Early Intervention Providers' Perspectives About Working with Families of Toddlers with Suspected ASD: A Qualitative Study

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Abstract

Part C early intervention (EI) providers are at the front line of service provision for children under 3 years old with developmental delays or disabilities. As such, they can play a key role in both the early detection of autism spectrum disorder (ASD) and the provision of ASD-specialized treatment. Focus groups were conducted with 25 EI providers from three agencies in a Northwestern U.S. county to understand their role in the identification of ASD and communication about ASD concerns to families. Results revealed the tension that providers experience between maintaining a positive and supportive relationship with families and raising the issue of possible ASD. Cultural influences affecting ASD care and suggestions for desired resources were also discussed.

Keywords Autism · Early detection · Early intervention · Early intervention providers · Communication with families · Part C services

Introduction

Autism spectrum disorder (ASD) is an early-emerging neurodevelopmental disorder characterized by a unique pattern of impairments in social, communication, behavioral, and sensory domains (American Psychiatric Association 2013). Specialized interventions that address these core domains of impairment can result in significant improvements when introduced at young ages (Dawson et al. 2010; Ingersoll 2010; Kasari et al. 2015; Landa et al. 2010; Wetherby et al. 2014). The importance of early detection and treatment has led to several professional guidelines and national initiatives, such as the Centers for Disease Control and Prevention (CDC 2004) "Learn the Signs. Act Early." campaign (https://www.cdc.gov/ncbddd/actearly/about.html) and the American Academy of Pediatrics (AAP) practice guidelines that

recommend universal ASD screening at 18 and 24 month well-child visits and referral of toddlers with positive screens to early intervention programs (Johnson and Myers 2007).

However, toddlers with ASD often are unable to access ASD-specialized services during the critical birth-to-3 years, a time when they may have the greatest impact on the developing brain (Black et al. 1998; Dawson 2008; Fox et al. 1994; Zwaigenbaum et al. 2015). Obstacles to early detection and treatment include the lack of adherence to screening guidelines by primary care providers (PCPs) (Zuckerman et al. 2013) and long waiting lists for diagnostic assessments that are often required to confer eligibility for ASD-specialized services (Barton et al. 2012). Although caregivers report becoming concerned about their child's development at an average age of 15–19 months (Coonrod and Stone 2004; Herlihy et al. 2015), the median age of an ASD diagnosis in the U.S. in 2014 was 52 months (Baio et al. 2018). This situation highlights the need to consider alternative approaches to service delivery for toddlers exhibiting ASD symptoms that: (1) are preemptive and symptom-driven, rather than exclusively diagnosis-driven; and (2) capitalize on existing frontline service delivery systems caring for toddlers and young children under 3 years old.

The Part C early intervention (EI) system presents a possible infrastructure for increasing early detection, providing

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timely diagnostic referrals, and offering specialized services when ASD is suspected. In fact, studies have found that toddlers participating in EI were diagnosed two years earlier than those who were not (Yingling 2019) and that toddlers referred for evaluation by EI programs were more likely to be diagnosed at an earlier age than those referred by PCPs (Twyman et al. 2009). Part C programs are funded through the Individuals with Disabilities Education Act (IDEA 2004), a federal grant that assists U.S. states in providing birth-to-three services to families of infants and toddlers with developmental disorders or delays (IDEA 2004). These programs are available in most communities in the U.S. and serve eligible families regardless of their ability to pay. Currently, over 370,000 toddlers in the U.S. receive services under Part C, almost half of whom come from minority or underserved backgrounds (U.S. Department of Education 2018) and might not otherwise have access to early treatment.

Part C services are family-centered and offer child assessments as well as family-based assessments to determine the resources and supports needed to promote the toddler's development. EI providers typically have varied professional backgrounds (e.g., special education, occupational therapy, speech-language pathology) and work collaboratively with families to identify goals and develop treatment plans. Services are provided in the toddler's natural environment (e.g., home or day care) to ensure that the strategies introduced during treatment sessions are relevant and can be used by caregivers independently during a toddler's daily life (Wolery 2000). The median length of time families spend in Part C services is 15 months (Noyes-Grosser et al. 2018), which affords the opportunity for continuity of care during the toddler's early years.

Due to the accessibility of EI services under Part C, and the early and sustained relationship that can develop between EI providers and families, EI providers are well-positioned to serve as a key source of information, support, and services for caregivers when ASD concerns are present. Unfortunately, despite the increasing prevalence of ASD, there remains a shortage of EI providers with ASD specialization (Arunyanart et al. 2012; Carbone et al. 2013; Cameron and Muskett 2014; Tomlin et al. 2013; Wise et al. 2010). In addition, relatively little is known about EI providers' perceptions of their roles or responsibilities when they suspect that toddlers in their caseloads may have ASD.

Most research in this area has employed mail surveys to assess EI providers' attitudes toward conducting ASD screening. For example, a survey of 242 birth-to-three providers in Indiana revealed that they are less likely to conduct ASD screening than general developmental screening, feel uncomfortable screening for ASD when parents have not raised this concern, and feel unprepared to talk to families about ASD given a lack of training in this area (Tomlin et al.

2013). Another survey of 230 Part C service coordinators in the Midwest revealed barriers to screening that included a lack of knowledge about ASD, about ASD-specific screening tools, and about communicating positive screening results to parents without increasing their stress (Pizur-Barnekow et al. 2013). A third survey examining the screening practices of 1396 occupational therapists working with children from birth to 6 years revealed a similar lack of preparedness for using ASD screening instruments as well as eagerness for information about ASD and methods for explaining it to families (James et al. 2014).

Two qualitative studies have addressed a wider range of issues related to ASD care. A study in Ireland involved five speech and language therapists (Cameron and Muskett 2014) who described challenges identifying ASD in young children, uncertainty about the correct way to talk to parents about ASD, and the importance of establishing rapport with parents prior to the conversation. In a more recent study of screening practices, Sheldrick et al. (2019) conducted interviews with 20 EI providers from one agency in the Northeast U.S. and found that considerations such as family engagement and parental readiness influenced not only the nature of their discussions with families, but also the family's willingness to act on positive screening results. In addition, the authors highlighted the existence of an "evidence gap" regarding optimal strategies for communicating with families about ASD.

The purpose of the current qualitative study was to expand upon this previous work and gain a more in-depth view of EI providers' perspectives, decision-making processes, and approaches used when they have concerns about ASD for toddlers in their caseload. Our specific goals were to: (1) examine EI providers' views regarding their role with families when ASD is suspected; (2) identify potential facilitators and obstacles to communicating with families about ASD concerns; and (3) obtain input regarding resources that would help EI providers facilitate communication, discussion, and shared decision-making with families when ASD concerns arise.

Method

Participants

Twenty-five (25) EI providers were recruited from three different Part C EI agencies located in a Northwestern U.S. county. The agencies range in size (10–60 providers), number of families served per year (80–800), and average caseloads per provider (15–40). All agencies were participating in a research project that includes data collection before and after provision of training workshops on ASD-specific screening and intervention. Focus groups were conducted

between February 2018 and July 2018, prior to the initiation of training activities. Demographic data were obtained via a brief survey and were missing for one provider. All participants identified as female and the majority were non-Hispanic White. The providers had a mean of 10 years working with children with ASD (see Table 1 for additional demographic information).

Procedures

This study was approved by the University of Washington Institutional Review Board, and all providers gave informed consent before participation. One focus group was conducted at each of the three agencies; three groups have been deemed sufficient to identify all of the most prevalent themes in a dataset (Guest et al. 2016). Each group lasted between 1½ and 2 h, and providers were compensated $100 (cash) for their participation. The number of providers per group ranged from 6 to 11, consistent with recommended procedures for thematic saturation (Guest et al. 2006).

The development of the format and structure of focus group sessions, as well as the data analysis, were led by the senior author, who has formal training and expertise in qualitative methods. The research team developed the focus group protocol, which probed for information in five areas that aligned with the research questions: (1) the providers' role with families; (2) identifying the early signs of ASD; (3) conveying ASD concerns to caregivers; (4) assessing caregiver's understanding and intent to take action; and (5) suggestions for materials to facilitate communication and decision-making with caregivers (see Table 2 for interview questions and probes).

The focus group moderators used a systematic and comprehensive protocol that had instructions for introducing the purpose, norms, and expectations to providers (e.g., confidentiality) as well as open-ended questions and follow-up probes for facilitating discussion.

Focus group questions were carefully constructed to elicit clear information and designed to allow synergistic discussion among providers, so that individuals in the same focus group could elaborate on points articulated by other participants to provide a deeper understanding of their perspectives, decision-making, and approaches when they have concerns about ASD. Sessions were audio recorded and a HIPAA-compliant third-party company transcribed all data. A member of the research team confirmed the accuracy of all transcriptions and anonymized any identifying information prior to coding.

Data Analysis

Focus group discussions were transcribed and uploaded to NVivo QSR 12 for data coding. The coding scheme was developed using a rigorous, systematic, transparent, and iterative approach that employed several steps. First, the research team independently reviewed one transcript selected at random to identify recurring themes. Second, they met as a group to develop a preliminary codebook that

Table 1 Demographic characteristics of sample

Variable	M	SD	Range
Provider age (years)	33.9	8.7	24–60
Experience in profession (years)	8.8	6.8	1–27
Experience working with children with ASD (years)	10.2	7.0	1.5–27

Variable	n	(%)
Gender: female	24	100
Race		
White or caucasian	21	87.5
Asian	1	4.2
More than one race	1	4.2
No response	1	4.2
Ethnicity: non-Hispanic	24	100
Professional background		
Special educator	11	44.9
Speech-language pathologist	6	25.0
Occupational therapist	5	20.8
Physical therapist	1	4.2
ABA therapist	1	4.2

Data were unavailable for one provider

Table 2 Interview questions and probes

A. Role with families

- What do you see as your primary role(s) in working with families in in your caseload?
- What do you see as your role when you suspect that a child in your caseload might have ASD?

B. Identifying ASD

- What sources of information do you weigh most heavily when evaluating whether a child may have ASD?
- What child behaviors might make you concerned that a child may have ASD?
- What types of social or communication behaviors?
- What types of restricted/repetitive behaviors?
- What behaviors carry more weight/influence?
- Which behaviors (or combinations) would make you most likely to consider ASD?

C. Conveying concerns about ASD to caregivers

- How do you decide whether or not to share your concerns about ASD with caregivers?
- What do you see as the pros and cons of talking to caregivers about your ASD concerns?
- In what ways do you convey your concerns about ASD?
- What do you explicitly mention about ASD?
- What do you mention about the behaviors you are concerned about?
- How do you refer to screening results?
- How do you incorporate visual materials?
- If you are concerned about ASD, what next steps do you suggest to families?
- What types of information or materials do you give to caregivers about these next steps?
- What aspects of this discussion is the hardest/most challenging for you?
- What would make it easier for you to address this challenge?
- What type of written or visual materials might make this conversation easier?

D. Assessing caregiver understanding and intent to take action

- How do you determine whether the caregiver understands what you are saying?
- How do you determine whether the caregiver agrees with what you are saying?
- How do you determine whether the caregiver plans to follow through with your recommendations?
- What aspects of the discussion do you think caregivers have the most difficulty understanding?
- What factors do you think influence a caregiver's initiative or ability to follow through on your referrals?
- Which factors make caregivers more likely to follow through?
- What circumstances, barriers, or challenges might prevent families from following through?
- What strategies have you found to be successful in getting families to take action?

E. Resources

- Are there any types of materials (written, pictorial) that might make it easier to initiate a discussion about ASD with caregivers?
- What type of content do you think it should address?

integrated the original themes conceptualized during the focus group protocol development (i.e., deductive approach) as well as newer themes that emerged from review of the first transcript (i.e., inductive approach). Next, the research team collectively determined which themes to incorporate into the final codebook. Operational definitions and examples of each theme were documented, as were rules about when to use or not use each code. The coding scheme was applied to the data to produce a descriptive analysis of each theme and was refined throughout the data analytic process. We used the approach of inductive thematic saturation to determine when data saturation had been reached, through constant comparison of data to ensure that three focus groups were indeed sufficient (i.e., when no new codes or themes emerge during the data coding process; Glaser and Strauss 1967; Guest et al. 2006; Saunders et al. 2018).

Data coding was completed by two independent coders, and interrater reliability was calculated for 2/3 of the transcripts. The coders met together on a weekly basis to discuss, clarify, verify, and compare themes; disagreements were discussed with the research team to attain consensus. Percent agreement was calculated based on the number of words agreed upon by two coders within a given theme; average agreement was 95% across all the themes.

Results

Four themes emerged from the focus group responses: (1) EI providers' roles regarding ASD care; (2) EI providers' approaches to raising ASD concerns with caregivers; (3) Cultural influences on ASD care; and (4) Ideal resources for facilitating discussion about ASD with caregivers. (See Table 3 for themes and sample quotes). Multiple EI providers in each focus group endorsed each theme. Often themes emerged in response to a question or discussion that arose spontaneously during the focus group.

Table 3 Definitions of themes and sample quotes

Themes	Quotes
EI providers' roles regarding ASD care	1. One of the primary roles I feel like I play in the family is helping identify where their kid is and where their strengths are, and also identifying kind of next steps and ways that I can help support the family into getting the kid to next steps, and helping them answer questions in their own minds about why things are happening and help steer them down directions 2. Yeah, we have the opportunity to be in the home and see families regularly. And so I think that they often form relationships with us and then they ask questions that are outside of what we have come there for 3. We're not just their cheerleaders or their sounding boards, but we're really like a person who they come to who is safe. We have such an intimate relationship with these families for a short time…we come to their house, you know, you see them at their most vulnerable place, and they're telling you all these things that are scary or hard for them, and they're really processing this huge thing that they're dealing with
EI providers' approaches to raising ASD concerns to caregivers	1. There's a lot that goes in, but I think some things that you think about is timeline, like if the child is close to turning to three, you might just have to jump into it, even knowing that the parent might hate you and not want you to come back…whereas if the child is coming in when they're two and we know we have a year, you know you can spend more time kind of trying to develop rapport and things like that 2. Whether it's hard to bring up or not, obviously it takes a lot of tact if you know it's going to be hard, and you have to be really respectful and understanding about how you're going to bring it up, and that their response might not be what we're hoping. But I feel really strongly that we have a responsibility to our families to discuss things like that 3. I'm always considering in my head my rapport and how much I've established with the family. In a perfect world, the curiosity really comes from the family, and then I empower them to seek out resources and also validate their concerns
Cultural influences on ASD care	1. I also think about the cultural background in the area of [city] that I work in, there's a lot of families [from different countries] that I've learned have some specific ideas about autism and the benefits or lack thereof of getting an autism diagnosis and services. Thinking about that too—although I've also learned that just because a family is from that culture group doesn't mean that they experience that same perception of autism 2. With different cultures sometimes you have to say things like you know your child best, like it's okay if you disagree with me, like tell me what you see, because I think sometimes people call us doctor, like when we go into their house and we try and clarify that. They see us more like the expert, and sometimes you just have to say, it's okay for you to tell me that's not right and that's not how your kid is and you don't think what I think is true
Ideal resources for facilitating discussion about ASD with caregivers	1. I think formatting, something that's like simple. You know, bullet points—nice to look at. Because I think a lot of the stuff we have is really paragraph-oriented 2. I'm wondering about a way to talk about…like the spectrum idea, but a way to talk about how their child's behavior is…more of a visual so they can explain to us like what their priorities are and what would help them function better in their day to day 3. I think for some parents it may be helpful to hear from another parent, like whether it's a video of somebody else sharing their experience as far as what their process was like and how they felt in that process just so they know that they're not necessarily alone, that other people have gone through it, could potentially be helpful for some parents, just like to calm them down a little bit and then maybe hear there was a long process but this is what happened and there was an outcome 4. I mean, again, a basic family-friendly definition, explanation

Theme 1: EI Providers' Roles Regarding ASD Care

EI providers described three general roles that were important for working with families of children with ASD: awareness of the early core symptoms of ASD; provision of ASD-specific resources; and establishment of supportive, trusting relationships with families.

Awareness of Early Core Symptoms

Almost all providers described the common red flags of ASD as the toddler's lack of eye contact, limited social engagement and communication with caregivers or others, lack of flexibility, and repetitive behaviors. In describing communication impairments, one provider emphasized that the

functionality of the toddler's language, or whether the toddler understands the general meaning of the word, is much more important than the number of words the child can say. Another provider suggested the importance of the toddler's *interest* in communicating with others. Lack of flexibility was described as manifesting primarily as having difficulty with changes to routines and/or transitions. A few providers described difficulty with self-regulation (e.g., inconsolable "meltdowns") as possibly fostering concerns about ASD.

Providing Resources and Referrals

The majority of EI providers reported sharing resources with parents that describe ASD symptoms and/or early intervention practices. Several providers recommend specific books, websites (e.g., Autism Speaks), or information sheets (e.g., CDC handouts), in an effort to prevent caregivers from obtaining misinformation about ASD online, which was referred to as "going down the Google hole." Some providers described working in an agency where families have access to a Family Resources Coordinator, who can connect them with other families with similar experiences, to serve as mentors or supports. Many providers reported that they offer referral lists with information about who to contact about obtaining a diagnosis, and others refer families directly to additional services based on their needs.

> When autism concerns come up in their mind I want to make sure that the parents…have that awareness and kind of know and see the bigger picture, and kind of see the things that I might be seeing and, you know, start moving them towards that track of like getting a diagnosis, and just that they're able to access services that, you know, long-term would help their child.

Some providers also described serving as a "sounding board" for families, and fielding questions about ASD symptoms, the diagnostic process, and intervention services.

> I think it's also important to be a sounding board because there are a lot of questions that come up…so it's like answering those questions and allowing them to have the moments to be really vulnerable and have concerns and say well, it's OK to have the questions and understand that.

Providers also emphasized the importance of *pacing* the delivery of resources to caregivers. One decision they face is whether they should give caregivers resources and information all at once, or gradually over time; they find that some families are comfortable receiving numerous resources right away, while others can handle only a little bit at a time. A few providers described not wanting to "bombard" the caregivers with too much information, and that they consider the family's "learning style" when determining how much

and what types of information to provide. One provider reported that she sometimes places families on a waiting list for services or an evaluation *before* discussing ASD concerns with them, so they are able to access the services they need as soon as they are ready.

Establishing Supportive and Trusting Relationships with Families

Multiple EI providers across the focus groups emphasized that providing support to families is an essential aspect of their role. In fact, some providers reported that they often serve as the *primary* support system for families.

> I think just being a support too, because a lot of times we [EI providers] are a parent's only support.

Providers described examples of offering instrumental as well as emotional support. Some providers described helping families with extra tasks during therapy sessions, such as looking after the children while the caregiver was occupied. Others described offering to accompany caregivers to the toddler's evaluation visits, which is a non-reimbursable activity. Many examples they provided concerned provision of emotional support to the caregiver during a difficult or vulnerable time.

> They're grieving for the child that they thought they had versus what they have now and sometimes they can kind of sit and not know where do go from there. So listening to them and kind of helping them navigate between all of their feelings.

Another form of support for caregivers includes pointing out the gains that the child is making.

> As like that coach-slash-cheerleader cause I feel like most parents, you help them problem solve but you also have to point out all the little tiny milestones that they're making and parents kinda need that little boost every week. 'You're working really hard. This is what your child's doing this week, what they weren't doing last week'.

Importantly, some providers pointed out that this aspect of their role is not unique to families with ASD concerns, as they also serve as the "primary support system" for other families in their caseloads.

Theme 2: EI Providers' Approaches to Raising ASD Concerns to Caregivers

Many providers commented on the challenges they face when they have ASD concerns about a toddler and the caregiver has not mentioned these concerns first. They described many different factors they consider in deciding

whether, when, and how to bring up ASD concerns with families, including the characteristics of the toddler and the family and their relationship with the caregiver.

Timing of Disclosure

Overall, providers agreed that it is important to choose the right time to bring up ASD concerns, primarily with respect to the caregiver's potential receptiveness to the information. Many providers described waiting to mention ASD concerns until they found the perfect "moment" or "opportunity." Often this moment occurred only after the toddler's caregiver mentioned being concerned. Most providers agreed that the timing varies from family to family, and it often is hard to gauge when exactly a family will be receptive to hearing about ASD concerns. Many providers described waiting to broach the topic until they have built a sense of trust with the family. One participant explained that establishing a trusting relationship can prevent the family from thinking that she is trying to "lead them astray" by raising ASD concerns.

> For me it's deciding when to bring it up, because sometimes I'm hoping for either that perfect moment or the parent to bring it up first and trying to debate… would it go better if I wait and see if it comes up within the next session or do I just need to do it? So for me, just timing it and deciding like OK, we need to talk about this now, that's a big challenge for me.

However, providers also described situations that would cause them to bring up ASD concerns earlier than preferred. Many providers agreed they would bring up ASD concerns sooner if the toddler showed clear red flags for ASD and/or had significant needs for ASD-specialized interventions or the systematic supports that an ASD diagnosis would confer. A few providers said they were more likely to bring up ASD concerns earlier if the family already had another child diagnosed with ASD, as these caregivers might be more receptive to the information.

> I guess with some families I feel more comfortable bringing it up when I know they already have a sibling with ASD, because I know that they probably are maybe recognizing it. But there's some families where I've seen them for probably two to three months and try to build that relationship with them so that I know that they trust me and trust that I'm knowledgeable and that I'm not going to lead them astray, and that I'm, you know, not going to do anything to purposely harm them or their child.

Multiple providers described feeling the need to raise ASD concerns before the toddler left their care. Some providers described bringing up ASD concerns earlier than desired

because the family was moving away. Others reported having to "jump into it" when the toddler was close to aging out of early intervention at 3 years old, due to concern that families would encounter less sensitivity in schools, or that school staff would overlook the child. One provider described the school district as "a little bit harsher" about bringing up ASD, so she discusses ASD concerns preemptively to prepare families to work with the school system. Other providers asserted that their responsibility was to be honest with families and discuss ASD concerns earlier to enable the toddler to access specialized services at a younger age.

> I kind of struggle, because I think…it's our responsibility to be honest with the family…I would be pretty heartbroken as a parent if someone didn't tell me and…I knew they had concerns and didn't address it with me.

Strategies for Disclosure

As noted above, providers reported that it is particularly difficult to raise ASD concerns if the caregiver does not already have such concerns. Many described taking an incremental approach to discussing ASD, in which they try to increase caregivers' awareness of the behaviors of concern. Some providers attempt to create a "window" for communication by asking the caregiver questions about specific behaviors of concern before mentioning autism or ASD. Others begin the discussion by pointing out ASD-related behaviors during their home visits, in the hope that the families will begin to notice these signs on their own. They explained that this approach can help families observe the behaviors of concern across multiple contexts and be less likely to deflect concerns as situation-based (e.g., the toddler avoiding eye contact only in a therapy setting).

> I think building that relationship can really work, and just doing that observation of, oh, I noticed this kid's doing this. Do you see that? Like doing that multiple visits before and kind of have them start wondering, why are we noticing all of these things? I think… that conversation tends to be a lot easier if parents are already noticing what you're noticing, so you can say like oh, we noticed all these things and they kind of keep happening after however long you've been in services.

Another strategy that many providers use to ease the process of raising concerns involves collaboration with other EI providers. If a toddler is working with multiple EI providers, they can strategize about the best way to bring up concerns to the caregiver. Sometimes the providers work together to share ASD concerns with caregivers,

and sometimes the provider who has the best rapport with the family is designated to raise the concerns.

> And I think it helps when all of the providers [who] are working with that child are kind of all doing that simultaneously. So it's like I'm noticing these [symptoms], maybe the speech therapist is noticing similar things, that…if you put everything together makes you wonder. So that it's not just like one person kind of bringing it up every week, it's a couple of people.

Many providers encourage families to talk to their toddler's pediatrician and agreed that it was easier to bring up ASD if the pediatrician has already raised concerns. Some providers indicated that instead of explicitly stating their ASD concerns, they will recommend a neurodevelopmental evaluation, where ASD might be a possible resulting diagnosis. They also emphasized the importance of allowing time for the family to process information about ASD, as some families initially refuse further evaluations or services. This extra time enables providers to continue discussing concerns with caregivers and answering any questions they might have. Many providers also described asking the caregiver questions periodically in order to gauge their current understanding and feelings related to ASD.

Perceived Risks and Benefits of Disclosure

Multiple EI providers described both advantages and challenges associated with sharing ASD concerns with families. The greatest benefit of bringing up concerns is that it enables the family to access a diagnostic evaluation and appropriate services and supports earlier. Some providers acknowledged that they were the most appropriate person to raise ASD concerns because their close relationship with the family could increase caregiver receptiveness. Providers also described how their position enables them to continue to support the family through the diagnostic process and help them access appropriate resources.

> I think the biggest 'pro' of us being the first is that we have built a really nice relationship with these families and we can be there to hold them and support them through this journey, and let them know we don't view their child any different.

Multiple providers reported that after bringing up concerns, they were able to have more open and honest communication with the family about the toddler, instead of "skirting" around the subject of ASD or withholding the names of treatments they are using. Some providers also reported that bringing up ASD concerns can validate the caregiver's own (unspoken) concerns about their child.

> I think another 'pro' is validating their concerns that they've been having…I've seen relief in a lot of parents, [who say] 'I've been worrying about this for the last 2 years – I'm glad that somebody else is seeing it too, and that we're able to get what we need to move forward and figure out what our next steps are.

Almost all providers endorsed the greatest risk of raising ASD concerns as the possibility that the family might "fire" them or leave early intervention services entirely. Many participants said they had, in fact, "lost" a family after raising ASD concerns. They described experiences in which the caregivers stopped responding, failed to show up for scheduled visits, or transferred to other services. Some caregivers became upset upon hearing the concerns, and others were offended that the provider would possibly view their toddler differently. One provider described the risk that the family would think she was raising ASD concerns because she had become incapable of serving the toddler's needs. Another provider described disclosure of ASD concerns as potentially breaking the trust she had built with the family.

> You risk the relationship piece and families not wanting to engage in services, or not having buy-in with you.

Other challenges associated with conveying concerns to parents included discomfort raising ASD concerns without being able to give a definitive answer right away, as well as difficulty explaining the long-term implications of ASD and the importance of starting services before age 3. Some providers reported that caregivers' prior negative experiences or incorrect knowledge of ASD made it difficult to bring up or discuss ASD, and others described difficulty raising concerns when family members had different opinions regarding the presence of ASD symptoms. Some providers also described being concerned about a caregiver's "delayed reaction" to their disclosure, and one described a situation in which the caregiver was initially receptive to the information, but once the provider left the home, the caregiver became upset and "rejected" the concerns.

> I think the immediate reaction isn't as hard for me. Like if they cry or they're upset I feel like I can handle that moment because I can be with them, but when I leave, that reaction is kind of what terrifies me… Where is their head going to take them, and did I leave them with enough support or answers to their questions. The delayed reaction is what's scary to me.

However, some providers also acknowledged that even if families initially rejected any ASD concerns or left services entirely, they often would seek further evaluations or services once they were ready.

Theme 3: Cultural Influences on ASD Care

Two categories of responses emerged related to the cultural issues theme: differences in knowledge and conceptualizations of ASD and disability across cultures, and communication barriers associated with working with culturally diverse families.

Cultural Conceptualizations

Providers reported that a family's cultural background often impacts their knowledge and understanding of ASD, and that there may not be a word for "autism" in some families' native language. Moreover, families from some cultures have had very little exposure to individuals with *any* type of disability. As a result, providers described having to be very "vigilant" about how they describe ASD, drawing attention to the specific behaviors of concern before using the term. Others stated that families from certain cultural backgrounds were confused as to why ASD was prevalent in their communities in the U.S. but not in their home countries. Many providers also reported that some cultures stigmatize disability, and that families were ashamed to be receiving extra services. One family did not want written evidence of their child's diagnosis for fear it would affect the child's future prospects for an arranged marriage.
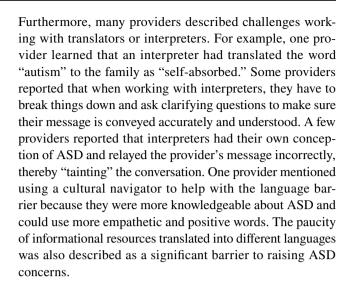
> They don't have autism as a diagnosis in [their country]…and see it being really common in their community here…and that there's a feeling that it might be bad to get a label of autism, that it's going to stay with the child forever.

Providers also mentioned that some cultures have different expectations for child development, which might lead to an apparent lack of caregiver concern. Some cultures believe that children should progress at their own pace, rather than one that is "expected" of them. For example, one caregiver was adamant that the toddler wait to start school at 5 years old, even though the toddler qualified for developmental preschool services at age 3.

Communication Barriers

Several barriers to working with culturally diverse families were described. Some providers reported difficulty explaining core symptoms of the disorder when "ASD" or "autism" cannot be translated directly into their language.

> When you have that language and cultural barrier… maybe even if you were using the correct word in the language, you've never heard of ASD, but then on top of it, it can be such a foreign concept.

Furthermore, many providers described challenges working with translators or interpreters. For example, one provider learned that an interpreter had translated the word "autism" to the family as "self-absorbed." Some providers reported that when working with interpreters, they have to break things down and ask clarifying questions to make sure their message is conveyed accurately and understood. A few providers reported that interpreters had their own conception of ASD and relayed the provider's message incorrectly, thereby "tainting" the conversation. One provider mentioned using a cultural navigator to help with the language barrier because they were more knowledgeable about ASD and could use more empathetic and positive words. The paucity of informational resources translated into different languages was also described as a significant barrier to raising ASD concerns.

Theme 4: Ideal Resources for Facilitating Discussion About ASD with Caregivers

Providers described different types of resources that would be helpful to share with families when discussing ASD concerns. They indicated the need for clear and concise information sheets in diverse languages that define and illustrate the ASD spectrum, including common behaviors, strengths of children with ASD, differences between girls and boys, and potential next steps for their toddler. They also suggested a "go-to" ASD resource website that provides simple explanations and guidance, as providers were concerned about the accuracy of information caregivers receive while "Google searching."

> I feel like there's so much information out there and there's constantly new research… but if you're just hearing about autism from somebody and it's not something that's ever crossed your radar, it's so overwhelming.

Others described the need for interactive visual materials that include pictures, flowcharts, and videos to help explain ASD and how to best support their toddler. Many providers recommended videos as a tool for illustrating the "red flags" of ASD and how behaviors can manifest differently across different children and age ranges. Providers advocated for visual materials as a way to navigate language and cultural differences, as well as help current and future providers increase ASD knowledge and understanding in families.

> Anything with pictures is a good thing because pictures don't need to be translated…if I have an interpreter at the appointment, I might be able to have them translate the little bit of text but being able to refer to pictures is always helpful.

Providers also described a number of different resources for themselves that would be helpful in interacting with families when ASD concerns are present. They expressed a desire for information to help them communicate more effectively with caregivers, by increasing their own understanding of the caregiver's mental state, how to recognize signs of overwhelmed caregivers, and how to navigate around caregiver stress, nervousness, and anxiety. They also expressed interest in materials that would increase their understanding of family challenges and how to navigate cultural differences. In addition, they indicated a need for resources that describe positive and productive ways to have ongoing conversations with caregivers about their toddler and ASD, such as when, and how many, informational resources should be shared with families, how to explain different treatment options, and how to assess caregiver understanding.

Discussion

This qualitative study examined Part C Early Intervention providers' perspectives about discussing early ASD concerns and referrals with parents, with the ultimate goal of identifying ways to improve provider-caregiver communication and increase shared decision-making. Our data provide new insights regarding EI providers' perspectives on working with families of children when ASD concerns are present, which is a topic of importance for several reasons. First, the increasing prevalence of ASD, combined with Part C's status as a primary referral resource for primary care providers, suggests that most EI providers will have toddlers with ASD in their caseloads. Second, EI providers' early and sustained contact with toddlers under 3 years old and their families places them in an ideal position to assist in early identification as well as provide ASD-specialized intervention and referrals within a supportive relationship. Third, the Part C system serves many families from traditionally underserved backgrounds, who may not otherwise have access to early habilitative services.

Overall, the EI providers in the focus groups appear to be aware of the early symptoms of ASD, to understand the importance of early, specialized intervention, and to employ thoughtful and tailored approaches for bringing up concerns. However, their responses also suggest that many are very cautious, and perhaps conflicted, about disclosing ASD concerns to caregivers. Many EI providers worry about negatively impacting their relationships with families by raising the possibility of ASD too soon. This concern is understandable given the family-focused partnership model that defines Part C services, as well as the potential fragility of some parents who have only recently learned that their toddler is not meeting developmental milestones. As such, focus group participants described the desire to "protect" families from upsetting information, for fear that they will leave Part C and be entirely devoid of support. This belief that providers serve as a family's sole support system may place a heavy, and potentially unnecessary, burden of responsibility on EI providers for a family's overall well-being. In fact, one recent study found that caregivers of children with ASD reported (retrospectively) their wish that they had been informed of ASD concerns earlier (Locke et al. in press).

Providers in this study reported taking a gradual approach to raising ASD concerns to avoid the possibility of disrupting their relationship with caregivers. One common strategy they described is asking the caregiver probing questions and gently pointing out symptomatic behaviors, without mentioning ASD explicitly until the toddler is about to age out of Part C services (i.e., close to age 3). Unfortunately, this desire to protect the caregiver may not be in the toddler's best interest if it prevents him or her from receiving ASD specialized services at an age when they might have the greatest impact (Dawson 2008; Zwaigenbaum et al. 2015). For example, both Applied Behavior Analysis (ABA) and Naturalistic Developmental Behavioral Interventions (NDBIs) have been associated with significant improvements in many aspects of development for toddlers with, or at risk for, ASD (Schreibman et al. 2015; Virues-Ortega 2010).

Another approach used by EI providers is waiting to discuss ASD concerns until caregivers raise the question of ASD first. However, this approach also delays the process of obtaining specialized services, given that EI providers likely possess greater awareness of ASD signs and symptoms than do most caregivers. In fact, the effect of this approach mirrors that of the "wait and see" attitude that continues to exist among many primary care providers (Locke et al. in press; Zuckerman et al. 2015).

While these results help illuminate the perspectives of EI providers, they also raise additional questions. How can we reduce the tension that exists between the toddler's need for early ASD services and the EI provider's discomfort communicating their concerns? At an agency level, one strategy might be to incorporate ASD screening routinely during intake evaluations, and outlining this process openly to caregivers. Creating a culture of ASD screening might serve to "normalize" the terms "autism" and "ASD" within the EI context, and help providers facilitate more open conversations with families if and when ASD concerns are present. By having an agency-wide policy for ASD screening, EI providers may initiate ASD conversations while describing them as a standard component of care. Incorporating routine ASD screening also may reduce the likelihood that "diffusion of responsibility" will occur when multiple providers work with the same family.
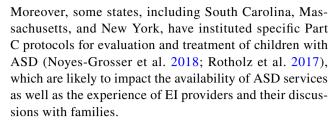
However, this approach alone is unlikely to be sufficient. While providers in previous studies expressed the belief that ASD screening should be conducted in EI, they also

cited barriers such as insufficient training, lack of knowledge about how to communicate positive results without increasing caregiver stress, and an inability to answer specific questions that caregivers might ask (Pizur-Barnekow et al. 2013; Tomlin et al. 2013). Likewise, EI providers in the current study reported a lack of information about *how* to talk to families about ASD concerns and manage the emotions that caregivers might display during these difficult conversations, and expressed a need for resources to help them anticipate possible caregiver reactions—such as anger, sadness, or denial—in response to ASD discussions. Potential approaches for increasing providers' knowledge base and self-efficacy might include offering relevant continuing education activities, providing coaching from supervisors and/or peers, and creating tailored shared decision-making materials to support communication with caregivers. Additionally, their discomfort discussing ASD concerns and explaining ASD may be attenuated by the availability of easy-to-access visual supports complemented by easy-to-read handouts. Ideally, these materials would be available in multiple languages to assist providers in guiding families from a diverse range of cultural and linguistic backgrounds.

Given the themes of "pacing" and caregiver "readiness" that were pervasive in the present study as well as Sheldrick et al. (2019), the Transtheoretical Model (TTM; Prochaska et al. 1992) may provide a useful framework for helping providers discuss ASD concerns. This model describes four stages of patients' (or caregivers') readiness to take action to improve health outcomes (i.e., precontemplation, contemplation, preparation, and activation/maintenance), along with specific discussion strategies that providers can use with families at each stage. The TTM has been adapted for numerous medical conditions and disorders (Gitlin and Rose 2014; Gitlin and Czaja 2016), and may help EI providers identify the family's readiness level, and pace their use of appropriate communication strategies, with the goal of fostering earlier ASD discussions and participation in specialized services.

While this study provides valuable insights into EI providers' perspectives on working with families in the presence of ASD concerns, several limitations must be acknowledged. First, our data were obtained from a relatively small number of EI providers in a single community. Although our sample is larger than those included in the other qualitative studies on this topic (Cameron and Muskett 2014; Sheldrick et al. 2019), and data saturation was attained, the extent to which the viewpoints of our participants may generalize to other Part C systems and geographical regions is unclear. There is great variability in the way that Part C is implemented across different states, with relation to the sources of funding, intensity of services, and criteria used to determine a child's eligibility (Noyes-Grosser et al. 2018; Rosenberg et al. 2013).

Moreover, some states, including South Carolina, Massachusetts, and New York, have instituted specific Part C protocols for evaluation and treatment of children with ASD (Noyes-Grosser et al. 2018; Rotholz et al. 2017), which are likely to impact the availability of ASD services as well as the experience of EI providers and their discussions with families.

Our participant characteristics and county demographics may also limit generalization of our findings to other parts of the country (and state). The county in which this study was conducted is highly diverse, both culturally and linguistically, with 170 different languages spoken. As such, it is not surprising that our results highlight the importance of cultural competency when discussing ASD concerns, though this emphasis may be less relevant for other regions of the country. In addition, our sample of providers was almost exclusively female and non-Hispanic White. Although these demographics are consistent with national averages for Part C EI providers (Hebbeler et al. 2007), additional research is needed to determine the potential effects of cultural mismatches.

In addition, it is important to acknowledge that the results reported herein are unlikely to reflect the full range of heterogeneity that exists in EI providers' practices, as participants may not have been comfortable openly disagreeing with their colleagues during the focus group. We did not find contradictory evidence (i.e., disagreement between participants) for three of the four themes. The one exception occurred within Theme 2, with providers describing different approaches to raising ASD concerns with caregivers (e.g., a gradual vs. more immediate approach). However, it is important to note that the absence of contradictory evidence does not mean that all providers agreed about their practices.

In sum, this study provides important information regarding the opportunities and challenges that Part C EI providers experience in their work with toddlers and families when ASD concerns are present. Their responses to the focus group probes shine light on the priorities and values that guide their decisions regarding disclosure of ASD concerns, as well as suggestions for resources that would increase their ability and motivation to initiate challenging discussions with the families they serve. The next step is ours: to develop and provide accessible resources for both providers and families that can support the earlier detection of ASD and the timely provision of evidence-based services.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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