



BIROn - Birkbeck Institutional Research Online

Hill, E.L. and Jones, A.P. and Lang, J. and Yarker, Jo and Patterson, A. (2015) Employment experiences of parents of children with ASD or ADHD: an exploratory study. *International Journal of Developmental Disabilities* 61 (3), pp. 166-176. ISSN 2047-3869.

Downloaded from: <https://eprints.bbk.ac.uk/id/eprint/28274/>

Usage Guidelines:

Please refer to usage guidelines at <https://eprints.bbk.ac.uk/policies.html>
contact lib-eprints@bbk.ac.uk.

or alternatively

Employment experiences of parents of children with ASD or ADHD: An exploratory study.

Elisabeth L. Hill^{a*}, Alice P. Jones^a, Jane Lang^{a,1}, Joanna Yarker^{a2} & Allyson Patterson^{a3}

a Department of Psychology, Goldsmiths University of London, New Cross, London, SE14 6NW, UK.

* Corresponding Author: Professor Elisabeth L. Hill, Department of Psychology, Goldsmiths University of London, New Cross, London, SE14 6NW, UK. Tel: +44 (0)20 7919 7886; Fax: +44 (0)20 7919 7873; Email: e.hill@gold.ac.uk

Keywords: attention deficit hyperactivity disorder; autism spectrum disorder, employment experience; barriers; facilitators; parents

¹ Present address: Division of Psychology & Language Sciences, University College London, UK.

² Present address: Affinity Health at Work, London, UK.

³ Present address: Furman University, South Carolina, USA.

Abstract

Parents of children with attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder (ASD) are often hindered by their carer status as they seek to obtain and maintain employment opportunities. These parents can incur financial, social and psychological distress related to their inability to commit to the demands of a typical work environment. This paper seeks to identify the course of employment for parents following a child's diagnosis. This paper also seeks to delineate factors that influence continued employment despite carer status, as well as the factors that prevent continued employment. A sample of 10 parents of children with a primary diagnosis of ASD and a sample of 10 parents of children with a primary diagnosis of ADHD were interviewed concerning their employment experiences before and after the diagnoses of their children. The interviews were analysed using interpretive phenomenological analysis and produced several discrete themes. Participants identified a desire for normality, as well as financial motivation, as the primary factors determining continued employment. These parents also reported various barriers to employment such as lack of availability of adequate childcare, colleague and manager misunderstanding, inflexible organisational policies, and inaccessibility of opportunity. These findings offer a qualitative overview of the vocational struggles of parents of children with ADHD and ASD while implying the necessity of support and education for this often-overlooked group of carers, as well as those who employ them.

1. Introduction

For many parents, employment represents more than just financial stability or personal autonomy; a job can function as a source of self-respect, self-esteem and social inclusion (Evans & Repper, 2000; Arksey, 2003). However, a parent who is willing, but unable, to

work not only loses out on income and pensions, but can experience negative social and psychological impacts (Towers & Swift, 2006; Waddell & Burton 2006; Towers, 2009).

While there is limited research within the area of developmental disorders and employment, there is a small body of evidence within the broader field of carer research. In a report for Carers UK, Steill et al. (2006) found that the majority of studies concerning parents of disabled children focus on the home situation (e.g., relationships, stress, finances, education) rather than the employment patterns of parents who wish to, but are unable to, work. Steill et al. also reported that parents of children with disabilities state a desire to work, but experience a number of problems maintaining employment. These problems are often related to workplace attitudes regarding their child's disability. Many organizations were reported to lack implemented family-friendly policies, parents experience difficulty juggling work and care, especially parents of children with developmental disorders. These children often have unpredictable problems or behaviour, which can contribute to difficulties obtaining childcare and incompatibilities between employment and support services. In these cases, working parents often rely on informal care or family support.

Most often the parenting burden and loss of wages fall to the mother of a child with developmental disability. This appears consistent across all cultures studied (see Cappe et al. 2011 in France; McCabe, 2010 in China). In one study, Bristol et al. (1988) found that mothers of boys with developmental disorders provided more hours of childcare than mothers of developmentally-typical boys. Similarly, Warfield (2005) reported that fathers of children with disabilities are more likely than their spouses to work full-time (see also Shearn & Todd, 2000) and report greater involvement and interest in their work. Because the amount of time a father dedicates to his work can determine the amount of time a mother dedicates to childcare, mothers in such families often feel the bulk of parenting stress, which is predicted by work interest, child behaviour difficulties, and household income (Warfield, 2005). The

role of employment in parenting stress is especially apparent in the case of mothers of children with developmental disabilities who do not work. Bourke-Taylor et al. (2011) found that mothers who work and have a disabled child report better health-related quality of life than mothers who have a disabled child and are unable to work.

The present study examines the costs to parental employment opportunities associated with two categories of relatively common and pervasive neurodevelopmental disorders: autism spectrum disorder (ASD) and attention-deficit/hyperactivity disorder (ADHD). ASD affects an estimated 535,000 people in the UK (approximately 1% of the population) and is diagnosed on the basis of atypical use of language and nonverbal communication in social contexts, which interferes with typical social functioning, as well as repetitive and restricted patterns of behaviour and interests, and interferes in social, occupational and/or other areas of functioning (DSM-5; American Psychiatric Association, 2013). ADHD, which affects an estimated 1,890,000 (3-5% of the population), is characterized by inattention and/or hyperactivity-impulsivity that interferes with functioning or development (DSM-5; American Psychiatric Association, 2013). Given the relatively common prevalence of these disorders, we expect that a proportion of the working population will be inevitably affected by parental difficulties related to the disorders. Workers, especially mothers, may need to reduce their hours or stop working altogether while parenting a child with a developmental disability such as ASD or ADHD.

When parents eliminate hours to accommodate children with disabilities, families inevitably lose out on wages. Several studies have estimated the salaries of parents of children with ASD at between 10 and 20% less than parents of children without ASD (Bone & Meltzer, 1989; Birenbaum & Cohen, 1993; Beecham et al., 2000; Järbrink & Knapp, 2001; Montes & Halterman, 2008). In the United States, this averages to about \$17,763 in lost wages per family, with parents of children with ASD working an average of five hours less

weekly than parents of children without ASD (Cidav, Marcus & Mandell, 2011). These lost wages are mostly incurred by mothers of children with ASD, who earn 35% less than mothers of children with other health problems and 56% less than mothers of children with no health problems. However, Ciday et al. report no significant difference between the wages of fathers of children with ASD, the wages of fathers of children with other health problems, and the wages of fathers of children without health problems.

In addition to lost family wages, ASD may impact the economy generally by removing parents from the employment sector and incurring social service expenses. The economic and practical costs to UK society associated with ASD have been identified at around £1 billion per year, including costs associated with unemployment (Järbrink & Knapp, 2001; Järbrink, Fombonne & Knapp, 2003; Knapp et al., 2009). Unemployment costs can result from a parent's inability to work, inability to fulfil intellectual potential at work, or difficulty in obtaining childcare. Furthermore, in a study of social service expenditure, Bebbington and Beecham (2007) found that English social services spend £50m annually on services for children with ASD. This figure represents 4% of the department's total expenses for children and families.

In addition to government spending, Järbrink et al. (2003) identified parental, service and cost impacts of UK children with the disorder in 15 parents of children diagnosed with ASD. In this study, all parents reported that their child's disorder had negatively affected their career and income. For those who were able to estimate these losses, the average weekly loss of income quoted by parents was £231, with the majority reporting losses between £100 and £450 per week. In addition to the loss of income, parents estimated that they spend 22 hours per week caring for a child with ASD when they previously would have been working for wages.

Similarly, the costs associated with ADHD are considerable. Though cost estimates for the UK are unavailable, data from the US suggest substantial loss. In a 2005 study, Birnbaum et al. reported overall costs associated with ADHD, primarily those related to treatment and medication, at \$31.6 billion. Especially relevant to the present study, \$3.7 billion of this figure represents the cost of lost work for both adults with ADHD and adult family members of individuals with ADHD. A study based in the Netherlands supports this finding, reporting that mean medical costs per year for the mothers of children with ADHD are over three times greater than costs for mothers of children with no such difficulties. Here, the mean indirect costs associated with absence from work were reported at €2243 for mothers of children with ADHD and €674 for control mothers (Hakkaart-van Roijen et al., 2007).

Beyond economic loss, families of children with an ADHD or ASD diagnosis typically experience general difficulties with greater frequency or intensity than their control-group counterparts. In a self-report measure of quality of life, Lovell, Ross and Wetherell (2011) found that parents of children diagnosed with either ASD or ADHD scored higher on all measures of psychological distress (e.g., depression, health complaints, lack of social support) than control parents. Harpin (2005) provides a review of the literature associated with ADHD-related difficulties across the lifespan for both individuals with the disorder and for their families. The data strongly suggest less satisfaction and greater stress among parents of children with ADHD when compared to parents of children without ADHD. This review, and later studies, reported an increased likelihood of disturbances to family and marital functioning, disrupted parent-child relationships, reduced parenting efficacy, and increased levels of parental stress (Foley, 2010; Kvist, Nielsen & Simonsen, 2011).

Parents of children with ASD are similarly afflicted with general difficulties in maintaining family cohesion and overcoming obstacles related to employment. Stein, Foran

and Cermak (2011) and Gray (2002) reported that mothers of children with ASD are more likely than those of neurotypical children to avoid or be excluded from social functions because of embarrassment related to their child's social behaviour. Additionally, these mothers reported that they do not have much time to socialize and do not receive adequate support from others (Sen & Yurtsever, 2007). As a result, between 41% and 56% of participants in another study reported giving up work altogether to care for a child with ASD (Olsson & Hwang, 2003). Such experiences of distress might contribute to the reduction or elimination of working hours, as well as general life satisfaction.

The current study adopts a qualitative approach to investigate the employment experiences of parents of both children with a primary diagnosis of ASD and children with a primary diagnosis of ADHD. Specifically, it aims to explore barriers and facilitators to employment experienced by parents of children with these neurodevelopmental difficulties.

2. Materials & Methods

2.1 Participants

A sample of 10 parents of children with a primary diagnosis of ASD and 10 parents of children with a primary diagnosis of ADHD participated in the study. All participants were recruited based upon their participation in a previous questionnaire study. The survey was distributed to carers via autism charities, autism and ADHD support groups, learning disability organisations, carer and parenting organisations, clinical practitioners, and schools. Questionnaire participants were invited to take part in a confidential follow-up interview regarding their experiences of work by including their contact details at the end of the questionnaire (confidentiality of personal information was ensured). Interviews were restricted to participants who lived in the UK and had been previously, or were currently, employed.

Of the parents of children with ASD, eight mothers and two fathers participated. All participating parents of children diagnosed with ADHD were mothers. This mother-bias aligns with previous research that suggests mothers are the primary caretakers of children with disabilities (Warfield, 2005). Table 1 summarizes the demographic and family profile of all participants.

2.2 Interview procedure

Participants were invited to take part in a telephone or face-to-face interview lasting 30-40 minutes each. Demographic details were collected from each participant, along with details about their child, their child's diagnosis and care plan. Using a semi-structured interview, we aimed to identify participants' employment experiences both before and after their child was born. Given the issues identified from the literature, we were especially interested in (1) their employment histories before and after their child's diagnosis, (2) factors influencing continued employment, and (3) the barriers and facilitators they experienced while working. We also considered any other information relevant to their experiences but not covered in the interview. Ethical approval was obtained from the Research Ethics Committee at Goldsmiths, University of London. Interviews were recorded and transcribed verbatim.

2.3 Analysis

Interview data were analysed using interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003; Smith, Jarman & Osborn, 1999). The transcripts were analysed using a qualitative approach based on procedures described by Vaughn, Schumm and Sinagub (1996) and used in past research to identify key issues in practical contexts, such as provision in schools for special educational needs (e.g. Frederickson, Jones & Lang, 2010). This approach allows researchers to identify information and issues relating to the specific areas identified

in the study aims and the semi-structured interview designed to address them. IPA emphasizes personal perceptions by exploring participants' views and offering a detailed interpretation; because IPA is comprised of fluid guidelines rather than a set of rules, researchers can adapt the technique in order to suit the aims of their research (Smith et al., 1999; Smith & Osborn, 2003). IPA has been used previously in research on managing challenging behaviour (Whittington & Burns, 2005). Because of the technique's flexibility, the judgement of the analyst is crucial in making sense of a participant's experience, and is employed most effectively with up to 12 participants (Smith et al., 1999).

In keeping with IPA guidelines, the present study analysed each interview as one set of data. To ensure reliability of interpretation two researchers, neither of whom had been involved in the study design or had conducted interviews, analysed each transcript independently. Each researcher read the transcript several times in order to formulate meaningful interpretations and become more responsive to the participant's experiences (Eatough & Smith, 2006). The researchers recorded initial notes in the left-hand margin, reflecting the key points to emerge from the data. As the researcher read the transcript a second time, s/he noted preliminary themes relating to the three key areas that were the focus of the interview schedule (employment history, factors influencing continuing employments, barriers/facilitators to employment) in the right-hand margin. This iterative process ensured that the researchers were continuously attempting to interpret the participants' personal perceptions as closely as possible. After the second reading, researchers clustered preliminary themes together that they agreed shared common features in terms of meaning. These clusters were assigned a descriptive label that represented the conceptual nature of their themes. To ensure reliability, the researchers discussed both the three key areas considered in the interview as well as the themes extracted from the text.

3. Results

Within the three topics addressed by the interviews, employment following the child's diagnosis; factors influencing continued employment; barriers and facilitators to employment, a number of themes emerged. These themes are summarised in Table 2 and discussed using illustrative quotes. Each quotation is followed by the participant number and group name (ASD or ADHD) of the interviewee who is quoted.

3.1 Focus area: Employment history following child's diagnosis

In the first topic of discussion – employment history – interviewees in both groups reported varied patterns of both past and present employment. Quantitative consideration of job changes revealed that within the ASD group, eight of the ten interviewees reported an attempt to work in some capacity (if not full-time) following their child's diagnosis. Within the ADHD group, all parents interviewed worked either full-time or nearly full-time before having children and then changed their working hours once they had started a family, although they reported that the change was not necessarily specific to their child's ADHD.

Information drawn out during interviews revealed that the employment patterns of the ASD participant group were characterized by frequent job changes; four of the participants reported three or more job changes since their child's diagnosis and three further participants reported they had made a move to freelance or self-employed work. All participants in the ADHD group reported some degree of difficulty with returning to work related to their child's condition. All, except for one who did not return to work at all, reduced their hours after giving birth, or maintained part-time hours. Many participants in both groups reported working in lesser roles than they had previously occupied. These parents took demotions from their previous jobs or began work in a completely different role, as their previous career did not offer the flexibility and support necessary to balance care and employment. Parents in both groups elaborated on the difficulty of balancing childcare and work:

I left work because I knew there was something wrong with him. I have tried a couple of times [to go back to work] but it hasn't really worked out ... it's hard to find a company that's quite understanding. (ASD2)

I left the GP surgery, because they were really inflexible about me having time off. (ADHD5)

Only two of the interviewees in the ADHD group retained their previous employment after having their child. One of these participants worked as a nursery nurse and took the child to work with her; the other returned to work in the same salon as a hairdresser. She commented on the difficulty of maintaining the position:

I do a few hours for the same company one day a week., but I'm not considered for more work, because they know that I can only do a few hours... if I'm called away they think I should be there, so it's really not that easy. But I can't think that anyone else would have me with the problems, at least they know and they keep me on just for the few hours. (ADHD2)

Over half of the participants in the ASD group reported that they had taken on a job within an organisation or department that focuses on supporting carers of challenging children or had taken on freelance/self-employed work, finding these work environments more flexible and adaptive. This was not an outcome that was noted by parents of children with ADHD.

The balance I have at the moment is great for me [as a freelancer]. I'm with people and it's very stimulating, but I have no stress, I have no boss, no office politics so I've tried to keep that side of things as stress free as possible to cope with the stress at home. (ASD4)

I am now teaching at a special school with children with challenging behaviour ... They look after the children during the day; they fully understand the pressures of it. There's never any hesitation if I need time off for an appointment.. (ASD6)

I now work for [a council] as a parent liaison officer ... They're excellent, I get carers leave but then they have to because they're about working with families and disabled children. (ASD9)

3.2 Focus area: Factors influencing continued employment

Two key themes emerged in consideration of the second area considered during the interviews. Though many parents in both participant groups reported a decreasing view of the importance of employment in relation to family responsibilities, these parents still cited employment as an important source of normality and financial stability.

3. 2. 1 Sanity and normality

When asked about their work and home life balance, five of the interviewees from the ADHD group described work as a form of escape and described their jobs as sources of independence, confidence, and validation of an identity apart from motherhood. Only one parent with ASD reported a similar feeling.

I feel like I have freedom. I feel like I have my own confidence back. (ADHD9)

It's just time out, it's independence, it's having conversation, it's leaving the worries at the door. As soon as you swipe your card and you walk in, you're somebody else. (ADHD8)

Work is sanity in a lot of senses, time out where I can be me, where I can control things that are happening, where people respond and listen to what I say ... where I can be a normal human being. (ASD1)

3. 2. 2 Financial motivation

Financial motivation emerged as a theme in both groups with many participants stating that they worked for the purpose of gaining additional income. Many of these parents took lesser roles than they felt qualified to do, as the financial motivation for employment far outweighed the desire for job satisfaction or personal motivation.

[My job] is nasty, horrible and the reason I do it is because I can get well paid ... I have a lot of flexibility provided I succeed at what they expect me to succeed at. (ASD10)

Additionally, some participants noted the difficulty in maintaining a balance between working too many hours and losing disability allowances. These parents indicated that they were reluctant to take on any further responsibilities at work lest they lose their Disability Living Allowance (DLA, a state benefit in the UK for adults and children with physical and mental disabilities).

3.3 Focus area: Barriers and facilitators to employment

Six themes emerged in discussions relation to the third and final area of consideration during the interviews. These are outlined below.

3.3.1 Understanding of the condition by others at work

The majority of the participants indicated that their employers, managers and colleagues had very little understanding of their child's condition, how it affected the family, or the care responsibilities involved. Parents considered that there was little understanding about the impact that a child with a neurodevelopmental disability could have on their ability to perform job responsibilities. Participants cited sleep deprivation and their child's need for constant supervision as hindrances often misunderstood by those in the workplace. Lack of understanding by others was considered to make engaging in work difficult:

...one of the biggest [challenges of working] is lack of sleep, that's a huge issue. He sleeps, when he's in his regular routine, he'll sleep midnight to 4am, but he has no sense of danger, so he can't be left unsupervised ... so I often sleep on his bedroom floor. (ASD1)

Participants also reported a lack of understanding from both the public and their co-workers concerning the needs of children with ADHD and ASD as they grew older. These parents' colleagues expected that the parenting burden would decrease substantially as children became teenagers and teenagers became young adults. However, the transition to adulthood can be especially difficult for these children and their carers.

He couldn't be potty trained at the normal age. He didn't walk at the normal age or crawl. Everything was delayed, absolutely everything, feeding, everything. (ADHD10)

[People at work don't understand] because he's older. [They think] it magically goes away once they get to 18. This is the worst time now ... once they leave school. (ASD3)

It's difficult because he can't do buses, so I have to take him to and pick him up from college [at 17 years old] ... you have to make all his meals, you have to go shopping, well he'd get lost. (ASD10)

3. 3. 2 Availability of childcare and support

Parents reported that the availability of childcare was a barrier to employment. Only two participants in the ASD group received respite support outside of the family (the child of one of these now refuses respite care), while no parents in the ADHD group reported respite care. Indeed, many parents of developmentally disabled children are not receiving any support at all. Many respondents reported that, while they could get 'wraparound' support for their other children, it was difficult to find appropriate childcare for their child with ASD or ADHD. These parents had no choice other than to take employment that allowed them the flexibility of being available to drop off and pick up their child, and to look after them during the holidays.

It's impossible to find child care for a disabled child after school, absolutely impossible. I was offered full-time work and I couldn't get a childminder, no-one was willing to take her on. (ASD5)

And the other holiday schemes that we've tried have been ringing us up after a couple of hours saying, you're going to have to remove him... so that didn't work and nobody else wants to look after him, because they find it hard work. (ADHD8)

Interviewees in both groups had also considered asking family to help with childcare and noted the difficulties of this:

Well, my sister did try to child mind a little bit for me, but she found it intolerable because she couldn't cope with him. I just don't feel that there is anybody out there who could cope with him. (ADHD2)

My parents can't really cope with looking after him ... we've got ... nobody locally who's prepared to take him. (ASD1)

Despite the example from the ADHD parent above (ADHD2), the majority of interviewees from the ADHD group had successfully organised family or friends to help with child care, or had shared caring responsibilities with their partner, compared to only two of those in the ASD group:

I have to leave quite early some days. My husband leaves between 7:00 and 7:30 and his mum comes over. She lives just round the corner, so she'll help. (ADHD4)

When he was little my husband would work in the day and then he would come home and I would work in the evenings. (ADHD9)

3. 3. 3 Organisational policies and work practices

This theme emerged as a real positive for some parents, with those who were able to work reporting that flexible workplace policies were invaluable in helping them to maintain their careers.

There are [core hours] I've got to be there, although if there's a medical appointment I can take time out but ... sometimes I can just put my foot down and say 'right that's it I am going home'. (ASD1)

Seven mothers in the ADHD group organised their working hours to fit in with the school day, school holidays, or other aspects of their child's needs (e.g., hospital appointments), for example:

I had that half an hour to get to work in the morning, and I had an hour after I finished, before I had to pick him up, so any issues that needed sorting out I was there. (ADHD4)

Like this week he had to have blood tests so, I normally have Thursdays off, but I've swapped my day off, because by the time I've taken him to the hospital and back to school, it's not worth me going to work. So I've just swapped my day off. (ADHD5)

Parents of a child with ASD also reported attempting to fit their work around their child's needs, although some stated that their attempts to do this were unsuccessful and they had abandoned their employment as a result. Others reported a history of abandoned employment

due to their child's diagnosis of ASD, but were currently in a role that was supportive and/or flexible, for example:

I kind of ditched [employer] because ... the trouble with supermarkets when you're at management level is that you're open to their hours and you have to be there 24/7 or at least be available 24/7 and I couldn't do that with his diagnosis. (ASD8)

Actually [current employer] is the first job that ever gave me carer's leave on a few times to go to interviews with [daughter]. (ASD9)

Where policies were less supportive, participants described having to sometimes take sick leave or make up excuses to spend time at home with their child or take them to hospital appointments:

I used to go on sick so I didn't lose the money I was earning. I used to say it was me that was sick coz I knew if I said it was [to look after my child] I wouldn't get anything. (ASD5)

Likewise, five interviewees in the ADHD group talked about the difficulties of getting time off work to attend appointments:

And also the amount of time that I had started to spend in school, with various appointments with speech therapist, occupational therapist, in and out the SENCOs office and so on, I just wouldn't have been able to work the hours I did, because the appointments have started taking up a lot more time. (ADHD1)

At the GP surgery, colleague-wise I was job sharing, so she was doing three [days] and I was doing two and she would never swap days with me, so I'd end up taking annual leave. And I was on really basic annual leave there so that was a bit of a nightmare. (ADHD5)

Some parents in the ASD group reported that their organisation had initially offered support and flexibility, but that this had not always materialised. This appeared to directly impact the participant's job satisfaction and confidence in their ability to do their job.

I explained at the interview about the emotional and physical impact that this [child's autism] has on us, their response was 'if you're the right candidate, whatever it takes we will support you'. When I started at the school, the head teacher was taking notes every time I was late, every time I was obviously tired and not performing, all the appointments I was having to go to and he was totting them all up... (ASD6)

3.3.4 Line manager support

The participants from both groups reported diverse experiences with regard to line manager support. The majority reported that the practical and emotional support from their line managers is invaluable; although others suggested that their bosses could do more to help them better manage their work and care commitments. There were examples of both positive support and a willingness to be flexible:

[my boss] came and knelt by my chair ... just to ask me if everything was ok. He was asking about [my daughter] and he was asking about me ... a lot of people don't ask

if you're ok they just ask if the person you're caring for is ok, sometimes you get forgotten. (ASD5)

And if he has a bad day at school and I need to leave early I can go, you don't want to take the time out because work is so pressured, but if you do need to take the time out there's someone to stand in. (ADHD8)

3. 3. 5 Colleague support

Participants from both groups who were in work reported that colleagues were generally supportive of their situation. The practical and emotional support offered appeared to have a substantial impact on how the participants described their job and was an important feature in helping them cope with the emotional strain of looking after a child with ASD or ADHD.

Sometimes I go in to work and if we've had an argument in the morning I might be a bit upset, but they know at work that I have problems with him and one health visitor in particular, who I chat to is very good on parenting and might say have you tried this or have you tried that? (ADHD6)

I went out at lunchtime to use the phone [to speak to my son] and came back in tears; she said 'well look, I'll take your first client this afternoon and just have a cup of tea'. (ASD3)

For those participants who worked with unsupportive colleagues, this had a substantial impact on how participants described their job:

On one occasion a colleague said 'look if things are that bad for you at home, then I don't see why you're working for a living'. Her attitude seemed to be that either my wife or I should be at home looking after the children; we were being self-indulgent by working. (ASD6)

3. 3. 6 Loss of Opportunity

Though many parents of children with ADHD and ASD are able to continue to work in some capacity in the years that follow a child's diagnosis, they mostly report reduced hours or roles. Other parents ended their careers as they became aware of their child's special needs.

I was registered as a receptionist [at the GP] and then obviously when he was born, I left there. Usually after I had [my other children], I'd go back [to work], but with [the child with ADHD], I couldn't... (ADHD10)

I had to leave my job, I couldn't cope with going backwards and forwards to the actual hospital and doing all these tests and working as well. (ASD5)

Of those who continued to work, some participants reported that they now work to pay for general expenses and treatment related to their child's condition, rather than to advance their careers. One mother of a child with ADHD reflected on a compromised career and unfulfilled potential:

But I don't see it as a career any more, my line manager keeps saying 'there's these management courses', but what's the point? I can't give the time that would be needed, because somebody else needs my time more, which does sadden me. I would

love to carry on progressing and doing more courses but I can't, so I have to accept that. (ADHD5)

4. Discussion

This study aimed to elucidate the difficulties associated with simultaneously maintaining employment and raising a child with ASD or ADHD. Our findings offer a qualitative overview of the experiences of these parents as they encounter and endure problems securing and maintaining employment. Parents were asked to talk about three topics: employment histories before and after a child's diagnosis, factors influencing continued employment, and barriers and facilitators to employment. Using IPA analysis, various themes emerged relating to these lines of questioning. These included frequent job changes and inflexibility of employers (employment history); work as an escape and financial motivation (continued employment); and availability of childcare, colleague support, and organisational policies (barriers/facilitators to employment), for example (see Table 2). These themes represent the pervasive and often overlooked struggles of a specific, yet large, group of carers, highlighting incompatibilities between employment, support and childcare options. In many cases, working parents were unable to rely on informal care or family support in unexpected situations when they should have been at work. Additionally, these findings are not reported elsewhere in the autism or ADHD literature, yet employment experiences have a significant personal and societal cost in terms of social, physical and economic health and well-being (Foley, 2010; Harpin, 2005; Montes & Halterman, 2011).

First, the research highlights the employment difficulties experienced by parents of children with developmental disorders. All parents included in this study had worked prior to having their children and all reported some degree of difficulty in returning to work in the same jobs. The majority of interviewees in the ASD group had moved jobs more than three

times, or became self-employed, since their child's diagnosis, some were no longer working out of choice and others out of necessity. While all interviewees indicated a desire to engage in productive work, many found it difficult to sustain employment due to the impracticalities of managing work alongside their carer responsibilities. For those who were able to sustain employment, this was frequently within voluntary or public sector organisations focusing on the delivery of child or special needs services (e.g., special needs schools).

Second, the analysis revealed the importance of employment for parents of children with these disorders, both for their senses of autonomy and normality, as well as for their financial stability. Despite the difficulties in juggling home and work commitments, half of the interviewees in the ADHD group were positive about their work, feeling that it afforded them an escape from their daily life as a mother, a place where they could be seen as a person in their own right and feeling of self confidence and freedom. Unfortunately, the majority of interviewees in the ASD group reported that the jobs they had taken since their child's diagnosis were not those they would have chosen to do had they had different child care responsibilities. All of the interviewees falling into this category reported that the work they were able to undertake to fit their child care demands tended to be at a lower level of responsibility than their previous level of employment. This suggests that parents of those with ASD may experience greater employment related negativity than those with a child with ADHD, although this should be considered more explicitly in future research.

Third, the research identifies a number of barriers and facilitators to employment. Participants in both groups reported that the lack of understanding of the condition by others at work led to difficulties; all participants reported that managers and colleagues had little real appreciation of how intense and demanding home life is, although many could give incidences of where colleagues and management had been able to be supportive. Participants repeatedly referenced the public's lack of understanding about their children's disorders,

especially in terms of the amount of attention and care these children require beyond the preschool years. Children with ASD or ADHD often do not develop at the typical pace and may need the amount and type of care usually reserved for a much younger child. For carers of children with ADHD or ASD, the teenage and young adult years can be far more difficult than expected, particularly when compared to the requirements of parents with typically developing teenagers and adults (continuing sleep difficulties and additional support in securing a job interview or travelling to a meeting were examples reported).

The absence of childcare available for children with difficulties also proved problematic for many interviewees in both groups, limiting the employment opportunities afforded to them. Many participants reported that while some organisations offered flexible working policies, many of these did not extend beyond those afforded to parents of typical children or that organisations paid lip-service to the policies. Line manager and colleague support was reported to be invaluable to those who were able to maintain employment. However, absence of line manager or colleague support was cited as a significant barrier to employment that led several participants to terminate their employment at a particular workplace.

The findings of this novel qualitative study of ASD and ADHD provide several parallels to previous work investigating the experiences of carers of sick or disabled children (Steill et al., 2006; Warfield, 2005). There are similar findings concerning difficulties in maintaining employment, juggling work and care, and managing incompatibilities between support services and employment. This suggests that the difficulties experienced by our sample are not specific to simply having a child, but reflect additional barriers associated with caring for a child with a difficulty. It remains to be seen whether these barriers are the same irrespective of type of disability (physical, mental, or developmental). In addition, as suggested by both the current study and prior studies, mothers in two-parent families tend to

take on the majority of the care responsibilities (e.g., Cappe et al., 2011; McCabe, 2010, Warfield, 2005). Taken together, these themes present novel findings of the employment experiences of parents of children with ASD or ADHD from which future research can build.

This research is not without limitations. First, the qualitative nature of this study limits the nature of the conclusions that can be drawn. However, given the limited availability of preceding research, this approach has allowed us to illustrate the effects of employment on parents with children with developmental disorders, as well as their family's mental and economic stability. This approach enables researchers to develop a framework for future, multi-method exploration of similar research topics. Second, although not restricted by the research criteria, only two of the twenty parents interviewed (10%) were fathers. This is consistent with published work (e.g., Warfield, 2005) but is a clear caveat to the interpretation of the study. Given the equality agenda and government encouragement for women to work, it is important to document the impact of child-related issues on either parents' employment status. While not a direct focus of the interviews, the lack of father participants is suggestive that it is mainly mothers who are experiencing work/childcare issues since typically it is those affected by the topic of a research project who are most likely to wish to be involved as participants. Third, for the purpose of this exploratory study, a broad participant criterion was adopted to capture the range and diversity of experiences. Given the heterogeneity of both ASD and ADHD, this includes a large age range, varying severity of disorder, and presence/absence of co-occurring disorders. However, this also allows an understanding of experiences across a representative range of parents, and is a key principle of qualitative research approaches. It may be useful for future research to focus on specific subtypes of developmental disorders (e.g., varying ASD or ADHD severity levels as outlined in DSM5) and age groups, in addition to comparing the responses outlined in the current study with those from parents whose child is diagnosed with a DSM5

neurodevelopmental disorder that is arguably less behaviourally problematic (including dyslexia). We predict that such parents will report some of the difficulties presented by parents with ASD and ADHD in the current study, but some themes will not be seen (e.g., difficulties securing or maintaining childcare outside of the home, practical support from family and friends in relation to childcare and employment needs). A further important comparison group will be parents of those with an ongoing medical condition or sensory impairment which requires the parent to attend many clinical, educational and training appointments but likely has a different recognition among employers, colleagues and childcare providers. Further quantitative longitudinal research may be able to confirm associations between child-specific factors, organisational factors and employment outcomes in terms of positive employment experiences for those caring for a child with either ASD or ADHD.

The current study provides a first step in qualitatively advancing our understanding of the predictors and impact of employment for this unique group of parents. The findings of this study offer some important implications for future research. First, there is a broad range of factors that predict the ability to maintain employment; including child characteristics, childcare, social support, and employer expectations. Second, both employment and unemployment significantly impacts parental psychological, social, and financial health and well-being. It is also the case that the majority of our participants were recruited through either ADHD or ASD support organisations (e.g., the UK's National Autistic Society). The themes identified in this study appear to be independent of support organisations, networks or groups. Indeed, the absence of discussion of support organisations or networks with regard to employment is interesting, and could be an important focus for such groups in the future. No participants mentioned any support, advice or guidance regarding parental employment offered by organisations, highlighting a potential need for the development of guidance

materials to support those parents who are trying to enter or maintain employment while balancing the care demands of their child.

This study also has important implications for practice. First, the findings point to a lack of guidance and support for parents of children with neurodevelopmental disabilities. There is a need for the development of guidance materials for parents related both to the child's condition generally, and to the impacts of the child's condition on parental employment. With this in mind, the development of guidance materials for employers, especially those supervising parents of special-needs children, would be beneficial. There is also need for improved access to childcare facilities and support for parents who want to engage in employment, particularly for those whose children have the challenging behaviours associated with ADHD/ASD alongside typical cognitive skills. Such guidance and support may encourage those who have exited the workforce to re-engage, and those currently working to better navigate the workplace.

Second, there is a need to review how organisations manage employees who care for children with ASD and ADHD. In light of the UK's commitment to carers (Department of Health, 1999; Carers (Equal Opportunities) Act, 2004), the public is becoming more aware of the special needs of parents of children with disabilities. Our findings suggest that the most supportive organisations were those public sector service based organisations that offered or supported special needs child care for their clients, while those working in other organisations found that promised support often failed to materialise. Improved understanding of the impact of having a child with a developmental disability could allow organisations to effectively respond to parent needs while managing business priorities.

5. Acknowledgements

We extend our thanks to the parents that participated in this study so willingly, as well as to Victoria Pryce for help with the interviews, Alex Benzi for help with the IPA and Ben Hicks for help with manuscript preparation. Funding for this project was provided by The Wellcome Trust (EH; JY) and the Department of Psychology, Goldsmiths, University of London (EH, AJ). AP was supported by the Furman Advantage Program of Furman University.

6. References

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders*. (5th edition.) Washington DC: Author.
- Arksey, H. (2003). People into employment: supporting people with disabilities and carers into work. *Health and Social Care in the Community*, 11, 283-292.
- Bebbington, A. & Beecham, J. (2007). Social services support and expenditure for children with autism. *Autism*, 11(1), 43-61.
- Beecham, J., Beck, E., Mandalia, S., Griffith, R., Walters, M., Boulton, M., et al. (2000). What is the cost of getting the price wrong? In *Unit Costs of Health and Social Care*, Netten, A., Curtis, L. (Eds.). PPSRU: University of Kent at Canterbury.
- Birenbaum, A., & Cohen, H. J. (1993). On the importance of helping families: policy implications from a national study. *Mental Retardation*, 31(2), 67-74.
- Birnbaum, H.G., Kessler, R.C., Lowe, S.W., Secnik, K., Greenberg, P.E., Leong, S.A. & Swensen, A.R. (2005). Costs of attention deficit-hyperactivity disorder (ADHD) in the US: excess costs of persons with ADHD and their family members in 2000. *Current Medical Research and Opinion*, 21, 195-205.
- Bone, M., & Meltzer, H. (1989). *The prevalence of disability among children*. OPCS Surveys of Disability in Great Britain. London: Her Majesty's Stationary Office.
- Bourke-Taylor, H., Howie, L. & Law, M. (2011). Barriers to maternal workforce participation and relationship between paid work and health. *Journal of Intellectual Disability Research*, 55, 511-520.
- Bristol, M. Gallagher, J. & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and non-disabled boys: adaptation and spousal support. *Journal of Developmental Psychology*, 24, 441-451.
- Cappe, E., Wolff, M., Bobet, R. & Adrien, J. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders

and in the development of relevant support and assistance programmes, *Quality of Life Research* 20, 1279-1294.

Carers (Equal Opportunities) Act 2004. London: Office of Public Sector Information

Cidav, Z., Marcus, S., & Mandell, D. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics*, 129, 617-623.

Department of Health (1999). *Caring about Carers: the national strategy for carers*. London: Department of Health.

Eatough, V. & Smith, J. A. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, 97, 483-498.

Evans, J., & Repper, J. (2000). Employment, social inclusion and mental health. *Journal of Psychiatric and Mental Health Nursing*, 7, 15-24.

Foley, M. (2010). A comparison of family adversity and family dysfunction in families of children with attention deficit hyperactivity disorder (ADHD) and families of children without ADHD. *Journal for Specialists in Pediatric Nursing*, 16(1), 39-49.

Frederickson, N., Jones, A.P. & Lang, J. (2010). Inclusive provision options for pupils on the autistic spectrum. *Journal of Research in Special Educational Needs*, 10, 63-73.

Gray, D.E. (2002). 'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24, 734-749.

Hakkaart-van Roijen, L., Zwirs, B.W.C., Bouwmans, C., Tan, S.S., Schulp, T.W.J., Vlasveld, L. & Buitelaar, J.K. (2007). Societal costs and quality of life of children suffering from attention deficient hyperactivity disorder (ADHD). *European Child and Adolescent Psychiatry*, 16, 316-326.

Harpin, V.A. (2005). The effect of ADHD on the life of an individual, their family, and community from preschool to adult life. *Archives of Disease in Childhood*, 90, i2-i7.

Järbrink, K., Fombonne, E. & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autism spectrum disorder: a pilot study. *Journal of Autism and Developmental Disorders*, 33(4), 395-401.

Järbrink, K. & Knapp, M. (2001). The economic impact of autism in Britain. *Autism*, 5(1), 7-22.

Knapp, M., Romeo, R., & Beecham, J. (2009). The economic cost of autism in the UK. *Autism*, 13(3), 317-336.

Kvist, A., Nielsen, H., & Simonsen, M. (2011). The effects of children's ADHD on parents' relationship dissolution and labor supply. IZA discussion papers.

Lovell, B., Moss, M., & Wetherell, M. (2012). The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD. *Psychoneuroendocrinology*, 37(4), 534-542.

McCabe, H. (2010) Employment Experiences, Perspectives, and Wishes of Mothers of Children with Autism in the People's Republic of China. *Journal of Applied Research in Intellectual Disabilities*, 23, 122–131.

Montes, G. & Halterman, J.S. (2008). Association of childhood autism spectrum disorders and loss of family income. *Pediatrics*, 121, e821-e826.

Montes, G. & Halterman, J.S. (2011). The impact of child care problems on employment: findings from a national survey of US parents. *Academic Pediatrics*, 11, 80-87.

Olsson, M.B. & Hwang, P.C. (2003). Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example. *Journal of Intellectual Disability Research*, 47, 328-341.

Sen, E. & Yurtsever, S. (2007). Difficulties experienced by families with disabled children. *Journal for Specialists in Pediatric Nursing*, 12, 238-252.

Shearn, J. & Todd, S. (1998). Maternal Employment and Family Responsibilities: the Perspectives of Mothers of Children with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 13, 109-131.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretive phenomenological analysis. In *Qualitative Health Psychology: Theories and Methods*, Murray, M., Chamberlain, K. (Eds.). Sage: London. 218-240.

Smith, J.A., & Osborn, M. (2003). Interpretive phenomenological analysis. In *Qualitative Psychology: A Practical Guide to Research Methods*. Smith, J.A. (Ed). Sage: London.

Steill, B. Shipton, L. & Yeandle, S. (2006). *Caring for sick or disabled children: parents' experiences of combining work and care*. Sheffield: Carers UK.

Stein, L.I., Foran, A.C., & Cermak, S. (2011). Occupational Patterns of Parents of Children with Autism Spectrum Disorder: Revisiting Matuska and Christiansen's Model of Lifestyle Balance, *Journal of Occupational Science*, 18, 115-130.

Towers, C. (2009). *Recognising Fathers. A national survey of fathers who have children with learning disabilities*. London: Mental Health Foundation.

Towers, C., & Swift, P. (2006). *Recognising Fathers: Understanding the issues faced by fathers of children with a learning disability*. London: Mental Health Foundation.

Vaughn, S., Schumm, J.S. & Sinagub, J. (1996) *Focus Group Interviews in Education and Psychology* (Thousand Oaks, CA: Sage)

Waddell, G. & Burton, A.K. (2006). *Is work good for your health and well-being?* London: TSO.

Warfield, M.E. (2005). Family and work predictors of parenting role stress among two-earner families of children with disabilities. *Infant and Child Development*, 14, 155-174.

Whittington, A., & Burns, J. (2005). The dilemmas of residential care staff working with the challenging behaviour of people with learning disabilities. *British Journal of Clinical Psychology*, 44, 59-76.

Table 1: Summary of participant demographic, child, care and employment details.

Parent ID	Relationship to child	Relationship status	Child's details			School	Employment status
			Diagnosis	Age	Siblings		
ASD1	Mother	Married	Autism	4	2	Statemented: Educated in special school	FT: teacher
ASD2	Mother	Single	Asperger's	16	1	Mainstream school with special language unit	Unemployed
ASD3	Mother	Single	Asperger's	21	0	Mainstream school	FT: nursery nurse
ASD4	Mother	Married	Asperger's	16	1	Mainstream private school	Freelance language teacher

ASD5	Mother	Unknown	Child 1: Asperger's Child 2: Autism	Child 1: 17 Child 2: 14	2	Child 1: Mainstream school with 3 hrs respite per week Child 2: Residential care/school	PT: careers advisor for carers
ASD6	Father	Married	Autism	4	2	Special school with respite care monthly	FT: teacher
ASD7	Mother	Married	Autism	12	2	Special school with autistic unit	FT: carer
ASD8	Mother	Married	ASD	8	0	Mainstream school	Student
ASD9	Mother	Married	ASD	21	1	Mainstream school with support	PT: parent outreach officer (LEA)
ASD10	Father	Single	Asperger's	17	1	Special school	PT: finance/ debt collector
ADHD1	Mother	Single	ADHD ASD	10	2 +3 partner's children	Statemented: educated in mainstream school with support (TA 25 hours)	Carer

ADHD2	Mother	Single	ADHD	6	2 older siblings (do not live at home)	Statemented: educated in special school (EBD)	PT: hairdresser
ADHD3	Mother	Single	ADHD ODD	11	5 (1 also has ADHD)	Statemented: educated in special school (EBD)	Carer
ADHD4	Mother	Married	ADHD	17	2	Educated in mainstream school – with support in special unit up until 6 th form college	FT: photographer
ADHD5	Mother	Married	ADHD Autism	9	1	Statemented: educated in mainstream with support – about to move to special school	PT: unknown
ADHD6	Mother	Married	ADHD	15	2	Mainstream: no support	PT: nursery nurse
ADHD7	Mother	Married	ADHD	8	1	Statemented: educated in special school (EBD)	FT: catering
ADHD8	Mother	Married	ADHD	8	0	Statemented: educated in mainstream with support – possibly moving to special school	PT: secretarial

ADHD9	Mother	Married	ADHD ASD	8	2	Statemented: educated in special unit in mainstream until 2 weeks before interview. Now moved to mainstream with support	PT: unknown
ADHD10	Mother	Married	ADHD Microencephaly	13	2	Statemented: educated in SEN school	PT: receptionist

Table 2: Summary of themes

Topic	Emerging theme
Employment history following child's diagnosis	
Factors influencing continued employment	Sanity and normality Financial motivation
Barriers and facilitators to employment	Availability of child care support Understanding of the condition by others Organisational policies and work practices Line manager support Colleague support Loss of opportunity