autism

Editorial

Early intervention for autism: Are we prioritizing feasibility at the expenses of effectiveness? A cautionary note

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The past decade has witnessed an increasing emphasis on community implementation of early interventions for autism spectrum disorder (ASD) in ways that are both effective and sustainable. The construct of sustainability in the public health context refers to the community viability and long-term impact of interventions, including issues of adoption and sustained use by community agencies, durability of activities and resources after initial funding, and long-term return on initial investment (Altman, 2009; Steckler and Goodman, 1989).

In the ASD early intervention field, the concept of sustainability is frequently—and mistakenly—equated with *affordability*, which refers to the initial costs of training providers and ongoing costs of implementing an evidence-based intervention. Accordingly, while factors promoting sustainment of interventions are under-researched, there is an increasing trend toward reducing intervention costs to make interventions more feasible for use in the community. In ASD, this is often accomplished by decreasing the intensity of an intervention or by lowering specialization standards or training requirements for those delivering the intervention. Three phenomena illustrate this trend: (1) the growing emphasis on low-intensity, parent-mediated early interventions (both in terms of publicly funded programs and new interventions being developed and tested; Nevill et al., 2018); (2) the increased reliance on paraprofessionals with minimal training or supervision to deliver interventions (e.g. behavior technicians who receive 1 week of training overall; Leaf et al., 2017); and, perhaps as a result of (1) and (2), (3) poor adherence to evidence-based practice protocol as providers adapt methods for their own context (Stahmer et al., 2005).

There are positive aspects related to these phenomena. Making interventions more affordable by reducing training requirements may facilitate initial acceptability and feasibility, especially in chronically under-resourced communities (Divan, 2017). Empowering parents with effective strategies to support learning and development in their own children is a key component of effective interventions, with benefits ranging from increased generalization of intervention goals to improvements in parental well-being (Casagrande and Ingersoll, 2017; National Research Council, 2001). Some adaptation may be necessary for efficacious interventions to meet the needs of providers and families across multiple settings and children with diverse characteristics (Lau and Brookman-Frazee, 2016). Finally, reducing training expenses and requirements may facilitate uptake and scalability of interventions, thus addressing the ethical imperative of providing intervention to the large number of children with ASD who live in underserved contexts.

However, concerns arise when reliance on caregivers or paraprofessionals is exclusive or excessive, in particular when there is little input from expert clinicians around complex decision-making (e.g. selecting intervention goals or strategies based on ongoing monitoring of child progress). For example, early intervention agencies often prioritize low-intensity parent-mediated programs that are accompanied by limited expert supervision and little or no direct child intervention; many low-cost interventions designed in the past few years follow the same trend (McWilliam, 2016; Wise et al., 2010). The dilemma of these low-cost packages is that interventions may become more feasible but ultimately less impactful. Diminished effectiveness, in turn, will result in an increased need for assistance and services later in life, thus producing a lower, rather than higher, return on investment.

Literature from other fields suggests that a disproportionate focus on affordability can compromise both effectiveness and sustainment of interventions. For example, several studies have documented lower adherence to protocol and poorer intervention outcomes when medical procedures (e.g. management of infectious diseases) are delegated to non-specialized workers (Brentlinger et al., 2010; Fulton et al., 2011; Zachariah et al., 2009). In contrast, delegating tasks to non-specialist interventionists was shown to be successful when accompanied by sustained specialist supervision and education (Glenton et al., 2013; Pallas et al., 2013; Philips et al., 2008). Similarly, in studies of prenatal home visiting, nurse home visitors have greater effect on maternal child outcomes than paraprofessional home visitors (Olds et al., 2002, 2004).

In ASD early intervention, initial evidence suggests that parent-implemented interventions may be less impactful than clinician-implemented programs (Nevill et al., 2018; Stahmer and Pellecchia, 2015) and that quality and quantity of training and supervision is critical to ensure positive outcomes for therapist-delivered interventions (Eikeseth et al.,

2009; Reichow and Wolery, 2009). Achieving fidelity to complex ASD interventions is challenging for credentialed providers and may vary based on the training and support they receive (e.g. Suhrheinrich et al., 2013). While more research on the association between provider specialization, training, intervention adaptation, and child outcomes is needed, the risk of lowering intervention quality in the pursuit of affordability cannot be underestimated.

This drive toward affordability is particularly distressing when less expensive interventions that might not meet recommended standards (e.g. adherence standards, adoption of a multidisciplinary approach, data collection to drive clinical decision-making, intensity) are routinely implemented based on the argument that provision of intervention to any standard is preferable to not delivering any intervention—potentially providing an excuse for public agencies to fail to mobilize the resources needed for appropriate intervention. International human rights treaties such as the United Nations Convention on the Rights of Persons with Disabilities (2006) and Convention on the Rights of the Child (1989) have articulated a human right for access to early intervention for young children with disabilities "that will help them achieve their full potential," with signatory states committing to mobilize the maximum of available resources to achieve these goals, including resources for training (Brown and Guralnick, 2012; United Nations, 2006). These United Nations conventions, which are almost universally ratified and consequently legally binding for most countries, are designed precisely to ensure that budgetary constraints are not used as a justification for providing substandard interventions.

Delegation of intervention responsibilities to parents without adequately resourced expert guidance may be counterproductive not only for the child but also for parents. Interventions for ASD are often difficult to master, even for professionals who chose a clinical or educational career path, as the complex needs of children with ASD require complex technical knowledge (hence the National Research Council recommendation for multidisciplinary approaches, and the need for extensive training and certification procedures). For parents, the expectation that they will implement complex techniques and be responsible for their child intervention delivery and outcomes may be overwhelming (Roberts and Dissanayake, 2013). In addition, being primarily responsible for the child intervention can affect caregivers' decisions on their employment, with many parents experiencing reduction in work hours, or exiting the workforce to accommodate the child intervention needs (Cidav et al., 2012; Horlin et al., 2014). The consequent reduction in income and other negative consequences (e.g. impact on family dynamics and mental health) might ultimately result in additional financial and human costs (Osborne et al., 2008).

Against this background, a shift in focus is needed from reducing *initial* costs of interventions (affordability) to maximizing long-term cost-effectiveness (sustainment), by ensuring that the initial investment on intervention will produce long-term child and family benefits. This is unlikely to be achieved by minimizing training and specialization requirements, or delegating complex tasks that should fall under the mandate of public services to families. Recent research from other fields has shown that high-quality early learning programs for disadvantaged children can deliver a high return on investment, with positive long-term benefits across educational, health, social, and employment outcomes (García et al., 2017). Preliminary evidence suggests that high-quality ASD early interventions may hold the same potential (Cidav et al., 2017).

It is incumbent to the ASD research community to investigate and ultimately promote all aspects of early interventions that facilitate sustainment beyond initial costs of effective early intervention. Key areas of inquiry within this agenda include (1) comparative research of low-cost versus intensive and specialist-delivered intervention versus non-specialist-delivered intervention; (2) research on the amount of training, expert supervision, and expert direct delivery that is needed to make parent-mediated and non-specialist implemented interventions as effective as expert-delivered programs, as well as research on the initial and long-term impact for child and families; and (3) understanding the components of intervention or training that are more relevant to produce child benefits so that unnecessary components can be dropped and interventions can be adapted to increase usability without compromising effectiveness (Vivanti et al., 2018).

A small but growing body of literature examines these factors, and community-based participatory models are increasingly being deployed in the field to understand and overcome barriers to sustainment of early interventions other than initial costs (Byford et al., 2015; Cidav et al., 2017; Penner et al., 2015; Wood et al., 2015). However, more empirical knowledge is needed on what may be the acceptable trade-off between feasibility and effectiveness of early interventions so that the child's rights to receive quality treatment continue to be kept at the forefront of the conversation on sustainability.

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