

Coming to understand the child has autism: Understanding parents' evolving readiness for engaging in care



Stephen Gentles, September 2019

From [Autism](#)

"Involving parents (or other family caregivers) in services and care for their child is generally seen as beneficial. Increased emphasis on family-centered approaches, for example, means that parents' expertise and knowledge of their child gets incorporated to improve care.

This is especially relevant in autism—currently thought to affect 1 in 59 children. In autism, variation from child to child, and the involvement of numerous specialists to address multiple concerns, means that parents are usually central figures in directing a child's care. Parents are also increasingly being asked to play roles *implementing* therapies with their child, helping generalize learning to the home and support key relationships.

But what if some parents aren't ready for high levels of involvement? A large qualitative study has helped make explicit parents' perspectives of being involved in navigating the possible solutions to a child's complex set of problems. The [first of two open access papers](#) from this study, which addressed the long-term process of navigating autism-related care, provides some key observations. First, parents carry significant burden related to this involvement. The burdens take two forms: the often-overwhelming loss of personal time, energy and financial resources required; and the high stress attributable to emotional challenges from engaging in multiple interventions and systems of care.

Unsurprisingly, parents were still generally highly motivated, or *ready*, to involve themselves in finding solutions to help their child (parents of children with autism are [known for high levels of engagement and advocacy](#)). But this readiness was not consistent over time. This study was designed to examine parents' navigating process over time, revealing its evolving *trajectory*. A hypothetical typical trajectory of a parent's evolving readiness illustrates, qualitatively, how parents' motivation was generally lowest *early* in their journey (below).

In other words, early on, when parents are just *coming to understand their child*

has autism, is a promising place to look for explanations why they may not be ready to engage in care. The [second open access paper](#), published in [Autism](#), provided an in-depth exploration of this early process. Parents' growing awareness and certainty of their child's autism was accounted for by a series of four optional steps (below). In parallel, the paper explains how parents develop their initial readiness for involvement throughout this process, including the barriers they overcome.

Parents in hindsight regretted two potential barriers: *denial*, and later, *grieving*. Importantly, these were *potential* barriers, because numerous parents described not experiencing them. Notably, only a minority of the 32 parents interviewed describing experiencing the intense sadness and loss of grieving. This empirical finding contrasts with earlier sources portraying grief as a standard parent response to diagnosis (discussed [here](#)). This matters because overemphasis on grieving can harm the parent-child relationship, as autistic advocate, Jim Sinclair, articulated in his landmark 1993 speech, [Don't mourn for us](#). While parents should never be blamed for grieving, strengths-based discourses like neurodiversity may be helping more parents respond by seeing value rather than loss."

[READ THIS ARTICLE](#)

Article details

Coming to understand the child has autism: A process illustrating parents' evolving readiness for engaging in care

[Stephen J Gentles](#), [David B Nicholas](#), [Susan M Jack](#), [K Ann McKibbon](#), [Peter Szatmari](#)

First Published September 11, 2019 Research Article

DOI: 10.1177/1362361319874647

Autism



[Stephen Gentles](#)

Stephen Gentles is a postdoctoral fellow at McMaster University and Autism Ontario. He has a background in health information and clinical epidemiology, and his research is aimed at promoting parent caregiver perspectives and developing knowledge and tools to support their involvement in pediatric care.

DISCLAIMER: This document reflects the views of the author. It is Autism Ontario's intent to inform and educate. Every situation is unique and while we hope this information is useful, it should be used in the context of broader considerations for each person. Please contact Autism Ontario at info@autismontario.com or 416-246-9592 for permission to reproduce this material for any purpose other than personal use. © 2020 Autism Ontario 416.246.9592 www.autismontario.com