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## Maternal experience raising girls with autism spectrum disorder: a qualitative study

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### Abstract

**Background**—A growing line of research has sought to characterize the different presentations of autism spectrum disorder (ASD) among boys and girls. Much less is known about maternal experience and mother–child relationship in children with ASD based on child gender. The present qualitative study aimed to investigate the mother–daughter relationship from the perspective of mothers who are raising girls with ASD with normal intelligence and functional verbal communication.

**Methods**—Eleven in-depth interviews were conducted with mothers of girls with ASD, ages 10–19 years. Data were analysed in an interactive process commonly used in naturalistic inquiry. Results provide insight into the unique maternal experience of raising a daughter with ASD.

**Results**—Mothers reported a sense of exclusion from the neurotypical population and male-dominant ASD population and transformation in relationship. Themes identified were skepticism and delayed diagnosis, disbelief from others, lack of information about girls with ASD, higher social demands in adolescence, puberty challenges around hygiene, disappointment about physical appearance, vulnerability in relationships and worries about future functioning. The mother–daughter relationship started with an early expectation of a close and intimate relationship that then underwent a transformation, which challenged maternal competence, reshaped expectations and created a different bond between mother and daughter.

**Conclusions**—The findings in this qualitative study highlight the impact of gender on the maternal experience of raising a daughter with ASD and contribute to a better understanding of the needs of both mothers and daughters. These results can help providers support the mother–daughter dyad by recognizing gender-specific challenges.

### Keywords

autism spectrum disorders; females; maternal experience; mother–daughter relationship; qualitative

## Introduction

Girls with autism spectrum disorder (ASD) are in the minority, with US epidemiological estimates of 1 girl to every 4.3 boys with a clinical diagnosis of ASD (Fombonne 2009). With the increase in US prevalence rates from 1 in 150 in 2002 (US CDC 2007) to 1 in 68 in 2010 (US CDC 2014), there has been greater inclusion of individuals without intellectual disability (Baker 2002; Fombonne 2009). This group of verbally fluent individuals with ASD, who have normal intelligence also, has the highest gender skew, with a ratio of 1 girl to every 6 boys (Fombonne 1999). Historically, lower IQ was reported in girls compared with boys (Volkmar *et al.* 1993; Fombonne 2009; Frazier *et al.* 2014), but recent findings suggest that the gender differences may be less pronounced in younger individuals with ASD, high risk siblings and multiplex families with girls showing higher cognitive and language ability in the very young (Zwaigenbaum *et al.* 2012; Messinger *et al.* 2015; Reinhardt *et al.* 2015). It is also known that girls with ASD tend to experience higher rates of misdiagnosis and greater delays in receiving a diagnosis (Rivet & Matson 2011). Different biases have been suggested in sampling and diagnostic criteria and tools, influencing the rate and timing of ASD diagnosis among girls (Rutter *et al.* 2003; Giarelli *et al.* 2010; Kreiser & White 2014).

Even without these biases, it is possible that girls with ASD have a unique symptom presentation. The most consistent gender difference observed in the higher functioning ASD population is in the restricted interest domain. Girls with ASD have fewer ritualized routines and stereotyped mannerisms and have interests that are more similar to those of their peer group (Winter-Messiers 2007; Knickmeyer *et al.* 2008; Nicholas *et al.* 2008). Differences in the prevalence of psychological and psychiatric co-morbidities are less clear (Rivet & Matson 2011; Kirkovski *et al.* 2013). Girls with ASD tend to have more developed social skills than boys with ASD, which may contribute to the misdiagnosis and gender skew (Head *et al.* 2014). Human neuroimaging studies suggest that the brains of girls with ASD are qualitatively different than those of boys with ASD, with some whole-brain studies suggesting that girls with ASD present with a more masculine neural pattern (Lai *et al.* 2017).

In this study, we were particularly interested in the subgroup of girls who have functional communication, with average to above average intelligence, sometimes referred to as ‘high functioning ASD’, as this subgroup is often socially integrated with the neurotypical population. In the school setting, they tend to experience more social challenges, especially in peer relationships (Holtmann *et al.* 2007; Koyama *et al.* 2009; May *et al.* 2014) than boys with ASD. Girls with ASD also report more sexual problems and higher levels of sexual anxiety (Zamora *et al.* 2014).

Little is known about the mother–daughter relationship in children with neurodevelopmental disabilities, let alone ASD. Past quantitative and qualitative studies with predominantly male samples suggest that raising a child with ASD is challenging (Mugno *et al.* 2007; Hayes & Watson 2013; Corcoran *et al.* 2015), and the maternal experience often involves grief, frustration, feeling of incompetence and stigmatization (Mugno *et al.* 2007; Woodgate *et al.* 2008; Corcoran *et al.* 2015). A more limited line of research describes maternal positive

experiences, such as resilience and personal growth (Nelson 2002; King *et al.* 2006). The maternal experience may be even more difficult when raising a daughter with ASD, as previous research has found that parents of girls with ASD report higher levels of stress during the process of diagnosis (Siklos & Kerns 2007) and after the diagnosis as well (Zamora *et al.* 2014). Parents of girls with ASD tend to rate their daughters as more affected, possibly because of the larger gap between their daughter's behaviour compared with their female peer group (McLennan *et al.* 1993).

In the typically developing population, the mother–daughter relationship has always been seen as unique, complex and emotionally charged (La Sorsa & Fodor 1990; Lawler 2000), with gender differences in the relationship observed in the first days of life (La Sorsa & Fodor 1990; Weinberg *et al.* 1999; Keller 2002). Past studies highlight the importance of the mother–daughter relationship in the creation of a female identity (Hirsch 1989; Collins 1994; Mens-Verhulst 1995; Lawler 2000). The transition to adulthood for typically developing female adolescents involves leaving the parental home, starting a job, marrying and having children (Fussel & Furstenberg 2005). Mothers of youth with developmental disabilities tend to be more concerned about basic life skills and social adaptation rather than individualism and independence (Lehmann & Roberto 1996). Furthermore, the child's level of social impairment, behavioural problems and cognitive disability as well as maternal level of pessimism, all impact the quality of the mother–child relationship (Orsmond *et al.* 2006).

Raising a daughter with ASD presents a distinct challenge because of the intersection of autism symptoms with the cultural expectations of female identity development (Kreiser & White 2014, McLennan *et al.* 1993). The only previous study that has examined the maternal perspective in a population of adolescent girls with ASD found that mothers had mixed feelings related to the diagnosis, encountered significant challenges when their daughters experienced puberty and had concerns regarding emerging sexuality and romantic interests (Cridland *et al.* 2014). While this study highlights some gender-specific challenges in raising a daughter with ASD, the focus was on the daughter's experience, and mother–daughter relationship was not examined.

The present study aims to investigate the maternal experience of raising a daughter with ASD, by examining the maternal perspective starting with the initial expectation early in the mother–daughter relationship and then considering the impact of diagnosis and disability throughout early childhood and adolescence on the mother–daughter relationship. This is a qualitative exploration of the female gender in the context of mothers raising daughters with ASD and normal intelligence.

## Methods

### Participants

Biological primary caregiver mothers were identified from prior interest in or participation in research within our Institute. Eleven mother–daughter dyads participated. All mothers were Caucasian and non-Hispanic, and all completed some college or more. Families were diverse in economic status (family income range from \$32 000 to \$150 000 a year), with all mothers working part or full time. Families came from diverse geographical locations with

some living in an urban environment and others in small towns and rural areas. Nine mothers were married to the daughter's biological father, one was divorced/remarried; and one was divorced/single. Age at conception of the daughter for mothers was 31.1 years (SD 2.3, 27–35 years). Mothers reported having either two (9/11) three (1/11) or four (1/11) biological children.

Daughters with ASD were between 10 and 19 years old at the time of their mother's interview (mean age: 14.8 years, SD 3.3). At time of participation in this study, all daughters had a clinical diagnosis of ASD and were reported as having functional and fluent verbal language. Of note, 10 of 11 girls had received a research diagnosis of ASD [using the autism diagnostic observation schedule module 3] through participation in a prior study. In addition, nine girls had participated in the NIMH Autism Center of Excellence GENDAAR study (R01 MH10028). No girl was reported as having significant hearing loss or visual impairment, seizures or other major medical concerns. autism diagnostic observation schedule calibrated severity scores were within the ASD range ( $M = 5.9$  SD 2.0, 4–9), and verbal IQs ( $M = 105$  SD 19, 69–129), nonverbal IQs ( $M = 102.7$ , SD 22.7, 73–140) derived from the Differential Ability Scales-II, reflected a broad range of capabilities. Parent report suggests that the girls also had other clinical concerns including depression (2/9), anxiety (6/9), self-injurious behaviour (2/9) but did not have diagnoses of bipolar disorder, schizophrenia or Tourette syndrome ( $n = 0/9$ ).

## Procedure

This study was approved by the local institutional review board. Mothers provided written consent for participation. A semi-structured interview, based on themes identified in previous studies exploring parental experience (King *et al.* 2006; Woodgate *et al.* 2008; Corcoran *et al.* 2015), was developed for the purpose of this study. Follow-up questions were specific to the individual answers provided. The interviews were conducted in person, by an experienced child psychiatrist (N. N.), either at the mother's primary residence ( $n = 8$ ), at our behavioural laboratory ( $n = 2$ ) or by phone ( $n = 1$ ). Each interview lasted about 90 min and was audio-taped and then transcribed. Transcriptions were made by undergraduate research assistants and checked for accuracy by two independent reviewers.

The interview was designed to explore the maternal experience raising a girl with ASD from early childhood to present, and the impact of ASD on the mother–daughter relationship. The interview included questions about mother's expectations early in her daughter's life, the onset of symptoms, the process of diagnosis, past and present school experiences and the impact of the diagnosis on the mother–daughter relationship.

## Data analysis

Data were analysed in an interactive process commonly used in a naturalistic inquiry (Erlandson *et al.* 1993), in which researchers aim to investigate a deep and full meaning of the informant's experience of a particular phenomenon. Data collection and analysis were carried out in concurrent and integrated steps. Two of the authors (N. N. and A. J.) independently read, re-read and examined the transcripts for identifiable themes. Responses were coded and grouped into categories on the basis of their thematic similarity. Categories

considered to represent key themes within the data were elevated to the status of ‘concepts’ and will be discussed. New data were continually compared against codes that had already been developed in order to find points of similarity and divergence. Throughout this process, the first author kept memos of observations and reflections.

## Results

Results were grouped into two main sections: (1) maternal experience of raising a daughter with ASD and (2) impact of ASD on the mother–daughter relationship. Themes of each section are described, accompanied by illustrative quotes. Names were redacted and replaced with the individual’s role in the family (e.g. ‘child’ refers to the daughter with ASD). Quotes are provided in Tables 1 and 2.

### Maternal experience of raising a daughter with ASD

**Skepticism and delayed diagnosis**—Despite early concerns, 9 out of 11 girls in our sample were diagnosed after the age of 6 years, with four being diagnosed after the age of 10 years. Most participants (9 out of 11) described consultation with a paediatrician about their early concerns and encountered skepticism that there was a problem. Later, concerns of teachers and maternal insistence, eventually led to a diagnostic evaluation. When the ASD diagnosis was finally given, most mothers reported feeling both sad and relieved.

**Disbelief from others**—Family and friends were skeptical of the diagnosis. Many of these doubts seemed to be connected to traditional female characteristics. One mother’s experience was having others not believe the diagnosis because her daughter was ‘so cute and chatty’. Some mothers experienced skepticism and denial from others because of biased expectation that ASD was a disorder of boys.

**Lack of information**—Mothers reported few opportunities to gain knowledge about girls with ASD. Some mothers described how the lack of scientific information and clinical experience of providers regarding girls with ASD affected their ability to understand their daughter’s needs and to feel competent as mothers.

**Increasing social demands with adolescence**—Many mothers described how the school environment became more challenging and harder to navigate as their daughters moved into adolescence. They noted that the expectations for social functioning seemed to increase with adolescence, particularly for girls. Several mothers emphasized their role in helping their daughters confront those challenges.

**Struggling with puberty and hygiene**—Our sample consisted of mothers of girls (aged 10–19 years) who were experiencing challenges related to puberty. Mothers reported how the changing female body was difficult for their daughters. This included specific challenges with menstruation and hygiene. One mother noted different social expectations in hygiene based on gender.

**Disappointment about physical appearance**—Most mothers also described how their daughter’s restricted food preferences, which were challenging to manage during earlier

years of childhood, became even more challenging during adolescence with concerns about excessive weight gain. Many mothers described worry and disappointment about their daughter's physical appearance, which did not meet societal standards of feminine beauty.

**Sexuality and vulnerability in future relationships**—Mothers expressed concerns about not only their daughter's ability to be part of a romantic relationship but also their ability to identify predatory sexual behaviour and take care of their own safety.

**Worries about future functioning**—Mothers reported difficulties navigating their daughter's need for independence (typical of adolescence) because of the daughter's limited ability to handle complex social demands independently (specifically related to having ASD). They were worried about whether their girls would be able to live independently, hold a job, maintain a relationship and have a family of their own. Many mothers were concerned that the already limited occupational options for ASD individuals would be even more limited for their daughters. Some daughters expressed a desire to never be mothers themselves, which provoked sadness in their mothers.

### Impact of ASD on the Mother-Daughter Relationship

**Early expectations of close connection**—Most mothers had a positive early vision of the mother–daughter relationship. Some described a desire to have a close relationship that would provide understanding and intimacy, similar to the one they had with their own mother or sister.

**Guilt and grief due to late diagnosis**—Mothers described feelings of guilt and grief about the delay in diagnosis and receiving services that contributed to their critical and negative attitude toward their daughters.

**Adjusting to the difference in early expectations and reality**—Many mothers described how their expectations for intimacy were not fulfilled. Mothers had to form a relationship with their daughters that was very different from their early expectations. Some mothers thought that assisting their daughter with ASD-specific challenges was an important part of their motherly role. Others described a sense of helplessness and incompetence even when they did their best to support and understand their daughters.

**Different quality of the mother–daughter relationship**—Most mothers described a painful process of reshaping their expectations and adapting to a relationship that was different to the one they expected. Of note, several mothers reported a positive transformation in the relationship after the ASD diagnosis that allowed them to better understand their daughter. When mothers reflected about the changes in the quality of relationship with their daughters through the years, they identified a different kind of bond, compared with the bond they had expected.

## Discussion

The data collected in our broad qualitative investigation provide insight into the unique challenges of raising a daughter with ASD and the mother–daughter relationship. In the



neurotypical population, the gender of the parent and the child impacts social interactions, feelings of obligation, degree of intimacy and the extent of help exchanged between generations (Rossi & Rossi 1990). Our findings suggest that gender also influences the experience of raising a child with ASD and that the maternal experience of raising a girl is different from past reports about raising a boy with ASD (Orsmond *et al.* 2006; Lounds *et al.* 2007). Our data also indicate that gender-related characteristics of maternal experience impact and interact with the evolving mother–daughter relationship throughout early childhood and adolescence. The concept of exclusion dominates the maternal experience of raising a daughter with ASD. To be a girl with ASD is to be twice excluded, once from the neurotypical female population and once again from the ASD community (Shefcyk 2015).

The mothers in our study identified multiple disparities in care. There was a lack of recognition of ASD red flags by paediatricians, which led to later referral for evaluation and diagnosis. Furthermore, there was a high level of disbelief among friends and family members in responding to their daughter’s diagnosis. The lack of scientific data about girls with ASD left mothers without resources to understand their daughter’s symptoms and challenges. All of these factors negatively impacted their sense of parenting competence. This is consistent with previous research that has shown that parents of children with ASD often report feelings of incompetence. In prior reports, these feelings have been linked to non-optimal parenting, failure to engage with services and higher rates of both child and maternal psychopathology (Zablotsky *et al.* 2013). Conversely, a mother’s confidence in her ability to parent her child in challenging situations has also been correlated with lower stress levels and a better sense of well-being (Dunn *et al.* 2001; Kuhn & Carter 2006).

The concept of transformation dominates maternal perspective on their relationships with their daughters. Mothers identified their own gender-related expectations about having a daughter. They were expecting an intimate and close relationship that would result in a shared female identity (e.g. Fox 1990). The reality of raising a daughter with ASD was very different. Many of the daughters had difficulty comprehending their changing bodies, social conventions related to hygiene and beauty, and possible futures roles as wives and mothers, all components of the female identity (Fullinwider-Bush & Jacobvitz 1993). Rejection of these components created a deviation from the early vision of shared female identity. Some mothers expressed sadness and hope for change, while others expressed understanding and acceptance of the different paths awaiting their daughters. Many recognized the need for finding new ways to feel close to the daughters and to replace the projected intimacy of their early expectation.

Most mothers in our paper were dealing with unique challenges of female adolescence. Mothers described that as their daughters entered adolescence, the gap in social skills from their neurotypical peer group widened. Many mothers reported struggling with feelings of incompetence and helplessness when trying to provide their daughters with the emotional support to manage increasing social demands.

Separation and self-definition are considered the two main tasks of adolescence (La Sorsa & Fodor 1990). Adolescent girls and their mothers ideally go through a process that moves them from a relationship that is characterized by dependence, to one that is interdependent

and then ultimately independent (Kenemore & Spira 1996). The daughters in this study had difficulty comprehending complex social situations, which challenged the typical process of differentiation and individuation of adolescence.

Mothers reported difficulties as their daughter progressed through puberty. Even in the neurotypical population issues related to puberty are common and challenging to most mother–daughter dyads (Marceau *et al.* 2015). Communication around menarche and menstruation, for example, was shown to be negative in tone and negatively affect mother–daughter relationship (Costos *et al.* 2002). Mothers of girls with ASD reported that while their daughters were physically maturing, there was a greater gap between their daughter’s behaviour and cultural expectations of the female identity.

Maternal worries about sexuality and vulnerability in romantic relationships are well founded. Sexual and physical abuse has been shown to be more common among girls with disabilities, especially those with autistic traits (Brown-Lavoie *et al.* 2014; Roberts *et al.* 2015). Research has also shown that youth with ASD is more likely to be bullied. Furthermore, attending public school and experiencing high levels of maternal stress are risk factors for being bullied (Weiss *et al.* 2015; Hebron & Humphrey 2014). Adolescent girls with ASD therefore seem to be in a higher risk group for victimization. As such, maternal stress is a component in a potentially vicious cycle in which their daughter’s vulnerability increases maternal stress, which further increases their daughter’s vulnerability.

Maternal concern about future functioning is also warranted. Mothers in this study thought that occupational opportunities for their daughters were likely to be limited. Youth and adults with ASD with average to above average intelligence are less likely to attend college, live and work independently or have daytime activities relative to those with intellectual disability, and many youths with ASD do not reach those milestones (Taylor & Seltzer 2010). The maternal perspective in this study is consistent with the literature showing that girls with ASD tend to be underemployed (Alverson & Yamamoto 2016; Taylor & Seltzer 2011).

## Limitations

Answering the question ‘What is it like to parent a daughter with ASD?’ would be further strengthened by including the perspective of minority and less resourced families. Also, including father–daughter dyads would allow a better understanding of overall experience of parenting daughters with ASD. Further, interviews were conducted at one time point, and this design does not allow for understanding changes over time of the maternal perspective.

## Conclusions

This qualitative investigation provided insight to the unique experiences and relationship among mothers and their daughters with ASD. Girls with ASD and normal intelligence form a unique group. They are faced with the social expectations of being girl while dealing with a specific disability in social communication skills. Our findings highlight impact of gender on maternal experience of raising a daughter with ASD and the evolving mother–daughter relationship. These findings contribute to a better understanding of the characteristics and



needs of the mother–daughter dyad, which can help providers support the gender-specific challenges of raising a daughter with ASD.

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### Key messages

- The qualitative data collected in this study showed that the experience of raising a girl with ASD is different from the experience of raising a boy with ASD.
- Gender-related characteristics of maternal experience impact and interact with the evolving mother–daughter relationship.
- A sense of exclusion once from the neurotypical female population and once again from the ASD community dominated maternal experience and affected maternal sense of competence.
- Puberty and adolescence are especially challenging because of the higher level of social expectations, difficulty in accepting changing body and difficulty navigating dependence and independence.
- The mother–daughter relationship started with an early expectations of a close and intimate relationship that then underwent a transformation, reshaped expectations and created a different bond between mother and daughter.

Table 1

## Maternal experience of raising a daughter with autism spectrum disorder

Skepticism and delayed diagnosis	<ul style="list-style-type: none"> <li>• ‘We started bringing concerns with our pediatrician really early. A lot of times they were like, oh, she is a late bloomer, but I still felt like there was more going on’.</li> <li>• ‘I kept asking to have her evaluated, but with her being a girl, it was even less likely that the pediatrician would refer us. I remember her saying that this is usually a boys’ thing and she is only a little different’.</li> <li>• ‘As the years went by I researched more. I kept asking for more and more tests because she appeared to be so very normal to most people but if you hung out with her for a while, there were just things that were so different’.</li> </ul>
Disbelief from others	<ul style="list-style-type: none"> <li>• ‘Most people, once I said, she got Asperger’s, would look at me like they didn’t believe me. When she was younger she was so cute and so petite and so doll-like that everybody just thought: “She is adorable, what are you talking about?” That cute charming-ness chattiness about her, people don’t associate with autism’.</li> <li>• ‘We live in a small town. Most people don’t know anyone that has autism, and if they do it’s probably going to be a boy, because autism is sort of a boy kind of issue. And my daughter was so sweet and people would just say, “What’s your problem? Why are you labeling her?”’</li> </ul>
Lack of information	<ul style="list-style-type: none"> <li>• ‘There isn’t much evidence or research for girls on the spectrum as there is for boys. That leaves you hanging a lot and asking how I will be able to support my kid?’.</li> <li>• ‘I had a hard time finding information that would help me because she was a girl. Everything I read was so much about boys. It was so frustrating and irrelevant. There was just nothing there that could help me figure her out.’</li> </ul>
Increasing social demands	<ul style="list-style-type: none"> <li>• ‘Now that Child is almost 15, she is expected to get dressed in a way that somehow fits in. She hates shopping and cares only if her clothes are comfortable. So I have to buy her stuff and to make sure that she fits in and doesn’t stand out in what she wears’.</li> <li>• ‘I think that expectations are different for boys and girls and that’s worries me a lot. She is expected to be social, to be involved in girls talking, to be tactful and she is not and will never be. It gets harder as she grows up’.</li> <li>• ‘Most girls her age is constantly on the phone, talking and texting, hardly showing their face and she has no one to call to... I think her, as a girl, being always alone, is more heart breaking. I don’t really know why, but that’s how I feel’.</li> <li>• ‘In fourth grade, she could read and comprehend at college level but the public school kept saying that they didn’t know what to do with her. They had never seen anything like this. And no one asks her to do things or to hang out. She was never invited to sleepovers. So, when we went to our college tour she met this boy who is very much like her, very quirky. He invited her to the prom in Another state. So, I flew her there and we went, because she’s never been invited to anything in her life, and she got to go to a prom with a guy’.</li> </ul>
Struggling with puberty and hygiene	<ul style="list-style-type: none"> <li>• ‘The hardest part is puberty. She does not like having her period, having breasts. She does not want to have kids. Everything with growing up and becoming a woman she does not like. I just tell her that this is part of life and try to make it a positive thing.’</li> <li>• ‘Every time I have to remind her ... go get a new pad on, go soak this, go wash that. You know you are going to start feeling cranky because your cycle is coming, you have to be prepared for that. I even put her on the pill so she can easily remember her period.’</li> <li>• ‘She is not taking care about her hygiene without being told. I keep on telling her, you just worked out, you really smell. Do I care more because she is a girl? I guess to some extent’.</li> <li>• ‘When a boy gets on the bus, smelling after soccer practice it’s not a big deal. It’s acceptable. When a girl has all her shirt wet and she smells, well, that’s unacceptable. I am not sure what I just said fits a feminist attitude, but this is life. I don’t want people looking at her. I can’t let her go around like this’.</li> </ul>
Disappointment about physical appearance	<ul style="list-style-type: none"> <li>• ‘When I am helping her bathe, I noticed her hips have stretch marks and around her breasts. She is basically my size, but a couple of inches shorter. It is a whole other adult in the house. And part of me is not only worried about the health consequences of gaining weight but also frustrated and disappointed because I wanted her to be thin and pretty. To buy her all those amazing summer dresses’.</li> </ul>



- ‘When she was little she was picky and then she narrowed her diet and it’s excessive. All she eats is Cheese-it and Gold fish ... if we go out to someone’s house, she just won’t eat. The same at restaurants. If they don’t have chicken strips or Pizza she just won’t eat. So that’s a problem. It’s a problem socially ... we did nutritional therapy and it was very unsuccessful. So she was really skinny, crazy skinny and now that she has a lot more freedom and with her driving license ... she is eating a lot more carbohydrates and sugar and she is also ... she is very large chested and that made it very hard for her to exercise because she is very uncomfortable. So that combination ... she used to be extra thin, pretty and fit ... until she passed puberty and now she is gaining weight’.

Sexuality and vulnerability  
in future relationships

- ‘The whole issue of boys and dating makes me very nervous. I worry that she will be taken advantage of. She doesn’t pick up on those cues and that’s a huge concern. And I don’t even know what to do about that. I don’t trust in her ability to look critically at somebody or look objectively at someone’.
- ‘She is very naïve and trusting. And voluptuous. She shouldn’t have that type of body. She is very beautiful. That wouldn’t be a problem if she would have been a boy’.
- ‘She states that she doesn’t want to get married. It’s pretty unusual not to want a boy to affirm your existence. She makes a lot of friends online, which is less threatening for her. I do hope that college will allow interaction with young man that will give her opportunity to learn whether or not this is something she wants to pursue’.
- ‘She wants to be able to go to her friends’ house. She wants to spend the night. She wants to go with people who love her. She wants to be out there, doing what her friends are doing, and so we are already sort of not letting her do everything. But I think that’s going to be enhanced, as she grows older. How do we explain that to her in a way that doesn’t just set her on a path that she is not fearful to be out there? That she doesn’t want to get away from me? She talked to me about running away when she was really young, like 4 or 5 years old. She ran away and lived in a bricked house’.

Worries about future  
functioning

- ‘It’s easy to say, oh, here is a boy with Asperger’s and he likes working on the computer so we will teach him how to do that and he will end up working in Microsoft. I don’t know if there is enough support to help girls be successful. I think with girls, their heart is wired differently, and you can’t apply the same approach to a boy on the spectrum and a girl and teach them in the same way. Is the best she is going to be is a cashier?’
- ‘I wanted her to have children. That was the hardest thing just to flip back. When Child found out that she was autistic, she never wanted to have children because she doesn’t want to pass that down’.
- ‘She doesn’t see herself ever having children. I can’t envision it either in my mind. It makes me sad but I try to put it away. I want her to have someone that she loves that she can really be close to’.

Table 2

## Impact of autism spectrum disorder on the mother–daughter relationship

Early expectations of close connection	<ul style="list-style-type: none"> <li>• ‘I really wanted to have a girl first, and was overjoyed when I found out that I was going to have a girl because as long as I have one girl I will be happy. I will have a hundred boys and I just want one girl. I am very close to my mom and my sister and that relationship is very dear to me. I knew I wanted the same with my own daughter’.</li> <li>• ‘I wanted mostly girls because I like girls. I wanted to have a daughter that likes the same kind of stuff that I do, someone that is fun to play with and dress up. Someone that will be close to me and I will be able to share stuff with, that I can really relate to, that understands me... I was hoping that we will be best friends and when she grows up we will stay close all the time’.</li> <li>• ‘The gender did not matter to me but when I found out that I was going to have a girl, I was hoping we would be really close, share things and understand each other’.</li> </ul>
Guilt and grief due to late diagnosis	<ul style="list-style-type: none"> <li>• ‘She was 13. Let’s face it. Those kids are usually diagnosed at around 3, 4. We lost 10 years. What are we going to do? How are we going to make up for these lost years? For 10 years she was treated like crap. You can’t explain it otherwise. What the girl had to listen to I mean when you are 12 and the doctor tells you, you are going to go to jail ... the school psychiatrist says you are lazy and spoiled rotten ... what was going through that brain?’</li> <li>• ‘I didn’t listen to her. She would just say how she hated school and how she hated visiting my parents and how loud everything is I forced her to do all those things. I arranged play dates for her and forced her to go and of course it just made things worse. It was a total failure. And then I got so angry. I was actually furious with her for years Although things are very different today, I can’t just push the delete button and pretend that it didn’t happen. We both know I didn’t listen’.</li> </ul>
Adjusting to the difference in early expectations and reality	<ul style="list-style-type: none"> <li>• ‘I had a really hard time accepting it. It wasn’t the daughter I imagined. It wasn’t the girl of my dreams. She wasn’t a little princess’.</li> <li>• ‘I don’t feel we could ever be really close because I don’t think she can be like that. I wish I knew more about how she feels. With her, it’s not the best friends I imagined. If I was having a really bad day, I might mention it a little bit to her but it wouldn’t be a heart to heart’.</li> <li>• ‘Sometimes I feel so helpless. A mom that is unable to help her daughter figure out the most basic stuff about herself. I would really like to help her understand and manage her own impulses and distractions and I don’t know how to do that. The way she thinks and responds is so different, so unlike me’.</li> <li>• ‘The biggest fear is that she would leave and not allow me be part of her life. She is very good at isolating herself and she is much happier when she doesn’t have to deal with anybody’.</li> <li>• ‘When she was three, nobody could understand her. She kind of developed her own language but I could understand her. I quit my job for about 5 years just trying to get this child to talk. I spent a lot of time just teaching her things and repeatedly teaching her things. Things she needs to know and only a mom can teach. And now, she gets depressed every once in a while. It might sound weird but every time she has gotten severely depressed, it’s like this connection we have between her and I. I just know it, something is not right’.</li> </ul>
Different quality of the mother–daughter relationship	<ul style="list-style-type: none"> <li>• ‘I think that what I wish Child and I had, like being able to have a deep conversation, that we will most likely never have. I think now I am OK with that because I understand her better. Of course there is a part of me that is sad and I wish I could understand more of her’.</li> <li>• ‘With her it’s much more logical of a relationship. It’s kind of a different quality. Our friendship has been built through logic. I could imagine Child and I travel together, because of her work or from my work, but we won’t necessarily be emotionally close’.</li> <li>• ‘Our relationship changed a 100% when she was diagnosed. I used to be angry all the time but then I started to understand. I knew she was trying. I didn’t before she was diagnosed. In a way, the diagnosis allowed me to become the mother I wanted for her. I was able to listen to her differently and help her thrive. So, the type of conversation we have is different but it is so meaningful for both of us. I try to keep my mental needs up and appreciate what we have got.’</li> </ul>