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Choice and caring: The experiences of parents supporting young people with Autistic Spectrum Conditions as they move into adulthood

Short title: Choice and Caring

Gemma Spiers

Social Policy Research Unit, University of York, UK

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Brief author biography

Gemma Spiers is a research fellow at the Social Policy Research Unit. Her main areas of research include health and social care for children with illness and disability and their families.

Choice and caring: The experiences of parents supporting young people with Autistic Spectrum Conditions as they move into adulthood

Abstract

This paper reports findings about parents' experiences of caring for young people with Autistic Spectrum Conditions (ASCs) moving into adulthood. In-depth interviews were conducted with 38 parents of young people (15-21 years) with ASCs. Data were analysed thematically. In the perceived absence of service support, parents' acted as 'care-coordinators' and 'life-supporters' for their child as they moved into adulthood. These roles came with little choice, emotional demands and personal restrictions. Being supported was important for parents, but preferences differed regarding what this should look like. Implications for policy are discussed.

Keywords

Autistic Spectrum Conditions, young adults, transition, transition services, carers, support, choice

Background

Improving transition to, and outcomes in, adulthood for disabled people is a key priority for the English government (Department of Health 2006, 2008; Department of Health and Department for Children Schools and Families 2007; Department of Health and Department for Education and Skills 2004; Department for Education 2013). Past research has shown that transition planning to adulthood and adult services for young disabled people is problematic, with few opportunities and high levels of unmet need once in adulthood (Morris 2002; Heslop 2002; Ward, Mallett, Heslop, and Simons 2003; Martin 2011; Bhaumik, Watson, Barrett, Raju, Burton, and Forte 2011; Sloper 2011).

For young people with Autistic Spectrum Conditions (ASCs), the difficulties of facing 'change' means transition to adulthood can be particularly challenging (Giarelli and Fisher 2013; Roncaglia 2013), and evidence suggests that transition support can be problematic (Beresford, Moran, Sloper, Cusworth, Mitchell, Spiers, Weston, and Beecham 2013; Reid 2007; Allard 2009; Griffith, Totsika, Nash, and Hastings 2012). Many, especially those with High Functioning Autism (HFA) and Aspergers Syndrome (AS), receive little statutory support at all during transition to, and in, adulthood (Barnard 2001; Beresford and others, 2013). A range of outcomes, including quality of life, relationships, independence, education and employment, also tend to be poor for adults with ASCs (Orsmond, Shattuck, Cooper, Sterzing, and Anderson 2013; Howlin, Goode, Hutton, and Rutter 2004; Barneveld, Swaab, Fagel, van Engeland, and

de Sonnevile 2014; Taylor and Seltzer 2011; Tobin, Drager, and Richardson 2014; Kamio, Inada, and Koyama 2013).

Evidence suggests that parents play a key role in supporting their child with an ASC in adulthood. The caring demands for parents of children with ASCs is well documented (e.g. National Autistic Society 2009; Myers, Mackintosh, and Goin-Kochel 2009) as is the emotional impact of care (e.g. Estes, Munson, Dawson, Koehler, Zhou, and Abbott 2009; Lee, Lopata, Volker, Thomeer, Nida, Toomey, Chow, and Smerbeck 2009). More recent evidence indicates such caring demands continue as they support their young adult child. For example, young people with ASCs can struggle to achieve independence when they move into adulthood, and many continue to live with, and depend on, their parents (Barnard 2001; Portway and Johnson 2005; Müller and Cannon 2014), resulting in restrictions to parents lives (Hare, Pratt, Burton, Bromley, and Emerson 2004). There is also evidence of high levels of caregiver burden for parents of adults with ASCs, which is associated with unmet need for the young adult child in areas such as mental health and social relationships (Cadman, Eklund, Howley, Hayward, Clarke, Findon, Xenitidis, Murphy, Asherson, and Glaser 2012).

A research study was commissioned to examine transition planning and support in England for young people with ASCs as they moved into adulthood (Beresford and others, 2013). The aim of the study was to investigate transition to adulthood and transition from children's to adult services for young people

with ASCs, from the perspectives of service staff, young people and their parents. For parents and young people, rich, qualitative data about their experiences of transition was gathered to help inform future service development. A strong theme emerging from the parents' data related to their experiences of caring and supporting their child as they moved into adulthood, and the demands associated with this.

Others have begun exploring issues around the role of parents in supporting a child with an ASC moving into adulthood (e.g. Hare and others, 2004; Portway and others, 2005; Giarelli and others, 2013; Müller and others, 2014), and the aim of this paper is to contribute to the evidence base on this issue, by presenting findings from the above study (Beresford and others, 2013). The paper focuses specifically on the theme of parents' experiences of caring and supporting their child as they move into adulthood.

Methods

Design

As noted above, the data reported here is from a wider study, the design of which was case studies, with five geographical areas in England as the case sites. Sites were selected as they were reported as having developed specific policies, pathways and services for young people and young adults with ASCs (for further information, see Beresford and others, 2013). In each site, we conducted a survey of families, and collected qualitative data from

commissioners, managers and practitioners (statutory and third sector), and parents and young people (aged 15-21) known to local services. The findings reported here are from data collected through the qualitative component with parents. The full findings are reported elsewhere (see Beresford and others, 2013).

Materials and data collection

Understanding parents' experiences of transition planning, and post-16 outcomes for their child, was the focus of this component of the study. Thus, in-depth semi-structured interviews were used as the data collection instruments. Topic guides informed by, and developed in consultation with, local parent representatives facilitated the interviews. Table 1 summarises the main topic guide themes.

Table 1 Topic guide themes

<i>Topic guide themes</i>
<ul style="list-style-type: none">• Parents' experiences and views of planning for their child leaving school, moving into adulthood, and moving between child and adult health and social care• Service support received during their child's transition (including statutory and voluntary)• Difficulties their child experienced as they moved into adulthood• The impact of impending or recent changes on the young person and the

parent(s)

- The young person's hopes and aspirations and the extent to which these had been achieved
- Outstanding needs of the young person and their parent(s)
- Parents' overall views about what works well or does not work well regarding support for transition and suggestions for improvements.

Interviews were conducted face-to-face or via telephone. Permission was sought to record the interview; this was given in all cases.

Sample

In each case site, parents of young people with an ASC diagnosis, and known to local services, were sent a questionnaire about services used for their child. 'Pre-transition' questionnaires were sent to those whose child was on the cusp of leaving school, and 'post-transition' questionnaires were sent to those whose child had left school. The questionnaires were sent to parents by statutory services on behalf of the research team. The research team was unable to send questionnaires to parents directly as this would breach data-protection for the statutory services. The statutory services were Connexions, and/or health and social care services. A total of 818 pre-transition and 111 post-transition questionnaires were distributed. A final question on both questionnaires asked parents if they would be interested in being contact about taking part in an interview for the qualitative component of the study. Questionnaires were returned directly to the researchers. We achieved a response rate of 12.8% for

pre-transition questionnaires (n=105), and 25.2% for post-transition questionnaires (n=28). This amounted to 133 returned questionnaires in total (see *Beresford and others, 2013* for further details).

Of the 133 who returned pre- and post-transition questionnaires, 90 parents (67%) expressed an interest in being contacted for the qualitative study.

Of the 90 parents who expressed interest in being contacted, we purposively sampled parents to represent the different features and characteristics we expected to influence experiences of transition planning. These were: a range of ASC diagnoses for the young person (ASC, “classic” Autism, HFA, AS); young people *with* and *without* a SEN, a range of ages spanning the move into adulthood (15 - 21 years); and type of schooling (special and mainstream). A total of 67 out of 90 parents met this sampling framework criteria and thus acted as our sampling pool. The target sample size was approximately 40 parents for the qualitative study. We expected this sample size to be sufficient to encapsulate the range of features outlined above, thus achieving a sample of informants with the features relevant to the study (Ritchie & Lewis, 2003).

Letters were sent to all 67 parents, reminding them of the study aims and explaining that the research team may contact them to invite them to take part in an interview for the qualitative study. Information explaining what taking part in an interview would involve was also provided.

Researchers sought contact with 52 out of the 67 eligible parents. Successful contact was made with 44 by telephone to enquire about their possible

participation. Due to time limits of the project, we were unable to contact any further families for recruitment. A total of 36 families agreed to participate and were thus recruited. This equated to 38 parents (for two families, parents/carers chose to be interviewed jointly). One of the parents in the sample was interviewed about two autistic children entering adulthood, thus 38 parents (36 families) discussed 37 young people. Those recruited were parents, except in one case where an extended family member was also a carer for the young person. The sample is referred to as 'parents' for convenience.

Table 2 gives details of the parent sample.

At the time of interview, the young people of parents interviewed were aged 15-21 years. They were: in school (n=9), in college (n=15), in higher education (n=2), in full or part time employment (n=5), in college and part time employment (n=1), using day services (n=1), or currently had no daytime occupation (n=5). Only two young people were not living with their parents; in both cases, living was supported (a care package and a residential placement). Table 3 gives the characteristics of the young people of parents interviewed.

Table 2 Parent Sample

Characteristic	Number of parents interviewed	Total
Parent type		38
Mother	32	
Father	2	
Extended family member	1	
Foster parents	1	
Adoptive parents	2	
Marital status*		
Married or living with a partner	30	
Separated/divorced or single	6	
Main source of family income**		35
Paid employment	27	
Social security benefits	8	

*No data for two participants

** No data for three participants

Table 3 Characteristics of young people whose parents were interviewed

		No. of young people whose parents were interviewed
Age of young person	15	1
	16	8
	17	3
	18	10
	19	5
	20	9
	21	1
Sex of young person	Male	29
	Female	8
Parent-defined diagnosis	ASC	2
	Autism	8
	AS	23
	HFA	4
SEN	SEN	30
	No SEN	7
School	Special school	12
	Mainstream school	19
	Experience of both	6
	special and mainstream	
Total		37

Ethical considerations

Ethical approval for the study was granted through an NHS Research Ethics Committee. Participants were given information about the research and their rights as participants. Written consent was obtained for all participants. Where interviews took place via telephone, a verbal consent was audio-recorded, and written consent obtained via post after the interview. After interview, support leaflets were given to all participants, which contained information about relevant sources of support both nationally and locally.

Analysis

The Framework approach was used to manage the data (Ritchie and Lewis 2003). This approach involves developing a thematic framework based on emerging issues and/or a-priori issues (Ritchie and Spencer 1994). The thematic framework is represented as a participant-by-theme matrix, and data from each participant are extracted into the matrix, or 'framework'. The thematic framework was developed using the overarching issues addressed on the interview topic guide, where the structure reflected the participants' story of what happened during transition. Using one transcript, two researchers piloted the framework separately, and minor amendments made. Transcript data were then coded according to the framework themes, and extracted into the framework.

For the findings reported here, extracted data were interrogated to further explore a strongly emerging theme about how parents experienced caring for their child as they moved into adulthood, and the demands associated with this.

This involved drawing out sub-themes on the experience of caring from the framework. Sub-themes identified were: *parents' roles as carers, the emotional experience of caring, how caring restricts and compromises parents' personal circumstances, and the experience of being supported*. These themes were used as the basis of a thematic analysis to explore parents' experiences of caring. As this was an emerging theme from the parent interview data-set, the analysis was largely exploratory and not led by a-priori issues. However, such themes were intrinsically linked to the interview topics, which concerned understanding parents' experiences and views of service support for transition planning (see table 1). The emerging theme (and sub-themes) of how parents experienced caring for their child was linked to such evaluative views of the service support for transition planning probed in the interview. However, the emerging theme went beyond the interview topics as it concerned the personal implications for the parent when they played a role in supporting their child's transition.

Findings

This section begins by reporting findings about the caring roles parents assumed as they supported their child into adulthood. It then goes on to describe the emotional challenges, and the restrictions and compromises in

parents' own life circumstances that accompanied these roles. Finally, parents' views about being supported as carers are reported.

Parents' caring roles

Most parents described playing a key role in caring for their child as they moved into adulthood. Two types of caring roles were evident. First, parents held a 'coordinator' role. This meant becoming responsible for planning and securing service provision in adult health and social care, and securing opportunities in employment and education. 'Coordinator' role activities described by parents included: instigating and arranging meetings with schools, colleges, employment services, and third sector service providers; researching and arranging post-school options (e.g. colleges, jobs, voluntary work); researching available support (statutory and voluntary sector); applying for financial support for the young person; "chasing" service staff for help and information; and attending college interviews with the young person.

Most (though not all) parents we interviewed assumed this 'coordinator' role to some extent, some more prominently than others. This role tended to be assumed in the absence of statutory service support, or in the presence of support that they felt was not meeting their or their child's needs:

'So we get half a bit of advice and it's never really followed up. They leave a lot of things to me and I don't get very far usually when I'm chasing people up trying to get help for things...'

(Parent of young adult with Aspergers' Syndrome, interview 11)

Second, parents could assume a 'life supporter' role. This meant retaining responsibility for supporting their child when the young person continued to be dependent on them in adulthood. This role included continuing to be responsible for the young person's domestic tasks, prompting personal hygiene and dressing, keeping the young person occupied in the absence of other daytime occupation, investigating and arranging social/leisure opportunities, helping the young person to organise themselves, teaching the young person about money management, and assisting the young person with decisions:

'I'm the one that takes him out, takes him for walks, keeps him interested in, helps him look for jobs, goes shopping with him, buy him his clothes, you know, do all these things for him.'

(Parent of young adult with AS, interview 3)

The young people of parents who appeared to be assuming this 'life supporter' role tended to be those entering early adulthood (18-21 years).

Where parents held these caring roles, their accounts suggest that such roles came with little choice, and could be burdensome.

There was much diversity among parents' accounts of assuming these caring roles as they supported their child into adulthood. However, there was a

tendency for these roles to be described in terms of struggle and difficulty. Such struggles and difficulties appeared to be because of, or exacerbated by, little service support, or support felt to be inadequate.

Where parents' caring role was particularly demanding, accounts indicated this role was accompanied by emotional challenges, and restrictions and compromises in parents' own life circumstances. The next section describes these themes in more detail.

The emotional experience of assuming these roles

The emotional experience of care was a strong, recurrent theme in the data, pointing to a significant burden placed on parents in the perceived absence of service support that met their needs. Where their child's move into adulthood was being, or had been, poorly supported by services, their accounts were often laden with terms that described compromised emotional wellbeing: 'emotionally draining', 'isolating and frustrating', 'tearful' and 'angry', being in 'despair', and 'crying all the time'.

Anxiety and uncertainty about their child's near and distant future were also common. This was even the case among parents who felt their child was adequately supported at the time of interview. Parents worried about what support would be available for the young person in future, where they would live, whether they would live independently, and what place there would be in society for them.

This uncertainty meant some parents did not feel able to 'look ahead'. The death or future absence of the parent also brought anxiety about who would care for the vulnerable adult child, and what would happen to them in this event:

'...my major concern for [young person] obviously is when I'm not around to make headway in all these areas... who's going to do it for

[young person]?'

(Parent of young adult with AS, interview 33)

'...that is every, every person's fears that has got a child that is disabled, either physically or mentally, it's their biggest worry, you know, what happens to them when I'm not here.'

(Parent of young adult with AS, interview 4)

The demands of these caring roles were perceived by parents to affect mental and physical health. For example, parents described experiencing depression, or exacerbation of existing health conditions. Some parents explicitly referred to being unable to cope, whereas others indicated a sense of resilience that they had built up in the face of constant stressors they experienced as carers:

'It does cause stress, but I mean I deal with it because that's what we're used to.'

(Parent of young adult with AS, interview 36)

‘...because you’re always dealing with stress and you’re always having to manage, I’ve got to the stage now where all of the difficulties which other people might find stressful and distressing are normal every day, to me, stuff.’

(Parent of young adult with AS, interview 24)

Where the experience of care (as either a ‘care-coordinator’ or a ‘life supporter’) appeared less of a struggle, and less emotionally challenging, two factors may help to explain this. First, the accounts of some parents whose child was still in special or mainstream school indicated they had experienced little difficulty so far.

Second, those who described their child’s move into adulthood as relatively unproblematic also tended to describe themselves and their child being well supported by services. Such support included having a written transition plan, being able to ask questions and access information, being supported by services to make decisions and having services to facilitate the young person’s move from school to college. Such service support (either statutory or voluntary sector) meant parents had little need to take on increased responsibility for the ‘coordinator’ care role. In turn, they did not appear to experience the intense emotional demands associated with this role. Where services were able to

support a young person's independence and daytime participation, this was also associated with a more positive emotional experience of care giving.

The emotional experience of parents caring for their child as they moved into adulthood did not appear to differ according to the child's diagnosis. Difficult, emotionally demanding experiences of care during transition were experienced by parents of children with autism, Aspergers, HFA and ASC alike. Similarly, undemanding transition experiences were experienced by parents of children with autism, Aspergers and HFA.

Restrictions and compromises to personal circumstance

For some, parents' caring role appeared to be engulfing. They described their lives as being spent on caring and 'not much else', and a 'full time job'. These accounts suggest that intensive caring responsibilities override other dimensions of the parent's life. This quote from a parent of more than one child with a diagnosis of Aspergers (one a young adult) illustrates this point well:

'Whether it's during the day or whether on my work or whether I'm, wherever I am, my whole life revolves around which, whichever one needs me.'

(Parent of young adult with AS, interview 19)

With the responsibilities of caring and supporting their child into adulthood, certain compromises in life circumstances were evident in some parents'

accounts. Among those who worked, some reported reducing or changing working hours, or leaving employment altogether to assist and support their adult child. Some anticipated leaving work or changing employment hours in the future for similar reasons (e.g. occupying the young person, assisting with travel to and from college).

A sense of personal restriction was linked with the child's increasing age:

'Q: ... All the changes that have happened ... how have they affected you?

A: Well your (sighs) your life's not really the same is it? You know, ... as she gets older I think it does get more restrictive for me.'

(Parent of young adult with ASC, interview 29)

These restrictions and compromises in parents' life circumstances demonstrate the lack of choice resulting from their caring role, a role that appeared to be assumed in the absence of support for their child's independence in adulthood.

Being supported

As reported above, many parents in our sample were playing a key role in supporting their child's move into adulthood. For some, there was a need for support, but the meaning of 'being supported' differed across the sample. Three types of support were described.

First, being supported could be something that was directed at the parent, and was about the *parent* (e.g. having someone to check how the parent was doing):

‘...it would kind of be nice to have like the NHS or Social Care or whoever basically just kind of checking up every now and again, not in an intrusive way, but just... how it’s going, how, how do you feel things could be?’

(Parent of young adult with AS, interview 34)

Second, it could be support directed at the parent, but about the *young person*, for example, developing skills to support their child:

‘I felt I needed more of a one-to-one rather than talk about the Aspergers in general...I needed someone to talk to me to say this is how to help [young person].’

(Parent of young adult with AS, interview 22)

Third, being supported meant having their child better aided by services to release demands on parents in the ‘life-supporter’ role:

‘...he needs somebody other than me to sort of take him in hand, say “Right, [young person], we’re going to try and find you this place where we’ll come in once or twice a week, make sure you’re all right,

I'm sure your dad would still be there for you if you need him", and get him out.'

(Parent of young adult with AS, interview 32)

This was particularly evident where the young person had no means of accessing meaningful daytime occupation. In these instances, parents became responsible for occupying the young person, trying to facilitate meaningful activity for them.

Though parents desired help in these ways, their accounts indicated that, typically, these kinds of support were not available to them. Again, this demonstrates how parents' caring roles could be assumed with little choice.

Discussion

The evidence from this study demonstrates how parents can have two types of caring role when supporting their child with ASC into adulthood: coordinating services and supporting the continued dependence of their adult child. The evidence suggests these roles are linked to the amount of service support received by the parent and child during transition. That is, these roles appear to be more prominent aspects of parents' lives when there is little service support, and vice versa. The data also suggests a lack of choice for parents in assuming these roles. Choice, and its relationship with service provision for the young

adult child, appears to be a key theme that intersects the findings presented here.

First, there was a lack of choice in the care-coordination role. In '*A transition guide for all services*', parents are recognised to often be 'at the heart of brokering support services' for their child and that 'their views and full participation therefore are essential during transition' (Department of Health and others, 2007, p50). The language of participation implies some degree of choice for parents, and indicates that transition planning is a joint activity between services and families. However, the evidence from this study shows this was not the case for many parents in the sample, who took on this care coordination role because of a lack of service input for their child's move into adulthood. In turn, they experienced the emotional demands that came with this role. Other studies have also shown that transition planning can be poor, with a lack of information, support and options (Morris 2002; Heslop 2002; Bhaumik and others, 2011; Martin 2011), and with parents having to coordinate planning themselves (Ward and others, 2003).

Second, there was a lack of choice for parents in the second of their caring roles: the 'life supporter' role they undertook when a young adult child continued to depend on them. Although parents do provide support to their children into adulthood, such supports are typically financial, material and emotional (Fingerman, Miller, Birditt, and Zarit 2009; Fingerman, Cheng, Wesselmann, Zarit, Furstenberg, and Birditt 2012). In addition, parents of young adults with

ASC in this study were providing supports in domestic tasks, personal hygiene, money management, personal decision making and daytime occupation.

This reflects what Portway and Johnson (2005) refer to as a 'deeper level of care' (p.79), provided by parents to adult children with AS in response to their prolonged dependence. In Portway and Johnson's study, this 'deeper level of care' included similar tasks to those reported here: providing companionship to their child, managing their child's life, and facilitating daily activities. Similarly, in Muller and Cannon's recent study, parents also described playing key roles in their young adult child's life – for example, finding employment and coordinating social activities.

Regarding parents' facilitation of daytime occupation, this seems to be linked to a lack of supported daytime participation opportunities, a concern reported by parents in Muller and Cannon's study . Other studies show that adults with ASCs often have poor outcomes with regards to independence, friendships and employment (Howlin and others, 2004), have few daytime activities (Taylor and others, 2011; Howlin and others, 2004), and have unmet support needs (Rosenblatt 2008; Bhaumik and others, 2011). Such lack of activity and support in adulthood can place increasing care demands on parents. Thus, the absence of life choices for adults with ASCs brings an absence of choice for parents when their caring roles extend in response.

As shown here, these increased care demands come with increased restrictions and compromises to other aspects of the parents' life. Similar findings have been shown elsewhere; parents caring for adults with ASCs experience restrictions to their relationships, employment, social life and housing options (Hare and others, 2004).

Finally, choice, and how it links to the receipt of service provision, emerges in the findings about 'being supported'. 'Being supported' held different meanings for different parents. For some, support was about sustaining their caring role (support directed at the parent). For others, it was about reducing the caring role (support directed at their child to release demands on them as carers). The latter indicates how the provision of services for the young adult can facilitate choice of caring for the parent by helping to limit the boundaries of their caring role.

Policy implications

Recent policy argues for increased opportunities for adults with ASCs, and for their supported move into adulthood. However, the findings presented here suggest this is not always fully realised in practice. As shown in this study, parents are responding by filling this support 'gap' as carers, but with little choice. Emotional difficulties, increasing responsibility and changes in personal life circumstances are implicated in such carer roles. This presents a question about the longer-term consequences for wellbeing for parent carers.

Limitations

There are limitations to the study and the analysis presented here. First, the low response rate to the family survey, which generated the sampling pool for the qualitative element of this project, resulted in a relatively small convenience sample from which to select potential participants for the parent interviews. However, we were still able to purposively sample from this to achieve our sampling strategy. Second, use of statutory services to recruit parents for the survey, which led to the sampling pool for the qualitative study, meant that those who were newly diagnosed and not in contact with services would be excluded from the study. Thus, the findings reported here are limited only to those in contact with services. Third, the analysis presented here draws upon data from a study that was not specifically about the experience of caring, but on parents' wider experiences of transition for their child. However, the experience of caring emerged as a strong theme. As a result, the data available allows only exploratory analysis. Despite this, the preliminary analysis here contributes to the existing small evidence base on these issues. A dedicated, focused investigation of the issues presented here, and the outstanding question above regarding parents' long-term wellbeing, is warranted.

Conclusions

In this study, many parents were responsible for coordinating post-school destinations and support arrangements, and providing 'life support', for their young adult child. Caring for and supporting the child into adulthood could be emotional and challenging, and some parents desired support *with* their caring

role, or support for their young adult child to *reduce* their caring role. The extent to which parents' continued to assume a caring role was linked to the receipt of service provision for their young adult child. Parents appeared to have little choice but to assume these roles when service support was lacking. As a result, parents can bear the consequences of this. Their caring roles expand in response to the lack of support for their young adult child's move into adulthood.

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