

Effectiveness of parent-led interventions for autism and other developmental disorders

Nitin Bindlish
Founder & CEO
Mom's Belief
Gurugram, Haryana

Roma Kumar
Chief Child Psychologist
Mom's Belief
Gurugram, Haryana

Manju Mehta
Senior Clinical Adviser
Mom's Belief
Gurugram, Haryana

Kristine Thompson Dubey
Head, Communications
Mom's Belief
Gurugram, Haryana

Throughout the world, parents of children with special needs face challenges when looking for support for their child. Whether the issue is one of accessibility, affordability or effectiveness or a combination of these issues these challenges persist in developed and developing countries. However, there is now a substantial body of research that identifies parents as necessary partners in the therapy provided to their child. Engaging parents in therapies for children with special needs improves outcomes and can also address the issues of accessibility and affordability. In most cases, this assumes a family-centered approach, as parents must participate in goal setting and decision making to be active partners and effective co-therapists for their child. This paper reviews some of the literature that documents the efficacy of parent participation in clinical interventions for a developmental disorder, disability or mental health issue in a child. The studies identify benefits for the child and the entire family, supporting the use of the parent-led intervention model in a variety of settings.

Keywords: developmental disorders, autism spectrum disorder, parents, intervention, empowerment

In parent-led interventions, parents receive knowledge, guidance, resources, training and/or mentoring in some combination from child development professionals such as child psychologists and occupational and speech therapists, or from community health workers who have been trained by child development professionals. When this support is provided, it empowers parents with the information, insights, skills and tools they need to advance their child's skills on their own. The support gives them confidence in their own ability to address their child's needs. It also leaves them in a better position to advocate for their child in their communities.

Review of literature

In his research, Venkatesan (2004) states that "One of the most powerful avenues to reach children with disabilities is by extending home-based training programmes between professionals to parents and caregivers." His training guide for parents, teachers and caregivers who care for children with developmental disabilities notes that the strengths of parents and professionals must be combined and optimized to create a foundation for a productive partnership. He adds that parents "have valuable information about their child's behaviour, interests, likes and dislikes, temperament, abilities, etc. They share a greater physical and psychological proximity with the disabled child. They spend more time with the child as compared to professionals, who can only afford a meagre hour or so on any given child with a disability."

Sloper (1999) points out the importance of support for parents who are engaged in interventions for their child. He highlights the role of the "key worker" a person the parents can approach for advice about any problem associated with the child's case or condition. The responsibility of the key worker is to maintain regular contact with the family and work with professionals from a range of services to support the child.

When reviewing literature on early interventions for young children with developmental delays and disabilities, Edelman (2004) found much support for a relationship-based approach. The National Scientific Council on the Developing Child (2004) for example, reveals the importance of the child's environment and the relationships that help form that environment particularly those with parents and other family members. Edelman states that parent-child and practitioner-parent relationships are more widely recognized as important for effective early intervention. He cites Kelly (1999) who promotes the relationship between parent and service provider as a potential predictor of the success of intervention, as well as Keenan-Rich (2004) who identifies the roles that other family members can play in intervention: "I became attuned to family strengths and increasingly discovered that different family members could play a part in intervention. There have been many older sisters who loved participating and playing teacher."

A number of studies look at the efficacy of parent-led interventions for specific developmental disorders and disabilities.

Gupta and Singhal (2005) look at therapies available for children diagnosed with autism spectrum disorder in India. They make the case for parent engagement as a way to address the shortage of qualified professionals in India. "In India, the demand for service providers far exceeds the supply of available professionals, and the cost attached to accessing these services can be high. The professionals can therefore train parents in setting up their own individualised treatment programmes for their child." They explain that this model has been successful in enabling parents to teach their child play and communication skills. "Involving the parents at this level, by providing more information and making them an integrated part of the child's education programme not only enhances the child's skills but is also instrumental in reinforcing belief in their own competencies."

In the case of children diagnosed with autism spectrum disorder, parent engagement in early interventions that focus specifically on

social communication have shown positive results. Green et al. (2010) recruited 152 children with core autism to determine the impact of increased parental sensitivity and responsiveness to child communication, as promoted through therapist-led sessions with parents. In addition to the training provided by the therapist, parents were asked to practice the strategies at home each day. Assessor-rated parent-child interactions following the intervention showed distinctly positive outcomes for social communication between parent and child.

Green participated in the follow-up study led by Pickles (2016) which demonstrates lasting positive effects from the parent intervention model for social communication. Conducted at a median of 5.75 years from the endpoint of Green's initial study, the follow-up study tracked 80% of the original 152 children at a mean age of 10.5 years. The study demonstrates an overall reduction in symptom severity over the course of the trial and follow-up period, upholding the clinical value of the parent-intervention model by showing long-term symptom reduction.

This intervention model was also adapted and introduced in South Asia by Rahman et al. (2015). The study of the adapted model examines the quality of parent-child interaction on the Dyadic Communication Measure for Autism and identifies the approach as being effective in the areas of parental synchrony and initiation of communication by the child with the parent. The intervention model was taught to non-specialist health workers in Goa, India, and Rawalpindi, Pakistan, who then worked with the parents recruited for the trial. Because the model was adapted and applied in resource-poor countries and found to be highly successful, it suggests that models that engage parents in low-to-medium-income countries can be employed as a way to address a shortage of trained professionals and resources for autism spectrum disorder and other developmental disorders.

In her research, Bennet (2012) highlights the importance of parental involvement for children with autism spectrum disorder, explaining that there is ample research that demonstrates the positive effects of parent involvement, including increased developmental skills and progress in an early intervention program for autism. She adds that this implies the need for parents and social workers to understand the benefits of parental involvement, as well as the detrimental effects of a lack of parental involvement.

A similar perspective from Walkup (2012) was published in the same year. "From the outset it is important to explain to parents that they will be a critical part of their child's learning and will be shown how they can help the child practice what they've been taught during therapy sessions." Beyond recommending parent engagement, Walkup encourages professionals to assess and address barriers to participation among parents and use communication and goal-setting activities to facilitate parent participation. She also highlights the importance of individualized support for parents that takes into consideration the parents' education levels, socio-economic status, professional and family responsibilities and the need to attend to other family members.

Hardan's (2014) research, which was reviewed in *Psychiatry Advisor*, studied the effectiveness of group pivotal response training for parents, as compared to a program that focused on basic information about autism. By the end of the 12-week study, the children whose parents were involved in the behavioral therapy training showed more improvement in language skills, which included both the number of things they said and the functional use of

words. Hardan explains how everyday interactions offer opportunities for parents: "The child might say 'ba,' and you reward him by giving him the ball. Parents can create opportunities for this treatment to work at the dinner table, in the park, in the car, while they're out for a walk."

Children with communication / language disorders also benefit from parent-led interventions.

In the case of young children who experience language impairments, Roberts and Kaiser (2011) found that parent-implemented language interventions offer an effective way to address language impairments in young children. They note that parents can learn how to use both general and specific language support strategies with their child. These kinds of interventions appear to be linked with substantial language growth in young children with different degrees of cognitive and language impairments.

Carnes (2012) reviewed the effectiveness of parent involvement in the case of children with communication disorders, noting the importance of a family-centered approach. Carnes states that a parent's knowledge about the child's strengths, routine, nature and interests is very valuable to the therapist. A parent's perspective on the cultural relevance of proposed strategies and the likelihood that they will work is also very valuable.

In her review of research on parent engagement in therapy for children with communication disorders, Chaney (2013) summarizes the work of Roberts and Kaiser (2011); and Ronski et al. (2011). "By supporting parents with children who are at risk for language delays, speech-language pathologists can teach parents to modify their communication styles, therefore improving the transactional nature of communication between parents and children and expanding natural language learning opportunities." Chaney also notes the suggestion from Ronski that equipping parents with effective communication strategies and improving their overall interaction with their children gives parents confidence in those interactions and a tendency to view their child's language impairments as less severe. Chaney reports: "Parents who invest in their child's language intervention by acquiring and implementing new communicative support skills not only feel more confident in parent-child interactions, but also successfully implement and generalize language intervention strategies."

Additionally, Chaney cites Kaiser and Hancock (2003) who state that parent-implemented therapies are more likely to be successful when the parent is "fully invested in the treatment process, working as a co-clinician alongside the speech-language pathologist, and is a vital member in all decision-making processes."

Equipping parents with intervention strategies for children with attention deficit hyperactivity disorder (ADHD), Down syndrome, intellectual disability, learning disabilities and other behavior issues has also brought positive results.

The ADHD Institute (2017) conducted a meta-analysis of eight randomized controlled trials of parent-led behavioral therapies in preschool children with ADHD. Results show significant benefits from the parent-led behavior therapy. The ADHD Institute also studied an eight-session parent training program, which shows an improvement across all domains of the Impairment Rating Scale, compared with the baseline (parent-rated). The largest effects are seen in overall severity / impairment, parent-child relationship and impact of the child's behavior on the family.

A review of recent work by DuPaul and Kern (2017) provides their finding that online training provided to the parents of children with ADHD can be as effective as training delivered to parents in person. Coverage of their study notes that a prevailing preference for pharmacological treatment and the challenges inherent in identifying and accessing support for a child can lead parents to overlook or avoid behavioral therapy. "While the American Academy of Pediatrics recommends behavior therapy support as the first line of treatment for preschool-age children with attention deficit hyperactivity disorder (ADHD), limited availability of clinicians, cost and challenges in transportation and child care as well as reliance on pharmacological drugs mean few families access such therapy for themselves and their children."

Gortmaker et al. (2007) studied the impact of parent-tutoring interventions on reading outcomes for children with learning disabilities. In the study, parents were trained to use intervention strategies with their child at home. The study shows that parent tutoring resulted in measurable, generalized increases in reading fluency in both high-word-overlap and low-word-overlap passages as a function of parent tutoring.

The Responsive Teaching early intervention curriculum was developed to help parents and caregivers use routine interactions with children with Down syndrome and other developmental problems to address their cognitive, language, and social emotional needs (Mahoney et al., 2006). The curriculum relies on "easy to remember" suggestions that adults can use in their daily interactions with their children. The curriculum is based on results from several studies that suggest that a child's cognitive and communication development can be promoted by parents through highly responsive interactions with them (Mahoney et al., 1985; Mahoney, 1988 a, b).

According to Forehand et al. (2013), the role of parent interventions in addressing child disruptive behaviors has typically been determined by the child's age or developmental level. Parent intervention was commonly used with behaviors such as oppositionality, noncompliance and aggression, which often emerge in the preschool years. Forehand provides the rationale: "Because of the developmental level of these children and the questionable impact of 'traditional therapy' with the child as the focal client, parents became 'co-therapists', implementing behavioral programs in the home." While Forehand notes that the approach to disruptive behaviors changes as a child ages and moves through adolescence, he points out that parenting skills are an important component of most of these approaches.

Forehand also examined parent interventions for child anxiety. Historically, interventions for anxiety began later in a child's life primarily in the seven to 14-year-old range and parenting components for anxious children in this age group were not seen as contributing to the outcome beyond the treatment provided to the child alone. However, parents are important participants in the interventions designed for younger children with anxiety, according to Forehand.

There are many studies that demonstrate the effectiveness of healthcare delivery models that identify the child and the parents as their focus. Referred to as family-centered care, the approach facilitates a deeper level of involvement from parents and other family members. Greater participation, collaboration and shared decision making are important components of family-centered care.

Kuhlthau et al. (2011) looked at professional papers dating back to 1986 that examined the use of family-centered care in the treatment

of children with special healthcare needs. They report finding "positive associations of family-centered care with improvements in efficient use of services, health status, satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost."

Dunst and Trivette (1996) also discuss the benefits of family-centered care. "Family-centered care is a special case of effective helping, and effective helping is a special case of an empowerment approach to working with people seeking professional advice and expertise." They elaborate on the importance of empowerment: "The term empowerment is used increasingly as a concept for reorienting policy and clinical practice so as to have competency-enhancing rather than dependency-forming consequences." Parent-led interventions for developmental disorders and other disabilities in children typically seek to develop the parent's skills for the benefit of the child. Consequently, the empowerment of parents is an important component of parent-led intervention models.

Evidence-based support for parents of children with special needs in India

In India, Mom's Belief supports special needs children by empowering their parents with professional guidance and highly tailored resources that are delivered to the home on a subscription basis.

The program acts as an enabler by giving parents a deeper understanding of their child's skills and strengths, individualized education plans that incorporate their goals for their child, and customized, hands-on teaching tools, activities and strategies that promote development and greater independence.

All components of the program are provided by the child psychologist who is assigned to the family and is available to the parents for ongoing training, mentoring, and monitoring. Participation in the program begins with the neuro-developmental profile, which is completed by the assigned psychologist in two phone consultations. The profile is completed using a battery of tests, including a detailed assessment that is specific to the child's diagnosis or issues. Videos submitted by parents supplement the information they provide to the psychologist, which gives him or her historical and visual inputs that contribute to the child's profile. The profile guides the development of monthly education plans and serves as the baseline for the child's progress in the program.

Once the education plan has been reviewed, discussed and finalized by the parents and child psychologist, the psychologist customizes teaching tools to support the education plan. The teaching tools are delivered to the home along with activities that parents can do with items typically found in the child's environment. The psychologist trains parents how to use the resources and activities and provides a daily schedule that guides the parents toward their established goals. Resource videos are also shared with the parents to demonstrate how resources are used; in turn, parents share videos of their child using the resources to help the psychologist monitor their use and maximize their effectiveness.

The guidance and support of the dedicated child psychologist constitute a critical component of the program. The psychologist fills many roles-teacher, trainer, mentor, monitor, cheerleader, sounding board and confidante-to give parents the professional advice, knowledge and encouragement they need to understand and work with their child.

The resources provided to parents are equally important. The R and D team at Mom's Belief has spent years researching, designing and developing hands-on teaching tools and activities that engage the child with color, motion and texture that draw them into the parent-led intervention. They have been designed to accommodate the various learning styles typical of the developmental disorders addressed by the program. They are also user-friendly for parents and fun for kids-characteristics that lend to their effectiveness. The resources are replaced with a new set each month, which creates a sense of anticipation and excitement in the child and prevents boredom. Resources are delivered to the home and collected after one month.

The child psychologist monitors the child's progress and reviews it with parents at the end of the month. The review helps the psychologist prepare the individualized education plan for the next month. After three months, the neurodevelopmental profile is completed again to gain a deeper understanding of the progress made.

The premise of the Mom's Belief program

The Mom's Belief program is based on the following beliefs:

- No two special needs children have exactly the same needs.
- One-to-one guidance and resources that are precisely tailored for an individual are far more effective than off-the-shelf resources or standardized programs.
- When parents understand their child's condition, skill levels and strengths and have access to expertise, guidance and customized resources, they can advance their child's growth and development.

Components and characteristics of the Mom's Belief Program

- A dedicated child psychologist who tailors the program's components according to the specific needs of the child, his or her environment and the goals of the parents.
- A family-centered approach that includes parents in decision-making, promotes the exchange of knowledge and the sharing of information and relies on open and honest communication between the parents and the dedicated child psychologist.
- A comprehensive neuro-developmental profile, completed using a battery of tests, including an assessment that is specific to the child's disorder / condition.
- An interpretive report that summarizes and explains the profile for parents.
- Collaborative goal-setting with short-term and long-term objectives used to structure the program.
- Monthly individualized education plans (IEPs) that incorporate these goals and objectives.
- Hands-on teaching tools that are customized to support the child's IEP.
- Activities and techniques that parents can use along with the teaching tools to achieve the goals of the IEP.
- A schedule that structures the home intervention for parents to keep them on track. A new schedule is provided every 15 days.
- Regular consultations with the family's dedicated child psychologist, conducted via Skype or by phone.
- Progress monitoring with a neuro-developmental profile completed every three months.

Program summary

In the Mom's Belief program, parents develop adaptive skills; learn how to reduce behavioral problems and promote desirable behaviors in their child; improve parent-child interaction; and create a more positive atmosphere for their family. Like other parent-led interventions, the Mom's Belief program is effective because it is built on the relationship between parent and child and takes advantage of the familiarity and proximity it offers. It takes place in the home environment, so it accommodates the child's schedule and moods, yet the child psychologist is available to address questions and concerns. Parents learn how to encourage new skills and improved behavior in the present, and they're equipped to shape behavior before it becomes problematic in the future.

The benefits of parent-mediated intervention models for children with autism spectrum disorder and other developmental disorders are well-documented. While individual models will vary according to the disorder (s) being addressed, location and availability of resources, cultural norms, and other factors, the key element of enabling and supporting parents with appropriate knowledge, advice and resources is critical. The key elements on which the Mom's Belief program is built are validated in several studies on parent-led interventions.

- Knowledge is power. The parent-mediated intervention model incorporates the expertise of professionals and makes that expertise accessible to parents, so the parents gain valuable and relevant information and insights.
- In Mom's Belief, a child psychologist is assigned to the family to assess the child's skills and behavior and tailor the program according to those specific developmental needs.
- Each child's program is guided by his or her comprehensive neurodevelopmental profile and the interpretive report based on that profile is shared with parents to give them a deeper understanding of their child's skills, challenges, strengths and potential.
- The designated psychologist helps the parents not just to use the teaching tools and activities but to understand their purpose and applicability in various skill areas.
- Professional mentoring helps parents understand and apply knowledge and insights. But it goes beyond that to help them build confidence in their own abilities.
- Aside from psycho-educating and guiding the parent, the designated Mom's Belief psychologist listens, encourages and instills confidence in parents building a relationship that is unlike the conventional relationship that most parents have with their child's doctor, counselor or therapist. The designated psychologist is a lifeline for parents.
- As a mentor and a source of knowledge and insights, the dedicated child psychologist helps to significantly reduce the anxiety experienced by parents.
- In time, the parents assume the role of facilitator, co-therapist, home supervisor, motivator and provider of emotional support.
- Parent-mediated intervention models are sometimes used to address a shortfall in services or resources, as seen in resource-poor areas. Parent-led intervention models give parents skills and resources that they can use when and where it suits them.
- Mom's Belief offers accessibility. Parents connect with their dedicated child psychologist by phone, Whats App, or Skype,

depending on their needs and preferences. Resources are delivered to the family, wherever they happen to live. Like other parent-led interventions, Mom's Belief lets parents work with their child when and where it's convenient for them.

- Parent-mediated interventions are, by their very nature, approaches built on the principles of family-centered care. Parents' perspectives are sought, respected and incorporated; their goals are identified, and their needs are accommodated. Joint decision-making is the hallmark of a family-centered approach.

- The Mom's Belief program is built on the premise that parents know their child better than anyone else. Consequently, the neurodevelopmental profile not only incorporates but depends on parents' experience and insights.

- Goal-setting is an important part of the program; it lets parents determine what is most important for their child and their family. With input from their dedicated child psychologist, parents are able to set feasible targets for their child.

- The dedicated psychologist and parents work together to create IEPs that reflect the parents' short-term objectives and long-term goals.

- Traditional therapy often assigns parents to the role of an external observer. Mom's Belief brings parents into the therapy equation by equipping them with skills, knowledge, resources and support, effectively putting parents in the lead.

Conclusion

The findings presented in this review suggest that there is growing evidence to support the efficacy of parent-led interventions for developmental disorders and in some cases, behavioral and mental health issues in children. While the nature of support provided to parents varies widely, the parents engaged in a majority of guided interventions gain new knowledge, skills, techniques and / or strategies. When structured according to the principles of family-centered care, the intervention model enables parents to apply new insights and skills to play a greater role through information sharing, goal setting, planning and delivery. The child benefits for life because the constant in the child's life-the person who knows him or her best-has developed the ability to promote the child's development and tap the child's true potential.

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