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Parent and Multidisciplinary Provider Perspectives on Earliest Intervention for Children at Risk for Autism Spectrum Disorders

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Abstract

Early identification and treatment of Autism Spectrum Disorder (ASD) in children younger than age 3 years is becoming an increasingly common area of concern and study. Research suggests that systematic, early intervention can significantly improve outcomes and reduce the cost of caring for children with ASD through the lifespan. Therefore, it is imperative that evidence-based practices (EBPs) for this young age group are translated effectively into community settings. One method of promoting EBPs and developing capacity for implementation is active collaboration between researchers and community stakeholders. This requires a precise understanding of the perspectives of stakeholders regarding the benefits and barriers of specific practices and early intervention in general. In the current study, we gathered feedback from families and a multidisciplinary group of community providers regarding early intervention values for infants/toddlers at risk for ASD and their families through focus groups. The opinions and values of the community sample were examined using mixed qualitative and quantitative methods to facilitate efforts to build long-term capacity for implementing efficacious ASD intervention for children younger than 3 years. Results indicated that, the values of community providers and parents were highly similar and were aligned with EBP strategies. Recommendations for translating EBPs for this population into community settings are discussed.

Keywords

autism spectrum disorders; community values early intervention; evidence-based practice; infants; toddlers

Autism spectrum disorders (ASDs) are characterized by impairments in communication and social functioning along with restricted, repetitive, and stereotyped patterns of behavior (American Psychiatric Association, 2000). By definition, the onset of ASD occurs before 3 years of age and affects all areas of development. Early identification of ASD in children under age 3 years is becoming increasingly common (Charman & Baird, 2002; Filipek et al., 1999; Mandell, Novak, & Zubritsky, 2005; Rogers, 2001). In fact, early signs of ASD

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including attachment and regulation problems, communication delays, difficulty engaging in social relationships, loss of previously acquired skills, and sociobehavioral difficulties are being identified as early as 12 to 18 months (Johnson, 2008; Ozonoff et al., 2010). Current estimates of the prevalence of ASD have increased to 1 in 100 children (Baird et al., 2001; Fombonne, 2003; Rice et al., 2007). The Centers for Disease Control and Prevention (CDC) recently identified early childhood developmental disorders such as ASD as a significant public health challenge, calling for early intervention directed toward preventing later mental health and developmental disorders (Cordero et al., 2006).

In the past, providers and funding agencies have hesitated to serve very young children in hopes that they would “grow out of” the social and communicative delays presenting early in development. Unfortunately, recent research indicates that these issues are not transient and persist over time in at least half of young children (Briggs-Gowan, Carter, Bosson-Heenan, Guyer, & Horwitz, 2006). Furthermore, social/communication delays in infancy are associated with ongoing linguistic, educational, and social difficulties (Stothard, Snowling, Bishop, Chipchase, & Kaplan, 1998) and are likely to require treatment in later childhood without early intervention (Cordero et al., 2006).

Research findings suggest that systematic, early intervention can significantly improve outcomes for children with ASD (Wallace & Rogers, 2010). Delivering evidence-based early intervention at the first indication of problems with infants and toddlers can potentially decrease the long-term cost of caring for children with ASD (Jacobson, Mulick, & Green, 1998). Current estimates of the annual cost of caring for individuals with ASD is $3.2 million per capita (Ganz, 2007). The saving achieved through early intervention is approximately $280,000 by the age of 22 years (Jacobson et al., 1998), illustrating that quality early intervention efforts are not misplaced. On both local and national levels there are calls for capacity building in the area of early childhood mental and developmental health promotion (Cordero et al., 2006; Commission on Children, Youth, and Families, 2005; Shonkoff & Phillips, 2000).

Researchers posit that providing multi-disciplinary, comprehensive intervention across linked areas (behavior, social, communication, regulation) early in development can have a significant positive impact on later cognitive and academic functioning (Shonkoff & Phillips, 2000). For children with ASD, researchers recommend interventions that include parent education, start as early as possible, and blend both behavioral and developmental strategies to address core issues such as engagement and joint attention while systematically improving specific communication and cognitive skills (Wallace & Rogers, 2010). Several controlled, single-subject and quasiexperimental studies (Ingersoll & Dvortcsak, 2006; Ingersoll, Dvortcsak, Whalen, & Sikora, 2005; Stahmer, Akshoomoff, & Cunningham, 2011; Stahmer & Ingersoll, 2004) and recent randomized trials (Dawson et al., 2010; Yoder & Stone, 2006), have shown that systematic blending of established behavioral and developmental methods accelerates developmental progress. On the basis of the evidence, researchers recommend a blended developmental and behavioral method as state-of-the-art treatment for serving children at risk for ASD (Dawson et al., 2010; Stahmer, Schreibman, & Cunningham, 2011). However, evidence-based practices (EBPs), which methodically combine developmental and behavioral strategies have not been widely studied in infants and toddlers at risk for ASD, and are not widely delivered in community settings (Hess, Morrier, Heflin, & Ivey, 2008; Stahmer, Collings, & Palinkas, 2005).

It is imperative that EBPs are translated effectively into community settings where the majority of children and their families can benefit from them. Community implementation of EBPs for ASD and other childhood mental health disorders has historically been a challenge for the field (Bondy & Brownell, 2004; Hess et al., 2008; Perkins et al., 2007;

Stahmer, 2005). Although efficacious interventions have been developed and tested in research settings, few community early intervention programs provide the necessary intensity or type of service to affect change. One method of developing capacity in a community while promoting EBP is to actively and directly collaborate with community stakeholders. Researchers have called for innovative models of intervention development and implementation that shift from the traditional, unidirectional models of translating research into practice toward a more reciprocal, interactive effort between researchers and practitioners (Bondy & Brownell, 2004; Meline & Paradiso, 2003; Weisz, Chu, & Polo, 2004). Weisz et al. (2004) stress that practice and research have been operating separately for a long time, and that the 2 traditions can inform each other to improve care. Before EBPs can be effectively implemented in community settings, it is critical to recognize the “gap” that exists between community services and EBP. One method of addressing this gap is by understanding the perspectives of community stakeholders regarding the benefits and barriers of specific practices and early intervention services (Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001; Huang, Hepburn, & Espiritu, 2003; Schwartz, 1999). This may be especially helpful for interventions in the early stages of development, such as those for infants and toddlers with risk for ASD, as there is room for modification of interventions before efficacy testing begins.

The current project outlines a dynamic, collaborative approach that provides an innovative method to move EBP into early care quickly and effectively for this growing population of young children at risk for ASD. Obtaining feedback from the community regarding EBP should facilitate early adaptation of efficacious practices for use in the community and expedite translation. As a first step, in the current study, a consortium of ASD stakeholders obtained feedback from families and a multidisciplinary group of community providers regarding early intervention preferences for infants/toddlers at risk for ASD and their families. The opinions and values of the community sample were examined using mixed qualitative and quantitative methods to inform efforts to build long-term capacity for implementing efficacious ASD intervention in community early intervention programs.

METHOD

BRIDGE collaborative

The BRIDGE Collaborative (described in Brookman-Frazee, Stahmer, Searcy, Feder, & Reed, in review) consists of researchers, multidisciplinary community providers, parents, and funding agency representatives dedicated to improving care for children at risk for ASD. “BRIDGE” signifies the bridge the group is building between research and practice, and represents their early intervention values: Bond-Regulate-Interact-Develop-Guide-Engage. The mission of the group was to identify an early intervention for infants/toddlers at risk for ASD and their families that adequately addressed concerns of all stakeholder groups (researchers, practitioners, funding agencies, and parents of children with ASD).

Intervention choices

Three interventions were selected by the BRIDGE Collaborative for presentation to the community and solicitation of detailed opinions regarding each. Through monthly discussions, BRIDGE members identified 4 key components necessary for an intervention to be considered for community presentation: (1) parent-implemented, (2) evidence of efficacy in children with ASD, (3) comprehensive focus across developmental areas, and (4) broad applicability for community providers and parents (across disciplines, theoretical orientation, and settings). Next, a systematic review based on established best practices guidelines and published reviews of intervention efficacy of parent-implemented interventions for very young children with ASD as well as other difficulties with relating and communicating (eg, attachment, trauma, language delay) was conducted. The group reviewed best practice guidelines including the National Standards Project for Autism (www.nationalautismcenter.org), Promising Practices Network (www.promisingpractices.net), Technical Assistance Center on Social Emotional Intervention for Young Children (www.challengingbehavior.org), Center on the Social and Emotional Foundations of Early Learning (www.vanderbilt.edu/csefel/), Zero to Three (www.zerotothree.org), Center for Evidence-Based Practices (www.evidencebasedpractices.org), and Research and Training Center on Family Support and Children's Mental Health (www.rtc.pdx.edu). In addition, literature in the areas of interventions for very young children with disorders of attachment, ASD, child welfare involvement, failure to thrive, maternal depression, and temperament difficulty was reviewed.

Potential interventions were further examined for community fit by BRIDGE through review of (a) published peer-reviewed research, (b) intervention materials including treatment manuals and training videos, (c) discussions with program developers, and (d) presentation by local experts utilizing the interventions. Potential interventions were discussed and members rated them on the basis of the level of research evidence with the population; quality, availability, and usability of the training materials; and fit of the methodology with current community practice. Although few interventions had strong evidence with infants and toddlers with ASD, several had emerging support at the time of the review. Final intervention selection took place through collaborative decision-making process of all group members using an outside facilitator. Program developers of the 3 selected interventions were each invited to provide half-day conferences to the community. These interventions included (in alphabetical order) Enhanced Milieu Teaching (EMT; Hancock & Kaiser, 2006). The P.L.A.Y. Project (Play and Language for Autistic Youngsters; Solomon, Necheles, Ferch, & Bruckman, 2007) and Project ImPACT (Improving Parents as Communication Teachers; Ingersoll & Dvortcsak, 2010). The order of the 3 half-day conferences was determined on the basis of program developer availability.

The first conference introduced attendees to Project ImPACT, an intervention that teaches families naturalistic developmental and behavioral intervention techniques to improve child social engagement, language abilities, imitation skills, and play (Ingersoll & Dvortcsak, 2010). Some teaching strategies in this approach are drawn from developmental interventions, such as Developmental, Individualized, Relationship-based (DIR)/Floortime (Greenspan & Wieder, 1999) model, the Denver Model (Rogers & Dilalla, 1991; Rogers & Lewis, 1989), Responsive Teaching (Mahoney & MacDonald, 2004), and Hanen (Manolson, 1992; Sussman, 1999) that have been shown to be effective for young children with ASD and other disorders. These strategies are labeled "interactive techniques" and are taught first to increase parent responsiveness to children's behavior and support children's social reciprocity. Other teaching strategies in Project ImPACT have been drawn from various evidence-based naturalistic behavioral interventions, such as Incidental Teaching (McGee, Morrier, & Daly, 1999), Milieu Teaching (Alpert & Kaiser, 1992), and Pivotal Response Training (Koegel et al., 1989). These strategies are labeled "direct teaching techniques" and are used to teach specific language, imitation, and play behaviors. Project ImPACT has published, publicly available training manuals for therapists and parents, options for group and individual implementation of the program, and program developers support a "train the trainer" model, where a program supervisor can learn to train other local providers in the program. Project ImPACT strategies have a long history of evidence in the literature (see National Standards Project (NSP); 2009). Recent studies using rigorous single-subject methodology reported that children receiving the intervention demonstrated significant gains in mastery of sociocommunication skills, and a significant decrease in autistic symptoms. Parents have been shown to use the intervention with fidelity and they report a significant decrease in parenting stress. In addition, both parents and therapists rate the acceptability of the intervention very highly (Ingersoll, 2009, 2011; Ingersoll et al., 2005).

The second conference provided an overview of P.L.A.Y. Project, a community based autism training and early intervention program based on the DIR model of Stanley Greenspan (Greenspan & Wieder, 1999). This approach focuses on parents supporting the development of their children at home through play and daily activities. Parents are taught to apply principles of relationship-based intervention, to identify their child’s preferred way of relating, sensory motor preferences and deficits, and current functional level of development (Solomon et al., 2007). P.L.A.Y. project is typically implemented in the home over a 1-year period (although there is flexibility in implementation), offers training materials from the program developer, and has a structured training program implemented solely by the program developer for all providers who wish to use the model. At the time of the conference, reviews of research with children with ASD indicated that relationship-based models had emerging evidence (NSP, 2009) and pilot studies provided support for the P.L.A.Y. Project specifically. A randomized clinical trial of the model is currently funded by National Institute of Mental Health.

The third conference introduced attendees to EMT, a naturalistic behavioral method of parent-implemented intervention, which adapts the strategies of Milieu Teaching for use with young children (Hancock & Kaiser, 2006). EMT combines behavioral and social interactionist approaches to language intervention in 3 components: (1) Environmental arrangements to promote child engagement; (2) Responsive interaction techniques to increase social, conversational interaction and provide opportunities to model new language forms; and (3) Milieu Teaching procedures to prompt, model, and provide consequences for use of language in functional contexts. At the time of the conferences, EMT had the most research support for promoting early communication and was in the process of being adapted to teach joint attention and early social skills to children with ASD (eg, Hancock & Kaiser, 2006, in press; Kaiser & Grim, 2005; Kaiser, Hancock, & Nietfeld, 2000; Kaiser & Trent, 2007; NSP, 2009). EMT is typically implemented by research staff; training materials are available through the program developer but not widely distributed, and training is typically done on a mentorship basis at the research laboratory.

The attributes of each of the interventions are presented in Table 1.

Study design

A mixed design was used to examine primarily qualitative results and confirm by quantitative methods. Qualitative methods via focus groups and BRIDGE group discussions were used to examine the perspectives of parents and early intervention providers regarding earliest intervention for infants and toddlers at risk for ASD and their families. A focus group approach was chosen to obtain an unbiased, comprehensive understanding of how different stakeholders view the current needs, and the types of interventions they would be most likely to provide or participate in. Focus groups are defined as the use of participants who have specific experience with or opinion about the topic, the use of an explicit interview guide, and exploration of their subjective experiences in relation to predetermined questions (Gibbs, 1997; Merton & Kendall, 1946). This approach is ideally suited for conducting exploratory investigations, such as the one reported in this article (Morgan, 1988).

After each conference, BRIDGE members met with the intervention developers to discuss the program, its fit within the community, intervention materials, and the willingness of the developer to work with the group. In addition, all BRIDGE members completed a survey, rating each intervention strategy (see Measures, given later) on a Likert scale.

Focus group participants

Community focus group participants included 9 parents and 9 community providers. Separate groups were held for providers and parents, with groups limited to a maximum of 10 participants to facilitate group discussion and active contribution. Each BRIDGE member provided names of potential parents and providers for participation. From the pool of suggested names, BRIDGE members selected a representative sample of disciplines, ages of their children, races/ethnicities, and agencies. This subset of invitees was contacted via e-mail with a brief description of the study and the dates and times of focus group meetings. Of the total parents known to BRIDGE members who were invited (n = 19), the majority agreed to participate (n = 10). Of the remaining parents contacted, 1 declined because of childcare issues and the remainder did not respond (n = 8). One parent who agreed to participate never attended the meetings. A majority of the contacted providers (n = 15) also agreed to participate (n = 9). The remaining providers either had previous time commitments (n = 2) or did not respond (n = 4).

Parents—Requirements of participants included being a parent or primary caregiver of a child with ASD, availability to attend each intervention conference and subsequent focus group meetings, and willingness to be audio-recorded during the focus group discussions. The parent focus group's sample consisted of 8 mothers and 1 father of children who ranged in age from 4 to 16 years. Of the 9 parents, 6 (67%) were Hispanic/white and 3 (33%) were non-Hispanic/white. Parent participants ranged in age from 31 to more than 50 years, with highest level of education reported as below a bachelor's degree (n = 1), a bachelor's degree (n = 4), a master's degree (n = 2), or a doctoral degree (n = 2).

A total of 7 parents attended an initial focus group orientation meeting (described later). Parents who missed this meeting (n = 2) were given the list of questions addressed at the orientation, and asked to provide written responses to the research team. A majority of parents attended each of the 3 intervention conferences and corresponding focus group meetings immediately after (100%, 67%, and 78% for the first, second, and third conferences, respectively). No parent missed more than 1 meeting. Parents who missed any of the conference presentations received a DVD recording of the conference presentation and were asked to provide feedback regarding the presented intervention. This request was honored by all parents except 1.

Providers—Requirements for participation included being a primary service provider to children with ASD, availability to attend each intervention conference and subsequent focus group meetings, and willingness to be audio-recorded during the focus group discussions. Of the 9 service providers who participated in the provider focus group, 6 were women and 3 were men. Group membership represented a range of disciplines, including occupational therapy (n = 2), psychology (n = 2), speech-language pathology (n = 2), early intervention management (n = 1), and early intervention provision (n = 2). Of the 9 providers, 2 were Hispanic/white, 6 were non-Hispanic/white, and 1 was Pacific Islander. Provider participants ranged in age from 27 to more than 50 years, with highest reported level of education as a bachelor's degree (n = 1), a master's degree (n = 6), or a doctoral degree (n = 2), and a range of 4 to 30 years experience serving children.

A total of 7 providers attended an initial focus group orientation meeting (described later). Providers who missed the initial focus group meeting (n = 2) were given the list of questions addressed in that meeting and asked to provide written responses to the research team. A majority of providers attended each of the 3 intervention conferences and corresponding focus group meetings immediately after (78%, 89%, and 78% for the first, second, and third conferences, respectively). Providers who missed any of the conference presentations were offered a DVD recording of the conference presentation and asked to provide their feedback regarding the intervention. This request was honored by all but 2 providers.

BRIDGE Collaborative participants—BRIDGE Collaborative participants (n = 14) represented 11 community agencies. The group consisted of 13 women and 1 man, who were speech-language pathologists (n = 2), behavioral specialists (n = 1), physicians (n = 1), psychologists (n = 2), occupational therapists (n = 1), psychiatrists (n = 1), parents (n = 3), researchers (n = 2), and funding agency representatives (n = 1). The group included 10 (71%) non-Hispanic/white/; 2 (14%) Hispanic/white; 1 (7%) African American; and 1 (7%) Asian member.

Focus group procedure

As described earlier, focus group participants were recruited by BRIDGE Collaborative members and represented families, providers, or funding agencies. Interested individuals were contacted via e-mail and provided a description of the study and an invitation to participate. Conference dates were provided to help invitees determine if participation was feasible.

Participants attended an initial focus group orientation meeting at which time the research team described the purpose of the project. Participants were asked to provide their general perspective about early intervention for infants and toddlers at risk for ASD. At this meeting, all participants received a copy of sample training materials and an overview article for each of the interventions, and a $20 gift card for attendance.

Three conferences, 1 for each of the interventions, were held on 3 Saturday mornings in Fall, 2009, and lasted approximately 3.5 hours each. Focus group participants attended the conferences free of charge. Conferences were also open to the community (including parents and providers) who registered and paid a small fee to cover the costs associated with hosting the conference.

Directly after the conference, focus group participants were directed to a meeting room where they received lunch and participated in the discussion of the intervention. The providers and parents met in separate groups, as researchers expected the values and opinions of these 2 stakeholder groups to differ and wished to objectively explore both perspectives. An early intervention provider facilitated the provider group and a parent of a child with ASD facilitated the parent group. Both facilitators were BRIDGE members with experience leading support groups and were provided with additional material on how to effectively lead a guided discussion. A second BRIDGE member took notes but did not participate in the discussion in either group. All sessions were audio-recorded for later transcription. Participants received a $10 gift certificate for attendance at each of the 3 meetings. Participants who attended all 3 focus groups received an additional $50 gift certificate at the completion of the 3 conferences.

Following the focus groups, audio recordings were transcribed by research assistants blind to the aims of the study. Transcripts were reviewed by the note taker from each focus group to ensure accuracy. Any discrepancies were reviewed by the research team. Discrepancies were primarily names of individuals, strategies, or interventions and terminology not familiar to the research assistant. Transcripts were then coded by 4 BRIDGE members: 2 researchers, a parent, and a provider (see data analysis section later). An expert in qualitative data analysis who was not familiar with the hypotheses then reviewed the transcripts and findings to ensure data were not biased.

Measures

Focus group interview—An interview guide was developed to examine participants' values and beliefs about use of interventions for this population, characteristics and materials related to the 3 intervention models, and barriers to service use and access. Questions for the guide were based on the study goals determined by the BRIDGE Collaborative. Questions for the initial focus group meeting targeted the participants' values and beliefs related to earliest intervention for the population. At each post-conference meeting, a second set of questions was used to discuss which aspects of the intervention implementation, theory, and materials participants liked and which aspects they found concerning. Each meeting began with basic questions and then moved toward more specific inquiries about the particular intervention methodologies (see Table 2).

BRIDGE Collaborative surveys—BRIDGE members provided specific feedback on each intervention using an evaluation form developed by the collaborative. BRIDGE members rated each intervention on a Likert scale (1 = poor to 5 = great) on the following parameters: theoretical orientation, intervention strategies, method of training parents, method of training interventionists, training materials, evidence base, ongoing data collection, community fit, and flexibility. In addition, they were asked to comment on the benefits/strengths and drawbacks/weaknesses of each intervention regarding each parameter.

BRIDGE Collaborative intervention values—Monthly meetings included discussion of early intervention values leading to intervention discussions and decision making regarding intervention choices. Detailed notes from each meeting were coded (see data analysis later) to determine early intervention values for the BRIDGE members.

Data analysis

Focus groups and BRIDGE values—Data analysis of focus group and BRIDGE meeting transcripts was guided by grounded theory (ie, theory derived from data and then illustrated by characteristic examples of data; Glaser & Strauss, 1967). Transcripts were independently coded by 4 BRIDGE members, 2 researchers, a parent, and a provider, at a general level to condense the data into analyzable units (themes). Segments of transcripts were assigned codes based on a priori (ie, questions in the interview guide) and emergent themes. Each transcript was independently coded by all 4 coders. Interrater reliability was assessed for one-third of each focus group transcript (Boyatzis, 1988). Disagreements in assignment or description of codes during development were resolved through discussion between investigators and enhanced definition of codes until reliability was established. Transcripts were coded with 90% reliability.

The constant comparative method (Glaser & Strauss, 1967) was used to identify primary and secondary themes, which were compared across groups to detect trends. Coded results were compiled by the first author and this information was reviewed by an outside expert in qualitative research who made recommendations for unbiased wording of the results.

BRIDGE Collaborative surveys—BRIDGE members Likert ratings were compared via a one-way analysis of variance to provide a quantitative examination of early intervention values. Narrative data were grouped into themes using the methodology described earlier.

RESULTS

Qualitative and quantitative results were integrated into primary themes ascertained through the focus group analyses. Several primary themes emerged during the analyses regarding important elements of an ideal early intervention for young children at risk for ASD.

Themes were generally related to intervention format, content, and community fit. Quantitative results from the BRIDGE survey are reported first. Then qualitative results are reported by theme and subtheme, interventions, and groups (parents, providers, BRIDGE members) and are summarized in Table 3. It should be noted that all of the interventions were rated highly by all participants. The purpose of this article is to characterize community values related to early intervention rather than to rank specific intervention methods. Therefore, results are presented generally rather than as related to specific interventions.

BRIDGE Collaborative surveys (Quantitative results)

BRIDGE Collaborative members surveys on each intervention demonstrated no significant differences in the quantitative ratings across interventions for theoretical orientation, methods of training parents or providers, and data collection methods. Data indicated a significant difference in ratings of the training materials for therapists and parents across interventions, favoring the materials that were readily available in published form ($P < .05$) over the materials available solely through the developer. Ratings of overall community fit indicated a statistically significant preference for the intervention with the most flexible format ($P < .05$). BRIDGE members rated 2 of the interventions differently based on their evidence base: 1 which they perceived to have the strongest evidence base and the other the weakest ($P < .05$).

Qualitative results

Intervention format—Several themes related to intervention format emerged in both the provider and parent focus groups.

Parent implementation/Coaching: Both groups discussed the importance of parents being included in the intervention and receiving coaching from a trained therapist. This fits well with BRIDGE values, as all of the interventions were chosen specifically because they involved parent implementation. However, some parents did express concern that not all families may be equipped to learn intervention strategies and that the full burden of intervention implementation should not rest solely on them.

Parent support/Group element: All the 3 groups (parents, providers, and BRIDGE members) mentioned the importance of parent support in various forms. Parent participants focused on the value of talking with other parents to learn how to understand more about their children and how to navigate the service system. Parents felt that only the intervention that offered a group format for presentation of materials offered adequate opportunities for parents' support.

The providers' discussion of parent support focused more on the need for emotional support and specifically mentioned the need for stress management strategies. Providers raised the concern that none of the interventions specifically addressed parent mental health issues.

Trains all caregivers: Beyond the concept of parent implementation, parents were adamant that all care-givers of a child with ASD receive training, or be offered the opportunity to receive training, and that siblings be included in the intervention as well. Their children's developmental concerns represented an issue that affected the entire family, including extended family and other caregivers. They perceived that training others in any intervention would provide parents added support. One intervention developer specifically discussed fathers' participation in the intervention, which was received positively in the parent group.

Includes siblings: Parents expressed unanimous concern that siblings suffered from feeling left out when therapists came to the home with toys and attention for the child with ASD. Neither the BRIDGE nor the provider groups specifically addressed these issues in detail; however, the BRIDGE group did agree with the parents' perspective once it was expressed.

Intervention content and tools

Fits with a variety of disciplines/philosophies—In terms of content, all the 3 groups favored an intervention that would fit with practitioners from a variety of disciplines and with varying theoretical orientations and training backgrounds. BRIDGE members strongly believed that this was necessary to ensure wide acceptance of the intervention and optimal dissemination.

Providers also thought a systematic blend of developmental and behavioral strategies was important for sustainability and penetration of the intervention in the community. Parents felt an intervention that explicitly and methodically combined developmental and behavioral strategies would help with coordination of interventions across providers.

Concerns were raised when interventions appeared to have a focus in only 1 theoretical "camp" and overall comments tended to be more positive, across groups, for interventions that integrated blended behavioral and developmental strategies

Comprehensive—All the 3 groups expressed the importance of having a comprehensive program focusing on all areas of development. Every group preferred interventions that focused on "all communication, not just verbal," and specifically mentioned nonverbal communication as an important area of concentration. However, groups sometimes perceived specific interventions differently. For example, after one presentation, parents stated that the intervention had more "focus on words," rather than other areas of communication, whereas providers perceived the intervention to be comprehensive and emphasizing gestures. The BRIDGE group also placed a great deal of value on early social development and expressed concerns when an intervention lacked focus on sensory issues, had a poor understanding of the role of emotions and relating in development, or lacked strategies to address sensory regulation.

Play based/Relationship based—All the 3 groups valued interventions that were play based, emphasized interaction between child and parent, and were child driven. For each intervention, parent and provider focus groups discussed whether the intervention would be "fun and engaging" for both parents and children.

User friendly for families—All groups discussed the clarity of the strategies presented at each conference and the ease with which parents could learn the techniques. Parents generally preferred structured intervention strategies, primarily because they viewed structure as linked to clear strategies that could be mastered. They specifically valued interventions in which parents received positive feedback and that "helped parents be successful" (parent participant). Techniques perceived as clear and user friendly were preferred by both parents and providers. All the 3 groups expressed concern for assessments and concepts that were hard to teach parents, or appeared too technical, abstract, or complicated.

Uses natural environment—Parents preferred interventions that used the natural environment. Families wanted to ensure that the intervention could be readily delivered both in the home and in the community. In addition, parents reported that interventions that were "easy to incorporate into daily activities" could reduce family stress. Other groups did not mention the issue of natural environment.

Family focused and individualized—All the 3 groups discussed the importance of having an intervention that was family focused and could be individualized to the needs and preferences of both caregiver and child. This seemed to be tied to intervention flexibility in terms of both format and content. Providers liked an intervention that "gives the family control" and expressed concern for an intervention that seemed "hard to adapt for challenging families." However, there was often disagreement between the 2 focus groups about the ease of use of specific strategies. In addition, the presentation style of the intervention developer often led to differing opinions about the same strategy. For example, after one presentation the parent group thought it "may be hard to follow the child's lead," whereas the next week they stated that following the child's lead was one of the most positive aspects of the intervention.

Quality materials—Having excellent teaching materials, including a clear manual to describe the strategies, was important to all groups. Availability and cost of the teaching materials were also discussed.

Clear goals—Both focus groups discussed the importance of having clear goals and clinical data collection to assess individual child progress, preferring interventions that linked distinct goals to intervention strategies. Providers expressed concern about interventions that "lacked information on how to choose activities." These issues had not specifically been raised by BRIDGE when initially choosing interventions, but BRIDGE members agreed with the providers' perspective once it was expressed.

Ability to monitor child outcomes—Parents indicated that although evidence base was important (see later); the true measure of an intervention was whether it worked with their own child. They wanted to know how a provider would determine if an intervention was working or not and expected a clear system of data collection They were particularly positive about the intervention that discussed ongoing assessment and quickly referred families to a different intervention if this was found to be "not a good fit." Parents expressed concerns about interventions in which the method of data collection was not clearly specified and confidence in the interventions that began with assessments and appeared data driven. Providers and the BRIDGE group also liked the idea of ongoing assessment and clinical data collection methods but, surprisingly, parents spent a great deal more time discussing this issue.

Community fit

Flexible format—The specific format of the intervention in terms of location, number of sessions, and group versus individual sessions was important to both parents and providers, but not initial concern for BRIDGE members. Flexibility across any of these areas was preferred by all groups as it was felt that change may be necessary to fit the needs of different families and provider agencies, as well as funders.

Parents noted that at some point, and for some families, home sessions would be most feasible, convenient, and effective; whereas for other families, the home environment would not be the most optimal place to learn new strategies. Parents felt that having some sessions in a group format might also provide an opportunity for parent support. Some providers, however, had concerns that the group format would not address individual parent support needs, negatively impact program individualization, and potentially increase waiting lists. Providers also expressed concerns about having limited flexibility in format options and how that might limit their options on the basis of their own agencies' policies or funding sources.

Parents' opinions about the specific length of time for the intervention varied. After one workshop, parents were concerned that the intervention "may be too long (12 weeks) for some families to commit." However, after hearing about another intervention that lasted a full year, both groups liked the "length of intervention (1 year) and fading of support" (visits fade from monthly to bimonthly, to quarterly). Both parents and providers expressed that parents may need a higher frequency of sessions than monthly in the beginning of year-long intervention.

Flexibility of format also seemed to be preferred in terms of increasing the likelihood of providing a fundable program. The BRIDGE group expressly examined the flexibility of the intervention formats and the willingness of each intervention developer to allow for adaptation across agencies.

Cost/Funding—BRIDGE members, parents, and providers were all concerned about how any early intervention program would be funded. There was a great deal of discussion on this point in all groups in terms of the intervention content and focus, length/number of sessions, and concerns regarding funding interventions in general for this population of children.

Quality providers—All the 3 groups felt an education requirement for provider eligibility was important. They also expressed a strong preference for providers with experience in understanding both ASD and how to work effectively with parents. However, providers did have concerns regarding how such requirements might affect the cost of the service.

Ability to build local capacity. Another important aspect to both providers and BRIDGE members regarding funding a new intervention was the ability to build capacity for training new staff within their own agency. They had extensive discussions regarding training plans and requirements. Providers were very positive about training formats that included ongoing supervision and mentoring. They had serious concerns about the cost of training if the intervention required all staff to be trained by the program developer. In fact, the lack of ability to train experts within their own agencies was a huge barrier for most providers and many BRIDGE members. All were most impressed with interventions that had clear training models and usable materials for providers.

Evidence based—Similar to the BRIDGE group, both parents and providers mentioned the importance of a strong evidence base for any early intervention. BRIDGE members had specific concerns that funders might only embrace interventions with a strong evidence base. However, their perceptions of the evidence base for each specific intervention sometimes differed from that of the BRIDGE group. This appeared to be due to the method of presentation of the evidence by each presenter, and the presenters' representation of the intervention as one that "worked." Parents and providers were savvy enough to understand that the evidence base for one intervention, though strong, was not specific to ASD. The BRIDGE group had the advantage of having spent a great deal of time examining the actual literature about each specific intervention and this likely explains the differing perspectives.

Other areas of concern/interest

Several themes arose that were not specifically related to the intervention models.

Early identification/early start to intervention—Parents consistently mentioned a desire for earlier identification to ensure the earliest possible access to intervention. Although this was discussed by the BRIDGE group, they determined that early intervention for the growing population of identified children would be their focus because other community groups were already effectively focusing on early identification.

Mentoring for parents—Parents felt that mentoring families and providing guidance in understanding a new diagnosis and the purpose of diagnostic assessments were important. This was not specifically mentioned in either of the other groups.

Coordination of services—All the 3 groups expressed a greater need for coordination of services and awareness of other resources in the community.

SUMMARY

In general, the values of community providers, parents, and the BRIDGE collaborative were highly similar. Some groups placed more emphasis on certain areas (eg, parents spent a great deal of time discussing the impact of the intervention on the family and providers spent more time discussing training methods), but in general there were not areas of major disagreement between groups. There were some areas in which the BRIDGE comments on specific interventions differed from the focus groups, typically those based on the additional information available to the BRIDGE group about the interventions. However, the overall intervention values were highly concordant across all the 3 groups.

DISCUSSION

Current understanding of best practice for young children with ASD indicates the importance of ensuring the earliest start to intervention, the use of EBP that can be individualized to the child’s developmental needs, and including parent involvement through coaching and implementation (Wallace & Rogers, 2010). To improve outcomes for children with ASD, it is imperative that these best practices are translated effectively into community settings. Experts across service sectors involved in the treatment of children with ASD are calling for a better understanding of the scope of community care for these children, including those in early intervention (Dunst, Snyder, & Mankinen, 1989; Schwartz, Carta, & Grant, 1996; Stahmer et al., 2005), education (Bondy & Brownell, 2004), speech and language therapy (Byng, Cairns, & Duchan, 2002), occupational therapy (Baranek, 2002), and clinical psychology (National Research Council, 2001). The data from this project provide preliminary evidence that a broad range of community providers and families of children with ASD value many elements of early intervention that are consistent with EBP. In addition, this view into the important aspects of interventions to community stakeholders can provide researchers insights into the best methods for integrating EBP into the community.

One important aspect of moving EBP into the community is the method used to present the evidence. The view of the evidence base for a particular intervention may be skewed when a presentation or workshop is a community stakeholder’s only exposure. Stahmer and colleagues (2005) found that if providers attended a workshop or training in an intervention, they perceived that intervention to be evidence based. Similarly, parents and providers in our focus groups accepted the program developers’ description of the evidence at face value. Anecdotally, it appeared that when researchers presented evidence about an intervention, though they explained the efficacy of the intervention, they were more likely to give more nuanced and candid descriptions of the limitations of the research and emphasize the next needed steps in the research process. More clinically focused developers tended to emphasize program effectiveness and appeared more confident in the outcomes from their intervention. The focus group participants indicated interventions as having a stronger evidence base when the speaker had more confidence and did not focus on limitations or nuances. This has led our group to see the important role collaboration plays in helping community members understand how to critically examine the evidence, and how to help researchers present data in way that is clear for community providers and does not downplay the evidence. In addition, it is important to recognize that evidence base changes over time. For example, the interventions chosen for this study in 2009 have additional evidence, and new evidence for other interventions has been added to the literature (eg, Carter et al., 2011; Dawson et al., 2010; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010). Therefore, it is important for researchers to help community stakeholders learn to continually look for and evaluate new findings as they become available.

One aspect of early intervention for children at risk for ASD consistently discussed by both providers and parents, but not typically emphasized by researchers, is that of addressing the needs of the parents in terms of support, care coordination, stress, and mental health issues. Although researchers have acknowledged increased stress and mental health concerns in parents of children with ASD (eg, Daniels et al., 2008; Tomanik, Harris, & Hawkins, 2004), and the relationship between early intervention and stress in this population has been examined (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; eg, Koegel, Bimbela, & Schreibman, 1996; Stahmer, 2005), there has been limited research examining methods of directly targeting parents’ needs. Research suggests that parent stress and depression affect participation in parent education and subsequent child progress (Dunst, Trivette, & Deal, 1994; Plienis, Robbins, & Dunlap, 1988; Robbins, Dunlap, & Plienis, 1991), indicating that this area warrants more scientific attention. Further discussions with community stakeholders regarding the types of parent supports that facilitate early intervention for this population could strengthen research questions and intervention development. This area is especially important, given the call for parent-implemented interventions, parents’ awareness that they cannot provide all of their children’s therapeutic services, and the concern that not all families are equipped to respond to parent education at all times. Parents clearly indicated that a relatively simple adaptation for providers and researchers to implement that would increase support is to include a broader range of caregivers in the intervention education, including immediate and extended family members. Historically, efficacy of parent education programs has been primarily tested in mothers. Interventions may need some adaptations for assured success with other caregivers such as fathers and grandparents (Winter, 2006) to meet overall family needs.

Although a recent review of the literature recommended interventions that combine both behavioral and developmental strategies, researchers (Wallace & Rogers, 2010) have traditionally advocated for one intervention, expressing concerns about endorsing an “eclectic” model (McGee, Morrier, & Daly, 2001). However, there has been general agreement among community stakeholders for decades that systematic integration of interventions is preferred for children with ASD and provides greater opportunity for individualization. This is an area where community providers have specifically informed researchers. The integrated developmental and behavioral model recommended by researchers is not an “eclectic” model but rather a systematic blend of strategies, which may differ from the community view of blended intervention. In fact, some research has indicated that therapists tend to mix strategies without using any strategy fully (Garland et al., 2010), which may not lead to effective individualized programming. This will not lead to successful outcomes and is an area where research can guide community practice. Again, researchers need to find appropriate ways to facilitate systematic combinations of efficacious strategies and methods to assist community stakeholders in using these strategies to ensure effectiveness. Researchers may benefit from observation of therapist adaptations to specific strategies to learn more about that individualization process. Examining fidelity of implementation of any EBP is an important aspect of measuring treatment success in community settings and assessing any adaptations that may affect child outcomes. Adaptations must be tested to ensure that an intervention retains its efficacy (Schreibman, Suhrheinrich, Stahmer, & Reed, in press).

Research examining translation of EBP into community settings has found therapists to be resistant to manualized interventions, claiming that manuals are restrictive and difficult to use in individualized intervention (Addis, Wade, & Hatgis, 1999). However, community stakeholders, including providers, in the current study were open to use of a treatment manual and valued clear materials and guidelines for intervention. They also valued individualized care, so flexibility in the implementation of the procedures of the manual was important. The structure itself did not seem to be a barrier to acceptance of the EBP. This is good news for researchers who are attempting to translate manualized care to enhance fidelity of implementation. Program developers may wish to explicitly describe how the strategies can or cannot be altered to fit the needs of specific children and families.

Funding and training were areas of great concern to community stakeholders. These areas are often overlooked by researchers developing new interventions. Flexibility in the way an intervention can be implemented (group, individual, clinic, home, timing) greatly enhanced acceptability by a wide range of providers. Because funding sources varied, and rules about funding often differed by agency and discipline, this flexibility was important. Researchers need to examine the dose effects of interventions to provide guidelines regarding the necessary duration, intensity, and location of an intervention to help translation.

In addition, clear training methods that allowed agencies to build capacity were highly valued. The mentorship model used in most university programs is not conducive to widespread training of community providers because of the limited number of students in any one program. On the contrary, a training model in which agencies pay a high fee to certify providers was not manageable for public agencies with relatively high turnover. Research teams must examine ways to train local experts to capacity in intervention models within a relatively brief period of time, so that agencies can subsequently train providers in their own community. Furthermore, ongoing support in use of the intervention and modifying it for individual cases is important to community stakeholders. Examining ways to use technology to facilitate continual supervision will be important.

A significant limitation to this study is the very small number of parents and providers providing input. Of considerable note, these stakeholders were those willing to take the time to participate in the project and came from one, homogenous area of the country. Therefore, these results may not generalize to other communities. However, we feel that this project provides a model for obtaining community feedback that can help to inform the translation of EBPs into community settings.

Both parents and providers independently mentioned (1) the need for parent education and coaching, (2) the importance of an evidence base, (3) an early start to intervention, and (4) applicability across disciplines and theoretical orientations. This confirms the BRIDGE Collaborative’s choice of these areas of focus as criteria for determining the early interventions for community review. The recommendations of the BRIDGE Collaborative were supported by the larger community. In addition, a high concordance between research and community values provides evidence that implementation of EBP may fit with community values for very young children at risk for ASD.

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Table 1

Attributes of Interventions Selected for Community Presentation

Intervention	Current Use in Community	Theoretical Model	Evidence Base	Training Options	Implementation Model	Time Period for Initial Parent Training
Project ImPACT	Yes	Blend of naturalistic behavioral and developmental	Established individual strategies; emerging evidence for packaged intervention	Publicly available provider and parent manual; supervisor and provider training available from program developer; trained supervisors able to conduct future trainings	Group or individual sessions with therapist; clinical or home setting	12 weeks
P.L.A.Y. Project	Yes	Developmental, relationship based	Emerging evidence	Materials available from program developer; provider training program conducted by program developer only	Typically individual sessions; home setting	1 year
Enhanced Milieu Teaching	No	Naturalistic behavioral	Strong evidence base; recognized as evidence-based practice	Materials available from program developer; training conducted on a mentorship basis at research laboratory only	Typically individual sessions; home setting	No time specified

Table 2

Primary Focus Group Questions

Parents and Providers
Initial introductory meeting
What are your thoughts on the efficacy of early intervention services for children between 12 to 24 months and their families?
What factors do you consider when choosing services to provide to very young children and their families?
How are parents involved/included in services you currently provide (providers only)?
What do you like about existing early intervention services?
How might existing services be improved?
Do you see gaps or limits in current services?
What would the “ideal” intervention for this group of children and families look like?
Postconference focus groups
What do you like about the intervention?
What (if any) are your concerns about the intervention?
How does this intervention address the list of factors identified at an earlier meeting?
Is this substantially different from the services in which you and your child have participated (parents) or you currently provide (providers)?
Is this feasible in your current setting (providers only)?

Table 3

Focus Group and BRIDGE Themes Related to Early Interventions

Summary of Community Values for Early Intervention			
Group	**Parents**	**Providers**	**BRIDGE**
Intervention format			
Parent implementation/Coaching	x	x	x
Parent support/Group element	x	x	x
Trains all caregivers	x		
Includes siblings	x		
Intervention content			
Fits with a variety of disciplines/Philosophies	x	x	x
Comprehensive	x	x	x
Play-based/Relationship-based	x	x	x
Easy for families	x	x	
Structured	x		
Uses natural environment	x		
Family focused/Individualized	x	x	x
Proactive, engaging/Fun	x	x	x
Quality materials	x	x	x
Provides clear goals	x	x	
Effective with own child/includes clinical data collection	x	x	
Community fit			
Flexible format for different agencies/Family needs	x	x	x
Cost/Fundable	x	x	x
Requires experienced provider	x	x	x
Ability to build capacity within own agency		x	x
Experiential training/Support for providers		x	x
Evidence based	x	x	x
Other areas of value			
Early identification/Early start to intervention	x		
Mentoring for parents	x		
Coordination of services	x	x	x
Awareness of resources	x		