

The experiences of orthodox Jewish parents of children with Autism Spectrum Disorder and Attention Deficit/Hyperactivity Disorder

Rachel Bass

Supervised by: Janine Crosbie, John Allbutt

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## The experiences of orthodox Jewish parents of children with Autism Spectrum Disorder and Attention Deficit/Hyperactivity Disorder

### ABSTRACT:

**Introduction:** Autism Spectrum Disorder (ASD) is characterised by deficits in social communication and imagination. Classic Autism, Asperger’s syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) are the prevalent forms of ASD (American Psychiatric Association, 1994). Since the 1980’s, the prevalence of ASD diagnoses has grown from 1:1000 to 1:100 (Dymond, Gilson & Myran, 2007). Attention Deficit/Hyperactivity Disorder (ADHD) is manifested in impulsivity, inattention and hyperactivity (American Psychiatric Association, 1994), and can be co-morbid with ASD (Kochhar, 2010). Despite an under-representation of ethnic minorities in ASD diagnostic samples (Sanua, 1983; Begeer, El Bouk, Boussaid, Terwogt & Koot, 2008), Rimland (1964) and Kanner (1954) suggested disproportionately-high diagnostic rates of Autism in the Jewish population (in Sanua, 1983). Parents play a significant role in the assessments and interventions for ASD/ADHD (Harte, 2009; Minnes & Steiner, 2009). This study focused on the experiences of orthodox Jewish parents of children with ASD/ADHD in Salford, Greater Manchester, UK.

**Method:** In this study, the experiences of 6 orthodox-Jewish parents of children with ASD/ADHD in Salford, Greater Manchester, UK, were explored using semi-structured interviews.

**Results:** Results were analysed using Grounded Theory. Parents described a three-stage journey to “planet ASD/ADHD”. The initial stage of denial, confusion and battling with the child’s difficulties was resolved by reaching the next stage, “awareness and acceptance of the child’s ASD/ADHD: a positive turning point”. The final stage, “Life on planet ASD/ADHD” was described in both positive and negative terms. Parents reflected on their family’s positive growth and on their appreciation of ASD/ADHD strengths. Negative experiences were community stigma, financial restrictions, discouragement, burnout and alienation, and perceived lack of support for ASD/ADHD in community schools. Finally, further research suggestions, limitations and reflexivity are discussed.

Key words:	Autism Spectrum Disorder (ASD)	Attention Deficit/Hyperactivity Disorder (ADHD)	qualitative	parent experiences	orthodox Jewish
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## Introduction

Outlined below are an overview of Autism Spectrum Disorders (ASD); the co-morbidity of ASD and Attention Deficit/Hyperactivity Disorders (ADHD); the involvement of parents in research regarding their child's ASD; ethnic epidemiology trends in ASD focusing on the Jewish population; an overview of the orthodox-Jewish community in Salford, Greater Manchester, UK, and finally, the research questions.

### Autism Spectrum Disorders: overview

Autism is a lifelong developmental disorder with neurobiological origins (Hill & Frith, 2003, in Lewis, Woodyatt & Murdoch, 2007). It is defined by a triad of disabilities: first, social interaction; second, communication; third, rigid and repetitive activity and interest patterns (American Psychiatric Association, 1994). Children with ASD present with chronic, overt anxiety; and avoidance of social interaction and novel experiences (Baron-Cohen, 2008). Baron-Cohen groups the deficits under one heading: the lack of theory of mind, meaning difficulty in "...postulating the existence of mental states and then using these to explain and predict another person's behaviour" (1989, p286). Other notable difficulties associated with ASD are disordered sensory integration, manifest either in craving or in avoidance of sensory stimuli (Larocci & McDonald, 2006). Executive function, the ability to plan and manage routine tasks and reactions to events, is also adversely affected in ASD (Brandimonte, Fillipello, Coluccia, Altgassen & Kliegel, 2011).

The term Autistic Spectrum Disorders (ASD), also known as Pervasive Developmental Disorders (PDD) currently includes classic Autism and the more high-functioning conditions Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Proposed changes to DSM-V include adopting ASD as an umbrella term for autistic spectrum conditions, replacing terms like Asperger's syndrome (American Psychiatric Association, 2011).

Although ASD was considered rare in the 1980's (Newschaffer et al, 2006), with ASD diagnoses rate of 1:1000 in developed countries, the diagnostic rate has risen to a current rate of 1:100 (Matson & Kozlowsky, 2011). The ratio in the UK is currently nearing 1:100 (Baird et al, 2006, in Tobias, 2009). Due to the rising diagnosis rates, ASD is of interest to researchers. It is debated whether the rising epidemiology is due to keener public and clinical awareness of ASD features, or whether it is caused by unidentified environmental influences (Rosenberg, Daniels, Law, Law & Kaufmann, 2009).

### Co-morbidity of ASD and ADHD

ADHD is characterised by inattention, impulsivity and hyperactivity, and is classified into three conditions: predominantly inattentive; predominantly hyperactive/impulsive; or combined (American Psychiatric Association, 1994). The ADHD worldwide prevalence rate is 5.29% (Polanczyk, de Lima & Horta, 2007).

Official ASD diagnostic criteria rule out co-morbidities (American Psychiatric Association, 1994) and this is acknowledged as controversial, as there is evidence to show co-

morbidity of ASD and ADHD (Goldstein & Schwebach, 2004; Reiersen, Constantino, Volk & Todd, 2007; Rowlandson & Smith, 2009; Yerys et al, 2009; Frazier et al, 2011). Children with ADHD have a higher percentage of Autistic traits compared to controls (Kochhar et al, 2010). Shared traits between ASD and ADHD include inattention and social awkwardness (Selikowitz, 2004). The trait-overlap results in difficulty applying clinical measures to differentiate between ASD and ADHD (Sizoo et al, 2009; Ghaziuddin, Welch, Mohiuddin, Lagrou & Ghaziuddin, 2010). Nijmeijer et al (2010) suggest that genetic and environmental factors interact to predict ASD in children with ADHD<sup>1</sup>.

### **Research with parents of children with ASD**

Parents of children with ASD can be important sources of information about their child's symptoms; their parenting experiences; and the interventions they use. Their involvement is valued for three reasons:

Firstly, parenting a child with ASD is a unique challenge compared to other developmental disorders (Ogston, Mackintosh & Myers, 2011), due to difficulties in diagnosis (Braidon, Bothwell & Duffy, 2010), lack of a clear prognosis for the child's future (Baron-Cohen, 2008), and the range of cognitive, social and emotional deficits (Dymond, Gibson & Myran, 2007). Secondly, parental reports consistently matched results of clinical diagnostic measures (Oliver et al, 2002; Goin & Myers, 2004; Ko, Wasserman, McReynolds & Katz, 2004; Youngstrom et al, 2004; all in Harte, 2009). Thirdly, interventions depend on parent education and involvement (Stoner & Angell, 2006; Stoner, Angell, House & Bock, 2007; Shyu, Tsai & Tsai, 2010; Wong & Qwan, 2010).

There is an abundance of quantitative research measuring aspects of the experiences of parents of children with ASD, for example: parental stress and coping styles (Lyons, Leon, Roecker Phelps & Dunleavy, 2010); social support and maternal well-being (Lin, Orsmond, Coster & Cohn, 2011); help-seeking (Shyu, Tsai & Tsai, 2010); aggravation in parenting (Schieve, Blumberg, Rice, Visser & Boyle, 2007); and psychopathology, marital adjustment and family functioning (Gau et al, 2011).

Qualitative methods such as interviews may contribute to the understanding of parent experiences, by giving a detailed picture of the subjective experiences of parents of children with ASD. Richer understanding was achieved, for example, using "photovoice", a parent-centred approach: parents photographed successful interactions with their autistic children and discussed photos in interviews. This helped shape learning in school (Harte, 2009). Qualitative studies about parenting children with ASD identified maternal stressors: for example, interviews by Gray (2003) showed mothers are more stressed than fathers by raising a child with ASD because of their higher practical involvement in caring for their child, even in egalitarian parenting environments. Furthermore, interviews enhanced understanding of stress as a lay experience rather than a clinical term (Kinman & Jones, 2005).

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<sup>1</sup> Certainly in the present study, all the children with ASD which were discussed either had co-morbid ADHD or first-degree relatives with ADHD.

Interviews are particularly suitable when examining experiences in cultural contexts (Silverman, 2006). Interviews can highlight cultural differences in parenting children with ASD. For example, an interview study compared the coping and the social support needs of parents to children with ASD in the USA and in China, showing that Chinese parents struggle to disclose their child's issues due to cultural values of family honour (Lin, Orsmond, Coster, and Cohn, 2011), and interviews with orthodox Jewish parents of children with Autism showed their unique understanding of Autism, accepting medical views but combining it with spiritual-cosmic explanations of the soul's mission in its current life (Shaked and Bilu, 2006). In fact, it has been suggested that psychiatric disorders are better understood when studied in different socio-cultural and ethnic contexts (Gaines, 1990, in Shaked & Bilu, 2006).

### **Ethnicity within ASD**

Ethnicity is a significant factor for ASD diagnoses, as ethnic minorities seem generally under-represented in populations diagnosed with ASD. Figures show disparities of over 20% between the diagnostic rates of White compared to Black and Hispanic children in the US (Mandell et al, 2009). Ethnic minorities are less likely to be included in referrals to ASD institutions (Begeer, El Bouk, Boussaid, Terwogt & Koot, 2008). The ethnicity diagnosis bias has been attributed to different presentations of ASD in ethnic minorities (Mandell et al, 2009) and to lower socioeconomic status (Thomas et al, 2012).

The Jewish population, however, appears to be an over-represented ethnic minority in ASD prevalence, according to data showing a high percentage of Jewish participants in ASD studies: Rimland (1964, in Sanua, 1983) noted a disproportionate presence of Jewish children in Autism study samples, and the original classic Autism study by Kanner (1954, in Sanua, 1983) consisted of 27% Jewish participants.

Two explanations can account for this: firstly, a possible genetic predisposition to ASD among the Ashkenazi (European) Jewish population. Due to the tendency of Ashkenazi Jews to marry within their group, the result is a unique genetic makeup, and a high predisposition to various genetic disorders (Charrow, 2004; Klugman & Gross, 2010). However, ASD heritability in the Ashkenazi Jewish population has not yet been researched. Secondly, it is suggested that the Jewish parenting style and the higher percentage of educated parents compared to other ethnic groups, influence both awareness of ASD and diagnostic rates (Sanua, 1983).

So far, only one study was conducted about the experiences of Jewish mothers of children with Autism, in the context of the ultra-orthodox<sup>2</sup> Jewish community in Jerusalem, Israel and concerning parenting children with profound Autism (Shaked & Bilu, 2006). Due to the suggested high prevalence of ASD diagnoses in Ashkenazi Jews, and due to the cultural aspects which may exacerbate this, an Ashkenazi Jewish community was the setting of this study. This study focused on the experiences of orthodox Jewish parents of children with ASD (and co-morbid ADHD) in Salford, Greater Manchester, UK.

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<sup>2</sup> Ultra-orthodox Jewish: the most strictly conservative religious sector in the Jewish population (Shaked & Bilu, 2006)

## **The Orthodox-Jewish community in Salford, Greater Manchester**

The Orthodox-Jewish community in Salford, Greater Manchester is the second-largest Orthodox-Jewish community in the UK. Surveys have estimated the community at 10,000 members, with a high birth-rate, growing at 7.8% per year –due to younger families immigrating from London, Gateshead and France. The average family-size is 6. There are currently 1545 orthodox-Jewish children aged 0-4 years in Salford. 10% of the children under the age of 13 in Salford are Orthodox-Jewish. 48% of the community members are under the age of 15 (Partners in Salford, 2011).

There are unique socio-cultural factors in the Orthodox Jewish community, both globally and locally.

Firstly, a traditional valuing of family life, on which a higher emphasis is placed since the systematic killing of 6,000,000 Jews in Europe during the WWII Holocaust (Diner, 2003).

Secondly, Orthodox Jews live in close proximity, due to religious needs such as shops selling Kosher food, in compliance with Jewish dietary law; and living within walking distance of shul (synagogue), due to the prohibition of using vehicles on shabbos (Sabbath, from Friday sunset until Saturday night). There are 30 shuls in Salford.

Thirdly, orthodox Jewish communities operate charity networks tending to community members' needs, and the Salford community is no exception (Partners in Salford, 2011).

Fourthly, major life decisions are guided by ethos of Jewish faith, and Rabbinical leaders mentor community members.

Fifthly, religious education is considered essential and expertise in Jewish studies is valued (Pirutinsky, 2009), however, in Salford, there is an acknowledged lack of culturally-sensitive, trained professionals to support the community schools in Special Educational Needs (SEN) (Partners in Salford, 2011).

Finally, the community is an insular society with its own social code. Marriage is seen as an ultimate goal; parents and mentors are involved in young people's marriage choices. Marriage candidates are assessed by their family's social status, which is determined by: religious observance; conformity to the community's ethos of behaviour; scholarly ability in Jewish texts; the family's physical and mental-health history; and the family's ancestry. Individuals who do not seem to conform or to fit in due to mental-health issues or learning disabilities jeopardise their family's chances to be socially accepted in the community, since their issues are poorly understood by the orthodox Jewish community (Schnall, 2006; Finkelman, 2009). This is because orthodox Jews carefully assess secular ideas, including material regarding mental-health, against their religious ethos, and are hesitant to self-educate about such matters (Boardman, Currie, Killaspy & Mezey, 2010). Still, there has been some improvement in the community's understanding of psychiatric morbidity (Starck, 2008). The growing awareness is perhaps due to necessity, as psychiatric disorders

are reportedly widespread in orthodox Jewish communities (Bilu & Witztum, 1993, in Schnall, 2006).

### **The research questions**

This study focused on the experiences of parenting children with ASD/ADHD from the perspective of orthodox Jewish parents from Salford, Greater Manchester. The population was selected for three reasons: Due to the suggestions of high prevalence of ASD in Ashkenazi Jewish families, due to the cultural features which may contribute to the parenting experiences, and due to the scarcity of research regarding ASD in Jewish populations. A qualitative interview approach was chosen as appropriate for cultural focus, and in order to gain as authentic a viewpoint as possible (Silverman, 2006). The purpose of this study was to address two research questions:

1. What are the experiences of orthodox Jewish parents of children with ASD and ADHD?
2. Are there unique cultural features in the experiences of Jewish parents of children with ASD and ADHD?

### **Method:**

#### **Design**

This was a qualitative semi-structured interview study using one group of 6 participants.

#### **Participants**

Participants were recruited from a Salford-based support-group for Jewish parents of children with ASD/ADHD. Six orthodox Jewish parents of children with ASD and ADHD participated in the interviews. Four were mothers who interviewed individually, and two were a married couple who participated in a joint interview. Family-size range was 3-14 children, mean size: 6.6. The parents' ages range was 32-55 years, mean age: 43.1. Two of the mothers were divorced, with primary custody of their children. Three of the parents had university degrees, and the other three parents completed secondary education. Three mothers and the father work part-time, one mother is in full time employment and in higher education. One mother is unemployed and fosters children. The ages of the 10 children with ASD/ADHD discussed in the interviews ranged from 6 to 19 years, mean age: 11.8. The diagnoses of the children were Asperger's syndrome (3 children), Asperger's syndrome with co-morbid ADHD (1 child), ASD (2 children), ASD with co-morbid ADHD and Dyslexia (1 child), ADHD (1 child) and ADHD with co-morbid dyslexia (2 children). All 10 children discussed had other siblings with ADHD. 1 of the parent interviewees had a diagnosis of ADHD, 1 other parent had diagnoses of ADHD and

Dyslexia, and 2 parents suggested that they have ADHD traits. None of the participating parents had an ASD diagnosis.

The participants were interviewed by the researcher, who is a mother of 3 children, one of whom is currently undergoing psychiatric assessments for ASD and ADHD. She is a fellow member of the Orthodox Jewish community in Salford, Greater Manchester, UK, and was not closely acquainted with the parents prior to the study. The interviewer had training in Rogerian person-centred counselling skills at undergraduate level.

## Measures

The question schedule for the semi-structured interviews (see appendix D) included question under the headings: the diagnosis process; interventions; everyday life with the child; education; and social support. The questions were non-suggestive and technical in nature. The interview style was influenced by Rogerian person-centred theory, under the principle that a non-directive approach, with empathic responses, elicits authentic experiencing (Rogers, 1961).

## Procedure

In order to involve support-group members in this study, organisation consent was granted (see organisation agreement letter, appendix A). The researcher visited the support-group to inform members about the study. Information sheets were left in the meeting room for potential participants (see participant information sheet in Appendix B). BPS ethical guidelines were explained by the researcher and outlined in the information sheets, emphasising: confidentiality; informed consent; right to withdraw at any stage without explanation; and the researcher's commitment to protecting participants from harm. The interview's potential to touch on emotive subjects was explained. Group members were advised to take at least 24 hours to consider their participation.

Six participants scheduled interviews, planned to last an average 60 minutes each. 4 participant mothers scheduled one individual interview each, and a married couple scheduled one joint interview. Interviews were scheduled between 9am-5pm, Mondays to Fridays, in January 2012, in a Salford-based community centre. The room's design was large office/meeting-room and the interviewer/interviewee faced each other across a desk. Interviews were conducted by the researcher.

The researcher first discussed the contents of the information sheet with the participants and answered questions, emphasising BPS ethical guidelines. Participants then signed a consent form (see appendix C), and gave information regarding family members' diagnoses. The interview then began. Four interviews flowed well, lasting an average of 85 minutes each, with the participants thanking the interviewer for the positive experience. One interviewee seemed uptight, and this interview lasted 30 minutes as per the participant's request.

The sessions were audio-recorded. Participant consent forms were kept separately from other interview materials, and all interview materials, such as the audio



recordings, were kept in locked boxes to which only the researcher has keys. Interview recordings were then transcribed by the researcher, omitting identifying details. Interview transcripts were kept in a password-protected PC accessible only to the researcher. Participants were assigned codes to which they are referred to in the transcript, for example: “mother A of child A”.

## Results

### Using grounded theory

The interviews recordings were transcribed by the researcher, using Jefferson style as described by Potter & Wetherell (1987): Text was underlined when interviewees spoke emphatically, and the symbol (>0.1) was used for pauses longer than 0.1 seconds. punctuation was added to the transcripts only for clarity purposes, while preserving the original meaning. (See transcript sample, appendix E). The transcripts were analysed using grounded theory, a method used to arrive at “a plausible – and useful - theory of the phenomena that is grounded in the data” (Braun and Clarke, 2006, p81). Stages of grounded theory analysis adapted from Lyons and Coyle (2007, pp. 88) were applied as follows:

1. Reading the transcribed data in depth, electronically noting initial ideas in the right margin (see transcript on attached CD).
2. Open coding: Analysing the entire transcript, assigning code names to the phenomenon apparent in sections of the text: words, sentences or paragraphs. (See analysis sample of stages 2 and 3 in table 1, p18). Since this stage of the process resembled inductive thematic analysis, the coding was done in two stages suggested by Braun & Clarke (2006) for thematic analysis:
  - Descriptive codes. The codes described the data without prior hypotheses or theoretical interpretations. Bits of text were electronically copied, pasted and categorised in a table under each code heading.
  - Interpretative codes: The data was re-read, interpretative codes were added to outstanding features of the text. Again, text was copied, pasted and categorised in a table under each code heading. This stage was supported by manual memos of developing concepts and new research questions in a research diary.

**Table 1: Samples of analysis stages 2, 3.**

Axial coding:	Open coding	text
Sub-category: Parents' personal growth	Stage 1: Descriptive codes "I'm a mother"	I realised...I'm a mother. I try to be a friend, but I'm a mother really.
Category: Parents' positive perceptions about ASD/ADHD	Stage 2: Interpretative codes Developed sense of identity as mother	

Sub-category: parents' feel discouragement (and burnout)	Stage 1: descriptive codes Mother wants child to be normal adult	[Child D] needs to put his act together if he's gonna get married and get a job and be normal (>0.1)
Category: Parents' negative perceptions about ASD/ADHD	Stage 2: interpretative codes Mother worries about child's future	

3. Axial coding: codes were re-examined against the extracts they represent and against the entire narrative. Some codes were renamed, added or removed. This process resulted in a final list of 425 codes initially grouped under 42 tentative sub-categories (in appendix F). Sub-categories and categories were then determined. Figure 1 (in appendix G) is a sample of codes arranged into sub-categories and into a category.
4. Selective coding: sub-categories/categories were re-edited as follows: if a category/sub-category was not upheld by at least one quote, it was deleted or re-named. This resulted in a list of 17 sub-categories grouped under 6 category headings, (in appendix H). The core category was identified as appearing frequently in the codes and unifying all main concepts in an explanatory manner.
5. Arriving at the theory: The core category was examined against all categories/sub-categories, codes and transcript and re-worded until it accurately represented the main concepts, forming an explanatory theory of the experiences of the participants. Causal relationships were determined as such if participants explicitly said so, for example: parents' acceptance of the child's ASD/ADHD is reported as causing positive change because parents had said so.  
In reality, coding and categorising continued interchangeably until the report was produced. The most thought-provoking stage was the precise wording of categories. The final result is expressed as a diagram in figure 2 (p22).
6. Theoretical sampling – the findings were discussed with one of the interviewees, and with the head of a Salford-based orthodox-Jewish charity supporting families with ASD/ADHD. The results were slightly adjusted according to their feedback.

As suggested for grounded theory, "bottom-up" analysis was used. Accordingly, no pre-hypothesis was formed; the literature review carried out in advance was minimal. The transcript was analysed line-by line, generating codes and categories tightly linked to the data, not to pre-existing hypotheses. The concepts were not necessarily related to the interview questions (Lyons & Coyle, 2007). The inductive approach to analysis was in line with the interviewers' person-centred approach (Rogers, 1961).

### **The experiences of orthodox Jewish parents of children with ASD/ADHD: journey to planet ASD/ADHD**

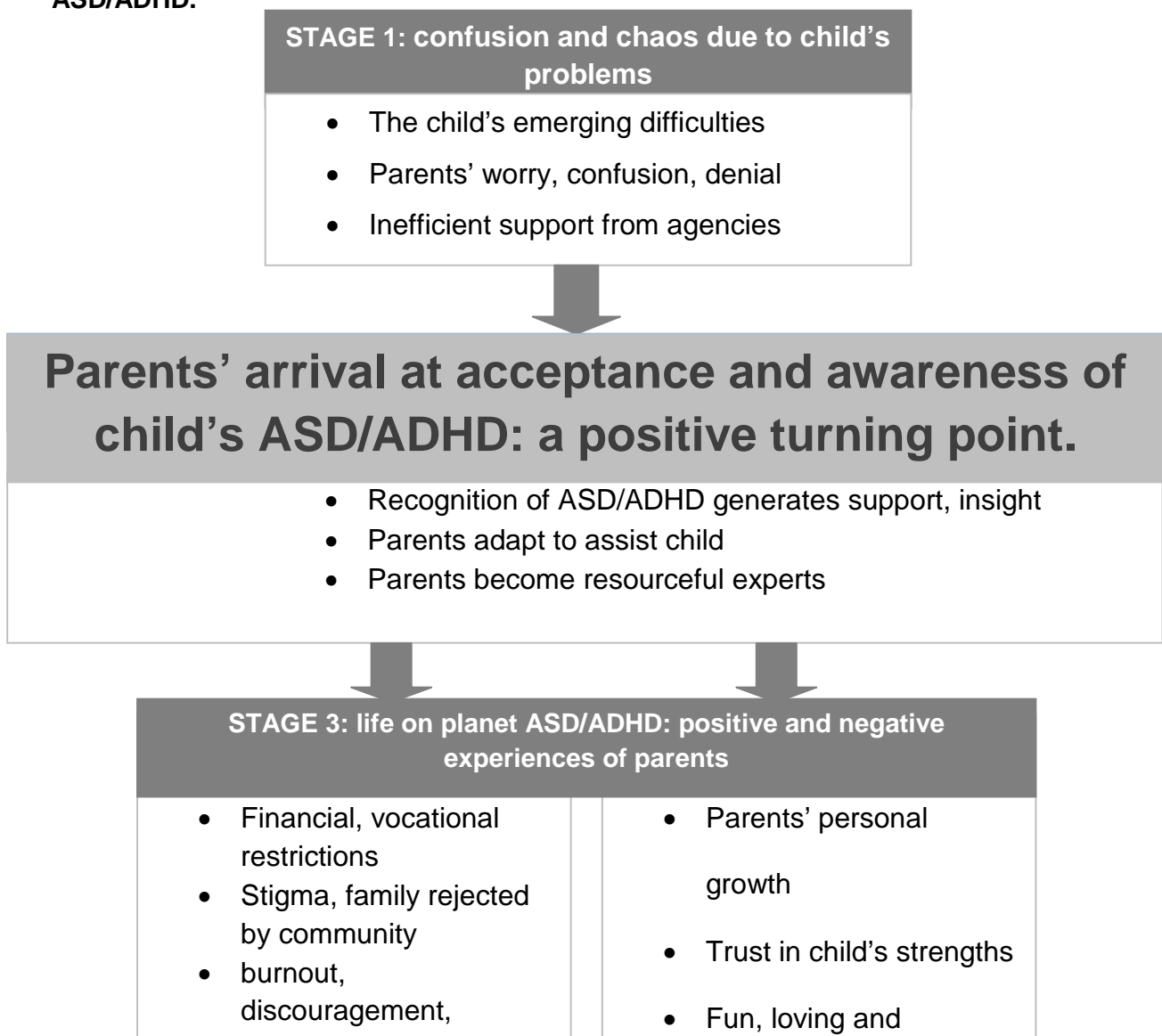
Note: throughout the results section, the term “all parents”=all 6 interviewees; “most”=4-5; “half”=3, “some”=2 and “one”=1 parent.

In this section, the results outlining the experiences of orthodox Jewish parents of children with ASD/ADHD are presented as a journey with 3 stages:

- STAGE 1: confusion and chaos due to child’s problems. Includes 3 categories describing the initial concerns and attempts to understand the child’s issues.
- STAGE 2: arriving on planet ASD/ADHD. Includes the main category: *the parent’s acceptance and awareness of the child’s ASD/ADHD: a positive turning point.*
- STAGE 3: Life on planet ASD/ADHD: includes 2 categories: positive and negative experiences of parenting children with ASD/ADHD.

As expressed in Figure 2, most parents saw their experience of parenting children with ASD/ADHD as “a journey” or “process”. Living with ASD/ADHD is compared to living on an alien planet for three reasons. Firstly, all parents referred to their alienation from people with Typically-Developing (TD) children. Secondly, insight into ASD/ADHD changed the parents’ understanding of human behaviour. Thirdly, all the families described their family as a unit with its own cultural values, such as celebrating their quirkiness.

**Fig. 2: a diagram outlining the journey experienced by Jewish parents of children with ASD/ADHD.**



## STAGE 1: confusion and chaos due to the child's problems

Stage 1 describes the initial confusion, worries and struggles due to the child's difficulties.

### 1. Category: the child's emerging difficulties

This category includes the child's emerging difficulties prior to diagnosis. These include anxiety/aggression, social communication deficits and struggles with everyday routine.

#### 1. a. Sub-category: the child's social communication problems.

Overall, the children with ASD were described as avoidant and unskilled in the area of social interaction and group work, as mother A of Child A put it:

*[Child A] never really interacted with the other kids.*

All the children needed visual cues to compensate for their disordered auditory processing. Some of the children experienced speech and language delay, but even the children with good vocabularies had difficulty communicating due to literal thinking. As a result, most of the children struggled in school and had low academic motivation. Some of the children were seen as gifted, with subtle underachievement.

#### 1. b. Sub-category: the child's struggle with everyday routine and with self-help

The children were described as extremely distractible. Their disordered sensory integration meant over-sensitivity to touch, taste, smell, sight and sound. This led to the parents' frequent reference to their children's self-help and everyday tasks as "battles". The children with ASD discussed in the interviews were described as having trouble sleeping, dressing, showering, eating, or self-monitoring hunger and pain. As parents described:

Mother A of Child A: *[he] didn't sleep*

Mother A of Child A: *[children with ASD] don't get dressed by themselves*

Mother C of Child D: *he wouldn't eat food*

All the children were picky eaters, and some children were picky dressers. School, shops, social events and travel were described as overwhelmingly novel or sensory-stimulating environments for most of the children. Most of the parents described preparing visual displays to guide correct behaviours or to explain the day's schedule.

### **1. c. Sub-category: the child's anxiety/aggression**

The children were seen as chronically and overly anxious, for example:

Mother E of Children G, X, Y: *getting him to nursery in the morning...he would kick and scream. He cried and cried.*

All the children were described as explosive following minor provocations at home, often destroying household property. Some were described as violent in school. One child used furniture to attack teachers and peers. Public meltdowns were experienced by parents as embarrassing, with onlookers criticising the lack of parental control. Mother A of Child A describes a school incident:

*he ran after someone with a baseball bat.*

### **2. Category: the initial worry, confusion and denial experienced by parents as symptoms emerge**

This category outlines the initial vague concerns felt by parents, accompanied with denial and secrecy about the situation.

#### **2. a. sub-category: initially, parents have vague concerns but don't know what to do.**

"I didn't know" was a recurrent phrase by parents describing the initial confusion at the emergence of symptoms during their child's infancy:

Mother A of Child A: *[whispers] I didn't know what I was looking for.*

Mother B of Children B, C, Z: *I had...those vibes, those worries.*

Parents did not know how to interpret the uneven pace of development and pedantic and impulsive behaviours. At this stage, parents invent coping techniques. Parents described bribing with sweets; using running water in the sink for its hypnotic effect; inventing a sign-language to help a nonverbal child; and popular interventions: no-sugar/no-additives diets, homeopathy or head-massage.

#### **2. b. Sub-category: parents initially denied ASD/ADHD**

Parental denial perhaps further slowed the diagnosis process. All parents refer to a stage when they reluctantly began to expect an ASD diagnosis after realising the child isn't outgrowing the issues. Mother D of children E,F described her denial:

*the guy says, you should check out autistic spectrum. And I'm like, "I've never heard (>0.1) that's not us (>0.1) we don't have that!"*

One parent said she was "terrified" and "felt awful" about going to CAMHS (Child and Adolescent Mental Health Services), due to stigma around mental health issues. This attitude is reflected in the community as a whole, with most parents to problematic children described as "not wanting to know". Despite the painful realisation of their child's disability, parents described the denial stage as an ordeal. For example:

Mother B of children B, C and Z: *"in the future, if I have any concerns, they are not going to wait... it's not, not knowing, it's gehinnom [hell]"*.

### **2. c. Sub-category: ASD/ADHD remain hidden disabilities due to stigma**

Parents said that although the children's behaviour problems are visible, the underlying ASD/ADHD are not obvious. ASD and ADHD are hidden disabilities. Because of the stigma attached to ASD and ADHD, most parents chose not to disclose the diagnosis to anyone other than professionals and support-group members. For example:

Mother C of Child D: *[my child's condition is] not publicly known.*

Parents expressed fear about the family's social status of the community, which must be upheld so that their children are admitted into the community's schools and benefit from good marriage prospects. As mother A of Child A reported:

*the community as a whole isn't educated about those kids' conditions. They are invisible...people won't join [the support-group] because of the stigma...because it affects shidduchs [marriage prospects].*

### **3. Category: Perceived inefficiency of agencies in diagnosing, intervening and supporting the parents**

This category describes parents' perceptions on the inadequacy of agencies prior to, and during, the diagnosis process.

#### **3. a. Sub-category: Parents' disappointment as school and/or the NHS miss or dismiss ASD/ADHD cues.**

Parents described teachers and doctors dismissing their concerns:

Mother B of Children B, C, Z: *"Will you listen to me? She is not fine"...How dare the school tell me three years ago that she's fine.*

Mother C of Child D: *The GP said, why don't you try and give him food?...(>0.1) useless, useless...Cos they really just think you're stupid and you don't know how to feed your child.*

All parents felt professional diagnoses weren't taken seriously and attributed this to lack of staff-training in ASD issues. Some parents concluded that school and parents need mutual trust, to enable effective communication and support for the child. Some parents failed to see the point of asking schools to help with the child's ASD/ADHD-related difficulties.

### **3. b. Sub-category: mental health professionals did not communicate clearly and efficiently**

All parents described the diagnosis process as long, drawn-out and complicated. Some parents experienced faults or delays in communication between the agencies involved in diagnosis. Half of the parents said they were not given sufficient information about the diagnosis process; about interventions; about disability benefits; and about supporting charities. As mother B of children B,C,Z reminisced:

*I had, still haven't got a clue what they did [at the assessment]..I got a letter she has Asperger's...nothing. A short paragraph...I didn't even know that she was meant to give me a whole bunch of leaflets! I didn't even know about the NAS [National Autism Society] society...Nothing!*

In this environment, all parents said they felt lucky to find one teacher/doctor who acknowledged the child's issues.

### **3. c. Sub-category: Parents' struggle with getting a SEN statement for the child**

All parents discussed getting a Statement of Special Educational Needs (SEN) to finance their children's support in school. Parents described the process as long and confusing, with challenges like multiple appeals and the collection of evidence of the child's problems. As Mother A of Child A said,

*the statement's hard. It's an insanely huge thing to get.*

Some parents felt that experienced parents should help inexperienced parents in navigating through the process.

## **Stage 2: arriving on planet ASD/ADHD**

Stage 2 describes a positive turning-point: the parents are ready to accept diagnoses and to understand and to get help for their child.

#### **4. Core Category: parents' arrival at acceptance and awareness of the child's ASD/ADHD: a positive turning-point.**

This core category describes what all parents termed the "important/best/key" change they underwent. This involves, firstly, acceptance as a positive turning-point:

Mother B of Children B, C, Z: *[child B]'s better, she's much better, cos I accept her for herself [now].*

And secondly, awareness as a positive turning-point:

Mother A of Child A: *we went to CAMHS. [getting a diagnosis] was the best thing we could have done.*

#### **4. a. Sub-category: Revealing the child's ASD/ADHD diagnosis elicits:**

##### **4. a.1. Insight into ASD/ADHD**

All parents described their urgent need to understand their child's problem, and some felt relief at the diagnosis. The diagnosis of ASD triggered action in parents and in school, and the specific labels helped parents to research interventions in a focused way. Parents engaged in extensive self-education at this stage. Their understanding of ASD/ADHD removed previous blame from them and from the child. mother A of Child A summed the benefits of ASD/ADHD diagnoses as follows:

*[once a diagnosis is given] you've got an explanation to what's wrong with your child and you know how to help them, everyone can have an understanding...of what it is they are dealing with.*

Most parents described a development of new insight on human behaviour, from the perspective of ASD/ADHD traits. This new perspective contributed to the metaphor "planet ASD/ADHD" as a culture with a unique outlook on the world.

##### **4.a.2. Insight into familial predisposition for ASD/ADHD**

Upon receiving the child's diagnosis, parents reflected on the presence of strong ASD/ADHD traits in other family members, including themselves. Mother A of Child A mentioned the family's new insights:



*It was like “mmmmm” [husband]’s dad said, “you know if you look back, my mother was Asperger’s and my dad”*

Some parents felt their own ADHD traits caused their empathy towards their children. Some parents described the family introspection on ASD/ADHD heritability following the diagnosis as a positive event. Half of the parents described ASD/ADHD traits in the family and in themselves as a negative factor, but some added they can better understand behaviours of family members with the awareness they gained about ASD/ADHD. One parent was frustrated by the family’s denial and secrecy about the ASD/ADHD traits and diagnoses among family members, and the resulting lack of family support.

#### **4. a.3. Social support**

Parents saw Autism as “a magic word” because it elicits support for the child and the family. Mother A of Child A used a metaphor to explain the support generated by revealing the child’s condition:

*It’s like when you’re pregnant... You spend the first few weeks...not feeling well. And then you tell them your secret...and all this help is available...But, if you’re quiet about having a child with a disability...you’re dealing with this alone. You educate people, you tell them what you’re going through, and people begin to understand, and everyone can...take pressure off you.*

All parents mentioned Jewish charities becoming available upon diagnosis, offering recreational activities to the children with ASD/ADHD and support-groups for their parents. One parent described how her husband’s joining a parent support-group led to his more accepting attitude towards their children.

#### **4. b. Sub-category: Parents flexibly adapt to assist their child with ASD/ADHD**

Looking after a child with ASD/ADHD required changes in the parents’ lifestyles. Keeping the child happy means getting up early to monitor restless children, adapting the family’ menu, avoiding family car trips and shopping, and reducing guest intake. All parents describe an acceptance of the ASD/ADHD diagnosis and an acceptance of the child as having the ASD label. This acceptance led all the parents to be flexible and patient, an attitude described as key to the child’s and the family’s well-being. As Mother A of Child A reflected:

*[since the diagnosis] I think we stopped pushing him into a bedroom with his brother...you realise there’s a limit...we stopped pushing I think sometimes.*

All parents enabled what they initially regarded as deviant behaviour, and described knowing when the child genuinely cannot deal with sensory stimuli, social event or academic demands.

#### **4. c. Sub-category: Parents take on role of resourceful experts in ASD/ADHD**

All parents mentioned monitoring their child with ASD/ADHD and understanding them thoroughly. They reported informally mentoring their child in social-skills. At this stage, parents described themselves as becoming experts in ASD/ADHD. Mother D of Children E, F describes parental expertise:

*CAMHS, you know, they're not really good, you know more than them and so do I...I got statements for two of my children all by myself...I found out the law, the Children's Act.*

Parents took independent initiatives in contributing from their experience to help others, advising and supporting both the child's teachers and other parents. One parent had published opinion pieces about educating children with SEN, and some parents discussed their plans for opening SEN schools.

### **Stage 3: Life on planet ASD/ADHD: positive and negative experiences**

Stage 3 describes the parents' positive and negative perceptions of life with ASD/ADHD.

#### **5. Category: parents' positive perceptions about ASD/ADHD**

In this category, parents described developing resilience and positive attitudes as a strong, independent family unit.

##### **5. a. Sub-category: The parents' personal growth**

All parents described personal growth. For example, changes from meek to assertive, from terrified to self-efficacious, from stubborn to accepting, from inactive to proactive, and from trusting to self-sufficient, as Mother B of Children B,C,Z put it:

*this has been a journey for me...I had...those vibes, those worries, the feelings, and there was this child in me, that I couldn't pick up the phone...I couldn't do it. And now, I've been through things and I put that child to sleep...and the adult in me is coming out...I'm much more in tune with the children and I will pick up the phone, no problem, and call the prime minister, I don't care. I'm much more assertive and I've learned to believe in my own feelings because they were right all along.*

Some parents explained how constant modelling of correct behaviour resulted in their becoming conscientious. Personal growth in religious terms was also evident in the parents' narratives: most parents described developing spontaneous prayer habits and deeper trust in God as resulting from feelings of helplessness. Finally, a sense of vocation as a parent and of self-identity as "a mother" was evident in all the narratives. One parent used the pseudonym "the Mother" in her publications. Some parents described raising children with ASD/ADHD as "a job" in itself.

#### **5. b. Sub-category: Parents trust in child's ASD/ADHD strengths:**

All the parents expressed their appreciation of their child's unique strengths and attribute this to their child's ASD/ADHD. Mothers described their children as good-looking, talented, brave, loyal, protective, sharply perceptive, compliant, and as having a strong moral code. Some parents appreciated the fact their children were unfussy about illness or about being bullied. All parents discussed trust in their child's ability to make progress; they did not excuse their child from all challenges. All parents felt that a positive educational approach, utilising the child's individual strengths, was key. Mother D of Children E,F expressed her opinion as follows:

*what I feel education should be like for this type of children is, forget all their deficits...my son...has a brilliant mind. Whatever strengths he has within the spectrum, they should work with.*

All parents saw improvements and felt some degree of optimism or success related to their child. Parents celebrated social, behavioural or academic progress. Parents expressed tentative hope that the community will become more educated about ASD/ADHD and more accepting of children with ASD/ADHD; or hope that the child will find suitable higher-education and an occupation.

#### **5. c. Sub-category: Fun, loving and accepting family unit**

All parents described their families as close-knit units offering safety, unconditional acceptance and a happy, fun, caring environment. Parents described their family attitudes as follows:

*Mother E of Children G,X,Y: I accept [child G] as he is. [passionately] He is the most gorgeous child.*

*Mother D of Children E,F: I've just pushed fun, that's what I've pushed, fun...we celebrate quirkiness.*

Most participants spoke of their children's unusual and unpredictable behaviours with an animated mixture of hilarity, acceptance and dismay. This outlook, accepting and even loving quirky behaviours, contributed to the terming of life with ASD/ADHD as life on an alien planet, with its insular cultural values.

## **6. Category: parent's negative perceptions about having a child with ASD/ADHD**

In this category, parents described negative experiences emanating from external sources, such as financial strain, weak school support and community rejection; and negative internal states of discouragement, alienation and burnout.

### **6. a. Sub-category: The impact of the child's ASD/ADHD on the parents' finances and occupation**

From a financial perspective, recreational activities and therapies are described by parents as helpful but costly. Parents were unable to afford much-needed private Jewish schooling, or private psychological assessments. Parents described fundraising, asking for concessions, or doing-without. all participant mothers described an inability to work or study because of the child's time-consuming and unpredictable needs: form-filling; getting their child into a school; home-schooling; getting their child a statement of SEN; monitoring and mentoring the child; preparing visual materials in order to communicate effectively with their child; and providing constant cognitive stimulation to prevent regression. financial/vocational restrictions resulting from the child's ASD/ADHD were evident in the following quote:

Interviewer: *did [the diagnosis] change your career direction?*

Mother A of Child A: *yeah. We sold the business...[raising Child A is] a job.*

### **6. b. Sub-category: stigma, community rejection and criticism of the child and of the parents**

Parents see stigma and lack of education in the community as the reason "different" people are not understood. The rejection reported by families with ASD and ADHD covers many areas: the children with ASD/ADHD -and their siblings- struggle to find schooling, friends, work-opportunities and shidduchim [marriage-prospects] in the community. Mother E of Children G, X, Y described negative community attitudes:

*within the kehilla [community]...there's no toleration with any of them [the family's children]...our child's got a bad name, and "your family and this that and the other"... [people] say we are a dysfunctional family.*

In addition, all the participants mentioned that revealing the ASD/ADHD diagnosis did not fully deflect criticism of the parents. Professionals or relatives criticised most parents for "labelling" the child and for their parenting methods; parents were aware their methods appeared deviant.

### **6. c. Sub-category: alienation from families with neurotypical children**

All parents perceived a lack of support from individuals within the community, with few real friends, who understand and help. Additionally, parents felt alien to the experiences of families with neurotypical children. This alienation, as described by Mother A of Child A, led to the use of the “alien planet” metaphor to describe life with ASD/ADHD:

*You don't get that our kids don't go upstairs to bed on their own...we don't realise how hard it is until you go visit someone with a neurotypical child, and they go, "...go to bed" and you get a shock. Twenty minutes later the child comes down, having had a shower, brushed their teeth, in pyjamas, and you go, "what?"...And you think, "no. no wonder you don't get what I go through".*

#### **6. d. Sub-category: parents experience discouragement and burnout**

Worry about the child's future, constant academic and socioemotional struggles, lack of social acknowledgement of the magnitude of the issue and rejection by the family's social circle, were described as causing discouragement:

Mother E of Children G,X,Y: *What's the point of asking anybody in this town? What's the point of asking for help?*

Some parents reported burnout and not using as many interventions as they felt they should for their child(ren) with ASD/ADHD. One parent spoke of “leaving it up to God”, of “having no fight left in me”. All parents reported burnout regarding their efforts to get benefits such as DLA [Disability Living Allowance] and a statement of SEN. As mother D of Children E,F summarised:

*I'm very tired of it...very burnt out.*

#### **6. e. Sub-category: Narrow school options; dissatisfaction with SEN support in community schools.**

Parents referred to their child's Religious Education [RE] as non-negotiable, and spoke of non-Jewish agencies underestimating the importance of their child's RE needs. Additionally, parents expressed their concern about finding schools that closely match the family's individual level of religious observance. Parents reported dissatisfaction with the narrow school options and the community schools' cliquey admission policies. Insufficient SEN provision was a concern shared by all parents, as Mother D of Children E,F reported:

*[The school] don't have particularly good teaching-assistants and certainly don't have anyone who's specialised [in ASD/ADHD].*

All the parents felt that teaching staff lacked awareness about ASD/ADHD. Particularly difficult manifestations of this were blaming the parents when the child's academic and socioemotional difficulties become obvious. As a result, the subject of

education was emotive, evident in explicit speech and, more implicitly, in non-verbal cues (in bold):

Mother A of Child A: ...and the (<0.1) *sssoring out school and all the rest of it...it depends on the school. We've had one school, one horrendous experience in a school, and now we've moved him and so far, [laughs and takes a deep breath], so far he's in a school that seem to get him*

And,

Interviewer: when you're looking at education for your children...

Mother B of children B, C and Z: oho, don't talk (>0.1)

*[Both laugh, sigh]*

## **Discussion:**

### **An explanatory theory of the experiences of orthodox Jewish parents of children with ASD/ADHD**

The findings of this study suggest an explanatory theory of the experiences of Jewish parents of children with ASD/ADHD. The core category around which aspects of the experiences revolve is *acceptance and awareness of the child's ASD/ADHD: a positive turning point*. Parents described their "journey" from confusion, anxiety, denial and secrecy while struggling with their child's overwhelming difficulties; their subsequent attempts to investigate the underlying cause of their child's issues, so they could better understand and help the child; the gradual and reluctant realisation that a clinical diagnosis is likely to be given to their child; towards acceptance of their child's ASD/ADHD diagnosis. This acceptance and willingness to acknowledge their child's ASD/ADHD is described by parents as the positive turning-point in their journey. The acceptance led to the parents' heightened awareness of ASD/ADHD issues, and triggered proactive measures on their part. Parents self-educated about their child's condition and were resourceful and independent in taking steps to help their child progress. This led to positive personal growth experiences and to the parents' ability to support other families through their ASD/ADHD journey.

A formal diagnosis, particularly that of ASD, triggered some change in attitudes outside the family, too. Schools, community charities, government agencies and service providers were reported as more willing to understand and to help once the child's problem behaviours were explained to them in terms of a disability and a clinical diagnosis. It would follow that revealing the child's diagnostic label is a useful

tactic, yet all parents acknowledged that disclosure of the diagnosis is problematic due to the importance of protecting the family's reputation and shidduchim, marriage-prospects, in the religio-cultural setting of the Orthodox-Jewish community.

In this environment, parents of children with ASD/ADHD report suffering from stigma-related prejudice due to their child's academic, behavioural and socio-emotional problems. Parents reported a widespread Jewish community trend of avoiding clinical diagnoses for ASD/ADHD -or keeping the diagnoses secret- in order to avoid prejudice and stigma. This trend is confirmed by Shaked & Bilu (2006; see also Starck, 2008).

On the issue of secrecy, half the parents acknowledged that their children's ASD/ADHD is readily observable in their conduct and that they require help. They therefore questioned the usefulness of keeping the diagnosis a secret. Given the prevalence rates of ASD/ADHD, it is likely that a significant proportion of Jewish families are experiencing ASD/ADHD issues but choose not to investigate the matter formally. This reflects a possible reluctance to involve governmental service agencies.

The discreet attitude within the community is reflected in the fact that out of 10,000 Orthodox Jews in Salford, only 5179 identified themselves as Jewish in the 2001 census. The reluctance to become formally known to the authorities may emanate from historical anti-Semitism and from the current high rates of local hate crime reported by Partners in Salford (2011). It follows that if close to 50% of the orthodox Jewish population were reluctant to disclose their existence to a government agency, there might exist a greater reluctance to report and liaise with authorities on taboo matters such as ASD/ADHD.

The evident problem experienced by the Jewish parents of children with ASD/ADHD who participated in this study is that of belongingness: compatibility with social values and status within a social group. It is a specific predictor of self-esteem (Gailliot & Baumeister, 2007). As evident in the hierarchical theory of motivation by Maslow (1954, in Alderfer, 1969), human needs begin with physiological survival, followed by self-esteem and belongingness. Accordingly, parents of children with ASD/ADHD, who fail to be compatible with the Jewish community's values of conformity due to their child's "difference", are thus deprived of the basic human need of belongingness. Therefore, the wish of some parents to be discreet about ASD/ADHD issues can be understood as an attempt at belongingness, and the existential pain of most parents, whose children's difference is readily observable, can be understood as well.

Can the stigma and alienation be resolved? Half of the parents hoped that public education campaigns, disclosure of ASD/ADHD diagnoses and involving community leaders will result in heightened community awareness and respect of children with ASD/ADHD. In the parents' experience, the missing factor regarding the community's attitude towards ASD/ADHD is *awareness and acceptance of ASD/ADHD*. Parents hope that the community's achieving of *awareness and acceptance of ASD/ADHD* will be a positive turning-point.

The core category of *awareness and acceptance of ASD/ADHD as a positive turning-point* seems the mediating factor in the matter of familial predisposition to ASD/ADHD. A research question arose while analysing the data: in the parents'

experience, is familial predisposition to ASD/ADHD a source of family support or a source of family stress? In families that achieved acceptance and awareness of ASD/ADHD in their young relative, the parents reported positive results. Family members' research and reflection on familial ASD/ADHD traits led to better self-awareness and acceptance between family-members, which the newly-diagnosed child benefitted from.

In contrast, families which did not achieve awareness and acceptance of ASD/ADHD were unable to support or understand the children with ASD/ADHD and their parents. The tendency of family members to have ASD/ADHD traits, coupled with their denial, was an adverse influence in the family's relationship dynamics. In answer to the research question, familial predisposition to ASD/ADHD is a source of support, provided that *acceptance and awareness of ASD/ADHD* are achieved.

### **Comparison of the results with existing research literature**

According to the inductive approach of grounded theory, a secondary literature review was carried out once the results were defined, to test the reliability of the findings (Silverman, 2006; Lyons & Coyle, 2007). The extreme difficulties in managing the child's everyday routines and self-help activities and the empathic role of parent support-groups are also apparent in US-based research by Banach, Iudice, Conway & Couse (2010). Parental denial, hesitation to obtain clinical diagnoses for children with ASD, the wish to reduce ASD-related stigma, and the benefits that disclosure of ASD diagnosis elicits, are similar to the findings by Russel & Norwich (2012), who interviewed parents of children with ASD in the UK. The parents' reports of lengthy diagnosis process; the need for support material such as information leaflets; and most importantly, the parents' need to have their concerns listened to, are main themes in the study by Braiden, Rothwell & Duffy (2006).

The parents' embracing the children's ASD/ADHD-related features, not only strengths but also quirky behaviours, and the wish for an individualised, positive approach to be applied in their education, matched some features of the social model of disability, which negates the definition of disabilities in medical and biological deficit terms (Anastasiou & Kauffman, 2011). However, the parents' views were not on the purely constructionist end of the scale, as all participants had also discussed their wish for their children's ASD/ADHD to be accepted as a disability so that they receive support.

In this study, parents did not supply clear rationales for the interventions they chose, and evidence-based practice was not a factor in their intervention choice. This is reflected in research showing parents of children with ASD chose interventions with no evidence base (Green, 2007), but instead based their decisions on their personal interpretation of the child's condition, for example: parents chose sensory therapy if they saw sensory integration deficits as the core issue of ASD (Shyu, Tsai & Tsai, 2010). Similarly, some Israeli orthodox Jewish mothers of profoundly-Autistic children saw Autism in spiritual terms, describing their children's souls as trapped in their body. Their choice of Facilitated Communication as therapy (the facilitator supports the child's arm and initiates communication via typing) reflected their wish to allow the child's body to give over divine messages from the soul (Shaked & Bilu, 2006).



The proactive action by parents described in this study is comparable to research about mothers of children with ASD engaging in problem-focused coping and the positive effect this had on their psychological well-being (Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008). On the other hand, Grey (2003) refers to higher maternal stress compared to maternal stress in families raising children with ASD, and suggests this is due to higher maternal contribution to their children's upbringing. Harte (2009) confirms that mothers are heavily involved with their child's education. As a result, despite problem-focused coping, mothers of children with ASD are chronically stressed. In a similar vein, in the current study, mothers reported burnout and discouragement. Since only one father participated in this study, a mother-father comparison was impossible. A mother-father comparison in the context of parenting Autistic children is of interest: evidence suggests that although fathers are less involved in daily interaction with their Autistic child, their unique interaction style –sharing activities such as household DIY, for example- can boost the child's communication through symbolic play (Flippin & Crais, 2011).

In general, most of the orthodox Jewish parent interviewees did report faith in God as a coping mechanism, and some spoke of spontaneous prayer, but all mentioned that the child's attending shul for prayers or the child's RE are stressors for the family. This is in line with findings by Ekas, Whitman & Shivers (2008) who found that, in a predominantly Christian sample, parents of children with ASD who interpreted the situation from a spiritual faith viewpoint had better socioemotional functioning. However, they found that religious activities did not positively correlate with socioemotional functioning. In a similar way was suggested that religious activities, such as attending church services with an Autistic child, are highly stressful.

### **Themes for further research**

Further research themes arose during the research, and can be examined in future studies. These include investigating specific factors in the experiences of Jewish parents of children with ASD/ADHD: The role of Jewish family size and of inter-family dynamics; parental experiences of burnout and possible mediators of the burnout experience; maternal versus paternal roles; and the factors underlying the parents' choice of interventions. From a genetic point of view, the prevalence of ASD/ADHD in the Jewish population is worthy of investigation, in light of the limited evidence suggesting a predisposition of ASD among Ashkenazi-Jewry.

### **Limitations**

There were several limitations to this study. Firstly, grounded theory guidelines (Silverman, 2006; Cooney, 2011) recommend multi-tiered stages of inquiry in which newly formed research questions can be explored further, which were beyond the scope of this study due to time restrictions.

Secondly, the sample size was limited to 6 participants, since at the researcher's undergraduate level, a larger sample size will have compromised the quality of the data analysis. Future studies in this topic will aim to recruit a larger sample to allow for more extensive testing of the theory, as recommended by Lyons & Coyle (2007).

Thirdly, the information given by the interviewees reflected their subjective experiencing and did not necessarily represent accurate facts. Their accounts may have been confounded by passage of time and by the emotive context of their experiences. This is particularly relevant in the descriptions of encounters with government agencies and schools.

Fourthly, as in any interview study, experimenter effects may have influenced the narrative, as the interviewee might aim to give answers to match what they perceive to be interviewer expectations. However, since the interviews were carried out from a person-centred approach, the effect will have been minimised.

Fifthly, the participants may not have been representative of the global parenting experiences related to raising children with ASD and ADHD in Jewish communities. British cultural influences might play a factor here, such as the widespread stigma towards mental health problems in the UK public (National Mental Health Development Unit, 2010).

Fifthly, the interviewees' experiences did not represent the apparently large parent group whom the parents referred to in their narratives as avoiding diagnosis and disclosure. Beyond religio-cultural reasons, such families might be driven by anti-psychiatry convictions, resisting the medical morbidity outlook on ASD/ADHD (Pilgrim, 2009). Naturally, families holding these views will be reluctant to participate in such a study. It is however evident in this study that the experiences of this group are better understood in light of the emerging theory.

### **Reflective analysis**

I acknowledge that data cannot be analysed from a purely neutral standpoint (Braun & Clarke, 2006). Therefore, my own background and my subjective experiences of carrying out this research are outlined below.

I am an orthodox-Jewish mother of three children, one of whom is currently awaiting assessments for high-functioning Autism and ADHD. My experiences allowed me to empathise with the interviewees, the one difference being that I had accessed peer-reviewed research about ASD throughout my study at the University of Salford. Still, the participants showed me practical, hands-on knowledge, experience, energy, determination and resilience, to the extent that I now see them as role models.

Prior to my decision to include inter-community problems in the report, I was torn between tribal loyalty to my insular community and the need to raise awareness to the experiences of the families. My personal hope is to see a change in the community's attitudes, and towards this end, I intentionally disclose and discuss my son's ASD/ADHD traits with acquaintances in the orthodox Jewish community. I experienced this study as personally and professionally significant to me.

### **Conclusion**

The two research questions can be answered as follows: the experiences of parents of children with ASD/ADHD within the cultural features of the orthodox Jewish

community in Salford were described as a journey to “planet ASD/ADHD” in which life is alien, difficult, unique and leading to personal growth. It is suggested that awareness and acceptance of the child’s ASD/ADHD is a positive turning-point in which all parents and families receive more social support and become independent, resourceful and more accommodating towards their child. Unique cultural features include stigma and lack of SEN support in light of RE needs, and it is hoped that community awareness and acceptance of the child’s ASD/ADHD will mediate this.

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