

Unique Opportunities and Challenges in Implementing Family-Focused Interventions for Children with Developmental Disorders

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The Institute of Medicine (IOM) and National Research Council (NRC) established the Forum on Promoting Children’s Cognitive, Affective, and Behavioral Health to engage leaders from academia, government, professional organizations, and philanthropy in dialogue about how to build a stronger research and practice base around the development and implementation of programs, practices, and policies to foster children’s health and well-being across the country. In April 2014, the forum hosted a workshop on strategies for scaling tested and effective family-focused preventive interventions. The workshop included discussion of successes and challenges to expanding the reach of family-focused interventions—such as the Positive Parenting Program (Triple P), the Incredible Years Programs, and the Nurse–Family Partnership—that have been shown to be effective for promoting children’s social, emotional, and behavioral well-being as well as for reducing caregiver stress and enhancing positive relationships between children and their parents (Menting et al., 2013; Olds et al., 2010; Perrin et al., 2014; Sanders et al., 2014).

Less explored in the workshop was that family-focused interventions have a unique beneficial opportunity for promoting health in children with developmental disorders. Early intervention, including efforts that involve family participation, is considered crucial for altering disorder trajectories and enhancing developmental outcomes (Warren et al., 2011) as well as preventing negative outcomes, in certain developmental disorders like Attention Deficit Hyperactivity Disorder (ADHD) (Halperin et al., 2012). However, family-focused interventions that target children with developmental disorders also present with distinctive implementation challenges. This paper discusses unique implementation opportunities and challenges for family-focused interventions in maximizing outcomes in children with developmental disorders, with a focus on Autism Spectrum Disorder (ASD).

ASD represents a particularly challenging developmental disability due to variability in behavioral symptom presentation and the possible presence of a range of co-occurring conditions, such as language delays or learning disabilities. Given the complexity of ASD, the lifelong nature of the disability, and the challenges of functioning in everyday settings, effective ASD interventions must include parent or caregiver involvement (Lord and McGee, 2001) to augment and reinforce the intervention the child is receiving. Although parent-implemented programs that focus on impairments of ASD are increasingly being developed and tested (Oono et al., 2013), programs that train parents in general positive parenting skills and child-directed interactions are available resources worth considering.

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OPPORTUNITIES

Clinicians and researchers have suggested (Zand et al., 2013) and empirically tested (Whittingham et al., 2009) that parental resilience in families with a child with ASD may be bolstered by programs such as Stepping Stones Triple P (Sanders et al., 2003), Incredible Years (Webster-Stratton and Reid, 2010), and Parent-Child Interaction Therapy (PCIT) (Eyberg et al., 2001). There is considerable efficacy for these programs in reducing problem behaviors in children with ADHD or Oppositional Defiant Disorder (ODD) (Van der Oord et al., 2008; Young and Amarasinghe, 2010). These programs also have extensive evidence-based data in increasing caregiver confidence (McIntyre, 2008; Plant and Sanders, 2007), reducing parental conflict (Sofronoff et al., 2011), and decreasing stress (Whittingham et al., 2009). These beneficial caregiver effects are important, for as caregivers have a greater sense of control and confidence, in the case of a family with ASD, they may in turn be more effective in implementing the disorder-specific interventions, such as in the Early Start Denver Model (ESDM) or Applied Behavior Analysis (ABA) (Lovaas, 1987; Rogers et al., 2012). In addition to increasing evidence on some comprehensive treatment models for ASD, specific, evidence-based practices can also provide important tools to help plan and implement intervention in school, community, and home settings (Salvado-Salvado et al., 2012; Wong et al., 2013). More research is needed in how parents, in particular, can effectively use these strategies.

Evidence-based practice has shown that a non-specialist can execute Stepping Stones – Triple P and other broad parenting programs. However, while typically ASD-specific interventions require a trained clinical professional, recent analyses suggest that a paraprofessional, rather than a highly trained clinician, can also work directly with a child and parents to both implement and effect change in children with ASD (Oono et al., 2013; Reichow et al., 2013). These findings are critical for children with ASD as well as other developmental disorders that require disorder-specific interventions. Additionally, given the rapid increases in diagnoses of developmental disorders such as ASD and ADHD, there is an increasing shortage of professionals who can train parents in interventions. Paraprofessionals and web-based tools that can teach parents broaden the scope of who can access family-focused interventions. Despite the importance of family involvement in their child’s interventions, it is well documented that parents’ implementation abilities vary (Meadan et al., 2009) in part from the burden of stress placed on the caregiver when having a child with ASD (Karst and Van Hecke, 2012).

CHALLENGES

Implementation challenges, which are inherent to scaling any evidence-based practice from the lab to real life, are magnified in families with children with developmental disorders. For instance, evidence suggests that having a child with developmental delay may increase the risk of dropout in parent-training interventions (Bagner and Graziano, 2013). Research underlying the risk of dropout is unclear; whether this risk is independent of other factors such as lower socioeconomic status, which is known to increase dropout, or higher levels of stress is unknown. Parents with a child with special needs may have greater concerns about their ability to parent their child compared with parents with a typically developing child (Giallo et al., 2013; Kuhn and Carter, 2006). In turn, it is not surprising that families may doubt their skills to implement behavioral interventions correctly, leading to frustration and dropout. Support systems that provide caregivers with regular feedback are critical. Recent research (Nefdt et al., 2010)

suggests that web-based tools (e.g., Autism Navigator™ or Enhancing Interactions) (Kobak et al., 2011) and easy-to-follow manuals (Bearss et al., 2013) may provide families with the necessary flexible support to increase retention rates.

An underlying reality in implementing family-focused interventions in children with developmental disabilities is the stigma associated with having a child with special needs – specifically surrounding a family’s concern about others knowing of their child’s condition. After diagnosis, families begin a coping process of having a child with a disability, and many families, even after receiving a diagnosis and action plan for care, are reluctant to tell other family members or friends—crucial components of a support network. Such caution creates an additional barrier to successfully implementing parent-training programs (Dempster et al., 2013). Families with a child with a developmental disability may also feel isolated after their child receives a diagnosis (Mueller et al., 2012). In cases of early identification, families may be less willing to address a child’s needs when they were not the ones to initiate concerns about developmental progress. Lastly, stigma exists within a cultural context (Kang-Yi et al., 2013). Therefore, while family-focused treatments in general must acknowledge family beliefs and coping strategies to be successful, they are particularly acute for cases in which the child has a developmental disorder.

FUTURE DIRECTIONS

Currently, there is no one treatment for ASD. Clinicians offer differing advice as to what is the best intervention and, in conjunction with false vaccine theories, many parents of children with ASD are skeptical or even distrustful of clinical professionals. Families typically must navigate decisions regarding medications, potentially enhancing wariness of clinicians (Coletti et al., 2012). Determining the best practices to reduce this distrust will be critical for the success of family-focused interventions designed for children with developmental disorders.

An important factor for successful caregiver intervention is generalization, which is how easily the intervention is adapted across settings (Webster-Stratton and Hammond, 1997). Parents may receive specialized training in a primary care or school setting, but then implementing the intervention in the home presents additional obstacles that are exaggerated in a child with developmental disabilities (Kaiser et al., 2000). Often children with developmental disabilities have greater difficulty making transitions across settings, which makes it harder for a parent to follow an intervention plan. Therefore, additional flexibility within the program as well as the skills taught to parents is necessary.

In the past few years, attention has focused on the use of family-focused interventions to augment school-based and clinical treatments that address gaps in developmental trajectories for children with developmental disorders. As discussed in this paper, implementation of family-focused interventions in these children presents unique challenges as well as opportunities to enhance interventions and existing treatments. As researchers, clinicians, and educators evaluate how to broaden the effectiveness of family-focused interventions in their respective settings, it will be necessary to consider these distinctions for children with special needs.

REFERENCES

- Bagner, D. M., and P. A. Graziano. 2013. Barriers to success in parent training for young children with developmental delay: The role of cumulative risk. *Behavior Modification* 37(3):356-377.
- Bearss, K., L. Lecavalier, N. Minshawi, C. Johnson, T. Smith, B. Handen, D. Sukhodolsky, M. Aman, N. Swiezy, E. Butter, and L. Scahill. 2013. Toward an exportable parent training program for disruptive behaviors in autism spectrum disorders. *Neuropsychiatry (London)* 3(2):169-180.
- Coletti, D. J., E. Pappadopulos, N. J. Katsiotas, A. Berest, P. S. Jensen, and V. Kafantaris. 2012. Parent perspectives on the decision to initiate medication treatment of attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology* 22(3):226-237.
- Dempster, R., B. Wildman, and A. Keating. 2013. The role of stigma in parental help-seeking for child behavior problems. *Journal of Clinical Child & Adolesc Psychology* 42(1):56-67.
- Eyberg, S. M., B. W. Funderburk, T. L. Hembree-Kigin, C. B. McNeil, J. G. Querido, and K. K. Hood. 2001. Parent-child interaction therapy with behavior problem children: One and two year maintenance of treatment effects in the family. *Child and Family Behavior Therapy* 23(4):1-20.
- Giallo, R., C. E. Wood, R. Jellett, and R. Porter. 2013. Fatigue, wellbeing and parental self-efficacy in mothers of children with an autism spectrum disorder. *Autism* 17(4):465-480.
- Halperin, J. M., A. C. Bedard, and J. T. Curchack-Lichtin. 2012. Preventive interventions for ADHD: A neurodevelopmental perspective. *Neurotherapeutics* 9(3):531-541.
- Kaiser, A. P., T. B. Hancock, and J. P. Nietfeld. 2000. The effects of parent-implemented enhanced milieu teaching on the social communication of children who have autism. *Early Education and Development* 11(4):423-446.
- Kang-Yi, C. D., R. R. Grinker, and D. S. Mandell. 2013. Korean culture and autism spectrum disorders. *Journal of Autism and Developmental Disorders* 43(3):503-520.
- Karst, J. S., and A. V. Van Hecke. 2012. Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review* 15(3):247-277.
- Kobak, K. A., W. L. Stone, E. Wallace, Z. Warren, A. Swanson, and K. Robson. 2011. A web-based tutorial for parents of young children with autism: Results from a pilot study. *Telemedicine Journal and E-Health* 17(10):804-808.
- Kuhn, J. C., and A. S. Carter. 2006. Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry* 76:564-575.
- Lord, C., and J. P. McGee. 2001. *Educating children with autism*. Washington DC: National Academy Press.
- Lovaas, O. I. 1987. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology* 55(1):3-9.
- McIntyre, L. L. 2008. Adapting Webster-Stratton's Incredible Years parent training for children with developmental delay: Findings from a treatment group only study. *Journal of Intellectual Disability Research* 52(12):1176-1192.
- Meadan, H., M. M. Ostrosky, H. Y. Zaghawan, and S. Yu. 2009. Promoting the social and communicative behavior of young children with autism spectrum disorders. *Topics in Early Childhood Education* 29:90-104.

- Menting, A. T., B. Orobio de Castro, and W. Matthys. 2013. Effectiveness of the Incredible Years parent training to modify disruptive and prosocial child behavior: A meta-analytic review. *Clinical Psychology Review* 33(8):901-913.
- Mueller, A. K., A. B. Fuermaier, J. Koerts, and L. Tucha. 2012. Stigma in attention deficit hyperactivity disorder. *Attention Deficit and Hyperactivity Disorders* 4(3):101-114.
- Nefdt, N., R. L. Koegel, G. Singer, and M. Gerber. 2010. The use of a self-directed learning program to provide introductory training in pivotal response treatment to parents of children with autism. *Journal of Positive Behavior Interventions* 12(1):23-32.
- Olds, D. L., H. J. Kitzman, R. E. Cole, C. A. Hanks, K. J. Arcoletto, E. A. Anson, D. W. Luckey, M. D. Knudtson, C. R. Henderson, Jr., J. Bondy, and A. J. Stevenson. 2010. Enduring effects of prenatal and infancy home visiting by nurses on maternal life course and government spending: Follow-up of a randomized trial among children at age 12 years. *Archives of Pediatrics and Adolescent Medicine* 164(5):419-424.
- Oono, I. P., E. J. Honey, and H. McConachie. 2013. Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews* 4:CD009774.
- Perrin, E. C., R. C. Sheldrick, J. M. McMenemy, B. S. Henson, and A. S. Carter. 2014. Improving parenting skills for families of young children in pediatric settings: A randomized clinical trial. *JAMA Pediatrics* 168(1):16-24.
- Plant, K. M., and M. R. Sanders. 2007. Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities* 28(4):362-385.
- Reichow, B., C. Servili, M. T. Yasamy, C. Barbui, and S. Saxena. 2013. Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower-functioning autism spectrum disorders: A systematic review. *PLoS Medicine* 10(12):e1001572; discussion e1001572.
- Rogers, S. J., A. Estes, C. Lord, L. Vismara, J. Winter, A. Fitzpatrick, M. Guo, and G. Dawson. 2012. Effects of a brief Early Start Denver Model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry* 51(10):1052-1065.
- Salvado-Salvado, B., M. Palau-Baduell, M. Clófent-Torrento, M. Montero-Camacho, and M. A. Hernandez-Latorre. 2012. [Comprehensive models of treatment in individuals with autism spectrum disorders]. *Revista de Neurologia* 54(Suppl 1):S63-S71.
- Sanders, M. R., T. G. Mazzucchelli, and L. J. Studman. 2003. Practitioner's manual for standard Stepping Stones Triple P: For families with a child who has disability. Brisbane, Australia: The University of Queensland and Disability Services Commission of Western Australia.
- Sanders, M. R., J. N. Kirby, C. L. Tellegen, and J. J. Day. 2014. The Triple-P-Positive Parenting Program: A systematic review and meta-analysis of a multi-level system of parenting support. *Clinical Psychology Review* 34(4):337-357.
- Sofronoff, K., D. Jahnel, and M. Sanders. 2011. Stepping Stones Triple P seminars for parents of a child with a disability: A randomized controlled trial. *Research in Developmental Disabilities* 32(6):2253-2262.
- Van der Oord, S., P. J. Prins, J. Oosterlaan, and P. M. Emmelkamp. 2008. Efficacy of methylphenidate, psychosocial treatments and their combination in school-aged children with ADHD: A meta-analysis. *Clinical Psychology Review* 28(5):783-800.

- Warren, Z., M. L. McPheeters, N. Sathe, J. H. Foss-Feig, A. Glasser, and J. Veenstra-Vanderweele. 2011. A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics* 127(5):e1303-e1311.
- Webster-Stratton, C., and M. Hammond. 1997. Treating children with early-onset conduct problems: A comparison of child and parent training interventions. *Journal of Consulting and Clinical Psychology* 65(1):93-109.
- Webster-Stratton, C., and M. J. Reid. 2010. The Incredible Years parents, teachers and children training series: A multifaceted treatment approach for young children with conduct problems. In *Evidence-based psychotherapies for children and adolescents*, 2nd ed., edited by J. Weisz and A. Kazdin. New York: Guilford. Pp. 194-210.
- Whittingham, K., K. Sofronoff, J. Sheffield, and M. R. Sanders. 2009. Stepping Stones Triple P: An RCT of a parenting program with parents of a child diagnosed with an autism spectrum disorder. *Journal of Abnormal Child Psychology* 37(4):469-480.
- Wong, C., S. L. Odom, K. Hume, A. W. Cox, A. Fettig, S. Kucharczyk, M. E. Brock, J. B. Plavnick, V. P. Fleury, and T. R. Schultz. 2013. *Evidence-based practices for children, youth, and young adults with autism spectrum disorder*. Chapel Hill, NC: Autism Evidence-Based Practice Review Group.
- Young, S., and J. M. Amarasinghe. 2010. Practitioner review: Non-pharmacological treatments for ADHD: A lifespan approach. *Journal of Child Psychology and Psychiatry* 51(2):116-133.
- Zand, D. H., B. Braddock, W. Baig, J. Deasy, and R. Maxim. 2013. Role of pediatricians in fostering resilience in parents of children with autism spectrum disorders. *The Journal of Pediatrics* 163(6):1769-1771.