers Project / Upbeet, did you use the Centre's services after age 21?**

Yes  No  Please tell us why \_\_\_\_\_

**If you started caring as a young carer, how is your experience different now you are an adult?**

Professionals (social services, GP, Job Centre) treat me with more respect	<input type="checkbox"/>	
There was less support for me when I turned 18 / 21	<input type="checkbox"/>	
I missed out on benefits	<input type="checkbox"/>	Other (please tell us) _____

**Tell us what you want**

**What do you think would make the biggest difference to your life as a carer: (✓ as many as you like)**

Support from professionals (GP, social work, agencies)	<input type="checkbox"/>	Support from family	<input type="checkbox"/>	Respite / breaks	<input type="checkbox"/>	Information	<input type="checkbox"/>
Support from other carers	<input type="checkbox"/>	Time to myself	<input type="checkbox"/>	Training	<input type="checkbox"/>	Counselling	<input type="checkbox"/>
Social activities	<input type="checkbox"/>	Regular holidays	<input type="checkbox"/>	Advocacy	<input type="checkbox"/>	More money	<input type="checkbox"/>
	<input type="checkbox"/>	Benefits advice	<input type="checkbox"/>	Other (please tell us)	<input type="checkbox"/>		<input type="checkbox"/>

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**If you could access training, would you like to do:**

Training to help with my caring role (manual handling, first aid, stress management)	<input type="checkbox"/>
Training to help me get a job (CV preparation, IT, job skills, literacy, English)	<input type="checkbox"/>
Training for my personal development / enjoyment (hobbies, relaxation, IT, languages)	<input type="checkbox"/>
Other training (please tell us)	<input type="checkbox"/>

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<b>Do you use:</b> (√)	Internet	email	facebook	bebo	blogs	chatrooms	twitter	other
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Anything else you'd like to tell us?

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Thank you for taking the time to fill out this form. You don't need a stamp to send it back to us.

You don't have to give us your name but if you would like to know more about our research or to tell us more about your experiences as a carer, please complete this section:

Name \_\_\_\_\_ Email (if you have one) \_\_\_\_\_

Contact number \_\_\_\_\_ Best time to contact? \_\_\_\_\_

I don't mind being interviewed  I'd like to take part in a focus group

Signature \_\_\_\_\_ Date \_\_\_\_\_

**Please return to: Dundee Carers Centre, FREEPOST, SCO 5751, DD1 9XE**

**Email: [gill.ryan@dundecarerscentre.org.uk](mailto:gill.ryan@dundecarerscentre.org.uk)**

