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ORIGINAL ARTICLE

Autistic People's Perspectives on Parental Diagnosis Disclosure: A Grounded Theory Study

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Abstract

Being diagnosed with autism has multiple implications for a person's life and self-identity. Although learning about autism at a younger age is correlated with quality of life, only a few studies have addressed parental disclosure thereof. This study conceptualizes autistic adults' perspectives on parental disclosure. The methods combine grounded theory with the emancipatory research paradigm, drawing on autistic people's personal knowledge. Eighty-five autistic adults participated in six focus groups (51 male, 33 female, 3 non-binary; $M_{age} = 25$); and 41 autistic adults were interviewed (22 male, 17 female, 2 non-binary; $M_{age} = 28$). Both focus groups and individual interviews addressed the way participants learned about their diagnosis from their parents, and their recommendations to other parents on how to disclose. Based on these findings, we developed autistic-driven recommendations for parental disclosure process. The participants viewed the diagnosis as validating their experienced otherness, helping them overcome shame, and promoting their self-understanding and self-advocacy skills. They recommended disclosure as soon as possible after diagnosis and stressed the importance of gradual disclosure according to the child's abilities. Furthermore, they suggested focusing on how autism manifested in the child's own life, rather than "autism" in general. Finally, they recommended presenting autism as a neutral or positive quality, highlighting its strengths and networking the child with other autistic individuals. In conclusion, this study reveals that parental disclosure is an ongoing and spiral process. The proposed model contributes significantly to post-diagnostic support for parents, providing a framework for effective communication about autism with their children.

Keywords Diagnosis · Parental disclosure · Disclosure delay · Identity · Emancipatory research paradigm

Introduction

Disclosure of autism diagnosis becomes complex when involving children. Parents of autistic children struggle when and how to reveal the diagnosis to their children, due to concerns with social stigma and fear that the child would misunderstand the diagnosis (Crane et al., 2019). Indeed, autistic people report that diagnosis disclosure by their parents has been delayed during childhood (Huws & Jones, 2008; Riccio et al., 2021; Smith et al., 2018). Parental disclosure requires considering the emotional impact, timing, and potential stigma associated with the diagnosis, as well as the child's own understanding and self-disclosure. The child and parent need to engage in recurring conversations concerning the implications of the diagnosis for the child's present and future life (Smith et al., 2018). Autistic adults report that the disclosure has also been followed by an adjustment process of revaluating their lives and developing an understanding of autism and themselves, followed by self-acceptance that improved well-being (Cooper et al., 2021).

While the benefits of knowing one's diagnosis have been established (Cooper et al., 2021; Jones et al., 2014; Oredipe et al., 2022), the practice of disclosing autism diagnosis to children and adults remains underdeveloped (Corden et al., 2021; Crompton et al., 2022; Leung et al., 2023). This article presents the second part of a study on autism disclosure delay and offers a model for disclosure to autistic children and adolescents. While the first part offered a model mapping parents' dilemmas and factors hindering or promoting disclosure (Almog et al., 2023), this part proposes in-depth

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understanding of the perspective of autistic adolescents and adults and offers recommendations regarding disclosure for both parents and professionals.

General Implications of Parental Diagnosis Disclosure

Several studies have dealt in general with parental diagnosis disclosure and its implications for autistic children and adults (Smith et al., 2018). Receiving such a diagnosis may be followed by positive reactions such as relief, as well as negative ones such as shock, disappointment, and difficulty coming to terms with the new identity (Huws & Jones, 2008; Jones et al., 2014). After diagnosis is disclosed, a learning process about oneself begins, involving cognitive, behavioral, and emotional aspects. Parents have reported improvement in the child's self-understanding of their strengths and weaknesses, as well as in their self-advocacy skills. The ensuing adjustment process also includes a research phase, in which the individual seeks more information about autism from the media, support groups, family, professionals, and other autistic individuals (Corden et al., 2021; Kiely et al., 2020).

Corden et al. (2021) examined the impact of disclosure on the sense of self, and found that feelings of dissatisfaction decrease as the years pass following the diagnosis, with participants feeling more satisfied with being autistic. In addition, greater dissatisfaction with one's autistic identity predicts lower self-esteem, while autistic pride predicts higher self-esteem. Riccio et al. (2021) found that autistic adolescents who had been voluntarily informed of their diagnosis by their parents tended to incorporate their unique strengths into their personal definitions of autism, compared to adolescents whose parents had not told them about the diagnosis, or had told them involuntarily. Oredipe et al. (2022) examined the effects of autism disclosure on well-being and quality of life (QoL) in a sample of autistic university students, and found disclosure at a younger age was associated with higher well-being and QoL. In contrast, Leung et al. (2023) examined a more socio-demographically diverse sample of autistic adults, and found that age of disclosure did not predict QoL and well-being in adulthood. Rather, having more autistic traits was a strong predictor of poorer outcomes. Their findings suggest that further research should focus be on *how* a diagnosis is disclosed or how one learns about being autistic, as well as on the social-emotional support the individual receives during and following disclosure.

Talking with Children about Autism

Despite the acknowledged advantages of disclosing the diagnosis of various disabilities, and the specific advantages of disclosing autism diagnosis as described above, there is a dearth of research regarding the how the latter should be disclosed to children and adolescents (Kiely et al., 2020; Riccio et al., 2021; Smith et al., 2018). Diagnosis is not disclosed in a single moment. Rather, it is a developmental process and has a spiral nature: it is not a one- time event. Kiely et al. (2020) examined 575 parents of autistic adolescents and found that those who disclose the diagnosis to their child reported having at least five conversations about autism. During these discussions, parents addressed various topics: how autism affected their child's strengths and weaknesses, how it could affect their future, and the potential causes of autism. Furthermore, many parents shared information with their child about other autistic individuals, including those they knew personally, celebrities, and fictional characters. Most used at least one informational resource to help their child understand the diagnosis.

Oredipe et al. (2022) asked autistic university students when and how they would "tell their own autistic child about autism?" The participants offered several recommendations, such as considering the child's developmental level, curiosity, and personality, but all emphasized the importance of early disclosure. They also recommended consulting with other autistic individuals.

Disclosing before adulthood leads to the formation of a less conflicted identity, with autism becoming an integral part thereof. Disability identity is both individual and communal, based on common experiences of exclusion (Forber-Pratt et al., 2017). Oredipe et al. (2022) found correlation between social identification with autism and personal self-esteem, mediated by collective self-esteem. In another study, participation in support groups in the autistic community was correlated with improved self-esteem after disclosure (Kiely et al., 2020). Given that autistic individuals commonly report poorer mental health than average (Cage, 2021), having a positive autism social identity appears to offer a protective influence (Cooper et al., 2017). Thus, it is extremely important to help autistic children develop self-advocacy skills and embrace a sense of positive autistic identity (Sterman et al., 2022).

While most studies examining parental diagnosis disclosure to a child focused on the parents reflecting on their own experience (Cadogan, 2015; Crane et al., 2021; Finnegan et al., 2014; Kiely et al., 2020), or on post-disclosure experiences of autistic adults (Cooper et al., 2021; Corden et al., 2021; Crompton et al., 2022), to the best of our knowledge no other study has offered guidelines for disclosure from the perspective of autistic people.

How to disclose the diagnosis is a major dilemma parents face, and lack of professional guidance hinders them from disclosing (Almog et al., 2023). Given the lack of research on the impact of providing explicit education to young autistic individuals regarding their diagnosis, the scientific community needs to develop evidence-based guidelines to support autistic children and their parents in this process (Kiely et al., 2020). Several autism organizations have developed written resources and toolkits for that purpose (e.g., National Autistic Society, 2020), but since these do not report the methods used to develop their recommendations, it is unknown whether these methods are evidence-based.

To improve mental health in the autism population, clinical approaches should foster positive autism identities (Cooper et al., 2017). The current research is informed by autistic adolescents and adults as experts by experience. The purpose of this study is theoretical as well as practical: to explore and conceptualize the perspectives of autistic individuals regarding parental disclosure in order to develop guidelines on supporting autistic children, their parents and professionals in this process, with a focus on fostering positive autism identities.

Methodology and Research Design

This study combines the grounded theory approach (Charmaz & Thornberg, 2021) with the principles of the emancipatory research, enabling the production of accessible and valuable knowledge about structures that reproduce barriers encountered by people with disabilities (Barnes, 2003). Autistic individuals describe unique insights given their lived experience and should accordingly be considered expert partners in autism research (Gillespie-Lynch et al., 2017), and key sources in perspectives and contributions for qualitative research (Grant & Kara, 2021).

Participants

Eighty-nine participants were included. Below, we provide their demographic data, divided into focus group and personal interview participants. Participants were asked to decide whether they wanted us to use their real names or pseudonyms, as some were activists in the Israeli autistic community and found it important to be represented by their real names.

Focus Group Participants

Sixty-eight individuals aged 13–54 participated in the focus groups. Forty were men, 26 were women, and two defined themselves as gender queer (see Table 1 for additional details). The inclusion criterion for the focus groups was a desire to discuss diagnosis disclosure. While some participants shared experiences extensively at the focus group, others hardly spoke (see Table 1).

Personal Interviews

Forty participants were interviewed personally; 19 were recruited through focus groups and 21 were recruited in other ways. The inclusion criterion for the interviews was the desire and the ability to talk about the diagnosis disclosure. For children under the age of 18, parental consent and participation throughout the interview was required.

The participants were divided into three groups according to the way they discovered their diagnosis – disclosure delay during childhood (1), immediate disclosure during childhood (2), or diagnosis during adulthood (3). Table 2 presents the three groups of interviewees.

Group 1 included participants who had experienced diagnosis disclosure delay; the number of years between diagnosis and disclosure varied from six months to 16 years ($M=8.77$, $SD=3.87$). The participants' ages varied from 17

Table 1 Focus group participants' characteristics

Focus Group No.	No. Of Participants	Gender			Age	
		Men	Women	Gender Queer	M (Range)	SD
1	18	10	6	2	27.5 (13–50)	11.41
2	25	13	10	2	30.2 (13–54)	10.24
3	12	6	6		23.8 (20–34)	3.7
4	11	6	5		25.6 (21–29)	3.1
5	12	8	4		25.4 (22–29)	2.4
6	8	7	1		22.68 (19–28)	3.97
Total[a]	68	40	26	2	25.71 (13–54)	6.98

Notes: [a]Focus Groups 1 & 2 took place in the Autisticonference as an ongoing workshop (day after day). All participants from Group 1 participated in Group 2, in addition to seven more participants. Thus, the total number of participants does not include those in Group 1

Table 2 Interviewee characteristics by Group

Group	No. Of participants	Gender			Age at Diagnosis		Age at Interview	
		Men	Women	Gender Queer	*M*	*SD*	*M*	SD
Disclosure Delay (1)	20	11	8	1	4.83	3.77	23.25	3.45
Immediate Disclosure (2)	13	5	7	1	10.65	4.7	22.15	5.05
Late Diagnosis (3)	7	2	5		25.07	9.68	30.43	11.59
Total	40	18	20	2	10.26	9.09	24.15	6.57

to 29 ($M=23.25$, $SD=3.45$); age of the diagnosis varied from 2 to 14 ($M=4.83$, $SD=3.77$).

Group 2 included participants whose parents had disclosed to them directly or shortly after the diagnosis. As seen in Table 2, the age of diagnosis in this group was higher ($M=10.6$, $SD=4.7$) than in the Disclosure Delay Group ($M=4.83$, $SD=3.77$).

Group 3 included participants diagnosed over the age of 18; age of diagnosis varied from 18 to 40. Two sought diagnosis after their child had been diagnosed with autism.

The significant increase in the percentage of women in Group 3 compared to 2 corresponds to findings about late diagnosis of autistic women (see Lai et al., 2016). Women are often diagnosed later in life due to a variety of factors, including differences in how autism presents in women, as well as underrecognition and misattribution of their needs to alternative diagnoses. Unsurprisingly, this group included mostly women, most of whom sought diagnosis following an ongoing experience of otherness.

Data Collection Settings

During the process of constructing a grounded theory, pieces of information and evidence are collected simultaneously in a circuit process (Charmaz & Thornberg, 2021), based on both personal interviews and focus groups with autistic people. The process is structured as follows: focus group > feedback > data analysis > personal interviews < data analysis > focus group > feedback > data analysis, etc.

According to the double empathy theory, autistic-autistic peer communication would be more effective (Mitchell et al., 2021). Following that, and in response to feedback during the pilot phase (Focus Groups 1–2; see below), the interviewer (Author 3), identified himself as an autistic coresearcher in most interviews and in Focus Groups 3–6. Most personal interviews could be considered an “autistic space” (Sinclair, 2010), because in most cases both the interviewee and the interviewer were autistic. This also corresponds to the principle of “nothing about us without us”, which is accepted in the emancipatory methodology.

Parental diagnosis disclosure might be a trigger for some autistic people, especially those who experienced prolonged diagnosis concealment. Thus, we enabled participation in the research in various ways (Gellini & Marczak, 2023): some people chose to participate in the group, but did not share their experience and were then interviewed individually. Others felt that participation in the focus group was sufficient for them. The high rate of participation in the personal interviews following the focus group attests to the empowerment potential of sharing experiences, as does the high rate of participants who have entered the research based on references by other participants (Vernon, 1997). Several participants have also specifically described the experience as therapeutic for them, expressing eagerness to learn about the research results.

The first two focus groups were held in November 2019 in Autisticonference, a joint initiative of Autistic Community Israel (ACI) and the Milestones Preparatory program (see below). Serving as a pilot, these groups were facilitated by Authors 1 and 4. While the first focused on how the discovery of the diagnosis affected the participants’ lives and identities as adults, the second group focused on recommendations for parents and professionals. During the discussion, the research team received suggestions to rephrase the questions in a way that would be clearer to autistic individuals. We were also criticized for the fact that at the time, the research team did not include any autistic members; subsequent focus groups included between one and three autistic individuals.

Focus Groups 3, 4 and 6 were conducted in cooperation with the Milestones Preparatory program and Focus Group 5 was conducted with the Kivunim Preparatory program. These are special transition programs for autistic people in emerging adulthood focused on independent living skills (Vortman-Shoham & Kenny, 2019). The program managers disseminated the request to participants, handled registration, and helped participants during the meeting. These groups were facilitated by Authors 1 and 3. The first part of the meeting was dedicated to presenting the study (30 min), and the rest of the meeting was dedicated to an open guided discussion (see Appendix A in Supplementary Material for focus groups’ questions guide). All focus groups lasted approximately 1.5–2 h and were fully recorded and transcribed.

Interviews

Data were collected also by semi-structured interviews (Kallio et al., 2016). All were audiotaped and transcribed. Lasting 60–120 min, the interviews allowed the participants to express the meanings they ascribed to their disclosure experience. The interview guide (see Appendix B in Supplementary Material) was developed by the Author 3. Due to Covid-19, most interviews were conducted via Zoom, which had the advantage of allowing participants to remain in their familiar and comfortable environment, control features such as lighting or sound amplification, and overcome geographical barriers. Participants who preferred to be interviewed in person were interviewed in their homes or dormitories in the Milestones preparatory program.

Recruitment Methods and Related Issues

This study utilized several recruitment strategies. Participants were recruited for the focus groups by our partners: Autisticonference, Milestones and Kivunim. For each focus group, they disseminated the request to participants, handled registration, and sent the participants information and a consent form. The invitation to participate in the focus group included a short description of the research goals and an example of questions that will be discussed in the group, along with technical details regarding dates and enrollment. At the end of the focus group, the participants were invited to provide their details if they wanted to be interviewed in person.

Participants were recruited for the interviews via the focus groups: these interviewees usually came to the interview better prepared to expand on the narrative they had shared in the group. Other participants were recruited through the virtual community: an ad about the study was posted in relevant Facebook and WhatsApp groups. Finally, the sample also included prior acquaintances of the researchers and participants.

Data Analysis

The analysis was conducted using MaxQDA20, a software application designed for qualitative data analysis (Rädiker & Kuckartz, 2020). Progressive qualitative analysis of focus group and interview transcripts was performed using an inductive system of categories and codes (Charmaz, & Thornberg, 2021). First, the research team, including two autistic coresearchers, read the transcripts and created a system of categories and codes. Some codes were broken down and others were merged to accurately reflect the participants' experiences. We discussed and developed the codebook in order to enhance reliability and coding consistency. Appendix C (see Supplementary Material) presents the categories and codes used for analysis.

Next, Author 2 analyzed all the information from the interviews, while Authors 1 and 3 analyzed the focus groups data. After the analysis the team interpreted the data and built a model that included participants' recommendations on parental disclosure. These were clustered into main themes, answering the following questions: Why tell? When to tell? How to tell? and What next? (post-disclosure process).

Trustworthiness and Reliability

The present study employed several measures to ensure trustworthiness and reliability. As mentioned above, a detailed codebook was developed. Data triangulation was ensured by conducting six focus groups and repeating similar questions in various forms. Peer debriefing among the authors was implemented throughout the data coding and interpretation phases as the primary mechanism for ensuring credibility (Rädiker & Kuckartz, 2020). This process was especially important given the presence of both professional and autistic coresearchers on the research team, as their individual biases and reflections needed to be considered and evaluated for potential influences on the research process. Additionally, a comprehensive database was created to preserve all relevant study documentation, including field diaries, categories of analysis, and their corresponding content (audit trail), which enabled the researchers to maintain an accurate record of their research procedures (Botha, 2021).

Finally, the grounded theory approach was another way of enhancing this study's credibility. While constructing grounded theory, the researcher builds a theory based on data collected in the field, examines and verifies it again with the researched reality. The theory is constructed by working in the field and returning to it to collect more data until a rich and meaningful theory is constructed (Charmaz & Thornberg, 2021).

Research Ethics

The study received the approval of Ono Academic College's Ethics Committee (approval number: 202,154), as well as of the Ministry of Welfare and Social Affairs Ethics Committee, which supervises preparatory programs for young adults with disabilities in Israel. There was no conflict of interests between the researchers from XXX College and the Milestones and Kivunim preparatory programs. Regardless, multiple ethical aspects were involved in this study, related to consent, respect, inclusion, and empowerment. Participants were given the option to choose whether they preferred to be identified by their real names or pseudonyms.

Some participants, particularly those actively involved in the autistic community, emphasized the importance of using their real names. As the issue of disclosure could be highly sensitive, Appendix D (in the Supplementary Material) presents the steps taken to create a safe and empowering space (Cascio et al., 2020, 2021).

Findings

We elicited four interrelated themes from the interview and focus group materials: (1) Why to tell? (2) When to tell? (3) How to Tell? and (4) What next?

Why to Tell? The Importance and Benefits of Knowing Your Diagnosis

This theme emphasizes the importance of sharing the diagnosis, as participants often view it as giving a reason for their struggles, helping them overcome guilt and shame and feel relieved and liberated. Specifically, they referred to several benefits of disclosure, as follows.

Understanding Yourself Better

Among the personal interview participants, feelings of otherness were described with reference to earlier life experiences: thirteen described otherness that started at elementary school, and eight described otherness already in kindergarten. Ten participants claimed that they felt different for as long as they could remember. Isabella (20) reflected: “I always felt different, but during adolescence, it began to bother me and I started asking why I feel this way”.

Since autistic children seem aware of their difference from an early age, hiding the diagnosis from them seems like a misguided parental decision. As stated by Grace (23) from Focus Group 2: “When the child is 6–7 years old, he already starts to feel the difference, you shouldn’t hide it or wait for him. Call a spade a spade! When I have the name, I will also have a source of support”. Leo (22), who also participated in the group, added: “All my life I grew up with the sense that something was wrong with me. It’s the name that gives you a toolkit to know how to deal with life”.

Participants described relief and self-understanding after the disclosure. Jason, creatively illustrated how the disclosure (at age 13) validated his unique identity: “There was a lot of acknowledgement in this thing, I had a way of explaining myself to people and also, it felt like in Harry Potter, I mean when he [Hagrid] tells him, ‘You are wizard Harry’.” Other participants, such as Anna (20), also mentioned a “very big relief, I knew there was a name for what I was experiencing”. Roni (23) also mentioned how getting to know her diagnosis helped her understand herself: “I felt like I finally understand who I am. And not like, oh, weird me, ‘cause, like, this was always there… So at least it has a name… It made me feel better”.

Some participants were raised in families that openly discussed the diagnosis. One of them wondered about the common behavior of concealing the diagnosis: “Wait, you say that there are parents who tell the child that he is not different? That sounds strange” (Ruth, 22). Others discussed how understanding the diagnosis allowed them to function better:

> I could “save the energy” for the things I needed… I could say – no, I don’t want to attend this family gathering because I have a test… and before that I didn’t know there was this link between social burnout and the fact I couldn’t… study afterward (Isabella, 20).

Due to the feelings of otherness and questions arising about being different in childhood and adolescence, participants highlighted the individual’s need to build a complete and positive story about themselves. Since autism refers to both a personal and collective identity, getting to know other autistic individuals is highly important for acquiring a positive identity.

Finding Like-minded Individuals

Finding like-minded people was mentioned by many participants, so the child would know that “He’s not alone in the world”. Charlotte (17), who had autistic friends before being told about her own diagnosis (at age 16), described the importance of having like-minded people in her life:

> There are other people who are with similar things, it’s not that it’s just me… and it’s not that I just identify with someone else’s unrelated thing. Now it’s me identifying myself with something that someone else has, just like me. It was like, “Yay!”

Roni (23) also shared this feeling, and talked about a “special experience, there are people there on the spectrum who can understand me, who can be my friends. They understand you better than other people who don’t experience it”.

Similarly, Evelyn (23) said:

> When I am in [transition program] with friends or staff… I act how I want to and I’m very free-spirited…. You have friends who have the same disability, … it’s something similar…. There are difficulties that we share with one another, and I feel safer.

Sara reported: "At the special ed classroom, I was finally with kids who have difficulties similar to my own and I wasn't the class weirdo". Gary (44), who was diagnosed as an adult following his child's diagnosis, said: "It's more than acceptance. You are in your place, where you belong."

It is evident that getting to know other autistic people is of great importance in creating a sense of belonging and shaping one's identity. Apart from getting to know autistic children and people from the community, the interviewees also recommended getting to know famous autistic figures. For example, 17-year-old Steven, who knew about his diagnosis since age 4, said: "I was very happy to find out that I am Albert Einstein and Mozart".

Acquiring Self-advocacy Skills

Getting familiar with the diagnosis improves the self-understanding of difficulties, abilities, feelings, needs, and challenges that autistic individuals face daily. It promotes the development of coping strategies and adaptive skills such as self-advocacy. Many participants highlighted the value of the disclosure for honing those skills: demonstrates this in her words:

> It's very important for people to be able to explain themselves in clear words and confidently… This is the opposite experience to what I experienced because I felt that I had no words to describe what I was feeling, and that I was in such turmoil, that I couldn't explain at all what was happening there… When you can't explain yourself, the distress is greater. And if you know how to explain, then you can get the help you need (Anna, 20).

Roni (23) described her feeling of improved functioning thanks to the disclosure:

> I felt better… that I could do many more things… as if I had no restrictions because I actually had a justification for behaving this way. On the other hand, I also began to understand social codes more at this stage and to make an effort… to understand the things that I have not yet discovered socially that this way is right and the other is wrong.

Understanding the diagnosis can empower autistic people to communicate their needs and advocate for themselves. As demonstrated below, having a clear understanding of the diagnosis may help access and apply for appropriate support services and accommodations.

Applying for Accommodations

Participants discussed how learning about the diagnosis helped them to be more proactive and demand their rights. Knowing the name of your diagnosis promotes the ability to apply for social services and accommodations in higher education or at the workplace:

> It's very important to give people the right words to use and give them the confidence to use them to explain themselves. Because when you can't explain yourself, the distress is greater. And if you know how to explain then you can get the help you need (Anna, 20).

To sum up, the first theme reveals the benefits of disclosure. Knowing one is autistic promotes self-understanding, self-acceptance, and accessing support. It also enables the autistic individual to find like-minded people, integrate the disability identity, and acquire advocacy skills.

When to Tell? The Time Motif

The timing of disclosure received considerable attention among the participants. Some suggested a specific age, while others felt that disclosure should occur once the child was mature enough, regardless of chronological age. Several participants referred directly to the time that elapsed from the diagnosis to disclosure. The parents' acceptance of the child's diagnosis and the child's awareness of their difference were also mentioned as key factors.

Age and Maturity

Many participants stressed that it was important to start discussing the diagnosis with the child as early as possible, to avoid feelings of shame: "Age three may not be the time to put labels, but if you get it into the child's experiences it becomes something that is talked about without shame" (Chris, focus group 2). Anthony (29) from Focus Group 3 claimed: "A child in kindergarten encounters the word 'autism' and wants to know what it means, so it is necessary to tell them. It's not that there's a right time to tell, there's just a least bad time." Other participants emphasized the child's emotional and cognitive ability as a critical factor in determining when to disclose, as opposed to age. However, there was widespread agreement regarding the importance of early disclosure.

Do Not Hide: Time Elapsed Since Diagnosis

Another temporal factor the participants mentioned was the time that elapsed from diagnosis to disclosure. Some claimed that the most important thing was to disclose or start talking about the diagnosis with the child as soon as possible after the diagnosis: "The quicker you know this, as an autistic person, and no matter what age it is, you know how to adjust yourself" (Gary, 44). Another participant said, "I think it should be told as soon as possible, not at age three because it is not relevant, but before adolescence. The longer they wait, the more it will harm the child" (Benjamin, 23, Focus Group 2). Other participants recommended disclosing early on, as children also need time to adjust and perhaps even mourn about it. Henry (24), (Focus Group 2) said: "We need to come to terms with the downside that autism gives us, such as extreme sensitivity, being emotionally overwhelmed, and distress". Later, he added that it took him years to come to terms with the fact that his facial expression always looked the same and that he could not use his face to express his feelings. Since dealing with such complexities takes years, it is advisable to disclose the diagnosis early on.

Participants from the Disclosure Delay Group in particular described feelings of anger and hatred towards parents who hid the diagnosis for many years:

> You need to know when the child is emotionally mature…. From the age of eight-nine, I started feeling different and only at age 14 did my mother tell me. I'd have rather been told at elementary school, so I could understand what [treatments] I received and what I could work with. Help me understand myself. (Robert, 28).

Olivia (26), diagnosed at age of 2.5, and informed of it only at 18, said: "There's no reason to hide the diagnosis. This concealment period is offensive".

Coming to Terms with the Diagnosis

At the same time, participants acknowledged the parents' need for time to become familiarized with their child's diagnosis and to accept it. James (22) admitted, "In the same way children can have difficulties accepting who they are at first, so can the parents". However, Peter emphasized that while two years might seem like a short time for an adult, it is a significant period for an adolescent. His recommendation to the parents was: "Take a week, a month, but don't refrain from telling". Ronen (50), a leading autistic activist, echoed a similar message: "The point is that being autistic is legitimate. Like any other identity, it is much more about the parents' upbringing. Any arbitrary choice of appropriate or inappropriate age is a fallacy".

Leo (21), from Focus Group 2, said: "You should tell the child when he is ready, just before the fears take over, you should take care of it before you have a problem." When asked, "Whose fears take over?", he answered, "Parents' and professionals' fears – they're afraid because they think we have this whole mourning thing". Clearly, although it is often claimed that autistic people do not understand other people's feelings, some of the participants definitely referred to the parents' point of view and the difficulties they faced.

The Child's Search Engine

Some participants mentioned the child's awareness of their difference as the determining factor. The moment the child asks questions, for instance, why they attend special education, or why they need to go to therapy, that is the right moment for disclosure. Nicole (49), who was diagnosed as an adult, said: "If the child asks "why do I need this therapy?", then I believe he knows he has some difficulty. From the moment they ask, don't hide a thing". Many participants mentioned that a change in the educational setting (such as joining a special ed class) signaled their difference and raised questions about their identity. For example, Ofir recalled:

> I was in a special education kindergarten [of only 9 children]. The kids were all "low functioning" compared to me, but they were like me, it seemed to me quite normative. And then I moved to an "ordinary" [mainstream] kindergarten, and I got the shock of a lifetime… Like, wow, why don't all these kids want to be my friends? What happened?

According to some participants, if the child asks directly about the diagnosis, the parents should disclose it. As Mia (19) said, "If she asks and wants to know and seems to come to this conclusion, then you should share it".

Note that children are exposed to information about autism in both the physical and the online world. Often, the diagnosis and its implications are discussed over their heads. Some participants shared that when questions were not answered at home, they tried to find information on the internet. Some had an unpleasant experience when googling "autism". Our findings indicate that autistic children have an internal search engine, due to cumulative life experiences that indicate their difference. Parents should be attentive to this search engine and be aware that a child who asks questions seeks disclosure.

How to Tell? Content and Management of the Conversation

In both focus groups and personal interviews, participants referred to the different ways parents should talk to their children about autism. This theme includes references to the content and management of the disclosure conversations. The first part will focus on the references made by the participants to the content of the conversation: expecting the parents to lead an affirmative conversation, in which the advantages of autism are mentioned; a conversation that focuses on the child's individual autism, rather than on a general definition of the diagnosis. Participants also recommended consultation with other autistics. The second part will focus on how the conversation should be managed: the parents' role is to prepare for the conversation, be clear and honest, and discuss the diagnosis gradually and in a holding surrounding.

Conversation Content

First, the participants pointed out the importance of *describing autism in neutral*, *factual terms*. Ronald (26), from Focus Group 4, put it well: "Autism is not a negative thing, autism is not a positive thing, autism is a thing". Participants also stressed that autism is innate for the child, since they were "born autistic" and knew themselves as such, even before the proper name of the diagnosis was revealed to them. As Shirley (24, Group 3) said, "You were born with the diagnosis already there, so you don't have any memories of life before the diagnosis". Similarly, John (22) explained that autism "exists in you. Just a name for something that has always existed within you". Edward, the youngest interviewed (13), said when asked about how parents and professionals should disclose autism:

> Another important sentence that they should say… is "well, you'll come to understand that it's a part of you". You should explain that it's a part of who he is, it's not something that disappears. And I think that's pretty much who I am.

Ruth (22) expressed the feeling that explaining about autism is unnecessary since it's so natural: "It's just like sitting a child down for a conversation and telling him: listen, your eyes are brown. Some people have blue eyes".

> Second, participants often mentioned that both parents and professionals should *adopt an affirmative approach* while disclosing the diagnosis to a child. This included avoiding a tragic tone, talking about autism in an accepting manner, and stressing its unique advantages. John (22), who discovered his diagnosis on his own at the age of ten and never discussed it with his parents since, said: "Don't let them come to me with tears in their eyes… you shouldn't relate to it like 'Hi, you were diagnosed with this or that disease'… some kind of cancer that's going to kill you". Steven (17) took a similar approach: "Autism isn't a monster hiding in the closet, waiting to jump out and get you. It's just a person with a different kind of brain, that's all". David (21) concluded: "This thing is not bad, even when you look at it this way, he's not weird or crazy either, he's just special, and between us, who isn't?"

Relatedly, the participants mentioned that parents should talk to their children in an open and accepting manner. William (20) said it was important for the children to "feel that they will always be with them no matter what". John (22) stressed that parents should disclose the diagnosis "in a way that also accepts him as he is and doesn't make him, you know, feel more upset about the great loss". Similarly, Isabella (20) emphasized the fact that "the child doesn't care much if you call it a platypus or a cat. It's mainly about you giving this child the sense that in the end, he is alright and that the difference he feels is legitimate".

Most participants also mentioned the importance of describing autism positively. Mark (28) said that when parents believe in "the child's abilities and their successes, [they] will be able to see the disability as an advantage". John (22) recommended: "Say it in an attitude that's really fun: listen, you are such and such, you have your abilities, it exists in you".

Third, one very important recommendation repeated by several participants was not to explain about autism in general or talk about its formal definition. Rather, participants recommended *to elaborate about the child's autism*, *focusing on their individual characteristics*:

> It may be that if you tell a small child, "You have Asperger's", then they will not understand the word…. I also think it might be less important to understand the definition of Asperger's… The title's not important, what matters are the details, and how it characterizes you (Emma, 27).

Another related issue mentioned by participants with autistic siblings was the need for individual, separate disclosure to every sibling. For example, Mary (28) said about her brother: "I think it cast a huge shadow on me, because I see myself like him, that I was abnormal and different". Thus, she recommended that parents disclose the diagnosis "in a concrete way that talks more about the difficulties and breaks down the diagnosis to who you are". Thus, since explaining autism "is as complex as explaining what communism is to a child" (Author 3), it seems that focusing on the child's personal autism is preferable. As many parents struggle with disclosure due to its complexity, focusing on the child's behavior, feelings, strengths and difficulties can be an easier. Another, complementary approach is to consult with other autistics.

Finally, the recommendation to *seek advice from other autistic individuals* was raised repeatedly in the focus groups. This is not surprising given that the focus group setting supported group identity. Danna (21), a transgender woman from Group 1, said that parents need to

> seek help from autistic adults. Parents should contact autism organizations like Milestone, because they can't understand autism on their own. Neurotypical parents probably wouldn't know. The child needs to discover that they have a community and peers because there will be more and more differences between them and their parents.

Danna (21) relates to the fact that autistic children live with a horizontal identity, differing from most of their family members, hence the need for processes that will enable not only parents but also the autistic individuals themselves to become familiar with their autistic identity and community. James (22) related to common barriers that obstruct parents' from seeking such help:

> Often, parents' prejudices can interfere with this. Try to listen to what they say even if there is some urge to think, "They're wrong, they don't have a clue anyway". Or… that the autistic people with whom they consult with give the impression of [high] functioning and then "they're not really autistic, why should I listen to them?"… above all listen to autistic people… and try harder.

This quote refers to the common claim about the representation of autistic individuals and the difficulty parents face in seeking help and support from the autistic community due to the perception that they do not represent their children.

Conversation Management

Some of the recommendations provided by the participants referred to preparing for and conducting the disclosure conversation. Another issue was the understanding that the disclosure was a process and not a single talk.

First, many participants claimed that disclosing the diagnosis to the child was *a parental duty*. They suggested that parents consult a professional before disclosing to their child, but stressed that it was parents' duty and that it should not be relegated to professionals alone. The parents should also make the necessary preparations for the conversation; as Neil said, "Don't do it out of the blue".

Second, the participants mentioned that parents should *be clear and honest* about the diagnosis. For example, Michael (29) said: "In my opinion, this should be communicated to the child clearly, in a way that is understandable and not in an abstract way". William (20) said parents should "be open with the child and talk and break everything down and put everything on the table. You have to deal with it, there's no way to solve it". Robert (28) recommended: "You really need to explain it gently. With a mindset of asking, 'There's something we want to tell you but we want to hear how you feel about it'".

Third, parental disclosure should be *gradual and child-adjusted*, considering the child's level of understanding. Since most participants recommended early disclosure, it had to be conveyed gradually. For example, Mark (28) said, "Revealing a diagnosis should be done by gradually telling him. Not all at once but explain gradually how it manifests". Paul (21) referred to feedback parents should attend to as the disclosure unfolds: "talk to them, explain the meaning… see how he behaves and then… sit with him and tell him". Other participants also stressed that "the language and terminology vary depending on the stage the child is in".

Being the only participant whose disclosure had been made by her psychiatrist rather than a parent, Olivia (26) had this recommendation for professionals:

> Go step by step at the child's pace. First, to observe how much the child is aware of or understands what is happening to them, and to help them reach an understanding, but not… like a bomb over their head, but to really talk about things so that giving the label will not be done as a sign of guilt or will be considered as a bad thing, but out of an understanding of identity formation.

Finally, some participants mentioned that disclosure should be made in a *safe and private place*, where the child felt comfortable. Mark (28) stated that it was not recommended to disclose to a child, as his parents had done, "while driving in a car, since the child has nowhere to escape". Linda (22) said: "It's best to tell them in the most comfortable setting possible, whether it's at home or outside, just not around other people, because it's something very… private". Preferably, the disclosure should take place where the child feels relaxed and safe and can be alone if they feel the need to.

What's Next? Post-Disclosure Processing

According to the participants, after the disclosure, both the child and parents needed to go through post-disclosure processing. This theme presented recommendations about the parent and child's post-disclosure behavior and seeking information about autism, as well as future predictions.

Parents' Post-Disclosure Behavior

Some participants claimed that parents "should be patient with the child" after the diagnosis has been disclosed. Others mentioned that parents "should not behave the same". For example, Richard (23) said, "My father made a terrible mistake in telling me that he would always treat me in a 'normal' way. I think he even regrets it a little." Participants mentioned that parents are expected to behave differently after the disclosure and integrate the meaning of the diagnosis into the everyday life of the child and the family, meaning they expect more understanding and recognition. This expectation is understandable since it reflects the participants' need for consistency about their autistic identity – after parents have disclosed, they are supposed to relate to it in their behavior towards the child.

Child's Post-Disclosure Reactions

The participants discussed different ways of coping. Some reacted with *denial*, ignoring the diagnosis or feeling confused and speechless, as David (21) describes: "At first they told me this when I was annoyed and not [in a] proper [state] to listen, so I didn't exactly know what I was going to say". He added that this made him react aggressively: "Only in fifth grade did I agree, or sixth grade – I finally agreed to listen". Emma (27) who was told at age 16, said: "At first, I felt so uneasy that I said, I don't have it. I think it was hard for me to accept… my diagnosis because it's hard to be different". However, even participants who initially felt angry usually underwent a process of acceptance, as can be inferred from Jessie's (25) words:

> At first, I took it as an insult… [my parents] gave me something, but I didn't even ask myself if I wanted it. So they gave me a kind of name, but even without them it's reasonable to assume that you would have been given that name, but as soon as you have accepted it and understood something and it is part of your identity, then I'm not angry at them like I used to be.

Despite this initial rejection, and as mentioned in the Introduction, integrating disability identity is a process that often begins with denial it, leading eventually to *self-acceptance*. Indeed, some participants, especially those diagnosed in adulthood, and especially women, felt that the diagnosis led to a sense of relief. As Mila (23), who had been diagnosed at the age of 18, put it, "It was one of the happiest days of my life because finally I could believe in my difference, finally I could understand that I'm not a broken neurotypical, I'm a whole autistic person". Similarly, Isabella (20) recalled: "It was a laughter of relief, it was like the pieces were really connecting… My psychologist was very serious about this and tried to prepare me and cushion the blow, but that was exactly what I needed to hear". Michael (29) expressed a similar sentiment: "I felt like it was a gift for me, I received it with love, I accepted myself."

Accordingly, parents should be aware that the child's initial response may vary along the spectrum between rejection and self-acceptance. Importantly, even participants who described difficulties identifying with the diagnosis at first admitted that after a while, they were able to embrace this identity. As Edward (13), who had known about the diagnosis since age 8, said:

> It took time. It's not that one moment… I didn't understand and then another moment. It took a year or two to come to terms with it between the ages of 9–10, grades 3–4, and to learn and understand, and there were times when I felt that I didn't want it to be me. But I slowly understood that it is me.

Consulting Dr. Google

One common post-disclosure behavior was seeking information online. Parents should be aware that the child might conduct an internet search. For some of our participants, this was a negative experience. One participant who had found out about her diagnosis at the age of twelve said: "I immediately searched the internet and everything, and immediately, many bad things" (Sophia, 20). On the contrary, participants who were diagnosed with Asperger's (before DSM-V) and googled the term described more positive experiences, which validated their feelings of otherness throughout the years. Immediately after disclosure by his parents, Ronald (26) "read about it on Wikipedia to verify this thing with myself… It's me. [I] feel that the definition was invented about me and not that I mistakenly fit the definition. It's me to a tee". Accordingly, parents should be prepared for any scenario and mediate the information the child is exposed to.

Predictions and Recommendations

In their recommendations, some participants referred to the practice of a “coming out” lecture about autism, by the child, for the child’s classmates. All participants who mentioned this claimed that the lecture at best ended the bullying they had suffered from classmates, or at least gave them a few days of positive attention, but in the end, had no significant value in terms of their social status. Linda (22, Group 3) shared that after her principal had urged her to lecture to her classmates and explain them about her being autistic, and that she wrote a message on the class WhatsApp group saying, “Hi, I’m autistic, I know you ask questions behind my back and don’t ask me at all. So hey, I’m autistic, and accept it”. She then shared, “Physically, I didn’t feel at all ready to come out with it. It was very difficult for me”. Thus, from the participants’ perspective, such a “coming out” lecture should be reconsidered. Nevertheless, it is extremely important that the child learn to manage disclosure to others in a way that is suitable to them, since this is one of the significant challenges for the rest of their life.

To conclude the post-disclosure theme, the knowledge provided by the participants can help parents and professionals to prepare for that phase, which also has an ongoing spiral nature. As learning about autism, identity, and the self is a gradual process, parents and children may be expected to go through this process again and again. In every stage, different questions will be raised and discussed.

Figure 1 presents the model that emerged from the data. As described in further detail above, in each of the four themes, subthemes include practical recommendations, dos and don’ts. The themes are presented on a continuum, as diagnosis disclosure is a gradual process rather than a single talk. Parents and children may experience it in different time periods and ages, each time having other thoughts and explanations. The four themes provide some answers to key questions regarding the diagnosis disclosure process. While the first (why?) and fourth (what next?) themes focus on identity and self-acceptance, the second (when?) and third (how?) offer practical guidelines that can help parents and professionals prepare and plan for the disclosure process. The discussion sections offer further recommendations for parents based on this model.

Discussion and Recommendations

Previous research has pointed out the benefits of disclosing autism diagnosis, specifically at an early age, to support better self-understanding, promote self-advocacy skills, well-being, and quality of life (QoL) (Cooper et al., 2021; Corden et al., 2021; Jones et al., 2014; Oredipe et al., 2022). However, we still know little about how best to do so (Corden et al., 2021; Crompton et al., 2020; Kiely et al., 2020), as no research before has yet attempted to provide guidelines for the parental disclosure process. The current research sheds light on the perspectives of autistic people regarding the parental diagnosis disclosure process. These insights are extremely important to consider, as we know that autistic knowledge has great importance for ensuring a positive autistic identity and well-being.

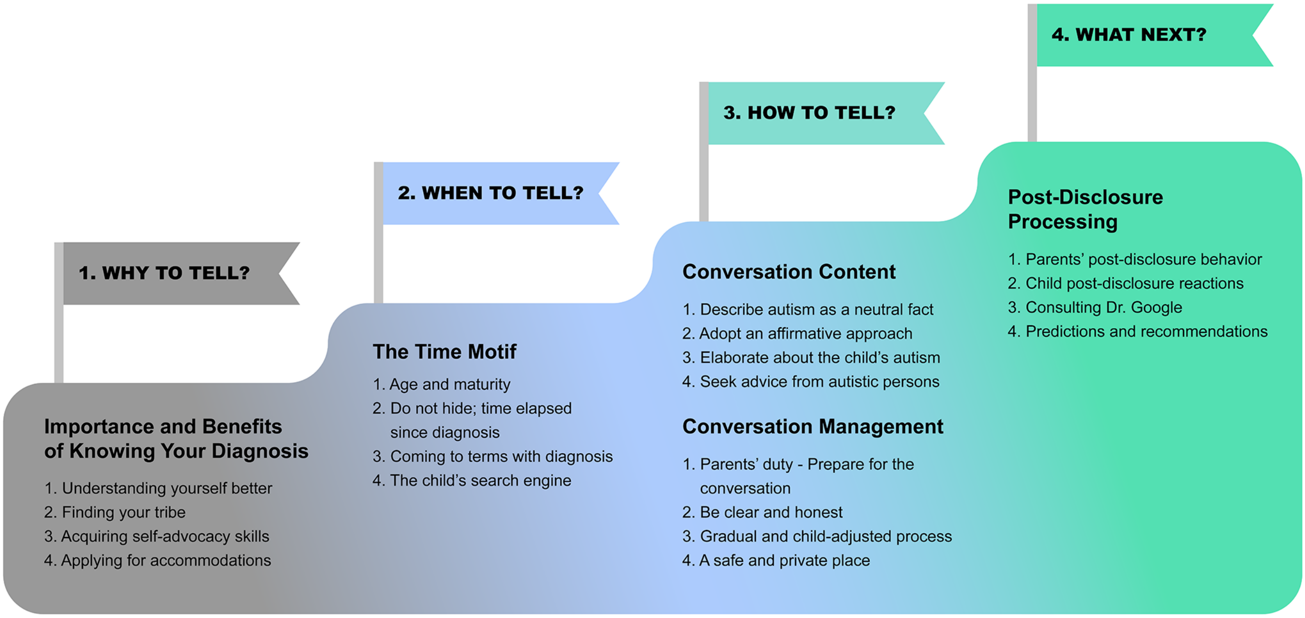

Fig. 1 Parental disclosure process: autistic-driven recommendations

As found in previous studies, parental diagnosis disclosure is a lengthy and spiral process: there is no single talk or moment. Rather, it includes several conversations between parents and their children, and occurs in different ages and on various topics related to being autistic (Kiely et al., 2020; Riccio et al., 2021). Our findings also suggest that parents should keep in mind that this is not a one-time conversation but a continual subject for discussion. Parents will need to slowly adjust and rethink what is suitable for the child, as in each life stage, there are things that are appropriate and more significant.

Autistic children vary widely in their cognition, language abilities, and social skills. Thus, parental diagnosis disclosure should be a gradual and child-adjusted process. Disclosure should be adjusted to the child's mental age, level of understanding and emotional and behavioral factors. As children grow older, the issues that concern them change, as do their mental capacity and cognitive abilities. Social demands also change in the transition to adulthood, forcing the child to cope with an environment that may not always be inclusive. It is therefore important to engage the child in continuous conversation, adjusting the content and depth of disclosure to the child's cognitive stage and understanding level.

Since disability identity formation, and especially facilitating a positive autistic identity, is a spiral process (Forber-Pratt et al., 2018), there is a need for recurrent conversations about the diagnosis. Moreover, the child might need time and space to internalize the different meanings of the diagnosis, so it is recommended to spilt the disclosure talk into "small" conversations, with a limited amount of information provided in each.

There is general agreement among the participants that autism is natural, innate, and integral to the person. In their eyes, this perspective on autism as an identity should be conveyed when the parent talks to the child about the diagnosis. Participants called for an affirmative approach towards parental diagnosis disclosure, respecting and accepting the child. Participants stressed that affirmative disclosure can help autistic children learn not only about their weaknesses, but also about their strengths. There is a need to develop parental education programs based on this affirmative approach, supporting a more positive identity foundation for autistic children.

Understanding oneself better can lead to an improvement in various skills and abilities, as mentioned in the first theme. Contrary to parents' fear that the child would misuse their diagnosis – described as "secondary gain" in the first part of the study (Almog et al., 2023) – it appears that familiarity with the diagnosis and its meanings are especially important for the research participants and helped them gain a more positive identity as time passed. The content of the conversation presented in the third theme can be used as a checklist for parents: use an affirmative approach, focus on the child's autism and mention the child's strengths and benefits.

The autistic identity approach focuses not only on the unique contribution of autistic knowledge on disclosure guidelines, but also on getting the child to know their peer group (Cooper et al., 2021; Corden et al., 2021; Jones et al., 2014; Oredipe et al., 2022). As found in previous research, acquiring autistic social identity relates to greater self-esteem and can lead to better mental health outcomes (Cooper et al., 2017), and to autistic pride (Corden et al., 2021, Riccio et al., 2021). Identity-based support is also crucial in the post-disclosure adjustment process, as there is a connection between strong affiliation with autism identity, associating positive attributions to autism, and collective self-esteem (Cage, 2021; Cooper et al., 2021). Given to the great importance of adopting a group identity for integrating identity among autistic individuals, it is important to create programs that will enable parents to seek assistance and support based on acquaintance with autistic people and communities.

After the disclosure, the reduced stress of both the parents and child, make shared decision-making possible. This is extremely important to the child's ability to manage their own diagnosis disclosure in their future.

The recommendations presented here provide detailed guidelines for disclosing autism diagnosis to children and adolescents. We hope the guidelines regarding the motivations for the disclosure, its timing, the content and form of the conversations and post-diagnostic issues, would enable parents and professionals to support the child in the diagnosis process and its aftermath.

Limitations and Future Directions

This study is based on a limited sample of autistic *individuals* who were willing to share their experiences and perspectives on the issue of diagnosis disclosure. We assume that for many people who have had their diagnosis concealed from them the issue is still too sensitive, but their knowledge is still important to solidify our understanding of diagnosis disclosure. We consider it crucial to expand the model developed in this study and to include autistics with intellectual and communication disabilities, Israeli autistics from ethnocultural groups not included in this study (particularly Arabs and ultra-Orthodox Jews), as well as participants from other countries. A more comprehensive representation of autistic people is essential for gaining deeper understanding of this complex issue.

Another limitation has to do with the fact that we did not interview parents who disclosed the diagnosis to their children to examine their opinions in relation to their children's reports. In order to develop a model supporting parents in diagnosis disclosure, this is another point of view that should be considered.

We find great importance in conducting research that will evaluate the effectiveness of the guidelines proposed in this article and the effects of applying it with parents and autistic children. Further research should also include quantitative tools to examine the effects of diagnosis disclosure on self-understanding and identity. This can be tested over several time points – before the disclosure, in its immediate aftermath, several years later, etc.

We hope that this study will contribute to the development of a robust body of knowledge on the subject of parental disclosure of autism diagnosis, based on the experiences of autistic people.

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Declarations

Compliance with Ethical Standards The study has obtained the approval of the Ono Academic College's Ethics Committee, as well as of the Ministry of Welfare and Social Affairs Ethics Committee, which supervises preparatory programs for young adults with disabilities in Israel.

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