



Parental involvement and participation are considered important factors for successful implementation of many different stimulation or rehabilitation programs.

Parent-professional collaborations:

intersections of expertise

By ISABELLE COURCY, PH.D.

Families play a key role in developing the autonomy and social integration of persons with autism. Parental involvement and participation are considered important factors for successful implementation of many different stimulation or rehabilitation programs. This promotion of the parent's role in their child's programs and interventions is in fact quite recent in autism's history. Indeed, many professionals, educators, and service providers now consider parents to be partners and co-educators. Whilst these changes indicate a wider recognition of the role played by parents, their relationship to other professionals and educators still seems problematic in certain ways. As a researcher, I was drawn to the discrepancy between a professed will to provide more agency to parents, and the difficulties parents express regarding these relationships¹. Why do so many parents feel unheard, as though no one truly listens or takes them seriously? What do we know of the hurdles they face? How can we make true collaboration happen?

Challenges in the parent-professional collaboration

Parents report numerous difficulties in collaborating with the professionals and educators who work with their child. Some parents recall that their initial concerns were not taken seriously by the healthcare professionals they first consulted about their child's development. Many express regret that the professionals present during the official diagnosis announcement didn't take enough time to explain their child's condition and the different interventions they could benefit from. When taking the necessary steps to obtain help for their child, many parents feel it was left to their own devices to seek out information on available services. It was often by chance or through social media that they became aware of financial assistance they could benefit from.

Many parents confronted with important waiting times criticised having to "shout louder than the others" and

¹ Readers interested in the research projects which collected this data can consult the suggested references at the end of this article



lodge official complaints in order to gain access to services. Some reported complying with certain professionals' expectations out of fear of losing access to their services. Others made the painful decision to refuse services their work schedules made it unmanageable. Also, tensions may arise from different perceptions of children's abilities. Whilst some parents feel that some professionals minimise their child's difficulties, others find that their child's strengths and potential are not taken into account. A lack of consistency between different fields also gives parents the impression that the service providers defend their own interests over those of the child. In sum, without calling into question the goodwill of any of the involved parties, these different obstacles lead to distrust and tense interactions between parents and professionals.

Recognising different ways of knowing and intersections of expertise

That being said, parents who report satisfactory collaborations with professionals and educators tend to feel like they are at the center of the collaborative relations built around their child. Parents, especially mothers, describe feeling empowered when able to participate in decision making. In addition to providing privileged access to information, this type of collaboration promotes their abilities as parents while boosting their confidence. The collaborative relationships parents appreciate are also described as providing their child with effective educational support, as well as practical knowledge for parents to further this learning with their child.

Despite the difficulties they encounter, parents will over time develop an excellent understanding of their child's character (strengths, weaknesses, preferences and interests for example). Mothers and fathers hold knowledge that is complementary to the educators' expertise. This knowledge, acquired through daily encounters with their child and multiple quests for information and services, can also be enhanced through interactions with educators and professionals. Therefore, an important way to create a real partnership with families is to recognise parents as expert on their own child. Whilst parents have specific questions and needs, taking their knowledge into account allows interventions to be better tailored to children's peculiarities, as well as an opportunity for professionals to learn from their daily observations and experiences. This exchange of knowledge can also contribute to a feeling of self-efficacy, which improves parents' participation and the quality of parent-professional relationships. Seen this way, a successful parent-professional collaboration is one which allows for reciprocal exchange of knowledge and that recognises intersections of skills and experiences. 🌸



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