


Who gets coached? A qualitative inquiry into community clinicians' decisions to use caregiver coaching

Autism
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Abstract

Clinicians' beliefs about an intervention's fit with an individual family influence whether they use it with that family. The factors that influence clinicians' decisions to implement evidence-based practices for young autistic children have yet to be evaluated systematically. These factors may partially account for the significant disparities in quality of and access to early intervention. We examined disparities in clinicians' reported use of caregiver coaching, an evidence-based practice, with families from minoritized or structurally marginalized groups, and the perceived reasons for those disparities, to assess the factors that influence clinicians' use of caregiver coaching. We conducted semi-structured interviews with 36 early intervention clinicians from publicly funded early intervention agencies in two distinct geographic regions in the United States. Clinicians identified social and structural factors, including perceived family characteristics and stigma, that influenced their beliefs about the fit of coaching with families from minoritized or structurally marginalized groups. These findings point to the presence of beliefs that likely exacerbate disparities in access to evidence-based practices and reduce the quality of care for minoritized families of young autistic children. These findings highlight the need to develop and deploy equity-focused implementation strategies to improve both access to and quality of evidence-based practices for young autistic children from minoritized groups.

Lay abstract

Providers' beliefs about an intervention's fit with a family can affect whether or not they use that intervention with a family. The factors that affect providers' decisions to use evidence-based practices for young autistic children have not been studied. These factors may play a role in the major differences we see in the quality of and access to early intervention services in the community. We looked at differences in providers' use of caregiver coaching, an evidence-based practice, with families from minority or vulnerable backgrounds, and the possible reasons for those differences. We did this to figure out what factors affect providers' use of caregiver coaching. We interviewed 36 early intervention providers from early intervention agencies in two different parts of the United States. Providers pointed out things like what they thought about a family's circumstances that affected their beliefs about how well coaching fits with minority and vulnerable families. Our findings bring attention to these beliefs that likely make accessing evidence-based practices for minority and vulnerable families harder and lessen the quality of care for these families of young autistic children. These findings highlight the need to come up with and use strategies to improve both access to and the quality of evidence-based practices for young autistic children from minority and vulnerable groups.

Keywords

caregiver coaching, disparities in care, early intervention, parent coaching

Each year in the United States, approximately 437,000 infants and toddlers with developmental disabilities receive publicly funded early intervention (EI) services through the Part C service system under the Individuals with Disabilities Education Act (IDEA) ("Part C Infant and Toddler Program Federal Appropriations and National

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Child Count 1987-2019,” 2021). Part C of IDEA specifies that all children below 3 years of age with or at high risk for a disability are eligible for these services to enhance their development and their families’ capacity to meet their needs. Children from birth to 3 years of age who show signs of autism spectrum disorder (ASD) qualify for publicly funded EI services. A central tenet of the Part C approach to service delivery is that services should support and empower the family, rather than be directed solely to the child with a disability. For young autistic children, caregiver-mediated interventions—that is interventions delivered by the child’s caregiver instead of a clinician—have gained increasing support as an evidence-based practice (EBP) aligned with the Part C approach to service delivery (Wallace & Rogers, 2010).

An essential component of caregiver-mediated interventions is coaching the caregiver to implement intervention strategies with their child. Coaching in EI is an interactive process between a clinician and a caregiver that involves observation, reflection, and action to promote the caregiver’s ability to support the child’s participation in family and community settings (Hanft et al., 2004). Clinicians coach caregivers using a repertoire of strategies such as active engagement, discussion, reflection, and feedback on the caregiver’s performance to increase the caregiver’s skills, motivation, and self-efficacy (Dunst & Trivette, 2009; Hanft et al., 2004; Rush et al., 2003). Effective coaching results in the caregiver’s use of intervention techniques, which leads to improved child outcomes (Rush et al., 2003; Stahmer et al., 2011). University-based randomized trials demonstrate that caregiver-mediated EI for young autistic children results in improved child outcomes across a range of developmental domains, as well as improved parental self-efficacy and treatment engagement (Green et al., 2010; Kasari et al., 2014; Rogers et al., 2012; Stadnick et al., 2015; Wetherby & Woods, 2006).

The growing evidence to support the use of caregiver coaching for families of young autistic children is paralleled by evidence of significant disparities in both quality of and access to EI for families from minoritized or structurally marginalized groups. Demographic characteristics, such as race, ethnicity, and socioeconomic status, are associated with use of community-based autism care, with families from ethnic and/or racial minorities or other traditionally underresourced groups accessing fewer services (Siller et al., 2014). In contrast to university-based studies, where intervention strategies are implemented with university personnel in controlled research settings, outcomes of community-based EI (i.e. interventions implemented by providers working in public service systems) tend to be attenuated, especially in low-income and minority communities (R. D. Boyd & Corley, 2001; Magana et al., 2012; Magiati et al., 2007). Attenuated

outcomes may result from poor caregiver coaching; preliminary evidence suggests that EI practitioners rarely coach caregivers of children with ASD (Aranbarri et al., 2017; Salisbury et al., 2009). Instead, they spend most of their time working directly with the child (Peterson et al., 2007). Poor implementation of caregiver coaching may be the critical element that makes community-based EI less effective than what is observed in randomized trials (Nahmias et al., 2015).

The reasons for these disparities in access to caregiver coaching are likely multilayered and complex. Previous research shows that clinicians’ beliefs about an intervention’s fit with an individual family or client influence whether they use it with that family (Irvin et al., 2012; Siller et al., 2014; Stahmer & Aarons, 2009). In a study comparing attitudes toward adopting EBPs for autism, providers reported that they thought many EBPs were not a good fit for children treated in community settings (Stahmer & Aarons, 2009). A study evaluating community clinicians’ use of a behavioral intervention for toddlers and preschoolers with sleep difficulties found that clinicians were less likely to use the intervention with families that they perceived as experiencing stressors often ascribed to families from lower socioeconomic status, such as inflexible or variable work schedules, close living quarters, and neighborhood safety concerns (Williamson et al., 2020). Similarly, EI providers described families as being either “conductive” or “unconductive” to family-centered practices, with unconductive families most often being those who were poor or minorities. These providers also said that they could use family-centered practices with only a small percentage of families, attributing characteristics often associated with poverty, as factors in their decision not to use family-centered practices with these families (Fleming et al., 2011). These findings indicate that community clinicians may decide which families are a “good” fit for certain EBPs based on perceived sociodemographic characteristics, exacerbating disparities in high-quality service access and use.

Understanding clinicians’ beliefs about implementing EBPs, and the factors that influence their decisions to implement EBPs for families from minoritized or structurally marginalized groups, is a critical step toward developing strategies to improve their implementation in underresourced communities and improve service equity and access. The objective of this study was to examine community clinicians’ experiences with and perspectives about using a particular EBP, caregiver coaching, for families of young autistic children. Specifically, we examined the presence of disparities in clinicians’ reported use of caregiver coaching with families from minoritized and structurally marginalized groups, and the reasons for those disparities, to identify malleable targets for equity-focused implementation strategies.

Method

Participants

We invited 48 eligible providers to participate in the interviews. Inclusion criteria were that the clinician was (1) employed by a Part C EI agency in any professional discipline and (2) serving at least three children in the as service classification at the time of the interview. Children below age 3 do not need a medical diagnosis of ASD to be eligible for autism-related services. Children below age 3 are eligible for ASD services if they are identified as at high likelihood for ASD. In Philadelphia EI, high likelihood is determined through a positive screen on the Modified Checklist for Autism in Toddlers (M-CHAT) and clinical observation (Robins et al., 2014). Agency leaders received information about the study from the research team and distributed information to clinicians. Interested clinicians contacted a study team member, who screened them for eligibility. We conducted semi-structured interviews with 36 clinicians from Part C EI systems in southeastern Pennsylvania, southern California, and northern Delaware. Informed consent was obtained from all participants prior to participation. Participants were compensated US\$25 for participating in the interview. The University of Pennsylvania and Philadelphia Department of Public Health Institutional Review Boards approved this study.

Qualitative interview data collection

Interviews occurred either in person in the community, such as a public library, or via video conference and were approximately 30 to 45 min long. Interviews were conducted by trained research staff and the principal investigator of the study. Training included participation in a multiday workshop in qualitative research methods and data analysis.

We developed the interview guide iteratively under the guidance of an expert in qualitative research and feedback from a community advisory board that advises our research. The community advisory board is composed of stakeholders from the autism community—including family members of autistic children. The semi-structured interview guide was developed using the Consolidated Framework for Implementation Research (CFIR) and the Theory of Planned Behavior to guide development (Ajzen, 1991; Damschroder et al., 2009; Damschroder et al., 2015). The interview queried about (1) strategies that EI clinicians use during interactions with caregivers, (2) views about the acceptability and appropriateness of caregiver coaching within EI, and (3) contextual factors that may influence the intervention strategies EI clinicians use with families (See Supplemental Material). We selected prompts to probe for barriers and facilitators at the intervention, provider, agency, and caregiver level. Additional prompts were

selected to probe for information about the perceived supports needed to implement coaching in daily practice.

Qualitative data analysis

All interviews were audio recorded, transcribed, and imported into *NVivo 12* software. Members of the study team developed a qualitative codebook through a collaborative and iterative process guided by the Consolidated Framework for Implementation Research and consistent with a grounded theory framework to develop an organized coding system that proceeded through several stages of data analysis (Bradley et al., 2007; Charmaz, 2000; Damschroder et al., 2015; Glaser & Strauss, 1967). First, the three coders independently read three initial interview transcripts and independently identified distinct themes that emerged from those transcripts. The coding team discussed and combined the list of themes through consensus discussion. Then, the coding team independently reviewed three additional transcripts and met again to adjudicate differences, develop coding rules, consolidate redundant concepts, and create additional codes to reflect new concepts not previously identified. The final codebook included 12 codes exploring barriers and facilitators to caregiver coaching with operational definitions for each code including sample quotes. After the codebook was finalized, the first author trained two additional undergraduate coders who demonstrated excellent reliability with the master coder ($\alpha = .94$; $\alpha = .92$). After we completed coding, the team met to identify prominent themes for further analysis and unanimously decided that Family Characteristics deeply influenced providers' use of caregiver coaching. Therefore, this article presents an examination of the Family Characteristics code.

We subcoded the "Family Characteristics" code using a process identical to that described above for coding the entire transcripts and identified four subcodes that emerged as consistent themes across interviews: (1) low socioeconomic background and lack of resources, (2) competing priorities, (3) caregiver and family system characteristics, and (4) culture. Table 1 presents definitions and examples of these subcodes. Below, we present the summary of our findings with key illustrative quotes.

Results

Table 2 presents participants' demographic information. Clinicians varied in their disciplinary backgrounds: 47% were special instructors (a job title referring to therapists or instructors with a background in psychology, early childhood education, or a related field who visit families' homes to provide intervention), 11% were occupational therapists, 17% were speech and language pathologists, 22% were physical therapists, and 5% classified themselves as other types of therapists, such as dieticians or

Table 1. List of codes and code examples.

Code name	Definition	Example
Low socioeconomic background and lack of resources	Issues relating to housing, food, technology, play materials, space, or lack of essential resources that were described as barriers to coaching.	<i>A lot of the families that I work with are also very low income, so they may not have a tablet or even a laptop and so we're having to do sessions on their phone, which I think makes it even harder for a toddler to focus on such a small screen and kind of engage and participate.</i>
Competing priorities	Caregiver priorities such as other children, working caregivers with young children, one or more children with special needs, multigenerational households, caregivers at long jobs and want to decompress when they get home, and so on that were mentioned as barriers to coaching. Excerpt may be related to SES and double coded or it may not be.	<i>Recently with a lot of families starting up with virtual schooling again with their other kids, it's really difficult for them to juggle having to be a teacher to their other kids on top of having to do their services with their younger child.</i>
Caregiver and family system characteristics	Caregiver personalities (defensiveness, assertiveness, etc.), mental or physical health issues, and/or approaches toward helping child (e.g. differing opinions/involvement/dynamics) mentioned as influencing providers' ability to coach caregivers.	<i>I sometimes worry that coached parents can get into [a] really difficult area, if that parent is an addict or maybe they're schizophrenic . . . there can be some really serious things going on.</i>
Culture	Aspects of families' cultural beliefs, traditions, and/or language stated as impacting the ability to coach caregivers.	<i>This specific [family] I'm thinking of, there's also a language barrier. She speaks Spanish.</i>

SES: socioeconomic status.

Table 2. Demographic characteristics of clinicians.

	% of clinicians
Gender	
Female	100
Male	0
Race/ethnicity	
White	67
Black	11
Hispanic/Latino	11
Asian	11
Clinician occupation	
Special instructor	47
Speech therapist	17
Occupational therapist	11
Physical therapist	22
Other type of therapist	5
Highest level of education	
College degree	19
Graduate degree	81
Years of early intervention experience, <i>M</i> (range)	9 (0.5–39)
Previous training in caregiver coaching	61

developmental specialists. Clinicians had an average of 9 years of experience working in EI, ranging from 0.5 and 39 years. Most clinicians held a graduate or professional degree (81%); the remaining clinicians had a college degree (19%). Of clinicians interviewed, 56% reported

receiving specialized training in autism interventions, and 61% reported receiving prior training in caregiver coaching. All interviewees were female and 67% were White, 11% were Black, 11% were Hispanic, and 11% were Asian. Participants in these interviews were representative according to demographic characteristics and years of experience of providers working in the broader service system.

Clinicians identified many family and caregiver characteristics that influence their beliefs about using caregiver coaching during Part C EI sessions with families of autistic children. They often described the need for families and caregivers to be a “good fit” for caregiver coaching. The families they most often described as being a good fit for coaching were those with caregivers who clinicians described as eager learners, had financial resources, and had ample time to devote to sessions.

Four major themes emerged regarding factors that influence community clinicians' decisions to implement caregiver coaching with families of young autistic children. Low socioeconomic status and lack of resources were described as factors that influence providers' use of caregiver coaching during EI sessions. Competing priorities for caregivers were also mentioned by providers as barriers to implementing caregiver coaching. In addition, providers discussed specific caregiver and family system characteristics that affect their use of coaching strategies with families. Finally, family culture influenced providers' use of caregiver coaching during EI sessions.

Low socioeconomic background and lack of resources

Almost all clinicians identified challenges with coaching low-income caregivers. For example, one clinician stated,

So with families that are coming from lower income and maybe mental health, there's mental health problems in the home, or whatever the case is, I think it's more of just building up a rapport with them and letting them know [about] the support services that's offered (instead of coaching).

When describing why they might choose not to coach caregivers during sessions, another clinician stated, "Some of like the maybe lower income families . . . they just have a lot of stress going on—it's hard to get through to them." Overwhelmingly, clinicians described poverty as an obstacle to implementing caregiver coaching. One clinician remarked that there is "only so much you can do" to support families living in poverty when describing why they do not implement caregiver coaching with some families:

Sometimes I think poverty can be part of it. Just not having the resources. I think sometimes it's—because there's only so much you can do. You do have the parents that will make excuses and just—and I don't wanna call it lazy. I'm not sure what it is, but they just are checked out. And I often wonder if it's because of lack of resources, or because they're thinking something's wrong and they don't know how to deal with it. It could be a lot of things. But I do see—poverty can be part of it, just because they don't have the resources, they don't have the support. It makes it challenging for them.

Most participants mentioned that low-income families are more difficult to coach than higher-income families. They described challenges with coaching low-income caregivers to use play-based intervention techniques, a fundamental aspect of EI for young autistic children. One clinician stated, "I would say the biggest challenge is when there are no materials at all. So, we have kids sometimes with poverty. There's just no toys. This child has no play skills because there are no toys." Similarly, another clinician stated, "We have to use everything in the natural environment (when coaching). That's really tough because a lot of families don't have anything. Or they have a bin of half broken toys." Providers expressed that there is not much they can accomplish in homes with few toys or other material resources. One provider said, "You can drop off toys that you find, and you can drop off items that you've made. You can give suggestions, but there are the parents that just really have nothing, so that you're really almost working with nothing."

Many clinicians also commented on perceived challenges with coaching caregivers who are experiencing homelessness or food insecurity. For example, one clinician said,

One family I can think of, for example. One of nine children—Parents were in and out of different issues of their own, so sometimes I was going to the grandparent's house, sometimes I was in the living room with all the siblings running around, and it was kind of tricky to establish what a natural routine for this child was because he was moving around so much.

Clinicians also discussed the appropriateness of coaching these caregivers. One provider stated,

I had a few parents that would be nodding off whether they were just exhausted or struggling with something, but the idea of "How about when you give your child lunch, you say 'More'?" Then when I went to the fridge with that child, I opened it and it was empty. These things are just not relatable . . . not where parents' minds are at and with families that are chronically homeless—their child's behaviors that are very frustrating even for me as a provider are unbearable for them.

Another clinician shared a similar account:

One time, a service coordinator came into a house for a quarterly review, and she was asking the mom, like if there are any changes on the IFSP [Individualized Family Service Plan]—if she wanted to change the outcomes or anything. Well, she didn't have a place to live after that day. She didn't have housing. It just was so insensitive to what was really going on in that family.

Similarly, one clinician provided this example as a situation in which she would not coach the caregiver: "like, the mom that's changed jobs 3 times. Very, very low income. She has no energy at the end of the day. She's concerned about bills. She's concerned about other things." Clinicians both struggled with balancing how to help families meet their basic needs and support their child's development. Overwhelmingly, they described families from poor or impoverished backgrounds as not being a good fit for caregiver coaching.

Competing priorities

Many families face competing priorities and many providers believed that those priorities interfere with caregivers' ability to participate in coaching sessions. Examples of competing priorities mentioned included caregivers' busy work schedules, having other children to tend to, and multigenerational households to maintain. Clinicians described the presence of other household family members as distracting to the caregiver and the provider. For example, one clinician said, "Some parents . . . they're living with extended family and so, there's a lot of traffic in and out of the home. And it is . . . it can be very distracting." Another clinician shared a similar sentiment: "I've done evaluations and sessions before where the siblings are there and sometimes, they're roaming free and it's really distracting."

Similarly, another clinician described challenges coaching caregivers living in multifamily households:

I've had some patients who they have three families living in a home, so if I come in to work with the child, the only place they choose for me to work is in one of the bedrooms but then they need to leave the room to go kind of address the rest of the family. So that's difficult when they're almost setting it up—you don't have a lot of options to work even in the same room [with the caregiver].

Clinicians also described that busy schedules interfered with caregivers' follow-through with intervention strategies. For example, one clinician stated,

What we see often is the parents have great intentions, but they're really busy during the week, and they have other children. And when you revisit the next session . . . and you ask them, okay, how are things going, did you try this, did it work? And sometimes we hear, oh, I'm gonna be honest, I didn't have any time, I didn't do it, I didn't get a chance to try any of these things.

Another clinician shared similar sentiments: "Some parents are really good about preparing them. And then some parents, every week you're like, well, how did that go? And they're like, oh, I didn't have time to try it." Clinicians often reported that they tend to use more child-directed intervention strategies, rather than caregiver coaching, when caregivers have difficulty with buy-in or follow-through.

Clinicians ascribed lack of motivation or engagement to caregivers with competing life stressors. For example, one clinician described the following as an example where they might not use caregiver coaching: "Probably just life stressors too like if they have something going on that's more important than this session on their mind, then they don't really care about getting involved as much." Competing demands related to complex households and multiple children were also described as barriers to the use of caregiver coaching:

Sometimes it's the strain that is put on parents right now—maybe there's multiple kids in the home that need their parents at the same time and juggling that. Sometimes it's environmental barriers. Sometimes—whether it's they're lacking equipment or they're lacking a safe setup where their child could just play; sometimes there's not an ability to go—say for instance if a goal has to do with a higher-level thing like a playground, sometimes that's just really not possible to take the child outside, so trying to simulate those things in the home [is hard]. Sometimes I really think that parents are really kind of burned out, and when I come into the home it's their break time.

Clinicians described families that are "really busy" or that have "so much going on" as families that do not consider coaching sessions as "high priority."

Caregiver and family system characteristics

Clinicians mentioned specific perceived characteristics of caregivers or their family system as barriers to coaching families, including mental health issues, personality traits, and personal life circumstances. Clinicians often described these challenges as insurmountable and indicated that coaching would not be effective. For example, one clinician said,

You can have the most eager parent who genuinely wishes to be so involved and be learning but they have a million other stressors in life that are getting in the way—you know—their work schedule or finances or trauma or addiction or whatever could also be getting in the way of their ability to participate and carry things over.

Clinicians also described caregivers with cognitive disabilities or mental health needs as being a poor fit for coaching. One clinician said, "I was gonna say the other challenges are sometimes when you have parents that have, oh, how do I say, a limited capacity themselves." Similarly, another clinician reported,

I have a mom I work with. She is very limited in special ed herself. All four of her kids have special needs. It's just kind of a low functioning family across the board, and she can be a really lovely person, but she is pretty clueless about her kids and I have very low goals for them.

When describing mental health issues with caregivers as interfering with coaching, one clinician stated,

It can be depression. It can be bipolar issues. It can be divorce. It can be abusive husbands, single parent struggling with money right now. Just a lot of stress and anxiety right now with what's going on in general.

Clinicians also described young caregivers as being difficult to engage in caregiver coaching. For example, one clinician said, "The nature of the family whether the mom has several young children or mom herself may be . . . we have some young moms who are just not as equipped to deal with it as maybe a more experienced mother." Another clinician similarly stated,

I have a very young dad right now, and the mom—the little boy is very autistic—Mom left, and he's raising the little boy with his parents, and he has no idea how to help his child.

Participants also described perceived characteristics about family structure that infringe on the provider's ability to involve caregivers in sessions. Examples of these characteristics included tension among family members, the child's living situation, and having multiple caregivers involved in the child's EI sessions at different times. For example, one clinician said,

So, things like that are definitely challenging because some families have multiple caregivers. Some days the child is with the aunt and some days the child stays with grandma. So, that can also be a challenge if there is not a consistent caregiver.

Clinicians also often described family strife or tension among family members as interfering with caregiver coaching. For example, a clinician said,

Or sometimes if you have families where the mom and dad have different views. So the mom sees a concern but the dad says there's nothing wrong with my child. That's a challenge as well too . . . Sometimes I've had parents say "well come when my husband's not here. The therapy sessions are a secret because I don't want my husband or my in-laws to find out because they think you know . . . they're saying that I am putting a label on my child or I am looking for something to be wrong with my child."

Culture

Participants described cultural factors such as language barriers and cultural beliefs as major barriers to coaching caregivers. They described examples of working with families who primarily spoke languages other than English as interfering with coaching. One clinician told us, "The language barrier makes it difficult, so like that family. . . might not always understand my feedback." Another clinician stated,

I've found that some families with a language barrier could be a difficulty. I have one child specifically the parents speak two different languages at home, so I think that's kind of difficult because obviously it's hard enough for a child to learn one language, let alone two. Sometimes there can be some cultural differences that can be a little difficult.

Another clinician also described how language barriers interfere with caregiver coaching:

The language barrier makes it difficult, so like that family that I mentioned before might not always understand my feedback. And I think like mom especially is so used to people just kind of—I think when people are faced with a language barrier, they often . . . get awkward and just try to like smile and nod even if they don't know what's happening or they'll say something and just kind of hope that the person understood without really checking. So, I think the language barrier and not knowing if they understood could be a barrier [to coaching].

Participants also discussed cultural beliefs, including stigma about an autism diagnosis or accessing mental health services, as obstacles to caregiver engagement in sessions. Providers described working with families dealing with cultural or familial stigma related to their child's diagnosis. For example, one clinician said, "I had one parent tell me . . ., 'my culture doesn't understand this

diagnosis and, as long as he can speak, everything will be fine.'" Another clinician stated, "They have multiple family members living with them. Again, cultural issues where their family doesn't know about the diagnosis." Participants repeatedly mentioned cultural and language barriers as influencing their decisions to implement caregiver coaching. Clinicians often described caregivers who did not speak English or were from ethnic minority backgrounds as inappropriate for caregiver coaching.

Discussion

Participants described several substantial challenges to coaching caregivers in families living in poverty, families with many competing priorities, families with complex family dynamics, and families who were ethnic minorities. Clinicians described their *decision* not to coach families who they thought were not a good fit. Clinicians most often described families from structurally marginalized and minoritized backgrounds as not a good fit for coaching. Participants did not identify any issues related to their own skill or report more perceived difficulty in working with marginalized and minoritized families. Rather, they described specific family characteristics that resulted in their decisions not to use caregiver coaching. The formation of these beliefs about families likely exacerbates disparities in access to EBPs and reduces the quality of care for minoritized families of young autistic children.

Autistic children from minoritized and structurally marginalized groups are more likely to experience delays in starting intervention services and are less likely to receive evidence-based care than are their White or higher-income peers (Algeria et al., 2010; Mandell et al., 2009; Nelson, 2002). When children in underresourced communities do receive EI services, outcomes are often poor (R. D. Boyd & Corley, 2001; Magana et al., 2012; Nahmias et al., 2015). Results from the present study indicate that community clinicians' perceptions of family "fit" with interventions influence their intentions to deliver those interventions to families from minoritized or structurally marginalized backgrounds, thereby exacerbating racial and ethnic disparities.

The clinicians we interviewed often described challenges with coaching caregivers during play-based interactions because there were no toys in families' homes. Although many EBPs for young autistic children emphasize the use of play-based interactions, growing evidence demonstrates that the same coaching can occur during daily routines, such as mealtimes and dressing (Wetherby & Woods, 2006). In fact, a fundamental tenet of Part C EI is supporting families in their natural environments and daily routines (Early Childhood Technical Assistance Center, 2021). Targeted training and implementation supports for clinicians working in community-based settings emphasizing flexibility within fidelity to coaching for

young autistic children can improve clinicians' ability to implement these interventions (Pickard, Mellman, Frost et al., 2021). Systematic treatment adaptations that account for family resources while maintaining the core elements of the approach can also ensure that lack of materials do not inhibit a family from accessing EBPs. For example, clinicians can coach caregivers to use social-communication strategies within play-based routines that do not require toys, such as singing songs and gross-motor games. Flexibility within fidelity and systematic treatment adaptations to support individual family and client needs can be critical levers to improve the implementation of caregiver coaching for families living in poverty.

Clinicians also described barriers to coaching caregivers from linguistically and culturally diverse backgrounds. Families who primarily spoke a language other than English often were excluded from caregiver coaching. The number of children from bilingual households in the United States continues to grow exponentially, representing more than one quarter of all children in early head start programs (Soto-Boykin et al., 2021). Excluding children from bilingual or non-English-speaking households from caregiver coaching will exclude a growing population of young autistic children from best practice in EI. In addition, clinicians often described families from culturally diverse backgrounds as more difficult to coach because of the family's cultural beliefs and stigma regarding mental health service use and developmental disability. The need for cultural adaptations to support all children and families is well established (Vivanti, 2019), yet our data indicate that many community-based clinicians are not making these adaptations. Cultural interviewing, utilizing visual supports, and incorporating interpretation services into standard Part C EI practice are examples of adaptations that could improve caregiver coaching effectiveness and have positive effects on both child and family outcomes.

The language community clinicians use to describe minoritized families was often pejorative and focused on family and caregiver deficits, such as "doesn't understand me," "clueless about her kids," and "not bought-in." Similarly, they used pejorative terms to describe challenges with caregiver engagement such as "lazy" and "doesn't care." The use of deficit-based descriptions when describing minoritized families highlights the beliefs and biases that often permeate clinicians' views of these families. The words that we use to describe families accessing care matter. Implicit bias training for Part C providers that helps acknowledge and overcome implicit biases about families from minoritized and structurally marginalized groups would be a critical first step toward counteracting the effects these biases can have on EBP implementation.

Implicit racial biases pervade health service systems in the United States and the autism service system is no exception (Straiton & Sridhar, 2021). For autism-related care, Black families have reported that clinicians often

dismissed the family's concerns about their child's development and attributed them to poor parenting and challenging behavior instead of autism, leading to lower quality or fewer services (Stahmer et al., 2019). The results of our study corroborate previous findings that suggest that racial biases affect clinicians' decisions about service delivery for families from minoritized and structurally marginalized groups. To combat the detrimental effects these implicit biases have on families' access to quality care, agency and system-level action is required to ensure equitable implementation of EBPs for all families. Another step toward eliminating implicit biases in service delivery for autism would be for EI agencies to recruit more Black, Indigenous and People of Color (BIPOC) individuals to join their staff to provide services to minoritized families (Stahmer et al., 2019). The overwhelming majority of providers we interviewed were White; however, the majority of families they reported working with were not White. Recruiting a workforce that culturally matches the service population can be a critical step toward improving diversity, equity, and inclusion for families of young autistic children and the providers who work with them.

Clinicians identified outer context and structural factors, including stigma, that influenced their beliefs about the fit of caregiver coaching with families from minoritized and structurally marginalized groups. Improving the implementation of EBPs such as caregiver coaching requires close attention to equity to prevent unintentionally widening disparities in quality and access to care. Previous research has demonstrated the effectiveness of modifying existing frameworks to address health disparities in marginalized populations (Woodward et al., 2019). The Health Equity Implementation Framework combines two implementation science conceptual models to explain disparities and factors that lead to health inequity in vulnerable populations (Woodward et al., 2019). It was developed specifically to identify disparities in access to and quality of healthcare. This framework was successfully applied to address the health care disparity in Hepatitis C treatment for Black patients being served through the U.S. Department of Veterans Affairs (Woodward et al., 2019). A qualitative interview guide was developed using the Health Equity Implementation Framework and results showed that implementation science researchers could easily apply this framework to address treatment inequity (Woodward et al., 2019). This framework could be similarly applied to understanding how beliefs influence community clinicians' decisions to implement EBPs with families of young autistic children while concurrently intervening to prevent the formation of these beliefs. EI leadership, clinicians, families, and researchers could work collaboratively to implement inclusive strategies and encourage continued anti-racist and bias prevention education within agencies. Based on the findings of this study, future studies could examine provider beliefs in the context of their

professional background, years of experience, and own cultural identity.

Limitations

There were several study limitations. First, the interviews were conducted before and during the coronavirus pandemic. The sample of respondents may be skewed based on those who were willing to participate given their personal circumstances. Second, we conducted some interviews via phone or via videoconference, and others in person. This inconsistency in data collection may have skewed some of our findings.

Conclusion

Many clinicians in the present study said they think that many poor families cannot effectively participate in their child's EI sessions. This forces us to consider Maslow's hierarchy of needs as it applies to EI services. Maslow's hierarchy of needs states that basic needs, such as food and water, must be met before higher-level needs can be properly addressed (Stewart et al., 2021). It is reasonable to argue that families struggling to meet their basic needs may not have the emotional bandwidth to fully engage in caregiver coaching sessions. Marginalized and minoritized families, arguably in the greatest need of EBPs like coaching, may not be receiving high-quality treatment due to their environmental and economic circumstances. Therefore, as an immediate first step, societal measures to help families living in deep poverty access basic, fundamental needs to improve their bandwidth and ability to be active participants in their child's EI sessions are essential. The challenges faced by families of young children with disabilities extend far beyond the reach of the EI system. However, a societal shift that moves toward ensuring that all families' basic needs are met can help move the needle toward improving equity and access to evidence-based care. Improved collaboration and coordination across service systems, streamlined access to social work and case management supports, and use of cash transfers are examples of evidence-based initiatives that can help poor and minoritized families access essential supports (Bastagli et al., 2016). These poverty eradication initiatives are ripe targets for implementation efforts and would benefit families receiving EI by providing them with the financial and social stability needed to engage in their child's treatment sessions.

Beyond poverty eradication initiatives, other adaptations to EI services can be implemented to improve caregiver coaching for marginalized and structurally marginalized families. For families with busy schedules, flexible scheduling could be used as needed to ensure that being busy is not a barrier to receiving this EBP (e.g. two 30-min sessions per week instead of one 1-h long session).

Clinicians could incorporate siblings into sessions when possible and have older siblings learn some easier strategies that they could practice with the child throughout the week. Families that do not have an abundant supply of toys for their child to play with could receive more coaching support within their usual daily routines instead of during play routines. These are just some of the many session-level adaptations that could be instituted in publicly funded EI that would improve the quality of caregiver coaching for all families, especially marginalized and structurally marginalized families.

EI clinicians have beliefs that influence their decisions to implement caregiver coaching with families from minoritized groups. These beliefs are likely driven by clinician biases, rather than a mismatch between the intervention and family characteristics. These findings highlight the need to develop and deploy implementation strategies drawing from frameworks that adopt a health equity lens to improve access to EBPs for young autistic children from minoritized groups. Failure to act on these pervasive issues within EI could lead to the worsening of disparities in access to and quality of EBPs like caregiver coaching for the most vulnerable children and families.

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Supplemental material

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References

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179–211. [https://doi.org/10.1016/0749-5978\(91\)90020-T](https://doi.org/10.1016/0749-5978(91)90020-T)

- Algeria, M., Vallas, M., & Pumariega, A. J. (2010). Racial and ethnic disparities in pediatric mental health care. *Child and Adolescent Psychiatric Clinics of North America*, *19*, 759–774. <https://doi.org/10.1016/j.chc.2010.07.001>
- Aranbarri, A., Miller, M., Stahmer, A. C., & Rogers, S. J. (2017, May 10–13). *Examining Part C early intervention services for families of children at risk—Or with autism spectrum disorder* [Conference session]. International Meeting for Autism Research, San Francisco, CA, United States.
- Bastagli, F., Hagen-Zanker, J., Harman, L., Barca, V., Sturge, G., Schmidt, T., & Pellerano, L. (2016). *Cash transfers: What does the evidence say? A rigorous review of programme impact and of the role of design and implementation features*. Overseas Development Institute. <https://cdn.odi.org/media/documents/11316.pdf>
- Boyd, R. D., & Corley, M. J. (2001). Outcome survey of early intensive behavioral intervention for young children with autism in a community setting. *Autism*, *5*(4), 430–441. <https://doi.org/10.1177/1362361301005004007>
- Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, *42*(4), 1758–1772.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 509–535). SAGE.
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, *4*, 50. <https://doi.org/10.1186/1748-5908-4-50>
- Damschroder, L. J., Hall, C., Gillon, L., Reardon, C., Kelley, C., Sparks, J., & Lowery, J. (2015). The Consolidated Framework for Implementation Research (CFIR): Progress to date, tools and resources, and plans for the future. *Implementation Science*, *10*, A12. <https://doi.org/10.1186/1748-5908-10-S1-A12>
- Dunst, C. J., & Trivette, C. M. (2009). Using research evidence to inform and evaluate early childhood intervention practices. *Topics in Early Childhood Special Education*, *29*(1), 40–52. <https://doi.org/10.1177/0271121408329227>
- Early Childhood Technical Assistance Center. (2021). *Operation of an early intervention program*. <https://www.ideainfant-toddler.org/pdf/Operation-of-EI-Program.pdf>
- Fleming, J. L., Sawyer, L. B., & Campbell, P. H. (2011). Early intervention providers' perspectives about implementing participation-based practices. *Topics in Early Childhood Special Education*, *30*(4), 233–244. <https://doi.org/10.1177/0271121410371986>
- Glaser, B. S., & Strauss, A. L. (1967). *The discovery of grounded theory*. Taylor & Francis.
- Green, J., Charman, T., McConachie, H., Aldred, C., Slonims, V., Howlin, P., Le Couteur, A., Leadbitter, K., Hudry, K., Byford, S., Barrett, B., Temple, K., Macdonald, W., Pickles, A., & PACT Consortium. (2010). Parent-mediated communication-focused treatment in children with autism (PACT): A randomised controlled trial. *The Lancet*, *375* (9732), 2152–2160. [https://doi.org/10.1016/S0140-6736\(10\)60587-9](https://doi.org/10.1016/S0140-6736(10)60587-9)
- Hanft, B. E., Rush, D. D., & Shelden, M. L. (2004). *Coaching families and colleagues in early childhood*. Brookes.
- Irvin, D. W., McBee, M., Boyd, B. A., Hume, K., & Odom, S. L. (2012). Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *6*, 565–572. <https://doi.org/10.1016/j.rasd.2011.07.018>
- Kasari, C., Lawton, K., Shih, W., Barker, T. V., Landa, R., Lord, C., Orlich, F., King, B., Wetherby, A., & Senturk, D. (2014). Caregiver mediated intervention for low-resourced preschoolers with autism: An RCT. *Pediatrics*, *134*(1), e72–e79.
- Magana, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and Developmental Disabilities*, *50*(4), 287–299. <https://doi.org/10.1352/1934-9556-50.4.287>
- Magiati, I., Charman, T., & Howlin, P. (2007). A two-year prospective follow-up study of community-based early intensive behavioural intervention and specialist nursery provision for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, *48*(8), 803–812. <https://doi.org/10.1111/j.1469-7610.2007.01756.x>
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGiuseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, *99*(3), 493–498. <https://doi.org/10.2105/AJPH.2007.131243>
- Nahmias, A. S., Pereira, J., Pellicchia, M., & Mandell, D. S. (2015, May 13–16). *Meta-analysis of community-based early intervention programs for children with autism spectrum disorder* [Conference session]. International Meeting for Autism Research, Salt Lake City, UT, United States.
- Nelson, A. (2002). Unequal treatment: Confronting racial and ethnic disparities in health care. *Journal of the National Medical Association*, *94*(8), 666–668.
- Part C Infant and Toddler Program Federal Appropriations and National Child Count 1987-2019. (2021). Early Childhood Technical Assistance Center. <https://ectacenter.org/partc/partcdata.asp>
- Peterson, C. A., Luze, G. J., Eshbaugh, E. M., Jeon, H.-J., & Kantz, K. R. (2007). Enhancing parent-child interactions through home visiting: Promising practice or unfulfilled promise? *Journal of Early Intervention*, *29*(2), 119–140. <https://doi.org/10.1177/105381510702900205>
- Pickard, K., Mellman, H., Frost, K., Reaven, J., & Ingersoll, B. (2021). Balancing fidelity and flexibility: Usual care for young children with an increased likelihood of having autism spectrum disorder within an early intervention system. *Journal of Autism and Developmental Disorders*. Advance online publication. <https://doi.org/10.1007/s10803-021-04882-4>
- Robins, D. L., Casagrande, K., Barton, M., Chen, C. A., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the Modified

- Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F). *Pediatrics*, 133(1), 37–45. <https://doi.org/10.1542/peds.2013-1813>
- Rogers, S. J., Estes, A., Lord, C., Vismara, L., Winter, J., Fitzpatrick, A., Guo, M., & Dawson, G. (2012). Effects of a brief Early Start Denver model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(10), 1052–1065. <https://doi.org/10.1016/j.jaac.2012.08.003>
- Rush, D., Shelden, M., & Hanft, B. (2003). Coaching families and colleagues. *Infants & Young Children*, 16, 33–47. <https://doi.org/10.1097/00001163-200301000-00005>
- Salisbury, C., Woods, J., & Copeland, C. L. (2009). Provider perspectives on adopting and using collaborative consultation in natural environments. *Topics in Early Childhood Special Education*, 29(3), 132–147. <https://doi.org/10.1177/0271121409349769>
- Siller, M., Reyes, N., Hotez, E., Hutman, T., & Sigman, M. (2014). Longitudinal change in the use of services in autism spectrum disorder: Understanding the role of child characteristics, family demographics, and parent cognitions. *Autism*, 18(4), 433–446. <https://doi.org/10.1177/1362361313476766>
- Soto-Boykin, X. T., Larson, A. L., Olszewski, A., Velury, V., & Feldberg, A. (2021). Who is centered? A systematic review of early childhood researchers' descriptions of children and caregivers from linguistically minoritized communities. *Topics in Early Childhood Special Education*, 41(1), 18–30. <https://doi.org/10.1177/0271121421991222>
- Stadnick, N. A., Stahmer, A., & Brookman-Frazee, L. (2015). Preliminary effectiveness of Project ImPACT: A parent-mediated intervention for children with autism spectrum disorder delivered in a community program. *Journal of Autism and Developmental Disorders*, 45(7), 2092–2104.
- Stahmer, A. C., & Aarons, G. A. (2009). Attitudes toward adoption of evidence-based practices: A comparison of autism early intervention providers and children's mental health providers. *Psychological Services*, 6(3), 223–234. <https://doi.org/10.1037/a0010738>
- Stahmer, A. C., Brookman-Frazee, L., Lee, E., Searcy, K., & Reed, S. (2011). Parent and multidisciplinary provider perspectives on earliest intervention for children at risk for autism spectrum disorders. *Infants & Young Children*, 24(4), 344–363.
- Stahmer, A. C., Vejnosa, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., Morgan, E. H., Lee, H. S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., Hassrick, E. M., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross-cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities*, 6, 752–773. <https://doi.org/10.1007/s40615-019-00575-y>
- Stewart, R. E., Mandell, D. S., & Beidas, R. S. (2021). Lessons from Maslow: Prioritizing funding to improve the quality of community mental health and substance use services. *Psychiatric Services*, 72, 1219–1221. <https://doi.org/10.1176/appi.ps.202000209>
- Straiton, D., & Sridhar, A. (2021). Short report: Call to action for autism clinicians in response to anti-Black racism. *Autism*. <https://doi.org/10.1177/13623613211043643>
- Vivanti, G. (2019). Towards a culturally informed approach to implementing autism early intervention: A commentary on Ramseur II et al., 2019. *Pediatric Medicine*, 2, 20. <https://doi.org/10.21037/pm.2019.06.01>
- Wallace, K. S., & Rogers, S. J. (2010). Intervening in infancy: Implications for autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 51(12), 1300–1320. <https://doi.org/10.1111/j.1469-7610.2010.02308.x>
- Wetherby, A. M., & Woods, J. J. (2006). Early social interaction project for children with autism spectrum disorders beginning in the second year of life: A preliminary study. *Topics in Early Childhood Special Education*, 26(2), 67–82.
- Williamson, A. A., Milaniak, I., Watson, B., Cicalese, O., Fiks, A. G., Power, T. J., Barg, F. K., Beidas, R. S., Mindell, J. A., & Rendle, K. A. (2020). Early childhood sleep intervention in urban primary care: Caregiver and clinician perspectives. *Journal of Pediatric Psychology*, 45(8), 933–945. <https://doi.org/10.1093/jpepsy/jsaa024>
- Woodward, E. N., Matthieu, M. M., Uchendu, U. S., Rogal, S., & Kirchner, J. E. (2019). The health equity implementation framework: Proposal and preliminary study of hepatitis C virus treatment. *Implementation Science*, 14(26), 1–18. <https://doi.org/10.1186/s13012-019-0861-y>