



Considerations in implementing evidence-based early autism spectrum disorder interventions in community settings

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Abstract: Evidence-based practices (EBPs) in early intervention for autism spectrum disorder (ASD) have the potential to improve children's developmental trajectories and address family needs. However, the successful use of EBPs in community early intervention settings requires careful attention to the context in which services are delivered. Implementation science, and specifically the Exploration, Preparation, Implementation, and Sustainment (EPIS) Model, provides a framework to examine context across multiple levels and identify barriers and facilitators to community EBP use. This article identifies several considerations most relevant for early intervention in ASD at the outer and inner context levels, as well as bridging and innovation factors. Outer context considerations include the policies and funding streams surrounding service delivery, the role of advocacy in shaping the service landscape, the availability of appropriate specialists to provide services, and family cultural characteristics. Inner context factors include the individual characteristics of both the children receiving the service as well as the provider delivering the service, in addition to the leadership and organizational climate surrounding the use of a particular EBP. We also discuss considerations of the specific innovation (in this case, EBP early interventions) to be deployed, as well as bridging factors.

Keywords: Autism spectrum disorder (ASD); health services research; child development; community

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Over the last two decades, research has identified a growing number of efficacious interventions for autism spectrum disorder (ASD) (1,2). There is mounting consensus around the common elements of what works, the ages at which various approaches are appropriate, and the specific ASD symptoms best targeted through psychosocial intervention (3,4). Despite this wealth of knowledge, a concerning gap between research and practice remains: best-practice interventions are not reaching communities where the majority of children and families can benefit from quality care. This gap is particularly evident in early intervention, where best practice guidelines and a wealth of developmental science research support the use of a combination of provider- and parent-implemented naturalistic developmental behavioral interventions (3). Unfortunately, these strategies are rarely utilized effectively

in community settings (5,6) Although this problem is broadly generalizable, the pervasive nature of ASD, the intervention complexity, and the intricacies of the service system require unique attention. Careful consideration of the context in which early ASD interventions will be implemented, specifically the fit between interventions and their context, may promote the broader use of evidence-based practices (EBPs) and ultimately benefit a greater number of children and families.

Using an implementation science framework to support community practice

Implementation science is the study of methods to promote the adoption and integration of EBPs and policies into routine care (7). A unidirectional model of developing

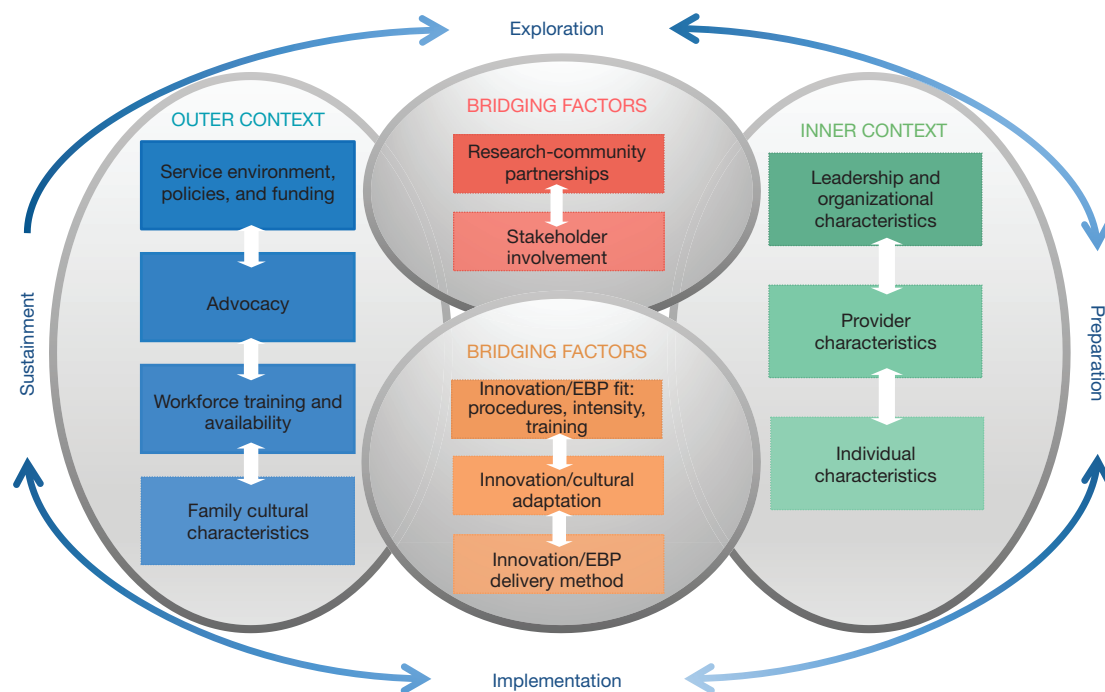


Figure 1 The EPIS (Exploration, Preparation, Implementation, Sustainment) implementation framework adapted from Aarons *et al.* (10), 2011 to support implementation of autism early intervention services. EBP, evidence-based practice.

and testing innovative practices in research settings and then subsequently rolling the practice into communities is rarely successful. Thus, positive intervention effects seen in research labs are not replicated in community practice (8,9). Implementation researchers have developed frameworks that specify the complex context for EBP implementation, and factors that potentially support or hinder the implementation of innovative practices in each stage.

The Exploration, Preparation, Implementation, Sustainment (EPIS) implementation framework has been used to examine ASD services, as it focuses on EBP implementation in publicly funded services targeted to children and families [Figure 1; adapted from Aarons *et al.* (10)]. The model highlights influential contextual factors within four phases: Exploration, Preparation, Implementation and Sustainment and examines potential barriers or facilitators to the implementation process that may occur in selecting, using, and sustaining an EBP (11).

The EPIS model emphasizes the role of context in implementation success. The outer context (e.g., service environment/policies, funding, advocacy), the inner context (e.g., leadership, organizational and provider characteristics), bridging factors (e.g., research-community partnerships), and innovation factors all likely affect implementation.

Understanding the influences at each phase allows for a targeted, proactive approach to potential barriers, thus maximizing the successful delivery of an intervention. The EPIS model can serve as a guide for understanding considerations for implementing community-based ASD early interventions.

Below, we discuss several contextual issues relevant for EBP implementation in community early intervention settings serving children with ASD. This discussion is not exhaustive, however, and additional contextual issues likely factor into each phase of implementing any EBP in complex systems.

Outer context

Several outer contextual factors can impact implementation, as follows:

Service environment, policies, and funding

Funding and policies play a large role in determining early intervention for children with ASD in the United States (US) and globally. For example, US children under age 3 with an ASD diagnosis or early signs of ASD are eligible for publicly funded early intervention services. US early intervention services emphasize service provision within the

natural environment (often the home), and mandate family inclusion in services. However, states vary greatly in system structure and administration; eligibility criteria; interagency coordination; and service delivery (12,13). Services can range from a monthly visit from a social worker, to intensive interventions involving 20 hours weekly of intervention and parent education.

In other countries, such as Taiwan, services are provided in school settings and may not include parent education (14). Some countries are just beginning to provide publicly funded ASD care and have adopted one specific intervention for all children (15). These policies, of course, affect the intensity and type of services that will be acceptable and feasible in different sites. In reality, most children with ASD in high-income countries do not begin services until about age 5, and children in low- and middle-income countries often do not have access to early intervention at all (16-18). Early engagement of children with ASD in treatment is a strong predictor of future outcomes. Thus, we must increase efforts to develop stronger policies and funding mechanisms to move effective EBPs into these diverse community settings (19).

Advocacy

Community advocacy and parent groups play a significant role in policy and service provision for children with ASD. Perhaps as a reaction to early theories that parents caused ASD, as well as a lack of community treatment options, parent organizations have been instrumental in obtaining the right for children with ASD to attend public schools and in developing a congressional caucus focusing on ASD. Parent organizations that fund research and advocate for evidence-based and alternative treatments have mobilized capital, researchers, and legislators toward changing ASD services (20). Families also influence services individually through legal channels to push service systems to increase service intensity, use specific interventions, and improve provider training (21). In a review of 45 legal cases brought by families against their children's educational programs, 75% were decided in favor of families (22).

In the US, strong advocacy from parent organizations and providers has led to both public and private insurance funding early intervention for ASD, increasing access to care for many children. However, in some states, regulations have been interpreted as supporting only one EBP. Advocacy on the part of professional organizations has led to the belief that one type of highly structured behavioral intervention exclusively fits the insurance

description. This outer context variable interacts with inner and intervention context variables. For example, highly structured treatments are often easier to implement for community agencies training paraprofessionals to work with limited supervision, thus making this interpretation helpful (23). This level of structure, however, is a specific challenge for early interventionists, as the high level of structure does not fit a developmental model, nor is it consistent with current best practice recommendations or policies that support naturalistic interventions (3). Consequently, this type of advocacy and interpretation of the regulations can affect services in specific areas.

Workforce availability

Another important outer context variable related to the service environment is workforce availability. In general, early intervention is more available in larger urban areas in the US, and high-income countries globally, due to access to highly educated specialists with training in EBPs. One response to limited access to professionals with ASD experience and cost-effective interventions has been to adopt parent-implemented approaches. These interventions, which target challenging child behaviors, parent-child interactions, and child social communication skills, have produced promising, sustained improvements in child developmental and behavioral outcomes, including low-intensity programs (24-26). Other approaches have addressed workforce training and cost issues through use of non-specialists to deliver EBPs for young children with ASD (27). These efforts have implications for other contextual variables including specialist training, cultural issues, and family engagement.

Family cultural characteristics

In spite of well-documented socioeconomic disparities in ASD diagnoses and service use, the field has essentially overlooked the diverse sociocultural contexts in which children live (28-30). Most ASD intervention studies have been conducted primarily with White, upper/middle-class families (31,32). The scarcity of early intervention studies inclusive of low-income families is particularly concerning in light of the additional financial stressors they face, as high service cost can limit care options (33). Low-income communities often lack experienced healthcare providers to provide parents with appropriate referrals, even when parents proactively seek out this information (34). Thus, children living with less well-educated caregivers or in low-income neighborhoods are frequently diagnosed with

ASD later than their more affluent peers, oftentimes after they enter the school system and beyond the age to take advantage of early intervention (35,36). In response, some researchers have adapted early interventions for children in low-income families, although limited community engagement impacted participation (37,38).

Enrolling families from diverse racial and ethnic groups in research and intervention may be a challenge (39). In general, barriers within the ASD service system are more substantial for low-income and ethnic minority families (40,41). In the US, delayed ASD diagnoses and limited contact with early intervention for both Latinx and Black children are particularly significant. Compared to White children, Black children were less likely to receive a developmental evaluation before age 3, or access early intervention (16,42). Similarly, children of Latinx parents for whom English was not their primary language in particular experience delayed access to care (43). Furthermore, Latinx and Black caregivers of children with ASD report mistrust of their child's providers, fewer therapy hours, perceived provider racial bias, and poor caregiver-provider interactions (40,44-47).

Other cultural factors can influence timely ASD intervention and treatment engagement, including autism stigma (45,48). In turn, stigma is associated with a negative impact on family life (49). In total, these factors suggest careful attention to the myriad of family- and community-related factors impacting early intervention options for children with ASD.

Inner context

Inner contextual factors focus on organizational elements impacting implementation. Below, we discuss three factors relevant to ASD early interventions.

Leadership and organizational characteristics

Traditionally, EBP training focuses on providers' role in learning and using the intervention. However, recent research highlights the importance of leadership in successful implementation of innovative practices (50-53). Researchers have identified specific behaviors and actions that demonstrate a leader's commitment to, knowledge of, support for, and perseverance during EBP implementation (54). Supports such as professional trainings, access to resources, and ongoing performance monitoring have been linked to better sustainment of an intervention, improved child outcomes, and decreased staff burnout and turnover (55). ASD intervention

studies specifically have identified a clear relationship between these organizational factors and child-level outcomes (56-58). It is critical we consider the role of the leadership and organizational support for both training and ongoing EBP use when implementing interventions in new communities.

Provider characteristics

Provider characteristics are crucial to treatment implementation. For example, knowledge about ASD and ASD EBPs are associated with later treatment fidelity (59). Additionally, provider attitudes towards EBPs predict use and sustainment of new interventions. For example, US early intervention providers generally expect to work directly with children with broad developmental delays. They typically do not have the expectation or education to coach parents effectively, nor to address ASD symptoms specifically (60). Although the early intervention field has begun to focus on how to optimally coach parents, as well as how to address ASD-related symptoms (61-63), we need to alter provider expectations and preparation for their roles in order to support successful implementation.

Individual characteristics

Intervention goals and strategies should be individualized based on the child's developmental needs, in combination with the family's priorities. Many evidence-based early interventions do this by using careful assessments, family collaboration, and comprehensive provider training (64). Researchers are just beginning to understand how to individualize strategies based on a priori child characteristics (65,66). This information needs to be translated into methods feasible for providers in order to be widely implemented.

The focus on parent-implemented intervention in ASD early intervention presents additional individualization challenges. Caregiver coordination of ASD services can place significant demands on families, and consideration of family characteristics during the ASD treatment planning process can improve early intervention initiation and retention (67,68). Although most studies find parent education and training reduces parental stress and increases family empowerment, a subset of parents (perhaps up to one-third) may not benefit from parent training if they have extremely high levels of stress (69-71). Therefore, parent involvement needs to be individualized based on the child and family's needs and capacities at the time of intervention. For example, play-based approaches which complement existing child-focused early interventions and address

parenting stress can provide parents with developmentally appropriate, less structured methods to support their children (72).

Innovation (EBP) factors

Given the outer contextual challenges, and the fact that most ASD EBPs were developed under controlled research conditions, EBP developers need to be flexible in shaping their interventions for implementation in community contexts. Moreover, particular attention must be paid to ongoing evaluation, in order to detect changes in effectiveness in a particular setting. There have been some attempts to increase the fit of an EBP with the intervention context (e.g., schools or community mental health clinics) by adapting specific procedures, intensity and training strategies, which have led to improved feasibility, acceptability and training outcomes in these contexts (73-75). For example, group-based ASD parent training models offer community agencies opportunities to simultaneously intervene with multiple families of young children, build peer social support, and reduce program costs (76-78).

Some researchers have begun to develop culturally relevant ASD interventions to meet the needs of diverse communities in the US, including Black and Latinx children with ASD, as racial and ethnic disparities persist even after controlling for socioeconomic differences (29,31,79). The majority of US studies have investigated service disparities between Black, Latinx, and White children and their families, although emerging research has identified barriers for Asian immigrant communities as well (80,81). Globally, researchers have culturally adapted EBPs, for example using a task-shifting approach in South Asia, and a combined parent-teacher training model for refugee families in Turkey (27,82). In total, these studies point to the need for more interventions designed to meet the needs of culturally diverse communities, as well a wider array of intervention delivery methods (e.g., online or group-based).

Bridging factors

One approach to tackle the complex challenges of implementing EBPs in community early intervention is to bring stakeholders together in a research-community partnership. Stakeholder involvement can address potential ideological differences; and increased communication between researchers and community partners can ensure community EBP implementation with higher levels of

acceptability, feasibility, and utility.

One example of this type of partnership in the context of early ASD intervention is the Southern California BRIDGE Collaborative [as described in Brookman-Frazee *et al.* (75)]. BRIDGE is a community-academic partnership developed to improve interventions for young children with or at-risk for ASD and their families. The Collaborative consists of clinicians, funding agency representatives, parents, and researchers with expertise in ASD and/or the intervention service system. Early in the development of the Collaborative (which began meeting in 2007), members jointly decided to target the implementation of evidence-based, parent-implemented practices in community settings as their primary purpose. Over the last 12 years, members have worked together to utilize specific implementation strategies (53,83) and address barriers in the outer and inner contexts in order to build community capacity to serve toddlers with ASD and their families. These strategies have targeted every phase of implementation (i.e., Exploration, Preparation, Implementation and Sustainment), with particular attention to many of the issues discussed here (e.g., individualizing service based on family need, effective provider training) (84). Indeed, the involvement of a community-academic partnership in and of itself is an implementation strategy that can improve EBP use in multiple settings (53,83,85).

The result of the Collaborative's work across the last decade is the broad local community implementation of a particular EBP that the Collaborative specifically adapted for use with toddlers with social communication concerns. Pilot testing found significantly greater improvements in positive parent-child interactions with the adapted intervention than in usual community care. Because funding agency representatives participated in the Collaborative to select the particular EBP, the adapted intervention is currently publicly funded for children at risk for ASD under age three, resulting in increased agencies requesting training and greater capacity and family access to services. Additionally, agencies who typically deliver highly structured interventions are now motivated to learn these more developmentally appropriate strategies, due to their tie to public funding. Overall, the Collaborative has been highly successful in deploying a particular EBP in the community due to the shared input from all stakeholders.

Conclusions and recommendations

Early intervention is a critical component to any ASD

service system. Despite the increasing prevalence of ASD, many children do not receive early intervention due to delayed diagnoses and various other factors. Community-based ASD early interventions can better identify children and provide interventions in more naturalistic environments for young children and their families. In this article, we have discussed several barriers and potential opportunities facing the dissemination and uptake of community-based early ASD interventions. Using the EPIS framework, we explored how both outer and inner contextual factors, along with the EBPs themselves, can work together to either impede or facilitate effective implementation within communities. We provided an example of a successful bridging factor, which harnessed the efforts and expertise of families, funding agencies, researchers, clinicians, and other stakeholders to address the common goal of improving the outcomes of young children with ASD and their families. We hope this framework will assist researchers in moving EBP into community early intervention settings successfully.

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