

Meeting the Needs of Young Adult Carers Consultation Report

Background

There is a wide range of support available for adult carers in the Borough: some of this is provided directly to carers, some to the people they care for with the intention of carer support. However we needed to see if this support met the needs of younger adults or whether we needed to look at alternative ways of meeting their particular needs.

A working group was formed to take this forward.

Composition of the Group:

The group includes representatives from:

Directorate of Adult Housing and Community Services, (DACHS)

Directorate of Children's Services including Children and Families and Connexions Services,

Action for Children Dudley Young Carers Project,

Time for Me Project (Barnardo's)

Dudley Council for Voluntary Service (DCVS),

The What? Centre,

Dudley and Walsall Mental Health Trust (DWMHT)

Dudley Primary Care Trust (PCT).

Aims of the Group

- To see how well current support meets the needs of carers of this age group and the people they care for
- To identify gaps in this support
- To work with carers in this age group to see how they think this support needs to be developed and who needs to do this.
- To gather evidence to support future bids for funding for support for this group of carers.

An important element of the group's work was to look at how young people with caring

responsibilities are supported as they make the transition from being classed as 'children' to being classed as adults. For this reason we decided to include carers aged between 13 - 25 years in the consultation

Method

The Group devised a questionnaire (Appendix 1) which was promoted by all group members. Individual letters were sent to adult carers on the Dudley Carers Network and other group members promoted the questionnaire to young people with whom they were involved. Dudley Council for Voluntary Service (DCVS) hosted an online survey linked to a facebook page. 37 young people completed the questionnaire – and as if to confound assumptions about young people and the internet – 35 of them elected to complete a hard copy. Details of their responses are at Appendix 2. People were asked if they would be willing to be further involved to explore the issues in greater depth. A number of young carers said in the questionnaires that they would like to be further involved but did not give sufficient contact details for us to get back to them.

Younger carers who had responded met with Nicki Burrows, Young People's Engagement Office at DCVS. She carried out two pieces of work with children and young people involved with either Barnardo's Time for Me project (Appendix 3) Action for Children Young Carers' Project . (Appendix 4)

Report from Nicki Burrows

The first piece of work involved a group of 9 white British boys and girls age 12 – 15yrs from Time 4 Me, a project supporting children and young people affected by parental substance misuse. The young people were asked a series of questions about their caring role, about the Time 4 Me project and about their ideas for shaping a future young carers project. The children were seen in two groups: 12 – 13yrs currently attending Time for Me and 14 – 15yrs who were ex members of the project¹

The consultation was replicated with a group of 10 white British boys and girls age 10 – 17yrs from Dudley Young Carers, a project supporting children and young people who care for a relative. These children were seen in two groups 11 – 15 yrs and 16-17 yrs currently attending the Dudley Young Carers project. The groups were encouraged to write

¹ Time for Me is funded to support children and young people up to age 14, the Young Carers Centre up to age 18

their thoughts on flip chart sheets, post anonymous comments in to a wishes and worries post box and use the flip camera to interview their peers.

Summary of Conclusions

The responses from each group have been combined

- These consultations provided the opportunity to explore further the responses given to the Young and young adult carer's survey. As one would expect the young people were very different in many ways, however the commonality of being a carer and the responsibilities this brings did identify a number of similarities across the board. These are as follows:
- The young people are generally very independent and fiercely protective of the person they care for and their immediate family.
- They often deny claims that their caring roles have a significant impact on other areas of their life.
- They are generally positive about their opportunity to care for someone and believe it is beneficial to them in developing a maturity that is often far in advance of their peers.
- However many feel isolated at times and experience negative feelings when the burden of caring gets to much
- a few young people believe that the only way to distance themselves from their responsibilities is to leave home, this is fraught with conflict and often guilt becomes all encompassing.
- Many of the young people shared their misgivings and mistrust of professionals who enter the home or teachers and staff within schools.
- Young carers report stronger and more effective relationships with nominated staff at school where these relationships have been brokered by a member of the team from the carer services they access. They also reported positive peer mentoring programme outcomes, this only appears to be available in a few schools.
- Staff in the carer specific services which young carers access are held in high regard for their empathy, understanding, and non – judgemental approach with the individual and other family members. Young Carers welcome the advocate role they play and in the majority of cases trust the information they impart.
- Young Carers believe the information provided by the carer services is accurate and beneficial to them. There is confusion at times the young people say they

receive mixed messages from family members, support staff and other agencies they would all like to receive clearer more concise information that is tailored to the needs of the individual or their family.

- Young Carers would like more detailed information about career choices, Further Education, Higher Education and training opportunities. There is no clear indication or evidence to suggest that this is any way different for a non carer.
- Young Carers value time with friends in similar caring roles this provides an opportunity for mutual understanding and the sharing of sensitive conversations without fear of judgement or stigma. They equally value time spent with friends and peers from other social groups and believe the skills, confidence and coping mechanisms developed in the caring role support environment have benefited them in building relationships with those who do not understand the needs and pressures they face.
- Young people would like their current service to stay pretty much the same as it is now; there is value in routine and a knowing that their friends will be there at the same time, same place each week / fortnight.
- Some value the segregation of support by caring role others find the type of caring role irrelevant and encourage sharing of thoughts and feelings as a way of reducing stigma and misunderstanding.
- Most young carers report that they would use an online forum specifically for young and young adult carers if it were available and would welcome an invitation to be part of the development of such a site.
- All recognised any service is constrained by funding; everyone would like to see an increase in activities and further opportunities. Some are involved in budgeting by committee and welcome this opportunity, they believe it helps them to budget and understand finance in their own lives and encourages inclusively and promotes youth participation within the service.

16-25 Age Group

4 Carers in the 16-25 age group met with Gemma Davies, a postgraduate Social Work student from Birmingham University². Gemma carried out a very detailed piece of work as part of her dissertation. That has now been completed and is currently being evaluated by the University. We hope to be able to add the dissertation to our resources as soon as this

² The university responded to a request to identify a student who might be interested in assisting with this work. Gemma's work complied with both the University's and the Council's Research Ethics procedures.

is done. In the meantime she has produced a summary report:

Report from Gemma Davies

Sampling:

The research consisted of four in depth interviews with young adult carers, all were women. The characteristics of the participants are detailed below and while they were varied, they were not representative of the wider population in the study site.

Age/ Gender	Ethnicity	Relationship of cared for person	Primary Illness, or disability	Occupational Status
25 Female	Asian/ British	Parent	Mental Health	Informal Carer/ unemployed
21 Female	N/K	Parent/Partner	Physical Disability / Mental Health	Full-time informal carer.
19 Female	White British	Sibling	Learning Disability	Informal Carer/ College
17 Female	White British	Parent/Sibling	Mental Health and Physical disability	Informal Carer/ College/ Part-time working

Findings:

There were several themes which emerged with some overlapping of the themes. These were:

- Experiences of Caring
- What caring involves and the experiences of caring.
- Impact of Caring on Relationships
- With family members, their cared-for person, friends, professionals.
- Experiences of Being a Young Carer
- Experiences of school, of any support received by the young carer's project and their experiences/hopes of transition.
- The Needs of Young Adult Carers
- Aspirations and how these are affected by caring.
- How young adult carers feel they can be better supported.

All of the carers identified having good relationships with their families and the persons they cared for, although there were some small issues with siblings. Each identified the stresses of caring and the effect it can have on different relationships, such as the relationship with their cared for person, family, friends, partners. One of the reasons identified was that caring was constant and the carers interviewed did not feel that they got much of a break from caring.

“What sort of support would you want if you could have any support?” (Interviewer)

“Someone to talk to, just to be there when you need them. Someone to like help me with my sister, instead of me having to do it all of the time and me getting stressed.” (Bob Marley)

Another reason involved feeling confused about their identity due to the role reversal when caring for a parent with mental health issues.

Three out of four of the participants felt that their extended families could be more supportive towards their caring role.

Of the three carers who had experiences of being a young carer and using young carer’s services, all valued their experiences and the relationships and friends they had met through such support. Their experiences of making friends reflected that of Young Adult Carers Nationally, as discussed in the literature review, which reviewed the work of Becker and Becker (2008) and the Lewisham Young Adult Carer’s Project (2009).

All of the carers held aspirations for their future, one carer wanted to continue to care for her mother, while another carer wanted to be able to move out of the family home and two carers held aspirations about their future careers. One carer wanted to set up her own childcare business and the other carer wanted to work on a cruise ship.

All of the carers identified that they would need support to be able to achieve their goals. In some instances this was support to reduce their caring responsibilities, however in most this was practical support and advice about managing finances, organising affairs and understanding forms.

All of the participants were known to the local authority and had been identified for the research through carers’ services. However when asked about what support they received the young adult carers did not identify with any support provided by the local authority. In addition when asked about carers’ assessments none of the carers were aware that they had had one. After asking about what it was, I explained to one carer, who then said she thought she had one as she was going to get a grant for a carer’s break. However she did not initially make any links to the local authority as the assessment had been arranged through the Rethink group she attended. Two of the carers felt that information about support was hard to find.

All of the carers felt caring was stressful, this was individual and it increased at certain times, was constant or reduced in certain circumstances.

All of the carers felt that they benefited from having someone to talk to and a source of emotional support. For some of the carers they found their families to be a good source for this support but also identified that this had limitations and the best emotional support they received was from people outside of their caring roles.

All of the young adult carers interviewed identified that formal support networks were important to them. For the three young adult carers who had experience of young carer's services, they felt that a continuation of this support or a similar type of support would benefit them and help provide them with emotional support from peers and professionals.

All showed a disappointment about the support they had received needing to end.

One of the young adult carers felt strongly about this and was working within a group to try to set up a project for young adult carers, her reasons given as:

"When you're in the group you get all the support from the group and the staff and your friends then you get to 18 and you leave and it's just a smack in the teeth really. You don't really have much more support or access to the centre or to the facility or be able to see the staff or anything." "I think that just because you become 18 it doesn't mean that your problems stop or go away and if anything it makes it worse because the support stops too." (Emily)

Conclusion

This has been a really helpful exercise and one that had not previously been undertaken in Dudley. It has given insight into the needs of Young Carers from a wide age range but particularly from the young adult carers, who are mainly in a transition stage, as these were the group that there was most uncertainty around their needs. The responses will help all services provided for Young Carers and Young Adult Carers provide the services most appropriate to the needs as expressed by these young people. It should also help commissioners in their role and help with any future bids should they become available. I would like to thank everyone involved in the work for their support and efforts particularly for those young people who took time to give us their views and hope that from this everyone working with and for, Young Carers and Young Adult Carers will be better prepared to provide the most appropriate support services.

What happens next?

The original reason for undertaking this research was to help identify the needs of this group of young people as they approach transition from children's services and join a service which provides support from young adulthood to older age.

- The report will now be taken to the Multi Agency Carers Strategy Group to determine what actions are necessary as a consequence of this report.
- It will be forwarded to the team producing Dudley's Local Account³
- It will be placed on the council's website as a resource for everyone

- In addition the report will contribute towards the tendering process for the young carers service (currently underway).

- Young people who have taken part in the research will be actively involved in the tendering process.

- We have also been fortunate to secure a small amount of funding to give something to the young people in return for their help:

Public Mental Health Small Grant Fund Award

We were awarded £1500 from this fund to be able to provide a small thank you for the young people who helped with this research. The young people have elected for a day with a portable video studio where they will have the opportunity to learn how to make a video- and produce one with a subject of their choice. We will have two sessions-for the younger and older age groups. Pizza is also involved! We will use the remainder of the money to support the group to continue meeting up and are exploring ways of facilitating this.

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³ A self-assessment produced each year to help establish how well their Adult Social Care services are performing against national and local priorities