

Moving towards a more ecologically valid model of parent-implemented interventions in autism

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Early intervention is critical for improving the long-term outcomes for children with autism (National Research Council, 2001). Training parents and other caregivers of young children with autism to implement treatment has been identified as a potential way to improve access to evidence-based interventions during the critical early years (Burrell and Borrego, 2012; McConachie and Diggle, 2007; Matson et al., 2009). Our field has a long history of successfully teaching parents to increase communication and other skills in their children with autism in research settings using primarily single-subject or quasi-experimental designs. Several recent studies that include randomized trials have shown very promising results for teaching parents of very young children with autism to integrate evidence-based strategies into daily routines with positive effects on core symptoms of the disorder (Kasari et al., 2014; Rogers et al., 2014; Solomon et al., 2014; Wetherby et al., 2014). However, many other trials evaluating the effectiveness of parent-implemented interventions have failed to demonstrate the large effects seen in studies of therapist-implemented interventions (Carter et al., 2011; Green et al., 2010; Rogers et al., 2012). A recent meta-analysis comparing studies of parent- and clinician-implemented interventions for children with autism found significantly greater improvements in clinician-implemented studies with small to no effects in parent-implemented studies (Nahmias and Mandell, 2014).

The disparity in outcomes between parent-implemented and clinician-implemented interventions may result from a variety of factors. First, manualized parent-implemented autism interventions can be complex and require extensive training and expertise to be implemented with high levels of fidelity (Rogers et al., 2012). Second, parents also have difficulty reaching the high levels of intensity typically provided in clinician-implemented trials, due to the many competing demands for their time. Third, parent-implemented interventions typically are designed to improve the child's play, imitation, and communication skills, with outcomes measured using standardized assessments after relatively brief periods of time (Carter et al., 2011; Drew et al., 2002; Green et al., 2010; Kaiser et al., 2000). These standardized assessments may not capture improvements in these domains as well as the more specific measures used in single-subject studies. Developing outcome

measures that capture meaningful change is a critical failure of the field and has led funders like the Simons Foundation to prioritize this area of research (<http://www.simonsfoundation.org/funding/funding-opportunities/autism-research-initiative-sfari/2015-novel-outcome-measures-for-asd-clinical-trials/>).

In contrast to parent-implemented interventions for children with autism, those designed to address other childhood psychiatric disorders traditionally focus on reducing children's disruptive behavior and improving family functioning (Boggs et al., 2004; Reid et al., 2004). These interventions have been shown to be effective in facilitating changes in both parent and child behavior, with demonstrated decreases in parental stress and improvements in parent-child interactions (Boggs et al., 2004; Eyberg, 1993). Unlike many autism interventions, these interventions for other disorders have more rigorously demonstrated effectiveness when community-based (rather than university-based) clinicians deliver them, suggesting that they may be more sustainable than proven efficacious parent-implemented autism interventions (Lyon and Budd, 2010; Reid et al., 2001). Although the needs of children with autism are in many ways distinct from the needs of children with other disorders, the needs of parents who are faced with the task of raising children with social-emotional challenges are similar across disorders.

We who develop parent-implemented autism interventions could benefit by borrowing from the practices of parent-implemented interventions for other disorders (Brookman-Frazee et al., 2006). Practices such as frequent and direct coaching of targeted parenting skills and focusing on goals that are intended to reduce parental stress and improve family functioning may be essential additions for parent-implemented interventions for children with autism. We may need to move away from seeing parent-implemented intervention as replacing more intensive treatment delivered by trained professionals and toward examining the role of parent-implemented strategies in improving family functioning and stress, in addition to facilitating child development.

Of fundamental importance is the need to improve parental participation and implementation; this is especially true of under-resourced parents. Attrition in parent-implemented intervention studies is high, especially in studies that have

explicitly attempted to engage low-resourced parents of children with autism, (e.g. 35% attrition by follow-up in Kasari et al. (2014)), and indicate the challenges of developing parent-implemented interventions that are feasible and sustainable over time. The samples included in most autism intervention research, including research of parent-implemented treatments, include families who are motivated and able to participate in research conducted in clinical settings. Low-resourced families may be excluded from this research due to difficulties with travel, cost, and time needed to access these interventions (Kasari et al., 2014). Intervention fidelity often is low, even when the sample comprises parents who appear motivated (Rogers et al., 2012). Studies of parent-implemented interventions in autism suggest some important areas to target to enhance participation, such as increasing (a) self-efficacy (Solish and Perry, 2008), (b) collaboration in treatment goals and in monitoring treatment progress (Brookman-Frazee, 2004; Brookman-Frazee et al., 2006), and (c) confidence that the intervention will produce meaningful outcomes (Moore and Symons, 2011). Additionally, simplifying interventions to include only the primary active components may help improve fidelity. Some more recent successful projects have used adult learning strategies such as reflective practice and motivational interviewing to enhance parent learning (e.g. Rogers et al., 2014).

The focus of the intervention and the outcome measures used in studies of parent-implemented interventions for children with autism also may need to change to reflect increased emphasis on relationship-based and family functioning outcomes. Engagement may improve when parent-implemented interventions include collaborative development of treatment goals and use of coaching strategies that increase parents' feelings of partnership in the process (e.g. Brookman-Frazee, 2004; Garcia and Weisz, 2002).

The overarching question when evaluating and designing parent-implemented interventions for children with autism should shift from "How can we maximize opportunities for treatment?" to "How can we best support parents in improving family functioning?" A shift from expecting parents to become therapists to helping parents succeed at parenting is more appropriate and may facilitate sustainment of strategy use and improvements in overall family functioning. Community-based participatory models may be an excellent way to gather parent input in the development and adaptation of parent-implemented strategies that will improve the relevance, use, and effectiveness of these programs both for children and their families.

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