



## ***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



*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

experiences and views of their diagnosis related to personal identity, social identity and relationships, and their negotiation of impairment.

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)*

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 manuscript, the use of retrospective recollections of experiences, and the parent

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

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 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.,



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