



Supporting Parents of Children with Autism Spectrum Disorder

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Parents of children with autism each have their own story that includes their own unique challenges. These parents often experience significant struggles that bring with them intense and varied emotions. In fact, many mental health professionals and researchers have explored in detail the journey that these parents may take. In a 2007 case study, researchers found that parents of children with autism may experience grief, exhaustion, social isolation, negative health outcomes, as well as negative effects on the family (Benderix, Nordstrom & Sivberg, 2007; Mandell & Salzer, 2007).

Speech-language pathologists are not usually trained to support parents who are experiencing such intense emotions. However, some academics argue that it is the professionals such as SLPs, who consistently work with these families, who are best positioned to provide families with what they need most (Geller & Foley, 2009). As SLPs, we understand the importance of thinking about how we can best support families of children with autism, and expert opinions appear to validate how critical our role can be. Parent-implemented intervention allows us to provide important emotional support by listening, understanding, helping problem solve challenging situations, and building parents' capacity to help their own child. Hanen Programs go one step further – they provide an instant support group.

What Supports Parents Best?

There are many factors thought to be key in therapist-parent relationships. Some qualitative studies have set to tease out what specific ingredients parents view as most helpful within speech and language interventions (Edwards, Brebner, McCormack & MacDougall, 2016; Glogowska, Campbell, Peters, Roulstone & Enderby, 2001). Based on the research, some of the factors that parents have found most helpful in interventions include practical help, emotional support, partnership, and a perceived effectiveness of therapy.

Let's take a closer look at what we can do to best support families of children with autism in our work.

How can SLPs Support Parents?

As Hanen SLPs, offering parent-implemented intervention, we can play a significant role in providing the support parents of children with autism have found to be helpful.

Let's consider the factors that parents find most helpful in intervention and how this applies to parent-implemented intervention.

<u>Factors parents found helpful</u>	<u>Strategies used in parent-implemented intervention</u>
	Supported by...
Practical Help	- Effective coaching and education around practical strategies to use in everyday routines and interactions
Emotional Support	-Active listening and acknowledgement of parents' concerns, goals and stressors -Seeking first to understand and then provide support as appropriate
Partnership	-Collaboration with parents -Goals are co-created with parents and therapists -Parents are supported to come up with their own home plans to support their child's goals
Perceived Effectiveness of therapy	-Building parents' capacity and confidence using an evidence-based approach to therapy

This type of support can be provided in one-to-one therapy, as well as in our Hanen parent programs. It is noteworthy that parent programs such as More Than Words® or Talkability™ provide an ideal context that naturally allows the therapist to provide practical help, emotional support, partnership and effective therapy. Hanen programs for parents have three objectives. These are to provide parent education, early communication intervention and social support.

Social support is the objective that is sometimes new for SLPs. So, what exactly are the benefits of social supports, including the mutual support that parents can provide each other within parent programs?

Mutual support groups have been around for quite some time. Although, traditionally, these groups are considered to be non-professional groups comprised of members with a common challenge or goal, mutual support is often a bi-product of our parent programs.

In a 2001 study, Solomon, Pistrang, and Barker conducted a survey of parents of children with special needs, to determine what they found helpful about participating in mutual support groups. This was one of the first studies of its kind to examine the effect of support groups for caregivers who have a child with special needs. Qualitative data from parent focus group discussions were analyzed to determine core categories of parent responses. Results revealed that parents found that the mutual support groups that they belonged to supported their:

- Sense of control and agency
- Sense of belonging to a community
- Positive self change

1. Sense of Control:

Parents consistently reported that the information and support garnered from other parents in their mutual support groups had many positive effects. Parents felt stronger and more confident in their decisions through the process of sharing with other families in a similar situation. Parents also reported that the group was an excellent source of

knowledge, allowing resources and ideas to be exchanged. In particular, they appreciated advice from other parents in relation to their concerns. In addition, some parents reported that an added benefit was the fact that they could also eventually help other parents.

2. Sense of Belonging/Community:

In the study, parents reported that they felt an increased sense of belonging as a result of the support group. Many appreciated the opportunity to openly share their experiences and emotions and may have truly felt understood for the first time - a welcome change from the feelings of loneliness, isolation, guilt and stigmatization that they may have felt previously. Another added benefit was access to a new social network after being a part of the group.

3. Self change:

Parents reported many positive changes including: increased confidence, self-esteem, and assertiveness and reduced feelings of intimidation, inhibition and embarrassment. Some parents also noted a change in their acceptance of their child's disability and in their parenting approach. In addition, some parents expressed that these positive effects had the dual benefit of supporting their child. For example, as their parenting approach evolved, there was a reduction in their child's challenging behaviours.

How More Than Words® and Talkability® support parents of children with Autism Spectrum Disorder

Hanen parent programs such as More Than Words® and Talkability™ are wonderful examples of evidence-based programs that have a clear structure that SLPs can use when working with parents. Although these are not, by definition, mutual support groups, the group experience can offer parents similar benefits. In addition to receiving clinical support and education, parents come together to discuss their challenges, frustrations, and successes. For many parents, this is the first opportunity they have had to connect with other parents who are experiencing similar challenges. Hanen programs provide a context for social support that cannot occur in individual therapy sessions. The group sessions create an environment in which mutual support develops. Parents have many opportunities to connect through facilitated discussions, as well as through paired or group activities, such as those that occur in many of the practice activities. They also connect during the breaks (always important to allow enough time for these), and before and after the sessions. Partnerships are formed between parents, creating many opportunities for problem-solving, practical help and sharing of ideas and challenges. As these relationships develop, parents start to feel that their emotional needs are being met.

When I have run More than Words® programs, I have often found that parents have opted to stay connected after the program ends by exchanging contact information, setting up meetings and creating groups on social media. It is clear that, as Hanen SLPs, we are not only facilitating development of the child's communication skills, but we are also providing the context for valuable social support for parents.

References

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About The Hanen Centre

Founded in 1975, The Hanen Centre is a Canadian not-for-profit charitable organization with a global reach. Its mission is to provide parents, caregivers, early childhood educators and speech-language pathologists with the knowledge and training they need to help young children develop the best possible language, social and literacy skills. This includes children who have or are at risk for language delays, those with developmental challenges such as autism, and those who are developing typically.

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