

**Critical Review:**  
**Does diagnosis disclosure result in positive outcomes for autistic children and youth?**

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This critical review examines the current literature on parental-disclosure of an Autism Spectrum Disorder diagnosis to a child and the subsequent impact and outcomes of that disclosure. Seven qualitative studies were reviewed including a systematic review, two surveys, and four semi-structured interviews. The studies varied in their ability to address the research question and their degree of evidence. Overall, the findings revealed that diagnosis disclosure tends to result in positive outcomes. During the disclosure process, parents should follow their child's lead with the timing and manner of disclosure. Discussions around autism and neurodiversity should begin early in order to positively frame and normalize differences.

***Introduction***

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication and social interactions, as well as restricted, repetitive patterns of behaviour, interests, or activities (American Psychiatric Association, 2013). It has been estimated that approximately 18.5% (1 in 54) of eight-year-old children are autistic (CDC, 2020). Due to the presence of social communication and social interaction difficulties, and the often co-occurring speech and/or language impairments, Speech-Language Pathologists (SLPs) are often one of the professionals involved in the care of an autistic child. SLPs often play a key role on the interprofessional team diagnosing the presence of this disorder (Autism Spectrum Disorder, n.d.).

When very young children are diagnosed, their parents may delay disclosure until the child reaches an age when it is believed that they will be better equipped to understand the diagnosis and the nature of the disorder (Finnegan et al., 2014). As communication specialists, SLPs will have long standing rapport with families after years of therapy, so they are well suited to help parents/caregivers navigate challenging discussions around disclosure; particularly disclosure to the child. Due to the frequent involvement of SLPs in the diagnostic process of ASD, it is likely that they have experience discussing the diagnosis with parents. They can act as additional support for parents when making decisions about disclosure to the child. The heterogeneity of ASD along with its core features being linked to identity and personal attributes contribute to the difficulty of educating youth about their diagnosis (Kiely et al., 2020).

Currently, there are no evidence-based guidelines around how and when to share an ASD diagnosis or the

subsequent outcomes of disclosure (Kiely et al., 2020). Previous research has focused on parental satisfaction and parental impacts associated with learning of their child's autism diagnosis (Abbott et al., 2013; Calzada et al., 2012; Finnegan et al., 2014; Midence & O'neill, 1999). It is important to gain a deeper understanding of how autistic individuals themselves, as opposed to their parents/caregivers, are affected by increased awareness of their ASD diagnosis (Cadogan, 2015).

***Objectives***

To critically review current literature on the impact and outcomes of diagnosis disclosure to autistic youth in order to inform clinical practice when supporting parents and caregivers as they navigate challenging discussions about diagnosis to their autistic child(ren).

***Methods***

**Search Strategy**

Online databases (PubMed, PsycInfo, Google Scholar) were searched using the following terms: (ASD) OR (Autis\*) AND ("diagnosis disclosure") AND ("outcome"). Other relevant articles were obtained through the reference lists of selected articles.

**Selection Criteria**

Studies included for review were limited to those that specifically explored diagnosis disclosure to the autistic child and the subsequent impact and/or outcomes that resulted from the disclosure.

**Data Collection**

This critical review analyzes a total of seven qualitative research studies: one systematic review, two surveys, and four semi-structured interviews that used thematic analysis or interpretive phenomenological analysis (IPA).

## **Results**

### Levels of Evidence

On a scale from level I (i.e., randomized controlled trial) to level IV (i.e., case study), the following studies all meet criteria for level III evidence as indicated by their non-experimental and multi-participant designs.

### Systematic Review

This type of study sees the researcher gather, evaluate, and summarize all the available literature in order to present the most current and relevant research findings on a given topic.

#### *Smith et al. (2018)*

This study investigated the process by which parents disclose a diagnosis to their autistic child(ren), with both the parent and child perspectives considered. The authors clearly outlined their search methodology and used the PRISMA checklist to guide article selection. Five qualitative articles were included: three peer-reviewed, one master's thesis, and one doctoral dissertation. Common themes were identified within the selected articles: processing, delay, explanation, stigma, and child self-disclosure. Each study was independently coded for the themes by the first and second author and interrater agreement was 1.0. The review findings included concerns identified by parents and recommendations from one of the selected articles. Specific to our research question, the authors identified the following positive effects of disclosure: providing the autistic youth with an explanation for their feelings and behaviours, the ability to understand why they utilized intervention services, recognizing why they received differential treatment from peers in school, and being able to consider self-disclosure as a form of self-advocacy.

Strengths of this study include the search methodology, contacting authors for unpublished works, a second reader for coding themes, and the authors' transparency regarding limited overall findings. Study limitations include a small sample size across all five studies (N=34) which hindered generalizability and no critical evaluation of the strengths and weaknesses, or data analysis, of the selected studies. The authors did not present individual study results. There were no discussions presented about risk of bias within and/or across the studies, researcher bias, funding or conflicts of interest. This review does not provide sufficient evidence to inform clinical practice or guidelines around disclosure.

### Survey Research

The following studies involved distribution of a survey to parents/caregivers of autistic children. Survey research is cost-effective, has the ability to reach a diverse range of participants, and often results in a large sample size.

There are several limitations to consider including restricted response options for close-ended questions, possible researcher bias in the interpretation of open-ended questions, and the overall validity and reliability of participant responses.

#### *Kiely et al. (2020)*

This cross-sectional retrospective survey analyzed patterns and outcomes of diagnosis disclosure to autistic child(ren). The survey included statements that the 578 parent/caregiver participants rated on various 5-point Likert scales in order to quantify the results and consider patterns and correlations for the following variables: disclosure and receipt of support, parental and physician disclosure practices and, relevant to this critical review, youth outcomes. Appropriate statistical analyses were used on the collected data. Generally, disclosure was perceived by parents to have a positive or neutral impact on the self-esteem (SE) (81%) and self-advocacy skills (59.6%) of their autistic child(ren). Disclosure was thought to help youth understand their strengths (69.2%) and weaknesses (68.2%) and better cope with challenges (50.8%). This study also revealed that barriers to disclosure included the parent's belief that their child wouldn't understand the diagnosis, it could harm their SE, and/or make them feel different from their peers. The following were identified as facilitative factors to positive disclosure outcomes: access to the autism community and support groups, open communication about their diagnosis (more than 10 discussions), and knowing others with ASD (real or fictional).

Strengths include its large sample size and appropriate methodology given the research question. Limitations include not considering the autistic person's perspective, no open-ended questions, no information about survey formation, lack of validity and reliability of the survey due to retrospective design, no access to clinical information about the autistic children in order to make specific connections between outcomes and developmental characteristics, and convenience sampling which restricted the generalization of results to white, educated families. Nonetheless, this study provides suggestive evidence for SLPs to use as they navigate conversations with parents by understanding possible barriers to disclosure, providing information about outcomes and how to best facilitate positive outcomes.

#### *Crane et al. (2019)*

This study evaluated parents' experiences of discussing autism with their autistic child(ren). Quantitative demographic results were presented descriptively and qualitative data was evaluated through thematic analysis. Themes were reviewed and combined or separated, while ensuring internal coherence and distinction among

themes. A negative case series was conducted to identify data that did not support a theme. The majority of children (68%) had been told about their diagnosis, and disclosure occurred on average, 1.3 years after diagnosis. Parents identified the importance of being open about the diagnosis. They suggested that disclosure should occur early and gradually. They emphasized the child's ownership of the diagnosis and believed disclosure was enlightening and empowering. Parents noted that discussions should be tailored to the child's needs and the timing and manner of disclosure should be child-led. It was also important to focus on the positives and embrace everyday opportunities to discuss autism.

Strengths of this study include the design, large sample size (N = 558), diverse means of participant recruitment, clearly outlined data collection and analysis process, presence of qualitative and quantitative data, use of open and closed-ended questions, sufficient information regarding survey formation and consultation with autistic parents beforehand, and the inclusion of quotes. Limitations include the parent rather than the autistic individuals' perspective; the primarily white, female, English-speaking sample; and the possibility of bias. Nonetheless, the results are compelling and can inform SLPs in discussions with parents regarding possible barriers and outcomes of diagnosis disclosure.

#### Semi-structured Interviews

This research provides richer descriptions of participant experiences and is useful with certain populations and clinical questions, such as diagnosis disclosure in ASD. Limitations include small sample sizes; possible researcher bias when interpreting open-ended questions and/or when creating, discarding, or grouping together themes; results may only reflect individuals who participated in the study; and interviews are often brief so participants may not feel comfortable sharing all of their thoughts or experiences.

#### *Huws & Jones (2008)*

This study evaluated nine autistic individual's perceptions of what autism is, what autism means to them, and how they would explain autism to someone who had never heard of it. The transcripts were evaluated using IPA. Participants reported that a delay in disclosure could lead to a variety of reactions (e.g., shock, disbelief, disappointment) and that the diagnosis allowed them to retrospectively understand previous life experiences and why they had been treated differently. Participants indicated that the diagnosis could lead to positive or negative effects, could be engulfing, and could be a source of new opportunities. Some participants reported that the disclosure was initially hard to acknowledge but they later learned to accept it, while others continued to dislike the diagnosis.

Strengths include the autistic individuals' perspective, clear descriptions of methodology for data collection and analysis, the use of quotes, the participant composition which is similar to the sex-ratio of ASD, and the transparency of the authors. They acknowledged the possibility of bias and outlined procedures to reduce bias, such as comparing developed themes to transcripts and using an external auditor to ensure credibility. Limitations include a small sample who attended the same college, the use of convenience sampling, retrospective recollections of events and experiences, and the possible impact of researcher bias. Nonetheless, these findings are compelling, and provide first-hand accounts of autistic individuals' experience with diagnosis disclosure which can help guide SLPs when counselling parents on possible outcomes of disclosure to the child.

#### *Finnegan et al. (2014)*

This study explored seven parents' experience of seeking and receiving a diagnosis for their autistic sons, their experience following the diagnosis, and their considerations in sharing the diagnosis with the child. The transcripts were assessed using IPA. Themes were compared to transcripts to ensure applicability. A theme relevant to this review was sharing the diagnosis. Parents considered whether or not to tell their child, and often disclosed when the child was believed to be ready and when the diagnosis could act as helpful rather than stigmatizing. Parents managed communication around autism, wanting to protect their child and prevent them from developing a negative self-image. They reported framing conversations in a positive or euphemistic way so the diagnosis appeared more useful or acceptable. Parents also mentioned both positive and negative outcomes of disclosure, however, they tended to view it positively and as an indicator of their child's increasing independence and maturity.

Strengths include a clearly outlined data analysis process with thick descriptions, the use of quotes, and the transparency of the authors. They acknowledged the possibility of bias and attempted to counteract it by comparing themes to transcripts, reviewing credibility of interpretations, and using an external auditor. Limitations include the parent rather than autistic individual's perspective, the absence of autistic females, retrospective recollections of experiences, the possible impact of bias, and limited information regarding data collection. This study presents suggestive evidence regarding outcomes associated with diagnosis disclosure which may assist SLPs in conversations with parents considering disclosure.

*Mogensen & Mason (2015)*

This study used a participatory methods approach to learn about the lived experience of five autistic adolescents (aged 13 to 19). Participants chose their preferred mode of communication with the researcher which allowed for ongoing flexibility based on their preferences and abilities. Thematic analysis first identified and listed recurring topics from the collected data and then considered their connections to the theoretical basis for the study (i.e., childhood sociology and disability studies). Development of core themes was established by considering links between the identified topics. The researcher solicited feedback from participants on the summary findings and research process. This study presents mixed findings about autistic adolescents' experiences and views of their diagnosis related to personal identity, social identity and relationships, and their negotiation of impairment.

Strengths include the autistic person's perspective, the use of quotes, the author's requests for feedback from participants, and the flexibility in modes and styles of communication; this is especially important given that autistic individuals can have difficulty expressing their thoughts or feelings verbally. Limitations include no clearly defined research question, a lack of demographic information to allow for transferability, and poor confirmability due to insufficient analytical rigour and auditability information. The author was also not self-reflexive. Due to significant limitations in research validity, rigour, and transparency these findings are equivocal and should not be adopted to inform clinical practice.

*Cadogan (2015)*

This study explored parents' perceived impacts of disclosing an ASD diagnosis to their child. This study was part of a larger project, and the transcripts were analyzed using thematic analysis. Parental disclosure often led to ASD-related discussions. These include open communication with the autistic child about their diagnosis and conversations regarding problem-solving, overcoming obstacles, ASD-related differences, and ASD-related difficulties. Open communication also facilitated opportunities to teach the child about autism, share resources, clarify misbeliefs, answer questions, and empower the child to advocate for themselves and their needs. Disclosure also encouraged a greater understanding of autism. It permitted children to make sense of their difficulties, understand why things had been harder for them, and answer questions about themselves. After disclosure, children became more aware of features associated with autism, including an enhanced awareness of themselves. It provided a framework to understand challenges with motor and social skills, problem-solving, and worrying. Parents also

identified specific reactions and impacts following disclosure. These include taking time to think about and process the diagnosis; seeking autism information; accessing resources such as accommodations, support, or books; using autism as an excuse for their behaviour; and developing self-regulation skills when feeling overwhelmed. Children experienced a variety of feelings and emotions following disclosure including acceptance, relief, a sense of comfort, identifying with the diagnosis, feeling labeled or stigmatized, and/or improvements in self-image. The majority of outcomes were perceived as positive.

Strengths of this study include the larger sample size, the clearly described data collection and analysis process, using open-ended questions to spark discussion, detailed information about the follow-up probes, the inclusion of interview protocol and questions in the appendix, the use of quotes, and the utmost degree of transparency and self-reflexivity. The author identified the possibility of bias and methods taken to address it and indicated the sampling method and how that could impact the results. To reduce bias, an external auditor reviewed the data, themes were compared to transcripts, a reliability check was performed, and faculty members examined the results and rationalizations. The author also justified all decisions, and compared the current methodology to other approaches. Some limitations are the possibility of bias, the lack of demographic information about parents and children, the extreme brevity of some interviews (18 min.), the study is an unpublished master's thesis, retrospective recollections of experiences, and the parent rather than the autistic child's perspective. However, the study findings are compelling and can inform SLP's clinical practice when counselling parents on possible outcomes associated with parent-child autism disclosure.

### ***Discussion***

A critical evaluation of the existing literature revealed that diagnosis disclosure tends to result in positive outcomes. The reviewed articles varied in their ability to address the research question and their degree of evidence, however, common themes across the literature included: understanding one's own life experiences and personal strengths and weaknesses (Kiely et al. 2020, Cadogan 2015, Huws & Jones 2008, Smith et al. 2018); using disclosure as a form of self-advocacy (Kiely et al. 2020, Smith et al 2018); and an improved ability to cope with challenges (Kiely et al 2020, Cadogan 2015). Kiely et al. (2020) identified that most parents perceived disclosure as having a positive or neutral impact on their child's self-esteem. They also found that giving the child access to the autism community/support groups, maintaining open communication about autism, and exposing the child to others who are autistic (e.g.,

familiar people, celebrities, and/or fictional characters) were all facilitative factors to positive outcomes.

This review has highlighted the importance of disclosing a diagnosis to the child and the current gaps in the literature concerning this topic. When autistic individuals described the outcomes of a delay in disclosure, it was often through negative terms such as shock, disappointment, or disbelief (Huws & Jones, 2008). Similarly, many parents felt that the child had a right to know their identity, and that peer disclosure or leaving the child to figure it out on their own could have a more negative effect than when parents explicitly disclosed the diagnosis (Finnegan et al., 2014). Children who experience a delay in disclosure may have already developed an internalized stigma about autism and disability that makes acceptance of the diagnosis more challenging. Early education about neurodiversity and the child's diagnosis will help to promote acceptance and positive feelings toward their autistic identity. Knowledge of their diagnosis will also empower autistic children and adults to self-advocate in order to have their needs met and boundaries respected; teaching this skill from a young age can only benefit them academically, professionally, and within personal relationships.

This research revealed that autistic children can have an improved understanding of self (i.e., personal strengths, weaknesses, etc.) when they are made aware of their diagnosis. Some parents also report that their children became more cognizant of the features associated with autism and demonstrated an improved ability to self-regulate (Cadogan, 2015). Self-regulation is an important skill that facilitates one's ability to engage in learning and intervention. Providing an autistic child with access to the information that can help them better understand their behaviours, their reactions, and their needs will help to promote feelings of self-efficacy in their ability to manage challenging situations and general life experiences.

There are, however, some limitations to the current critical review. First, all of the available research was restricted to qualitative or survey designs, which introduce limitations to the generalizability of results. Second, the included studies relied on small, homogenous samples. The parent participants were often white, educated mothers while the autistic participants were required to be verbal or literate and able to engage in meaningful conversation about their lived experience. These factors have serious implications for generalizability and applicability to the heterogeneity of autistic children and their families. Third, the reliance on retrospective recollections can skew participants' interpretations of past events.

Future research should include: prospective studies with a focus on the autistic perspective, particularly among children and youth, regarding diagnosis disclosure; child factors that demonstrate readiness for disclosure; larger more heterogeneous samples; and development of evidence-based guidelines to help support parents and professionals in the disclosure process.

### ***Clinical Implications***

Though the articles varied in their degree of evidence, this critical review yields valuable information that can inform clinical practice. When parents are considering disclosing an autism diagnosis to their child, they should follow their child's lead with the timing and manner of disclosure; the process should begin early and gradually. Parents can start by giving general information about neurodiversity, in a positive way, to help build a strong foundation of celebration and normalization of differences. Then, when the time comes for more explicit conversations about their own diagnosis the child will be more likely to embrace their autistic identity.

### ***References***

- Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of autism spectrum disorder: A qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry, 18*(3), 370–382. <https://doi.org/10.1177/1359104512455813>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Autism Spectrum Disorder*. (n.d.). American Speech-Language-Hearing Association. Retrieved from <https://www.asha.org/public/speech/disorders/autism/>
- Cadogan, S. (2015). Parent reported impacts of their disclosure of their child's ASD diagnosis to their children [Unpublished master's thesis]. University of Calgary. <https://doi.org/10.11575/PRISM/27257>
- Calzada, L. R., Pistrang, N., & Mandy, W. (2012). High-functioning autism and asperger's disorder: Utility and meaning for families. *Journal of Autism and Developmental Disorders, 42*(2), 230–243. <https://doi.org/10.1007/s10803-011-1238-5>
- CDC. (2020). Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites,

United States, 2016. *MMWR Surveillance Summaries*, 69(4), 1-12. <http://dx.doi.org/10.15585/mmwr.ss6904a1>

Crane, L., Jones, L., Prosser, R., Taghrizi, M., & Pellicano, E. (2019). Parents' views and experiences of talking about autism with their children. *Autism*, 23(8), 1969-1981. <https://doi.org/10.1177/1362361319836257>

Finnegan, R., Trimble, T., & Egan, J. (2014). Irish parents' lived experience of learning about and adapting to their child's autistic spectrum disorder diagnosis and their process of telling their child about their diagnosis. *The Irish Journal of Psychology*, 35(2-3), 78-90. <https://doi.org/10.1080/03033910.2014.982143>

Huws, J.C. & Jones, R.S.P. (2008). Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual & Developmental Disability*, 33(2), 99-107. <https://doi.org/10.1080/13668250802010394>

Kiely, B., Adesman, A., Rapoport, E., & Gutman, A. (2020). Patterns and outcomes of diagnosis disclosure to youth with autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, 41(6), 443-451. <https://doi.org/10.1097/DBP.0000000000000802>

Midence, K., & O'neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism: The International Journal of Research and Practice*, 3(3), 273-285. <https://doi.org/10.1177/1362361399003003005>

Mogensen, L. & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder. *Sociology of Health & Illness*, 37(2), 255-269. <https://doi.org/10.1111/1467-9566.12208>

Smith, I.C., Edelstein, J.A., E. Cox, B.E., & White, S.W. (2018). Parental disclosure of ASD diagnosis to the child: A systematic review. *Evidence-Based Practice in Child and Adolescent Mental Health*, 3(2), 98-105. <https://doi.org/10.1080/23794925.2018.1435319>