



The Elephant in the Room: Talking to Children with ASD about their Diagnosis

Executive Summary

Respectfully Submitted by:
Adam McCrimmon, Ph.D.
Associate Professor
School & Applied Child Psychology, Werklund School of Education
University of Calgary



Raising a child is a difficult endeavour that can be made more challenging when the child has a developmental disorder. Indeed, this additional struggle can enhance stress regarding parents' skills and decisions (Huws et al., 2001) and research has indicated that parents of children with a developmental disorder struggle during the process of receiving a formal diagnosis for their child and the subsequent decisions that need to be made. The focus of this study was on parents of a child with Autism Spectrum Disorder (ASD) as research has shown that such parents experience greater stress than parents of children with other developmental disorders (Sanders & Morgan, 1997). Specifically, this study explored parents' experience of deciding if and how they should disclose information about the diagnosis to their affected child.

ASD is a neurodevelopmental disorder characterized by deficits in socio-communicative functioning in conjunction with restricted and/or repetitive patterns of behaviours, activities or interests as described in the current Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychological Association [APA], 2013). Specifically, affected individuals experience qualitative impairments with the skills required for healthy development of social reciprocity and peer relationships, in addition to delayed or atypical language acquisition and difficulties with pragmatic language use and repetitive motor movements, fixations on routines, or intense preoccupations with certain topics or objects.

Research and clinical efforts have outlined the typical process through which children and their families work with professionals (typically from a variety of disciplines) to understand the nature of possible atypical development demonstrated by the child in order to obtain a diagnosis for the child (Mansell & Morris, 2004). Assessment and diagnosis of ASD most often, though not always, occurs before elementary school; clinicians often strive to diagnose children as early as possible (i.e., at or before the age of 2) as earlier diagnosis results in enhanced prognosis and access interventions and supportive services at an earlier stage in development, thus improving developmental outcomes (Remington et al., 2007). Parents typically receive the results of the assessment upon its conclusion and then seek support and services for their child. Once a diagnosis has been conveyed to parents, they must come to terms with the implications for their child, a process commonly referred to as "diagnostic resolution" (Pianta & Marvin, 1993). Part of this resolution includes the challenge of deciding if, and subsequently how and to whom, the diagnosis is disclosed (Huws et al., 2001).

To date, researchers have explored the topic of disclosure of a chronic medical diagnosis to children (i.e., pediatric cancer or HIV) whereas disclosure of psychological disorders has received dramatically less attention. Indeed, there is a need for ASD-specific literature pertaining to the process of diagnostic disclosure by parents as knowledge of their diagnosis presented in a developmentally appropriate way could potentially assist affected individuals in the development of a positive self-concept and identity within their own environment (Huws & Jones, 2008). All in all, every child and situation is unique, and therefore the disclosure process is complex and many factors need to be considered.

The primary goal of the current research study, The Elephant in the Room project, was to explore the lived experience of parents and their decision-making in terms of their disclosure process of ASD to their child. This study aimed to enhance understanding about the decision making process in an effort to support future parents through this challenging time in their lives. This large scale project incorporated a multidisciplinary team of faculty and students at the graduate and undergraduate levels and involved over 300 families from around the world (although only 40 of these families were invited to complete all aspects of the study).

The 40 families who completed all aspects of the study were from Alberta and participated in a semi-structured interview about their experience and perspectives with disclosure of their child's ASD diagnosis. Twenty families had disclosed the diagnosis and 20 had not. Interviews were transcribed and analyzed via Interpretive Phenomenological Analysis.

Results from the disclosed participants yielded themes pertaining to 1) their context for disclosure, 2) the planning they took prior to disclosure, 3) their reasons for disclosure, 4) barriers to disclosure, and 5) perspectives on when to disclose, with subthemes within each of these. Additionally, participants discussed the process of disclosure, with themes pertaining to 1) how disclosure happened and 2) the conversation of disclosure. Participants who disclosed also discussed the outcomes of disclosure, with themes pertaining to 1) positive experiences, 2) negative experiences, 3) an enhanced level of understanding, and 4) no change. Finally, participants also provided advice to families contemplating disclosure, including 1) normalizing the experience of disclosure, 2) preparation for disclosure, 3) timing of disclosure, 4) the child's ability to understand the disclosure, 5) the process of disclosure, and 6) how to disclose.

In contrast, results from the non-disclosed participants yielded themes pertaining to 1) why they chose not to disclose, 2) the information that they have shared with their child to date,

and 3) supports that have been beneficial in their journey as a parent of a child with ASD. Additionally, non-disclosed parents also provided more specific detail for their reasons for and against the possibility of disclosing in the future and on when and how they may possibly disclose in the future.

Overall, the results of this study provide important information about the parental experiences with disclosure of an ASD diagnosis to their affected child. Over 300 parents from around the world responded to our initial request for participation, which speaks loudly to the importance of this topic to parents and to the field in general. Those that also completed interviews provided invaluable info about their experiences with disclosure and reasons for disclosing or not. These results will serve as the foundation for subsequent studies that expand upon this new information by allowing us to explore disclosure from within additional contexts (e.g., age of child at diagnosis and/or disclosure, geographic location from within Canada and/or other internationally) that will provide further support for parents and contribute to our understanding of being a parent of a child with ASD.

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