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Biographical disruption: Experiences of mothers of adults assessed for Autism  
Spectrum Disorder

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### **Abstract**

Background: Little is known about the experiences of parents whose sons or daughters are diagnosed with ASD during adulthood.

Method: Six mothers of adults recently diagnosed with ASD were interviewed about the ASD assessment process. Thematic analysis was used to analyse the interviews.

Results: Two superordinate themes are described: 1) biographical continuity, and 2) biographical disruption. Mothers did not experience significant disruption around the ASD assessment itself, as they had sought an explanation for their son/daughters behaviour since childhood. Therefore, being referred for an ASD assessment was simply another assessment for their son or daughter and was thus a *biographical continuity*. Mothers experienced *biographical disruption* once an ASD diagnosis was received, as they realised that an ASD diagnosis did not result in any additional support, and found this greatly frustrating.

Conclusions: There is an unmet need for post-diagnostic support among adults diagnosed with ASD, and for their parents.

**Keywords:** Autistic Spectrum Disorder, qualitative research, family functioning and support, adult, diagnosis.

The receipt of a diagnosis of Autism Spectrum Disorder (ASD) has significant consequences for the person who has received that diagnosis, and for their close family members (Griffith et al., 2013; Midence & O'Neill, 2009; Osborne & Reed, 2008; Punshon, Skirrow & Murphy 2009). ASD is a group of neuro-developmental disorders characterised by a lack of social reciprocity, difficulties in nonverbal communication, and restricted repetitive behaviours (American Psychiatric Association, 2013). These features have persistent effects on development and independence in adulthood (Howlin, Goode, Hutton, & Rutter, 2004). Despite the lifespan significance of ASD, the vast majority of research about ASD is focused on children, and a recent review found that just 21% of research with people with ASD included populations with adults over the age of 20 (Jang et al., 2014). This pattern is also found in research focused on parents of individuals with ASD; there are far fewer research studies about the experiences of parents of adults on the autistic spectrum than about parents of children. We could not locate any published research about the perspectives of parents whose son or daughter had been through the diagnostic process in adulthood.

## **ASD in Adulthood**

Epidemiological data suggest that ASD affects around 1% of the adult English household population (16 years and over), with a weighted prevalence of 9.8 per 1000 (Brugha et al., 2011). Prevalence rates were higher in men, among those living in social housing, and those with low educational qualifications. Brugha et al., (2011) proposed that this is likely to be a reflection of the impact ASD has on an individual over time, rather than these being a risk factor. The adults identified as having ASD in the survey did not show an increased use of services, suggesting that adults with ASD

were not being clinically recognised or supported (Brugha et al., 2011).

A recent report found that there are increasing numbers of adults who approach services in the UK wishing to be assessed for ASD (WAG, 2009). However, there are few published data about how many adults wish to be assessed or who are assessed for ASD. Jones, Goddard, Hill, Henry and Crane (2014) reported that their participants ( $N=128$ ) were diagnosed with an ASD at a mean age of 34.41 years ( $SD=13.6$  years). In addition, participants had mixed experiences of the diagnostic process, with 40% reporting they were very/quite dissatisfied, and 47% reporting they were very/quite satisfied (Jones et al., 2014).

Within the UK, there are practical difficulties in diagnosing adults within the universal healthcare system (National Health Service: NHS). Traditionally, adult support service teams are divided into those that support individuals with intellectual disabilities (ID) and teams that support individuals with mental health difficulties.

This results in individuals with ASD in many areas of the UK unable to access appropriate diagnostic or support services, as a woman with ASD articulated in a UK qualitative study: “I’m on the high functioning end [of the autistic spectrum], and so I don’t fit mental health, I don’t fit learning [intellectual] disability, I just fall through the gaps between departments” (Griffith, Totsika, Nash & Hastings, 2011, p. 540).

### **What is the ASD diagnostic process like for parents?**

Previous research about families’ experiences of the ASD diagnostic process has been with parents of children. These studies have shown that parents are often dissatisfied with the assessment procedures, particularly the time it takes to receive a diagnosis, and with the overall management of the process by service providers. These findings

have been reported from parents of children in the UK (Howlin & Moore, 1997) and parents from Canada, New Zealand, Australia, and the USA (Goin-Kochel, Mackintosh & Myers 2006). Some research has highlighted additional difficulties experienced by parents of children diagnosed with Asperger syndrome (which, although no longer a recognised diagnosis by DSM-V (2013), is often used in UK clinical settings) such as longer delays and greater frustration in obtaining a diagnosis when compared to parents with a child with autism (Howlin & Asgharian, 1999).

In a recent analysis of published qualitative research about children and youth with autism published between 1993-2011, Swinth, Tomlin, and Luthman, (2015) found 79 studies that met criteria, with the majority of publications from the United States, the UK, and Australia. The authors wrote that the diagnostic process across the countries was universally reported as highly stressful, lengthy, and confusing for parents, and that the slowness of the diagnostic process was felt to delay access to needed ASD services. Thus evidencing the commonality of the experience of frustration with the diagnostic process for ASD across the globe.

Family members frequently play a vital support role in the care of their adult relative diagnosed with ASD (Griffith, Totsika, Nash, Jones & Hastings, 2012). Therefore, it is important to extend the research on diagnostic experiences to the family members of adults with ASD.

Most previous qualitative research on the subject of adults diagnosed with ASD has focused on the impact of the diagnosis on the adult and their family members, rather than the process of the assessment itself (Punshon et al., 2009). The experience of being a parent of a child assessed for ASD is likely to differ from the experience of parents whose son/daughter is assessed for ASD in adulthood. This may be due to differences in the presentation of autism symptomology in these two samples, perhaps

those that are diagnosed in childhood may more likely to present with strong symptomology of ASD such as language delay, and those diagnosed later may have more subtle presentations of ASD symptomology which may not be so obvious when the child is young. This is speculative as there has been no research addressing whether there are differences between people diagnosed with ASD at different life stages, but is partially supported by findings by Howlin and Asgharian (1999), who reported that parents of children with Asperger syndrome experienced longer delays with diagnosis than those who had children with ASD. As little is known about the subject, in the present research we examined the experiences of parents of an adult son/daughter who had recently been assessed for, and diagnosed with ASD. Our aim was to explore parents' perceptions of their son's/daughter's ASD assessment and diagnosis process.

## **Method**

### **Participants**

Six mothers of adults diagnosed with ASD participated. One parent was the mother of an adult who also had a mild ID in addition to ASD. The age of participants ranged from 46 to 66 years old (mean age =56.5 years) and the ages of their sons/daughters at the time of diagnosis ranged from 17 to 47 years old (mean age = 25.2 years). All names have been changed to protect identity. Table 1 provides details of participants and their son/daughter, including age at diagnosis, any other diagnoses, living and employment status, and support currently received. Four mothers said that their son/daughter was heavily reliant on them for support, one moderately reliant, and only one mother reported that her son was not reliant on her for support. Thus, although not the original intention of the study, the sample has a high proportion of

mothers who are highly involved with the day-to-day organisation of their sons/daughters lives.

### **Procedure**

Ethical consent for the study was granted by a NHS Research Ethics Committee, and informed consent was obtained from all participants prior to conducting interviews. This study and was a part of a wider study looking at stakeholders opinions about ASD assessment. Criteria for inclusion in this part of the study included: (1) a parent/carer, and (2) whose adult son/daughter had received an assessment for ASD within three years preceding the interview date. Twelve information packs were distributed to parents across Wales through diagnostic services, and six participants were recruited - a 50% return rate. Participants were recruited via the lead clinician in their area, who distributed information packs that contained an information letter and consent form. Participants expressed their interest by returning the consent form to the researchers. Once written consent was received, the researcher telephoned the participant to arrange a suitable time to conduct the interview.

A semi-structured interview was developed for the purposes of this study. Interview questions were about the parents' perception of their son/daughter getting a referral for an ASD assessment, the assessment process itself, receipt of diagnosis, the professionalism and communication skills of the diagnostic team, and support received post-diagnosis from services. Participants did not have a copy of the interview script, but received an outline of the topics to be covered in the information sheet provided.

All interviews were conducted in English via telephone and were recorded using a digital recorder. Carrying out interviews via telephone has been shown to lead to few differences in findings when compared to face-to-face interviewing (Sturges & Hanrahan, 2004) and this method has been used successfully with parents of adults with ASD in previous research (Griffith et al., 2012). All interviews were one-time interviews, lasting between 13 and 62 minutes (mean = 37 minutes). In addition to written informed consent, verbal consent to record the interview was obtained prior to the start of each interview.

### **Methodological approach and data analysis**

Interview data were analysed using thematic analysis as described by Braun and Clarke (2006). Part of the process of thematic analysis is acknowledging the background of the researchers and how this may have influenced the analysis. The two authors who analysed the data both have a professional background working with people with ID or ASD, and neither have close family members with ASD. Throughout the analysis, the researchers were careful to acknowledge and ‘bracket’ off any preconceptions they had and to adhere closely to what emerged from the interview data, keeping, as far as possible, an inductive approach to data analysis. Thematic analysis was the chosen method as it is a “bottom-up” approach that is well suited to investigating personal experience. This method codes data that arise from examination of the interviews rather than matching data to pre-existing theories. As well as identifying and analysing patterns (or themes) within the data, thematic analysis allows for inherent interpretation of aspects of the research question. The recorded interviews were transcribed verbatim. The first author then read each transcript several times highlighting meaningful statements and making a note of

particular points of interest or significance. The reading of each transcript was repeated and emerging themes identified until the investigator was satisfied that all data had been categorised into themes. For each transcript, the themes and supporting quotes were extracted and tabulated into a document, so there were six individual tables, one for each interview.

Following this detailed coding of each interview, themes and quotes were compiled into a list of all the emerging ‘master’ themes, along with additional emerging sub-themes which best represented the interviews collectively, as described by Braun and Clarke (2006) and Graneheim and Lundman (2004). The data were triangulated with the second author, who read one original transcript and worked alongside the first author throughout the analysis and write up. Although each author brought their own insights into the data, there were no disagreements about the interpretation of the data during the analysis process. Emergent themes were discussed and refined throughout the analysis and write up. Table 2 provides an example of a master theme table, and demonstrates how some of the data were organised into themes and subthemes.

## Results

Two superordinate themes were identified, which encompass the experience of mothers as their son/daughter was assessed for ASD. There are five subordinate themes. Table 3 shows the relationships between these themes. Superordinate theme 1 is ‘Biographical continuity’, with two subthemes: 1a) Securing a referral for an adult son/daughter: “*Nobody ever picked it up*”, and 1b) Son/daughters assessment for ASD: “*It went over everything with a fine toothcomb*”. Superordinate theme 2 is ‘Biographical disruption’, with three subordinate themes: 2a) The fight for post-diagnostic support for their son/daughter: “*We had laid ourselves bare and then we were left hanging*”, 2b) Mothers need support too: “*I've read a book but its not the same as being able to sit down and talk*”, and 2c) Fearing the future: “*I'm an older parent...I'm not going to be around*”.

### **Superordinate Theme 1: Biographical Continuity**

Mothers described the early stages of the ASD assessment process (the referral and the assessment itself) as a *continuation* of the search for an explanation for their son or daughter’s behaviour. They had felt most of their lives that there was something different about their child, and five described having various assessments and wrong diagnoses throughout childhood and adolescence. Thus, when their adult son/daughter was referred for an ASD assessment, this was regarded as a continuation of normative circumstances, as simply another assessment. None of the mothers reported the referral or the ASD assessment itself as having any significant emotional impact. Instead the ASD assessment was a continuation of the life-long search to determine why their son or daughter experienced difficulties.

**Subtheme 1a. Securing a referral for an adult son/daughter: “Nobody ever picked it up.”** Three mothers said that their son/daughter had been in contact with NHS services since childhood (i.e. Neurology, Mental Health Services). These parents said they suspected ASD from a young age, yet it was not confirmed by services. Mothers felt that misdiagnosis was primarily due to the lack of awareness and knowledge of ASD among professionals. Retrospectively, mothers could see that their children were misdiagnosed as having mental health problems.

Jackie: The restlessness, the lack of concentration, the repetitive speech, it was all put down to her mental health. So she was lost in mental health.

I knew there was something else...and I mentioned it to the psychiatrist, to CPN's [Community Psychiatric Nurses], to social workers and nobody ever picked it up because they didn't have the knowledge themselves.

The mother whose son had contact with Neurology services for his epilepsy describes a pediatric neurologist who recognised ASD in her son as a child. However, rather than label him with ASD, the pediatrician chose to diagnose him with a “higher language disability” instead. Kath said: “I was led to believe that it was in Adam’s best interests not to label him...it was thought it would rock the boat. But then his behaviour just spiraled out of control.”

Both of these parents strongly regretted not having an earlier diagnosis. One mother, Jackie, felt that the psychotic episode her daughter experienced and subsequent months spent in hospital may not have happened had she been diagnosed with ASD earlier.

Similarly, Kath felt that her son would have more easily accepted his ASD diagnosis if it was given at a younger age.

Kath: If he had the diagnosis when he was younger possibly he would have been happier to attend a support group so he would have friendship...but because he was diagnosed as an adult, he was not very accepting of the diagnosis, it was too late for that.

Another parent persevered for several years to identify why her daughter was different from other children. She explained that they received no formal assessment for her daughter whilst she was in a children's unit, and described the unit as "useless". It was only after a transition to adult services that her daughter received a referral for an ASD assessment.

A fourth parent described a similarly lengthy and frustrating process in her attempts to obtain an ASD assessment for her son, commencing in childhood and continuing into adulthood. Unlike the three parents described above, her son was not known to NHS mental health services. Rhian said: "We had a parade of people come round and just shrug their shoulders...and say he doesn't come under our remit because he hasn't got special needs, educational needs".

Three mothers recalled referrals to inappropriate teams both in childhood and adulthood.

Helen: “The GP referred him to the mental health team. So unfortunately that took ages because it was just referred around from team to team... they didn’t seem to know how to deal with it really. Because he’s 37, nobody seemed to know where it was to go”.

Parents were asked to estimate the time taken from initial suspicion of ASD to securing a referral for diagnosis, and this ranged from six months to twenty years. For four families, this spanned from childhood through into adulthood. Five of the six parents described being greatly frustrated by the process, due to professionals not being able to identify possible ASD, inappropriate referrals, and long time scales. For all parents, the referral to ASD services was welcomed, did not come as a surprise, and was a continuation of an issue that had run throughout their son’s/daughter’s life.

**Theme 2. Son’s/daughter’s assessment for ASD: “It went over everything with a fine toothcomb”.** When asked about what the ASD assessment itself was like, all parents reported the use of questionnaires and structured interviews, although they were unable to recall the name of any specific assessment tools used. The time scales of the assessment varied greatly, and ranged from a single 2-hour appointment to several appointments over six weeks. Five family members were very satisfied with the assessment appointment(s) despite their previous frustrations at obtaining a referral. Jackie said “Well it was very in-depth, it went over everything with a fine

toothcomb. She did a lot with me as well like going over what Sophia was like as a child”.

One mother, Helen, whose son also had a mild ID, felt dissatisfied with a particular aspect of the assessment. She was not invited to be in the room when the clinician talked with her son as part of the assessment process, although she wanted to know what was happening and to help the assessor. Overall, all parents, including Helen, described the ASD diagnostic teams overall as “professional” and “open” and felt comfortable with the clinicians and their approach to assessment. Menna recalled: “She [clinician] was excellent, she had the right approach with my daughter...she had the understanding of how to ask questions”.

Five parents reported receiving the diagnosis of ASD quickly, three received a diagnosis by letter between one and three weeks following the assessment, and two received the diagnosis verbally. All parents were satisfied with both the time taken and the method employed to provide a diagnosis describing it as a “major breakthrough” and “an absolute relief”. However, one mother was dissatisfied about the lack of communication following the assessment and reported long waits before a formal diagnosis was received. She described that her son waited “a long long time” to receive a diagnosis of ASD.

When asked the question “How would you rate your experience of the assessment process?” Parents often used words such as “frustrating”, “appalling” and “poor”. Therefore, despite very positive experiences during the ASD assessment itself, these

seemed to be overshadowed by the great difficulties experienced pre- and post-assessment (i.e. long referral processes, long waits to receive a diagnosis, and poor support after the diagnosis -See themes 3 and 4).

### **Superordinate Theme 2: Biographical Disruption**

It was only *after* their son or daughter had been diagnosed that parents reported experiencing biographical disruption. The immediate response after receiving an ASD diagnosis was that it felt “right” and mothers reported feeling relieved. The disruption began when, once ASD was identified and their chapter of ‘seeking a diagnosis’ was closed, mothers began to seek support both for themselves and their son/daughter with ASD. Mothers quickly found that no support was available, and recalled the period immediately after the diagnosis as the most frustrating and stressful. Even though they now knew their son/ daughter had ASD, this did not result in helpful practical outcomes. Mothers felt they were left to cope as they had done before, except that the hope or expectation that a correct diagnosis would help their son/daughter was gone; this greatly disrupted their lives.

**Theme 3. The fight for post-diagnostic support for their son/daughter: “We had laid ourselves bare and then we were left hanging”.** All parents remarked there was no support for their son/daughter after being diagnosed with ASD, and in a variety of ways each described a sense of abandonment. Three parents described that they felt “being back at square one” despite now having a diagnosis. This was because, although relieved and grateful for a diagnosis, this was only of benefit to their son/daughter if they had support for their difficulties, and in their experience no support was offered. This was greatly disruptive and frustrating. Two mothers felt that

support was segmented, and that the new ASD diagnosis was not incorporated into other services received, such as mental health services.

Jackie: That's the thing we were just left. We had an assessment and Sophia saw an occupational therapist but that was on the cards to do with her mental health. The Asperger's side of it, there was absolutely nothing, we were just given the number of the Asperger's group and that was it.

Following the initial sense of abandonment, four parents pursued help for their son/daughter. The period after diagnosis where parents sought support was disruptive. This was frequently described in terms such as "begging" and "fighting" for support. One mother described her frustration at not being able to access support for her son, even though he now had an ASD diagnosis, because he did not meet criteria for any services.

Kath: Adam could get no help from social services because he wasn't diagnosed with an additional learning [intellectual] disability, they didn't count the Asperger's. So I then went knocking on the door of mental health, they couldn't help me either. I was told you need a referral from your GP, the GP would say no you can just self refer. And nobody helped. And in the end I actually said 'Look I am absolutely begging for help now. I am not going to go until I get a referral for help, who on earth is going to help Adam if I suddenly die today?' And it worked. But it had taken almost a year.

Although many parents said they did not receive any support following diagnosis, several report some provision, the most common one, reported by four parents, was ‘signposting’ (reciving contact details of local groups that may help) to a local support group for people with ASD. At the time of interview only two sons/daughters had attended their local support group. Of these, one attended once and did not go again, and the other found the support group very valuable, as it was an ASD-specific group.

Jackie: Sophia could see some of them had degrees, some of them had really good jobs...she didn't want to tell anybody she had Aspergers but now she will. It's two years on, I think for her she sees a big difference, it's a better environment for her than going to mental health groups. She never fitted in and looking back they were totally wrong for her. She loves the Aspergers group. It's for people with Aspergers...just Aspergers.

One family member explains how she secured three half days of support per week from the National Autistic Society, funded by her Health Board. She had to “*fight*” to get this, “We didn’t get that because that is what everybody is offered”, and was only due to her continued persistence and her threats to approach the Parliamentary and Health Service Ombudsman if support was not put in place.

**Theme 4. Mothers need support too: “I've read a book but its not the same as being able to sit down and talk”.** Four parents were offered a local support group for carers of people with ASD, two of these were run by local service agencies, and two were run by the National Autistic Society. The two family members signposted

to a service-run group found it beneficial, and described the supportive nature of the group.

Kath: The tremendous relief I felt...I hide my feelings an awful lot of the time, at the last meeting, I could feel that mask slipping and I thought I was going to cry, I'm normally very controlled, so something is hitting a nerve, I obviously feel that these are people who understand how difficult it is.

Four mothers expressed a desire for support for themselves as carers of adults with ASD. Two spoke of a longing for the assessment process to include their experiences as parents. One mother described being a parent of someone with recently diagnosed Asperger syndrome as “hugely frustrating” (Jackie).

Although mothers acknowledged the relief and sense of kinship that could be gained from local support groups, they also expressed a desire for contact with a professional person post-diagnosis as a form of support to better understand the behaviour of their son/daughter and how best to respond to their needs. No-one reported that this was available or offered by services.

**Theme 5. Fearing the future: “I’m an older parent...I’m not going to be around”.** All mothers described a sense of relief in obtaining an ASD diagnosis for their son/daughter, and felt it was a positive development. Yet five mothers were very concerned for their son’s/daughter’s future. Specifically, they were anxious about the responsibility of care and the amount and consistency of support needed.

Two expressed concern that their son/daughter would experience great difficulties without decent support.

Rhian: I'm very scared, he's a vulnerable adult but because of the way he portrays himself, a generic social worker turning up will probably think he's going to be fine on his own and he'll get put somewhere...full of [substance users] and then goodness know what will happen

Two mothers were afraid of the difficulties their sons/daughters were likely to face in accessing help, especially as they, as neurotypical people, had found this such a challenge.

Kath: I began to think, well if I, as a relatively articulate intelligent woman, could not find help, how on earth can we expect people on the autistic spectrum to find this help? And to be sent away and be told you go back here, or there, or its nothing to do with us, or there's no call for it. I mean its ridiculous! If there was ever a time in Adam's life where he wanted help I would like to think that he could find it himself and not have to go hunting.

Additionally, three mothers were concerned about services for people with ASD more generally, and wanted future service staff to be trained so as to improve awareness and knowledge of ASD in adults. Services for adults with ASD were described as a “*Grossly underfunded area*”.

Optimism for the future was expressed by two parents who had received post-diagnostic support for their son/daughter from a recently developed adult ASD service within their local health board. One mother described the home visits from a Community Psychiatric Nurse, who helped her son come out of his bedroom and into the house. “If this service is given the funding and input then actually I think his future could be a lot better”.

### **Discussion**

The current findings provide unique insight into the experiences of mothers of adults assessed for ASD. The cause of ‘biographical disruption’ came *after* the ASD diagnosis was received. The disruption and frustration arose from the tension between relief that after many years of struggle, a diagnosis that finally felt ‘right’ had been obtained, and then the discovery that the hard-earned label of ASD did not change anything – their son/daughter were still left without support from services. Mothers feared for their future when they would no longer be able to provide support for their son/daughter themselves.

These mothers’ lives were not disrupted by the ASD assessment itself, in fact, the process of an ASD assessment was one of ‘biographical continuity’ because it was just one more assessment in a long line of assessments that their son/daughter had. Although the aim of the research was not to explore the experiences of mothers whose son/daughter were reliant on them for support, five out of six reported that they were heavily or moderately relied upon by their son/daughter for everyday organisation and care. It is important to note that this is likely a more focused group of mothers than originally intended, who have particular experiences that may not be shared by mothers of adults who are independent and diagnosed with ASD in adulthood.

There were parallels between the findings in this study with qualitative research conducted with parents of children, in that the assessment process was felt to take too long, and was sometimes poorly managed (Goin-Kochel et al., 2006; Howlin & Moore, 2007). The differences seem to lie in parents of people diagnosed with ASD as adults having a longer period of uncertainty around the diagnosis, which meant that the ASD assessment process itself may be less emotionally straining for parents of adults, because it was one in a long line of assessments their son/daughter had had throughout their lives. Conversely, parents of children diagnosed with ASD would have a shorter wait for diagnosis, although it may be a more intense period of stress. In this study, parents were dismayed to find that after gaining a diagnosis, there was little support offered to their adult son/daughter. Due to specialist children services and education, lack of post-diagnostic support may be less stark for parents of children diagnosed with ASD. The differences outlined here are speculative at this stage, and further research to examine the topic is needed.

All parents reported awareness of unusual behaviour in their son/daughter beginning in childhood, yet ASD was not identified until adulthood, despite frequent visits to health professionals. Parents felt this was because professionals did not pick up on ASD traits, or know where to refer their son/daughter. This is similar to findings reported by Punshon et al. (2009) who found that 40% of their cohort either suspected they had ASD but felt that lack of knowledge among staff meant that it was not recognised or that they were mis-diagnosed. Among this particular sample, as all showed unusual behaviour during childhood, this has clinical implications about improving childhood services so that ASD is recognised earlier. Increased awareness of ASD symptomology among school staff, and health professionals may help to diagnose ASD in earlier childhood. Some mothers felt that an earlier diagnosis of

ASD would have benefited their son/daughter and themselves, one mother strongly felt that an earlier ASD diagnosis would have helped prevent her daughters' severe mental health problems as a teenager, as she would have known the root of her difficulties, and would perhaps have received a more tailored type of support from services. This study suggests that mothers felt that they and their son/daughter would have greatly benefited from having an ASD diagnosis during childhood, therefore enabling earlier adjustment to the diagnosis and supports to be put in place.

Experiences of the assessment appointment(s) were largely positive; thoroughness and professionalism were reported across the sample. A formal diagnosis was received immediately when given verbally, yet took between one week and six months when received by letter. Lengthy waits at this stage of the assessment process caused much frustration, highlighting the importance of quick feedback of ASD assessment results. This is consistent with previous research, which identified that parental satisfaction with the ASD assessment was negatively correlated with how long they had to wait (Howlin & Moore, 1997).

The current findings suggest that post-diagnostic support was uniformly lacking for these families. Although service providers regarded 'signposting' (giving contact information about other services) as post-diagnostic support, and provided this service to several of the parents in this study, parents did not regard 'signposting' as being supportive, despite some who reported how useful the 'signposted' support groups were. All mothers reported a sense of being abandoned after a diagnosis, and reported a need for support other than 'signposting'. Instead, mothers wanted continued

contact with a professional person with the skills and knowledge to provide individualised care to their son/daughter.

Parents were fearful of what would happen to their son/daughter once they were no longer able to care for them, similar to findings reported by Griffith et al. (2012), who interviewed parents who also had adults with ASD heavily dependent on them. The experiences of service support for people with ASD thus far did not reassure parents of the quality of future care of their son/daughter. Parents worried that their son/daughter would not be able to navigate services in order to access support, since this was almost always described as a '*fight*'. This is consistent with the findings of Hines, Balandin, and Togher (2013), which describe parental communication with services as '*battling*'.

These findings have several clinical implications. First, the referral pathway was not straightforward for many parents, due to various levels of NHS staff not recognising ASD symptomology, leading to referrals to inappropriate services over a number of years. This highlights the need for further training in ASD symptomology among all levels of NHS staff and supports the already established need for a clear referral pathway for adults with suspected ASD. Clear and timely communication is key to parents reporting a positive experience of ASD assessment. A major issue underlying this is that ASD symptomology was misunderstood by numerous NHS professionals and school staff during childhood. There is still a need for knowledgeable staff and improvement in child diagnostic pathways so that children with Asperger syndrome get a timely diagnosis. Second, timescales from referral to assessment and to diagnosis are a key factor in influencing satisfaction levels. Assessments in the future

need to occur within agreed timescale boundaries to ensure positive experiences. Third, there is a discrepancy between what services regard as post-diagnostic support, and what mothers recognise as support, parents in this study did not recognise ‘signposting’ as a source of support, despite two people attending support groups as a result of the ‘signposting’. Evidence from this research suggests signposting is considered unsatisfactory and that some parents would like continued contact with services post-diagnosis. Finally, the professionalism and warmth of diagnostic teams was noted and appreciated by family members, this is an example of good clinical practice being implemented across Wales.

As there is no prior research on family members perception of their son’s/daughter’s assessment for ASD, it is not possible to compare results directly with any other studies. However previous research by Griffith et al. (2012) showed that parents of adults with ASD felt there was a lack of understanding within services regarding ASD, a striking resemblance to the lack of awareness and knowledge perceived by family members in the current study pre- and post assessment. This finding corroborates previous research that suggests accessing services is a tiresome and frustrating experience for family members (Griffith et al., 2012; Hines et al., 2013; Punshon et al., 2009).

#### *Limitations and future research*

As with all qualitative research, this research had a small sample size, although a sample size of 6 is deemed suitable for initial studies by qualitative researchers (Braun & Clarke, 2013). There is a possibility that the generalisability of this research may be limited. However this research is qualitative and thus the aim is to delve

deeply into the particular experiences of people from a social constructivist standpoint. While tentative generalisations can and are made from qualitative research, the leap between how particular people experienced particular events to more general claims do have to be made cautiously. Although there were a lot of differences in the details of the stories of the diagnoses, the main underlying construct of ‘biographical disruption’ with the source of the stress being lack of support after the diagnosis of ASD was true for all.

This study only included mothers, little is known about the experiences of family members such as fathers, siblings, or partners, and the type of support they may need. Additionally, little is known about the perceived experiences of the adults themselves who have undergone the assessment process for ASD as adults. Future research would be valuable in extrapolating whether similarities exist in the experiences of the adult assessed for ASD and their parents. One mother had a son with a mild ID, so the sample was not strictly homogenous, as is typically sought in qualitative research, although the inclusion criteria was based upon whether participants adult sons/daughters had an ASD diagnosis in the last three years, and so is still homogeneous in that sense. The experiences of this mother did not differ much from the reports from mothers of sons/daughters without an ID. Finally, the majority of this sample was of mothers whose son/daughter was heavily reliant on them for support, and their experience may differ from mothers whose son/daughter lives totally independently. Perhaps future research could examine the experiences of parents of independent adult son’s/daughter’s diagnosed with an ASD.

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**Table 1.** Demographic information on participants and their son/daughter.

Mother's name	Mother's age	Relationship	Son's/daughter's name	Son's/daughter's age	Other diagnoses	Living arrangements
Kath	57	Mother	Adam	24	ADD, epilepsy, depression	Lives with mother; heavily reliant on her support; not employed
Rhian	46	Mother	George	17	Possible ADHD	Lives with parents, heavily reliant on their support; not employed
Annette	53	Mother	Rhodri	24		Lives away at university during term time; is not reliant on mother
Menna	62	Mother	Leah	21		Lives away at university during term time, is moderately reliant on mother
Jackie	55	Mother	Sophia	28	Schizophrenia, OCD	Lives with mother, heavily reliant on her support; not employed
Helen	66	Mother	Ben	37	Learning disability	Lives at home, heavily reliant on mother's support; employed

**Table 2.** An example of a table of master and subthemes taken from the master theme ‘Relatives assessment for ASD’.

<i>Master theme</i>	<i>Subthemes</i>	<i>Supporting quotes</i>
Assessment for ASD	Communication: Excellent, professional, right approach	‘Excellent, very professional, she had the right approach with my daughter...yep she was excellent (Menna)’
	Relative given space to talk No judgment	‘Well I felt she let him talk a lot and listened and there was no sort of reaction from her showing any judgment, or surprise or shock...she was great with that. She just let him express his feelings completely (Jackie)’.
	Nice, understanding Previous experience	‘They were very nice to Ben. Very understanding. Said that she’d seen people before who’d been on the spectrum so had an idea of what was going on, um... well, as I say they were very nice really (Helen)’.

**Table 3.** Superordinate and subordinate themes.

Superordinate theme	Subordinate themes
1. Biographical continuity	1a) Securing a referral for an adult son/daughter: ' <i>Nobody ever picked it up</i> ', 1b) Son/daughters assessment for ASD: ' <i>It went over everything with a fine toothcomb</i> '.
2. Biographical disruption	2a) The fight for post-diagnostic support for their son/daughter: ' <i>We had laid ourselves bare and then we were left hanging</i> ' 2b) Mothers need support too: ' <i>I've read a book but its not the same as being able to sit down and talk</i> ' 2c) Fearing the future: ' <i>I'm an older parent...I'm not going to be around</i> '