

Planning for the future: exploring the experiences of older carers of adult children with a learning disability.

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Accessible summary:

- There are a large number of adults with learning disabilities who live with and are cared for by their parents.
- There is a need for interventions to support older carers with their caring role and to plan for a time when they can no longer continue caring.
- This research looked at a local support service in England that aimed to support carers over 55 who had an adult child with a learning disability living at home.
- Twelve carers were interviewed individually.
- The study highlights the unmet needs of older family carers and shows the value of support from a carer perspective.

Abstract:

There are a significant number of adults with a learning disability who live with and are cared for by their parents. There is a pressing need for interventions to support older parent carers with their role and to plan for a time when they can no longer continue caring. This article reports on the experiences of older parent carers who have been in receipt of an intervention to support future planning, in a rural part of England, delivered to older carers of their adult children with learning disabilities. Semi-structured carer interviews (n=12) were conducted and analysed thematically. Four themes were identified (1) emotional needs of carer (2) futures planning (3) accessing other services and resources (4) links to adult care services. Carers welcomed the flexibility of the intervention and its focus on support for them, relieving their sense of isolation. The research highlights the unmet needs of older family carers and shows the value of tailored support from a carer perspective. The findings have implications for national social care provision delivered to carers of adult children with learning disabilities in rural areas.

Keywords: care management; disabled children; family support; parenting

INTRODUCTION

In line with European trends, the United Kingdom (UK) has an increasing proportion of older people with over 11.8 million being aged 65+ and a projected increase of 8.6 million over the next 50 years (ONS 2018). In England this ageing population includes around 1.4 million people with learning disabilities (ONS 2018) with increasing numbers co-residing with their parents. Over two-thirds of people with a learning disability live with a family carer (Emerson et al. 2012) 40% of whom are aged 60+ (Walker 2015).

These older parent-carers frequently provide long hours of vital care and face a range of financial, social and health difficulties, and sometimes experience a shift in roles with the person with the learning disability taking on a caring role for their parent (Walker 2015). They also face concerns about the welfare of their children once they are unable to care for them (Dillenburger and McKerr 2010). Previously people with learning disabilities often pre-deceased their parents (Taggart et al., 2012), however older parent caring is an ever increasing phenomenon. The issue is not unique to the UK. Hamedanchi et al. (2016) reported that in Iran older parents felt acute concern about their child's future after their death while in Italy the recent 'dopi-di-noi' (After Us) law enables severely disabled people to receive government assistance when parents can no longer take care of them (Eusebio et al. 2017).

For parent carers of people with learning disabilities, the question of considering future alternative living arrangements or support is likely to be stressful. Some are not ready to make plans whilst others have doubts about the quality or appropriateness of provision or are unsure how to access information and support (Bowey and McGlaughlin 2007). Many carers therefore either have no plans in place (Taggart et al. 2012) or have only established them following a crisis or dramatic change in family circumstances (Prosser 1997). However studies have demonstrated that when information and support around future planning is

provided in a careful and sensitive manner parents are keen to engage with it (Ryan et al. 2014).

In England, The Care Act (2014) sought to strengthen the rights of carers and placing a statutory responsibility on authorities to assess and meet their needs, including offering relevant information and signposting. The UK Government has made a commitment to improve the lives of those living with learning disabilities (DH 2015) by mandating the NHS to reduce health inequalities between those with and without a learning disability. The National Institute for Health and Care Excellence in England has also published guidance on the care and support of older people with learning disabilities which has a focus on future planning (NICE 2018).

Even with such guidance carers remain likely to find planning future living arrangements and support for their son or daughter stressful. A number of organisations produce documents to help older carers plan for the future (Foundation for People with Learning Disabilities 2010, Sense 2018) however few appear to be proactive in engaging carers in this process. Bowey and McGlaughlin (2007) argue that a supportive, proactive approach is required to help families work through the process. Although there are previous studies which ask carers about the range of support available to both themselves and the person they care for (Taggart et al. 2012, McKenzie et al. 2018) there appears to be a lack of published work looking at specific interventions which are focussed on carers. This paper therefore fills this gap by examining one such proactive initiative, which focusses on the carer, and reports on their experiences of being involved.

The Planning Future Support Programme

In 2015 the County Council, the Local Government organisation responsible for the commissioning of social care in a rural East Midlands county, commissioned a third sector organisation to develop and implement a programme to support carers over the age of 55

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who had an adult son or daughter with a learning disability living at home. The main aim of the programme was to ensure they had sufficient future plans in place to avoid a crisis when carers could no longer continue in that role.

As part of the programme a toolkit - 'Planning for the Future' was developed. This aimed to enable support workers employed, and trained, by the third sector organisation to assist carers in developing plans for the future.

Over 12 months 92 older carers became involved in the programme, primarily through direct contact with the organisation or following referral from a health or social care professional. Carers met with a support worker on a number of occasions. The number and length of meetings were not fixed, but varied depending on the emotional needs of the carer and discussions around their current situation with regards to future planning. A range of person centred tools were used to understand in more detail the needs of the carer and the cared for person (DH, 2010). Actions were agreed - to be taken either by the support worker or the carers - which culminated in the development of contingency and future care plans.

This paper reports on data from a series of semi-structured interviews with 12 carers to whom the intervention was specifically tailored.

METHODS

Ethical considerations

The Research Ethics Committee of the University of Lincoln and the County Council granted approval for this study.

Design

The aim of this study was to gain an in-depth understanding of the views and experiences of older carers who had taken part in the Planning for the Future support programme. A

qualitative approach utilising individual semi-structured interviews (Barker and Linsley 2016; Green and Thorogood 2018) was used to explore the views of carers following their involvement.

All carers who had taken part in the programme were invited to take part in the study and 12 agreed and were invited to be interviewed. Each interviewee was provided with a participant information sheet giving details about the study and the nature of their involvement and were reassured that their participation was voluntary and that they could withdraw from the study at any time. After reading the information leaflet, and having opportunity to ask questions, all participants provided written informed consent.

Interviews were arranged at a time, date and location convenient to the participant, in all cases this was the carer's home. In one case additional family members were present and provided further information during the interview. Two members of the research team conducted the interviews between 21 June and 13 July 2016. All interviews were digitally recorded and transcribed verbatim. At this time participants were assigned a unique ID code and any identifiable information was removed from the interview transcript.

Interviews ranged from 20 to 80 minutes and followed a topic guide designed to ensure all key points about the carers experience of the programme were explored including their views of how the service was delivered, how it had helped, whether they had made any changes and what future plans they now had in place.

The characteristics of the respondents are shown in Table 1. Carers ranged in age from 57 to 78 (mean 66) with sons or daughters aged between 22 and 52 (mean 36.5). All were

white British, which reflects the relative homogeneity of the underlying population. Nine respondents resided in 'built up' areas, as defined by the Defra (2015) although only 5 of these were classified as urban with the remainder being rural settings. In three cases, the person with a learning disability was not the parents' only caring responsibility: some had an additional disabled child or older parents or younger siblings also living with them. Most carers reported some degree of ill health including long-term conditions which may have a future impact on their caring ability.

Analysis

Interview transcripts were analysed using Braun and Clarke's (2006) six steps of thematic analysis. The verbatim transcripts were read by two authors and independently coded in NVivo (Ver.10). Discussion between authors resulted in the identification of 14 initial codes which were organised into themes. The authors later met to review the themes and identified the following dominant, recurring themes (i) emotional needs of the carer, (ii) future planning, (iii) accessing services and resources and (iv) links to adult services.

FINDINGS

Emotional needs of the carer

In all cases it was evident that the carers valued one-to-one visits from the support worker and for the majority this was the first time they had been offered any support aimed at themselves rather than their son or daughter.

We'd never done anything like this before. It was always [son's name]'s needs but this time it was our needs.....It would be nice if this project did continue because nobody ever thinks about the carer (Carer 4)

They welcomed the flexibility to choose the timing and duration of the visits. Eight of the carers had received 3 or 4 visits, however the range was between 2 and 9. Two carers reported needed extra time between visits to carry out actions and these requests had always been accommodated. For others it was difficult to plan in advance due to their caring roles and they had found it easy to cancel or change appointments if required.

I had to cancel [a support worker's visit] but because we had each other's mobile it was easy to cancel anyway. It was very flexible (Carer 9).

For most carers this was the first time they had been offered any support aimed at themselves rather than their son or daughter. Carers also talked about the isolation they felt due to their caring role and the benefits of simply having someone to share their situation with:

I know there is somebody out there now basically. And I'm not on my own in all this because sometimes I just need a break (Carer 8)

It was all done very professionally. [support worker] was very good at her job. She didn't make you feel like she was intruding. The way she asked questions, she gave you the option if you didn't want. Very friendly and caring. The fact that she has a daughter with epilepsy. She knows what it's like. (Carer 11)

Carers reported that their isolation had often worsened as they got older and as other friends got older 'they have got problems of their own' (Carer 1). Another stated that she was unable to attend carer's groups due to her rural locations and no longer being able to drive.

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Over half of the carers had kept contact details for the support worker who had visited them and knew how to contact them if required. However, they also appreciated that this was a time limited programme with task focussed support being offered around future planning.

Future planning

The ultimate aim of this programme was to help carers put in place a contingency (emergency) care plan and a future care plan which would be used if, or when, the parent could no longer continue in their caring role.

Almost all carers implied that they had given some previous thought to planning for the future, however in most cases they had not made any specific plans and the visits from the support worker were the motivation they needed to start the process:

It was a nice gentle push because it was like 'next week I expect you to have started it!. I don't think we would have got round to it otherwise. Not that quickly. (Carer 4)

It's one of those things you say you're going to get round to doing and never do so really helpful in that way. (Carer 9)

Carers had discussed who would look after their son or daughter when they were no longer able to. In cases where there was no family available to take on this role the support worker had been able to help identify appropriate future care or provide options about independent living if appropriate. Some reported that they had been given details about suitable care homes which they had visited, while one carer had made the decision that they would prefer their son to live with a foster family, an option they had not previously been aware of.

In addition to considering where their son or daughter would live, discussions about the future also covered other issues such as setting up wills and obtaining power of attorney. Where required the support worker had been able to provide details of solicitors who were experts in these areas:

I told her [the support worker] that we had been talking about it at Christmas that we must make wills because we kept putting it off. And she gave me a name. I got in touch with [solicitor's name] and I've now done that. (Carer 11)

In one case, discussions around these topics had led to the conclusion that the carer and his long term partner needed to get married to secure the future for their daughter.

Two of the carers implied that despite meeting the support worker, and often being happy with the service received, they still did not have a formalised plan with which they felt totally comfortable. In one case the carer was concerned about the feasibility of her daughter offering to take on future care of a learning disabled sibling because of the nature of the sibling relationship. Another carer stated that the health of her son was changing and in the future he may need additional care. She had made a plan, but was frustrated that she was unable to take any future additional needs into account.

He isn't as bright as he was and my concern was what was going to happen to him as he needs more care. And the young lady and I investigated all avenues and there is absolutely nothing you can do. You can't make any provisions. It depends how [son] progresses. It's a case of 'Well if he needs extra care, we'll put extra care in'. (Carer 6)

Although the majority of carers had made detailed future care plans with the support worker, some were unsure who now had access to these plans and what had happened to them. In other cases, the plans had been stored away and carers had not shared them with anyone, even those named within it.

I don't know where the information that she's got goes to. But hopefully it is in the system somewhere. (Carer 11)

A number of carers highlighted their concerns about what would happen to their son or daughter should they be involved in an accident or unable to look after them due to an emergency. In these cases an emergency response plan was developed through a service run by the local County Council. Many carers talked about the benefits of having both a

contingency emergency plan and a future care plan in place, which had given them peace of mind and made them feel less anxious about the future.

We now feel more settled. If anything happens to one or the other, we haven't got 'oh now what do we do'. It's all in place. (Carer 4)

Due to the programme focussing on carers, the project worker had only met the cared for person in half of the cases and none had been involved in any of the discussions about their future or the preparation of final plans. Whilst none of the participants raised this as an issue, it does mean that any wishes of the cared for person have not been taken into account in future plans.

Accessing other services and resources

In addition to talking about future needs the support worker also discussed current needs with the carers. A number of them talked about the benefits of this and how they had previously faced difficulties accessing services. In some cases, this was due to receiving very little information and therefore being unaware of the services and support available to them, as opposed to services just not being there:

It's alright making sure the services are there. But if people don't know about the services how can they access them? It is getting knowledge to people who are carers. (Carer 10)

In a number of cases additional support, some in the form of extra funding, had been obtained following these discussions. For example, one carer, who currently had no formal respite for her son, talked about receiving some funding:

The money is going to go through now. I've had a letter this morning so we can take him away for the weekend or I can spend a bit of time with [husband] (Carer 8)

Another had been put in touch with Age Concern who had been able to help her claim some additional benefits as she had recently been forced to retire on the grounds of ill health. Although this was not planning for the future, such support may help to keep the cared for person in their own homes for as long as possible.

Links to Adult Care Services

All carers reported that their son or daughter had an Adult Social Care Practitioner whom they saw at least once a year.

You see your social worker once a year. There's not a lot of contact (Carer 10)

One mother reported that because her son was no longer living with her full time she had no formal involvement with the Adult Social Care Practitioner, but still wanted to have a formalised future plan in place. As far the carers were aware none of the Practitioners had discussed future plans with the cared for person.

Carers this study welcomed the fact that this service was separate to Adult Care Services and delivered by support workers trained, and employed, by a third sector organisation. They felt that they were able to be more open with someone from an independent organisation and were not being judged about their responses and situation. They also saw the support worker as an advocate who was able to speak openly on their behalf and not constrained by Adult Care Service policies and procedures. In one case the carer also had the perception that the support worker had more time to spend with them than a Social Care Practitioner would have done.

You are more open. And you talk in a different way. It was a very easy conversation all the time. It wasn't all like question and answer. It was all done in a conversation which was free of pressure. (Carer 5)

Definitely because social services are so handicapped. They have set policies. Whereas with carers it's carers for carers. Which makes a big difference because they understand more what carers need so that makes a big difference. (Carer 10)

DISCUSSION

A key recommendation of 'Valuing People', a government strategy in England to support people with learning disabilities (DH 2001), was to offer support with planning for the future where someone with a learning disability lives with a carer aged 70+. Over three quarters of the carers in this study were aged below 70, yet their responses suggest that they would have welcomed support earlier. Ryan et al. (2014) supported this need for early planning, especially when it includes arrangements for short-term emergencies. Black and McKendrick (2010) reported that only a third of older carers had an emergency care plan in place, and in this current study having an emergency care plan alleviated the fear of being suddenly incapacitated and unable to ensure the safety of their son or daughter.

Several carers who took part in the programme reported that this was the first time someone had shown interest in them, rather than their son or daughter. Given the legal requirement to offer a carer's assessment, this may appear surprising, but is in line with research by Seddon and Robinson (2015). This lack of interest, and consequent absence of information, is often cited as a key barrier to future planning, with many families not being aware of possible options (Bibby 2012). The majority of carers in this study had received new information from their support worker which they valued highly, especially when it broadened their opportunities (e.g. discussion of foster care) or offered particular help (e.g. details of a specialist solicitor). Ensuring that GPs and other health professionals are equipped to signpost carers may be a way to help ease this situation.

A number of barriers to carer engagement in future planning have been identified including a lack of confidence in present and future provision and poor relationships between families

and professionals (Innes et al. 2012). The flexible delivery of this programme enabled project support workers to build up trusting relationships with carers over time. This gave them opportunity to make suggestions about future planning and assist with actioning those that they felt appropriate. Magrill (2005) reported that family carers welcomed the opportunity to talk about future plans as long as it was carried out in a careful and sensitive manner. Carers in this programme valued the independence of the project support worker, who was employed by a third sector organisation rather than social services and was therefore seen as an advocate, rather than a gate-keeper . However, this raises the issue of which organisations should be responsible for providing support to assist carers with making future plans.

Due to funding constraints this programme was time limited and although the majority of carers still had contact details for their support worker it is likely that the latter may have moved to different roles once the programme ceased. Some carers therefore raised the issue of how they would update their future care plan if changes were required. NICE (2018) recommends such plans are reviewed every year and Dillenburger and McKerr (2010) emphasised the need for on-going discussions around future plans since there may be changes in the needs of the person with a learning disability or in the health, family circumstances or work pattern of the nominated replacement carer (often a sibling).

The carers in this study felt that they were becoming more isolated as they aged because of their own poor health or their rural location. Home visits from support workers were therefore vital in helping those in areas where lack of public transport impacts access to services.

NICE (2018) recommends that planning for the future should be led by the person with learning disabilities with input from family members and carers as appropriate. In this study, carers welcomed the focus of the programme on themselves, but this meant that their son

or daughter was not included in the futures planning process. Circles of Support, an initiative which helps those with learning difficulties realise their future dreams and aspirations, was offered through their carers, but only one person took this up. Although it may have been difficult for many to participate in some of the legal and financial discussions there undoubtedly a need for an inclusive forum for the discussion of distressing topics. Although Stancliffe et al. (2016) demonstrated that adults with a learning disability have a significantly poorer understanding of the concept of death than the general population, Bowey and McGlaughlin (2005) showed that 73% were aware that their carer would not always be available and some had experienced the death of one parent already. Inevitably parents do die and providing access to skilled support will help those with learning disabilities understand something about their future plans and needs.

Limitations

Although our sample size was relatively small, this is in-line with other research of this nature (Baker and Edwards 2012) and the issues identified by the participants were generally shared. It is difficult to make inferences about reasons why others decided to take part. Potential participants may not have felt comfortable taking part in research or may not have felt the programme was particularly useful to them. There are also those who did not engage with the programme at all where the discussion of future planning may just have been too emotive.

In research of this nature, it is often hard to both identify and include those most marginalised and at-risk population groups. Given the homogeneity of the sample, it is not possible to draw out any inferences about differences by ethnicity, culture or social class. The needs and wishes of people who could not communicate verbally also remain notably lacking.

Conclusions

Given the changing population structure and the ever growing numbers of older people with learning disabilities, many of whom live with and are cared for by their parents, it is vital that carer needs around future planning are better understood. There is a lack of research specifically examining the experiences carers in receipt of interventions around future planning. This study examines one such initiative, reporting on the experiences of carers and as such offers a timely insight with relevance to future policy and practice.

The findings clearly identify unmet needs of older family carers of those with learning disabilities and the support received was widely welcomed by those who took part in this study. The carers appreciated its flexibility and focus on support for themselves, which often relieved their sense of isolation. For carers it was also important that the worker was independent from statutory social services. In most cases the programme provided an impetus for decisions and actions such as making contingency plans for emergencies, writing a will or putting in place an enduring power of attorney.

However, further work would be required to look at how robust any plans for the future will be, given the lack of involvement of this person (and sometimes, the nominated future carer).

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Word Count (including references): 5000

Table 1. Participant Characteristics

| | | Number of participants |
|------------------------|---------|------------------------|
| Gender of carer* | Male | 2 |
| | Female | 11 |
| Age of carer* | 55 – 64 | 4 |
| | 65 – 69 | 6 |
| | 70+ | 3 |
| Age of cared for child | 20 – 29 | 4 |
| | 30 – 39 | 3 |
| | 40 - 49 | 3 |
| | 50+ | 2 |
| Rural or urban | Rural | 7 |
| | Urban | 5 |

*one interview included 2 carers