

HELP SHEET

HELP AT A GLANCE

Sharing the Autism Diagnosis with your Child

.....

Parents navigate school and health systems, coordinate interventions and community support, as well as adapt family life in order to best support their child with Autism. In addition, a common question that weighs on parents is how and when to share the Autism diagnosis with their child. Parents may worry about causing their child undue grief when delivering the information, alternatively, by not sharing the diagnosis, they may be concerned the child won't have the appropriate knowledge to understand their differences.

A Brief Review of the Research:

A recent study that reviewed the literature on parental disclosure of the ASD diagnosis to children noted that most parents shared the information by adolescence but stated a need for more exploration of this topic to better understand and inform the process of disclosure (Smith, Edelstein, Cox & White, 2018). One small-scale study of teenagers with Autism, reported that knowing their diagnostic information assisted in developing their sense of self and identity (Mogensen & Mason, 2015). Another study of high functioning youth with Autism provided some insight into how disclosure of the ASD diagnosis can have both positive and negative outcomes for the individual, such as feelings of stigmatization, and others feeling a sense of relief with the knowledge (Huws & Jones, 2008).

Research conducted through the University of Calgary explored parent perspectives about sharing the ASD diagnosis with their child (McCrimmon, 2016). Of the 40 participants engaged in the study, half of the group had shared the diagnosis with their child or teen.

Parents acknowledged both the benefits and disadvantages of sharing the information with their child, but with the majority perceiving the process as positive for their child (McCrimmon, 2016).

Overall, the research highlights the fact that every family context is different and no two children with Autism are the same. Therefore, the delivery and timeframe of sharing the diagnosis will be variable depending on these factors. Some helpful points to consider when thinking about this topic and moving forward with a planned approach include:

- **Consider the child/youth's readiness to hear the news in terms of their developmental level, not their chronological age.** Tailoring information in a way that appropriately matches their profile is optimal. If a child has average or greater cognitive ability, a parent may choose to have a straightforward discussion that provides concrete information. If the child has a cognitive impairment, the parent could use visuals or a simple social story to present the idea of differences.
- **Consider how much information to share and the best way to deliver it.** For example, a parent may choose to provide limited information slowly over time, or provide general information about individual differences, strengths and challenges. Alternatively, a parent could carry out a planned conversation specifically discussing what it means to have Autism and continue this dialogue as more questions arise. Additional resources such as visual stories, books explaining Autism or highlighting successful people with Autism can support the process.
- **Consider sharing ASD information when the child/youth starts asking questions about their differences.** Curiosity and information seeking can be a natural entry point for discussion about learning and social differences. Providing familiar examples, such as immediate family members or friends, and explaining that everybody has a profile of strengths and weaknesses can support the discussion in a way that avoids making the child/youth feel isolated.
- **Consider reviewing books and additional resources ahead of time to support the process and to have on hand.**

Book suggestions:

- Crissey, P. (2005). **“I have Autism”: A child’s first look at Autism.** Greenville, SC: Super Duper Publications.
- Elder, Jennifer. (2005). **Different like me: My book of Autism heroes.** London, England: Jessica Kingsley Publishers.
- Faherty, C. (2000). **What does it mean to me? A workbook explaining self-awareness and life lessons to the child or youth with high functioning Autism or Aspergers.** Arlington, TX: Future Horizons.
- Kershaw, P. (2011). **The ASD workbook: Understanding your Autism spectrum disorder.** London, England: Jessica Kingsley Publishers
- Pike, R. (2008). **Talking together about an Autism diagnosis: A guide for parents and carers of children with an Autism spectrum disorder.** London, England: National Autistic Society.
- Verdick, E., & Reeve, E. (2012). **The survival guide for kids with Autism spectrum disorders (and their parents).** Golden Valley, MN: Free Spirit Publishing.

Online resource suggestions:

- Anderson, C. (2010, October 13). ASD diagnosis: What do we tell the kids? Retrieved from https://iancommunity.org/cs/articles/telling_a_child_about_his_asd
- Autism Speaks. (2010). Asperger syndrome and high functioning Autism tool kit: A tool kit to assist families in getting the critical information they need in the first 100 days after an Asperger syndrome or high functioning Autism diagnosis. Retrieved from <https://www.autismspeaks.org/tool-kit/100-day-kit-school-age-children>
- Amaze. (2019). Information Sheet: Sharing an Autism diagnosis [PDF file]. Retrieved from <https://tinyurl.com/wwvg45m>

References:

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.

McCrimmon, A. (2016). The elephant in the room: Talking to children with ASD about their diagnosis- Scientific report [PDF file]. Retrieved from (<https://tinyurl.com/w4lcfga>)

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.

Smith, I. C., Edelstein, J. A., Cox, B. E., & White, S. W. (2018). Parental Disclosure of ASD Diagnosis to the Child: A Systematic Review. *Evidence-Based Practice in Child & Adolescent Mental Health*, 3(2), 98–105.