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Community Perspectives on Developmental Screening of American Indian and Alaska Native Children

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Abstract

Children are highly regarded and treasured as the future of American Indian and Alaska Native (AIAN) communities. Developmental disorders, however, are more frequently undiagnosed and untreated in AIAN children compared to others in the United States. Developmental screening can help communities ensure that their children reach their full potential, but lack of culturally sensitive and valid screening measures complicates screening among AIAN children. This can, in turn, delay access to early intervention and undermine the ability of AIAN communities to support children's optimal development. This study explored families' and professionals' perceptions of screening systems and processes in AIAN communities and to identify gaps and opportunities. 53 interviews and 23 focus groups were conducted with 157 parents and early childcare professionals in four AIAN communities. A conceptual framework to describe systems of screening for young children was developed by AIAN early childhood program partners and early childhood researchers working together on a Tribal Early Childhood Research Center Community of Learning; this framework guided study design and interview guides. Transcripts were coded for themes in alignment with the conceptual framework; 13 key themes and 81 subthemes were identified. Findings are discussed in terms of implications for enhancing screening efforts in Tribal communities.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report.

ETHICS STATEMENT

The study was reviewed and approved by the Colorado Multiple Institutional Review Board (COMIRB) and the appropriate tribal oversight authorities in the participating partner communities (including an Institutional Review Board in one partner community).

Keywords

American Indian and Alaska Native; Early Developmental Screening; Measurement

The prevalence of developmental disabilities has significantly increased in the last decade. One in 10 children under five years of age in the United States is diagnosed with a developmental disability (Zablotsky et al., 2019), including attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder, learning disability, intellectual disability, blindness, hearing loss, cerebral palsy, or language and social emotional delays (Zablotsky et al., 2019). Relative to their English-speaking white peers, ethnic and racial minority children with developmental challenges are less likely to be identified early or receive needed special education services (Morgan et al., 2015). Given the robust evidence that early detection and prevention help improve outcomes for children and families, this inequity is particularly concerning (Guralnick, 2011; Raspa et al., 2015).

American Indian and Alaska Native (AIAN) children may be at particular risk for inequities in early intervention efforts. Reports indicate that AIAN children have the highest rates of childhood disability (5.9 %) in the United States – higher than Black (5.1%), Non-Hispanic White (4.3%), biracial (5.2%) and Hispanic (4.3%) children (Young, 2021). Interpreting these differences, however, is complex. Race and ethnicity are often confounded with poverty and rurality. Children living in poverty and/or rural communities are at elevated risk for developmental disabilities (Young, 2021; Zablotsky & Black, 2020), and AIAN children are more likely than children in other groups in the United States to experience poverty and to live in rural or remote locations. AIAN children also experience other structural and systemic factors (e.g., discrimination, poor access to services) that threaten their healthy development (Cheng, Goodman, & the Committee on Pediatric Research, 2015; Sarche & Spicer, 2008).

Another challenge to estimating disability among AIAN children is that common screening tools do not sufficiently consider the cultural and geographic contexts in which AIAN children grow up. This is problematic as it undermines the accuracy of screening and subsequent diagnostic evaluation, renders comparisons across populations questionable, and makes guidance for parents and providers uncertain (Whitesell, Sarche, & Trucksess, 2015). Furthermore, data on the reliability and validity of screening tools for AIAN children is lacking, making it difficult to interpret results. Development and validation of developmental screening tools for AIAN children has remained a low priority, both in national research efforts and in Tribal communities (Whitesell et al., 2015). At the national level, validation efforts focus on larger population subgroups while measurement research with AIANs remain under-resourced. In Tribal communities, where resources are often limited overall, upstream efforts such as screening, prevention and early intervention can be overwhelmed by pressing downstream public health needs (e.g., diabetes or substance abuse treatment). Validated screening tools and processes, however, are necessary to ensure that AIAN children's needs are identified, and effective early intervention targeted to those needs are implemented.

Effective screening is not limited by measurement issues alone. The consequences of unvalidated screening tools for AIAN children are exacerbated by high levels of historical trauma. AIAN communities' lack of trust in educational and governmental systems are the legacy of years of federal policies that disrupted families and cultures, including the forcible removal of children from their families to federal boarding schools and adoption of Native children by White families outside of Tribal communities (Sarche & Whitesell, 2012). This generational disruption of parenting hindered the normal transmission of parenting strategies, child development knowledge, and behavior expectations (Brave Heart & Spicer, 2000). Many parents have also learned to be wary of governmental involvement with their children, and thus often see screening as a potential threat (Whitesell et al., 2015). Although AIAN communities are diverse, with large variability of resources and complex interplay across Tribal, federal, state, county, and private service sectors (Gone & Trimble, 2012; Novins & Bess, 2011), many are rural and remote with disproportionately poor environmental resources, economic opportunity, and access to services. AIANs in urban centers, the legacy of federal relocation policies in the middle of the 20th century, are often low income and removed from resources provided through tribes or federal treaty obligations (e.g., Indian Health Service). Subsequently, resources to provide diagnostic evaluations in response to positive screening results and provide early intervention, if necessary, are often limited across these contexts.

Nationwide efforts to improve screening, detection, and prevention of developmental delays have expanded in recent years. These include efforts by both the Administration for Children and Families ("Birth to 5: Watch me Thrive!," 2021) and the Centers for Disease Control and Prevention ("Learn the signs. Act early.," 2021). However, these initiatives have had a limited impact in AIAN communities. In response, the Tribal Early Childhood Research Center (TRC) brought together a Community of Learning (CoL) to design a study focused on the use of early developmental screeners for AIAN community and cultural contexts. The CoL engaged a total of 32 individuals, 15 of them Indigenous (representing 11 different American Indian, Alaska Native, and Māori cultures). Seventeen CoL members were academic researchers with expertise in AIAN early childhood; 13 were program partners from Tribal and urban Native early childhood programs (five home visiting, four Head Start, one child care, and two behavioral health); and two were program officials from the Administration for Children and Families. CoL's are central to all research conducted by the TRC and ensure that diverse perspectives are incorporated throughout the research process.

Although the initial vision was a pilot study to inform a large-scale validation study of developmental screeners for this population (the Pilot Exploration of Developmental Screening in Tribal Communities; Tribal PEDS), community partners on the CoL quickly pushed to expand the focus beyond the reliability and validity of existing screeners. They urged us instead to explore *how these tools are actually used* in AIAN communities. Guided by the CoL, we identified two study aims: (1) to understand screening systems in Tribal communities, how screening tools are used in practice, and the effectiveness of screening for improving children's developmental outcomes; and (2) to explore the feasibility of a larger study to examine the reliability and validity of common screening tools specifically for AIAN children birth to five years. The study described here was designed to address the

first aim; a companion paper (Asdigian et al., under review) reports on the study designed to address the second aim.

The engagement of community partners in the CoL, along with experts in developmental screening and early childhood programming in Tribal communities, was also critical for creating a conceptual framework to describe screening systems (Figure 1). This framework was informed by findings from an earlier study that explored early developmental screening in Tribal communities (Whitesell et al., 2015) and by medical models that focus on both the accuracy of screening and efficacy at both individual and system levels (Committee on Diagnostic Error in Health Care, Services., Institute of Medicine, & The National Academies of Sciences, 2015; Fryback & Thornbury, 1991).

With guidance from the CoL, we applied these concepts to early developmental screening in AIAN communities to create the Tribal PEDS conceptual framework, identifying four key elements of the screening process that cut across different levels (i.e. screening tools, individual children, and community). The first element, *Reasons for Screening*, includes both indicated screening (screening *individual children* due to concerns) and universal screening (screening all children, regardless of concerns, as a matter of policy or program requirements). The second element, *Effectiveness of Screening Tools*, focuses on *screening tools* and whether or not they *can* provide accurate results and, when used in practice rather than in controlled research contexts, whether or not they *do* provide accurate results. The third element, *Impact of Screening*, focuses on the value of screening for *individual children*; that is, whether children receive diagnostic and/or intervention services based on screening results that lead to improved outcomes. The fourth element, *Relative Benefit of Screening*, considers whether the benefits of screening outweigh the costs for the *community*. Using this conceptual framework as a guide, we worked in partnership with the CoL to design a qualitative study to better understand how early developmental screening systems operate within AIAN communities and to identify critical gaps and opportunities for future research and practice.

Participants

We partnered with early childhood programs in four AIAN communities (see Table 1). Partner programs were recruited from existing TRC collaborators and represented diverse regions and Tribal contexts. Partners included two Tribally-administered Head Start programs, a Tribal behavioral health system, and a Tribal Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program. Three of these sites were under the jurisdiction of federally-recognized sovereign Tribal Nations; the fourth was an Urban Native organization. To protect the confidentiality of the participating sites and in accordance with each site's organizational and/or Tribal approval, we do not provide information about the sites' or communities' identities.

A total of 157 parents[1] and early childhood professionals[2] participated across the four sites (see Table 1). We conducted 53 interviews (18 with parents, 35 with early childhood professionals) and 23 focus groups (3 with parents, 20 with early childhood professionals). Both parent and professional participants were recruited through study partner programs

in each community. We invited parents who had young children (birth to five years) and professionals who worked with young children in some capacity (e.g., teachers, home visitors, child care workers, program directors, intervention service providers) to participate. Past experience with screening – either as a parent or a professional – was not a requirement for participation. Each participant received a $25 gift card to Walmart or Amazon.

Procedures

The study was reviewed and approved by the Colorado Multiple Institutional Review Board (COMIRB) and the appropriate organizational or Tribal review authority at each site. At the three sites under the jurisdiction of sovereign Tribal Nations, approval was provided by one Tribal Chairman, one Executive Director of the Tribe, and one Tribal Institutional Review Board. Approval at the fourth site, within an Urban Native Organization, was provided by the Operations Director of the organization.

Visits were made to each partner site for data collection. We worked with local partners to identify and schedule parents and early childhood professionals for key informant interviews or focus groups. Research staff conducted an informed consent process with all potential participants and collected signed consent forms before beginning interviews or focus groups. Interviews and focus groups were conducted at partner facilities or in community locations convenient for participants, and audio recorded, with permission of participants.

Each data collection visit also included a training session for program partner staff that focused on screening practices, interpreting results, and communicating results to parents. A second visit was originally planned with each partner community, but these were not possible due to the COVID-19 pandemic; findings were instead shared with each partner community through virtual meetings with the TRC study team.

Measures

Interview guides were developed by the TRC study team through an iterative process of consultation with the CoL. One guide was developed for use with parents and another for use with early childhood professionals.[3] Within each group (parents and professionals), the same guide was used for both key informant interviews and focus groups.

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[1]Extended family and community parenting are common in AI/AN communities; therefore, we use the term *parent* for anyone actively engaged in parenting children, including not only biological parents but also family members or others filling primary caregiving roles for children, either in lieu of biological parents or in addition to them. Thus, we interviewed grandmas, aunties, and uncles, as well as mothers and fathers.

[2]*Early childhood professionals* included those working in programs with young AI/AN children (e.g., Head Start teachers, home visitors, childcare providers; directors and other staff of these programs), those delivering other kinds of services to young children (e.g., physicians, physicians assistants, nurses, speech therapists, behavioral health care providers, developmental specialists, social workers, school staff), and others identified by program partners as relevant to children and families in their communities (e.g., elders, cultural experts).

[3]It is important to note that some interviewees had dual roles and were both parents and professionals. Therefore, in some cases individuals originally intended to be interviewed as a professional also shared responses from their experiences as a parent; less often, individuals interviewed as parents also shared experiences from their perspectives as early childhood professionals. These cross-over responses were generally noted at the point of coding (i.e., categorized under both roles). However, in a few cases interviewers recognized the need to pivot from one interview guide to the other at the outset of an interview and these participants were recategorized from parent to professional or vice versa.

Questions were based on the Tribal PEDS conceptual framework and designed to elicit perspectives on each component of the screening process (i.e., questions about *Reasons for Screening, Effectiveness of Screening, Impact of Screening*, and *Relative Benefit of Screening*). Within each component, specific questions and probes were included to prompt reflections on specific aspects of screening systems and processes within the community.

Data Analysis

Key informant interviews and focus group discussions were transcribed and independently coded for themes by three trained study team members using ATLAS.ti 8 software. The interview guides were used to generate a set of initial codes and create a codebook. The coding protocol defined codes, documented examples of when to use them, and detailed procedures for coding.

Due to the large number of interviews and interview transcript data, coding was completed in two cycles. *Cycle 1* included *structural coding* based on the topics of inquiry in the interview guides. During this cycle, additional codes were developed to identify novel emergent findings not yet reported in the literature. Cycle 2 coding involved *identifying key themes* from coded transcripts and developing recommendations about best practices for developmental screening in Tribal communities. This analytic methodology derived from a review of best practices in qualitative analytic methods (Miles, Huberman, & Saldäna, 2014; Saldana, 2016; Ulin, Robinson, & E.E., 2005) and consultation with qualitative analytic experts (A. Meyer, personal communication, 10/16/2019; D. Fernald, personal communication, 7/19/2019; E. Perrin, personal communication, 10/25/2017, 12/1/2017, & 1/17/2018; C. Sheldrick, personal communication, 10/25/2017, 12/1/2017, & 1/17/2018). A consultative and reflexive team analysis approach was used to reach consensus on analytic methods (Krueger, 1994).

The coding team met weekly throughout both cycles to review coding, address questions, and resolve discrepancies. The protocol was regularly updated as decisions were made about specific codes and rules for coding practices.

Results

Key themes were identified within each element of the conceptual framework (see Table 2). Many themes represented responses given by both parents and professionals. Comments that were primarily associated with only one type of participant are noted, and quotes from individual participants are identified as either *parent* or *professional*.

Reasons for Screening

As shown in Table 2, three key themes were identified in the transcripts, aligned with *Reasons for Screening* in the conceptual framework: (1) motivations for screening, (2) typical screening practices, and (3) the context of AIAN children's development. Within each key theme, subthemes were also identified, as detailed below.

Motivations for screening

Universal screening.: Most screening that occurred was in response to federally-funded program requirements. Timing of screening was linked to program schedules (e.g., 45 to 90 days after start of the school year or enrollment in a program). Screener packets were often included with enrollment paperwork; some reported ongoing routine periodic screening while others reported additional screening only if indicated.

> *"We've got to do screening because the funding says we have to do screening. So, we're going to screen everyone."* [Professional]

Universal screening at well-child visits, by physicians or other healthcare providers, was mentioned most frequently at a site that was part of a healthcare system, although screening in these contexts was noted at all sites. However, duplication of screening efforts was noted by some parents who expressed frustration at being asked to repeat screening in both early childhood program and healthcare settings.

Indicated screening.: Screening in response to parent or professional (usually teacher) concerns was also mentioned in all communities. Professionals noted that listening to parents' concerns was important and emphasized that parents' observations, opinions, and intuitions about children are critical to identifying problems early.

> "I think parent concern goes a long way. If a parent is concerned, I will always take that at face value. Parent concern to me is a huge, it's a huge weight. And there are some parents who have inaccurate views of what children's development looks like, but generally, if parents are around other kids and they're concerned about their kids' development, I think it carries a decent amount of weight. Or if maybe not the parent but maybe additional family members who are around that child are also expressing that they have some concerns, then I think we always have to take that, and that's valuable in and of itself for screening. At the very least for a screening." [Professional]

Some parents whose children were screened based on a concern reported being relieved when screening results showed that their children were actually on track developmentally, while others reported positive reactions when their concerns were validated through screening and they received referrals for further evaluation and services.

> "I was scared that he wasn't going to be okay. So, I loved knowing that he was meeting the benchmarks and that I could be doing things to help him meet the next ones. I feel confident as a parent to have that." [Parent]

Typical screening practices

Common screeners.: The most common screeners participants reported using were the *Ages and Stages Questionnaire*, the *Ages and Stages Questionnaire Social-Emotional*, the *Survey of Well-being of Young Children*, the *Developmental Indicators for the Assessment of Learning*, the *Devereux Early Childhood Assessment*, and the *Modified Checklist for Autism in Toddlers, Revised*.

Screening rates.: Rates of screening for children enrolled in Head Start/Early Head Start, MIECHV, or Child Care (CCDF) programs were estimated to be high (75-100% at one site). However, estimated rates of screening for children outside of Tribal early childhood programs – who did not have program-based opportunities for screening – were perceived to be much lower, ranging from 10-50%.

Although screening at well-child visits was noted, participants indicated that many families did not have access to regular well-child visits, due to a lack of local providers or lack of resources. Screening through public health departments, health organizations, and private preschools was not generally seen to reach high percentages of children. Parents' refusal to participate in screening was sometimes noted as a barrier to screening.

Context for AIAN children's development

Contextual factors influencing AIAN children's development.: Exposure to stress and trauma, family disruption (e.g., due to death, incarceration, suicide, or family or community substance-use problems), environmental risk (e.g., poverty, housing instability and overcrowding, broader health inequities, isolation), and the lack of early childhood services were all reported as contextual factors that created challenges for young children in AIAN communities.

> *"A lot of the children that I deal with had been removed from their home due to substance abuse, physical abuse, neglect and things of that nature. And so, a lot of times what we see is, you know, these children, because of whatever issue was going on in their home, they haven't had a long history of medical attention*." [Professional]

The level of trauma in some AI/AN communities was thought to potentially skew perceptions of what is considered normative child behavior and leading some parents to overlook problematic behavior. Concern was also expressed that children exposed to frequent traumas and stressors may not have their basic needs met and, as a result, would be at risk for developmental delays and poor health outcomes.

Historical trauma and AIAN children's development.: Some participants perceived that historical trauma impacted young children's development over and above current trauma exposure. Federal assimilationist policies of the past (e.g., forced boarding schools, relocation) disrupted family structures, parenting practices, and Native language and cultural practices and the effects of these historical disruptions continued to reverberate through the generations. Reflecting on the need for cultural healing and restoration to repair the damage done, one participant noted:

> *"One of the other big lessons I learned when I was working here is that the trauma, I know we talk a lot about ACEs now, but … some of these families have been really traumatized by the education system and the healthcare system. And so they bring that into their parenting of their children. And so sometimes screening that we do is scary for them because then they're afraid [for]their child, [that] their child [is]going to experience the same thing that they did."* [Professional]

Cultural influences on AIAN children's development.: AIAN culture was viewed as having a positive impact on children's development. Participants observed that very young children in their communities have a sense of pride about being Native. Strong cultural values, intergenerational and interdependent family structures, and community commitment to children were cited as supports for healthy developmental outcomes. The protective role of culture was seen as critical for mitigating developmental risk in the face of contextual challenges and the legacy of historical trauma. Participants emphasized the importance of elders and of children learning their Native language.

Health and developmental concerns among AIAN children.: ADHD and autism were the most frequently cited developmental concerns, followed by asthma and other respiratory issues, food scarcity (and the resulting nutritional deficiencies), poor oral health, social-emotional and behavioral concerns, sensory issues, speech and language delays, and post-traumatic stress disorder (PTSD). Participants also expressed concerns about the impact of increased technology use (e.g., smartphones) on children's development, through reduced face-to-face interaction and the disruption of language development.

> *"Smartphones are replacing conversations, interrupting family dinners, and opportunities for children to learn language."* [Professional]

Effectiveness of Screening Tools

The analysis of responses to the set of questions related to the *Effectiveness of Screening Tools* for use with AIAN children yielded four key themes: (1) effectiveness of administration strategies; (2) trustworthiness of screening tools; (3) interpretation of results in the context of culture; and (4) preparedness of the screening workforce. Subthemes were also identified (see Table 2).

Effectiveness of administration strategies

Screening methods.: Some communities and programs reported extensive use of online screening tools, while others relied mostly on paper forms. *Independent Screening* (i.e. when parents completed screening forms on their own) was common, whether online or on paper. Parents reported appreciating being able to complete the screeners wherever and whenever they wanted, working them into their busy lives with young children. However, they also shared challenges, noting that they sometimes did not know how to answer questions and would have liked to consult with their child's teacher. Some also admitted rushing through screening just to get it done, and some worried that online screening, in particular, might not be accurate.

> "*It's a little nerve wracking because you don't know for sure when you're doing it yourself. You know, you look at it and you're like, oh, well I think my child's on track, so then I haven't heard back. So, but it's nice in comparison, having someone that's trained to do them sit there and do them with you and they're like, oh, well they're on track. And it's just that little bit of reassurance. Whereas when it's online, who's that being submitted to? I don't even know who. I don't know who sees it. I don't know who reads it. I don't know who screens it.*" [Parent]

Collaborative Screening – i.e. when parents completed screening forms together with an early childhood professional – was also common. Parents liked being able to ask for clarification of confusing questions, receive literacy support, or have a trusted professional's input about their children's behavior to support accurate responses. Parents also appreciated the opportunity to discuss the screening process and to seek guidance on supporting their children's development. From parents' perspectives, the downside of *Collaborative Screening* was primarily scheduling screening around busy schedules.

> *"It was so much easier having someone and then if there was a question that was confusing, they were there to help me through it and work me through it. Some of the questions about language development they can get a little confusing. The ASQ there have been some [questions] that I have to read it six or seven times before I understand. So, I did like having someone there to help me work through it."* [Parent]

Professionals noted that *Collaborative Screening* should be conducted in a private setting with a familiar, trusted individual. They also viewed in-person screener administration as useful for helping parents understand screener questions, supporting more accurate responses, and providing an opportunity for professionals to probe for information about the context of a child's behavior and offer guidance on how parents can support their child's development.

The importance of trust.: *Who* administers screeners was seen to be more important than *how* screeners were administered. Many parents expressed fear about how screening results would be used by systems and professionals. Parents worried that their children would be permanently labeled based on screening. Some expressed concern – likely rooted in a history of AIAN children removed from families (i.e., boarding schools, child welfare policies) – that their children would be taken away from them if screening identified problems. Parents thus had concerns about disclosing personal information and expressed hesitancy in doing so unless they trusted the individual administering the screener. Professionals concurred that trust was essential to accurate and effective screening.

> *"A home visitor communicates about the purpose and the role and the use of screening. And it's all about the relationship they have with their families, and they don't start the screening tool right away when they get a new family, they work to build that relationship first. Then the parents are there, they perceive things better when there's someone that they trust is in their home and they only want the best for them. It's perceived a little better than just throwing it at them."* [Professional]

> *"Don't make me a statistic."* [Parent]

Opportunities for conversations that emerge during the screening process, particularly in-person screening, were also noted to be important for transparency in screening and feedback, which parents said helped alleviate their anxiety and supported them in taking screening seriously.

> *"And that's why it's so important that we start up that relationship because nobody wants to hear that about [their child] - especially from someone who you don't have a relationship with."* [Professional]

Regardless of the outcome, providing feedback to parents about screening was seen as critical to maintain the trusted relationship. Parents expressed frustration when they did not receive feedback because it left them wondering if their child was okay and wishing for more guidance.

> *"I would like if something was wrong with my child, I would want to hear it from somebody that knew him. I'd rather hear it from somebody that knows him, knows him from more than just these pieces of it [from screening]."* [Parent]

Trustworthiness of screening tools

Overall accuracy of commonly used screeners.: Most participants thought screeners worked well for children in their communities. They believed cutoff scores were appropriate and systematic patterns of either false negatives or false positives were not noted. Screener sensitivity was generally seen as appropriate for identifying potential problems for further evaluation, although some parents expressed concern that screening might not be sensitive enough. Professionals in one community said they adjusted for community norms by using different percentile cutoffs for scoring, setting the cutoff lower than recommended to make it more sensitive.

Both professionals and parents noted that some screeners were very long and overwhelming to complete, and that this might lead to inaccuracies.

> *"[Screeners] can work really well, but they don't work really well if you're not reading them carefully or taking the time to answer them*." [Parent]

Parents also reflected that they tend to see their children through 'rose-colored parent glasses' and that could influence their responses and the accuracy of screening results.

Concerns with appropriateness of specific screener items.: Some participants raised concerns about the fit of some screener items within their cultures and communities. For example, participants noted questions about behaviors used to indicate potential social or behavior problems that could, instead, reflect appropriate respect for cultural norms (e.g., avoidance of eye contact). In one community, where subsistence hunting is a strong part of the local culture, teachers shared a book they use in their classroom about the community coming together for a hunt to provide food, and noted how this cultural practice is at odds with social-emotional screening "red-flags" about harming animals. Participants also noted that young children learning Native languages alongside English (or before English) might be a disadvantage if the screening tool is focused narrowly on English language acquisition. In some Native communities where children are taught from a young age to be quiet and reserved (e.g., to sit back, listen, and observe), screeners were noted for flagging potential developmental problems among children who were, in fact, exhibiting culturally appropriate behavior.

Participants also thought some questions were too specific (e.g., whether child could cut a square with scissors) while others were not specific enough (e.g., whether or not a child would react in a certain way depended on too many factors, such as whether or not they were tired). Parents said they were at a loss for how to answer such questions.

> "*The wording, they're super specific, and it's almost subjective. [Questions are] specific, [you think] they do this kind of, but he doesn't do this.' It's almost like they're trying to put your kid in a box. Rather than just being more, I don't know, more flexible. It's very black and white, so you don't know how to answer it…And there's nothing that's [like] a box that's just like, 'With assistance.' Like I can check, 'He can do this with assistance,' or something like that would be more helpful.*" [Parent]

Participants also noted that some questions referenced unfamiliar objects (such as planes) or children's ability to interact with certain objects or circumstances which were limited in their communities (e.g., walking up stairs in a community without two-story buildings, reactions to strangers in small, tight-knit communities). Participants also noted that the young AIAN children encounter conflicting messages about appropriate behavior—within their Tribal culture and mainstream culture; such messages make it hard for them to know what is socially appropriate.

> *"[T]hey hear "look at me/don't stare; don't look at me/look at me aren't you paying attention?" etc.*" [Professional]

Screeners as only one of many sources of information.: Many participants pointed to the need to interpret screening results in conjunction with other information. The value of the parents' observations (beyond those captured on screeners) along with observations by teachers, home visitors, childcare providers, and other early childhood professionals, were noted to be important. A child's medical history was also suggested as a critical piece of information to consider. Participants also emphasized the importance of considering a child's family, culture, and community in interpreting screening results.

> *"I could lend some expertise in what I know about speech and language development, but if I don't know that community, it's going to be hard for me to be really accurate."* [Professional]

Interpretation of results in the context of culture—Screening was seen as most effective when professionals scoring screeners, interpreting scores, and delivering feedback were culturally sensitive and familiar with the local culture.

> *"I think for me it was always not just the test but how it was explained and given to the parents because they're quite, quite concerned that their child isn't developing. In the end, the person who was interpreting those tests need[s] to be very sensitive regardless of where the person is, but particularly in a Native American culturally relevant place. In many ways we're very, very place bound here."* [Parent]

Sensitivity to privacy in the screening process was also emphasized, given tight networks in Tribal communities. Parents expressed concerns about who would see screening information and how it would be used.

"You are always bound to know someone or be related to someone in Indian communities." [Professional]

Cultural values and practices regarding children and parenting influence children's development and, thus, responses to screeners. Screening and subsequent interventions were seen by some as tools of colonization, as attempts to acculturate AIAN children and force AIAN people to raise their children to meet Western norms for developmental progress.

"I have an uncle, when he was small, he was really hyper. And his family, they weren't really traditional. So, they used to say, 'Oh, he needs to go see the doctor. Maybe the doctor can give him some medication to calm him down.' But our side, we're more traditional. And they were like, 'No. Don't give him that medicine. Let's pray. Let's [burn] cedar. Let's give him some of our kind of the Native medicine. Let's give him some of that and see if he calms down instead of leaning towards the medication and trying to feed him all this medication.' Or as my grandpa would say-'The white man's medication.'" [Professional]

"Seeking help outside your family is a colonization issue." [Parent]

AIAN children have a rich array of experiences not represented on standard screening instruments, this not allowing their strengths and knowledge to be captured. In addition to this AIAN children are sometimes not exposed to the experiences measured on those instruments. Concerns were raised that AIAN children could appear to be lagging behind simply because the wrong questions are asked. For example, participants noted that questions about reaction to the dark ignore seasonal variation in sunlight, with long dark days in the winter and long light days in the summer, that shape Alaska Native children's experiences.

Preparedness of the screening workforce—Most professionals reported receiving no training (formal or informal) about developmental screening and stated a need for it (including annual refreshers).

"[T]hat's probably our weakest link, our training. We're so big now, we have to bring people in." [Professional]

Professionals expressed a desire for more training on building rapport with families during screening, gaining experience to handle different situations that arise in screening and being able to problem-solve them, talking with parents about significant developmental problems when they are identified, reducing stigma about developmental problems and interventions, using information about children's circumstances to better understand screening results, improved cultural awareness and using screeners in culturally appropriate ways. Professionals also cited the need for ongoing refresher trainings. The lack of funding to support training in communities was noted.

Impact of Screening

Key themes regarding the *Impact of Screening* were: (1) communicating screening results to parents; (2) referrals and resources for evaluation and services; and (3) improvement in children's outcomes.

Communicating screening results to parents

Approaches to providing feedback.: Methods for delivering screening results to parents varied in both format and extent across communities. Some families received results in writing (mailed, hand-delivered, or emailed). Others received results in person (e.g., at parent-teacher conferences, home visits, or doctor visits). Many parents reported receiving results only if their child screened positive.

> *"It just tells you thank you for submitting the Ages and Stages and that's it. I don't like that feeling, being hung up on. Well, what was the outcome, you know? How did it go? Are they where they need to be? And then hearing well, no news is good news. Okay, well that's not helpful."* [Parent]

Some professionals reported only sharing positive screening results because of limited program resources; others said they believed it was only important to share results of positive screens (i.e., potential concerns), and that "*no news is good news*".

Parent preferences for receiving feedback.: Many parents expressed frustration with only receiving results when concerns were noted and most said they wanted to receive results regardless of outcome.

> *"It did feel kind of pointless doing my surveys in the doctor's office because they never actually talked about anything. [They] never said anything other than they're doing good."* [Parent]

> *"Basically, I feel like we fill it out and it just goes in their file and that's the end of it. And it's not looked at [or] share[d]."* [Parent]

Some parents said screening feedback and guidance was especially important with their first child.

> *"[As a] First-time mom, it was more intriguing on why they were asking certain things as opposed to having two children the second time around. And yeah, they'll do it in two or three weeks. And you know, it's a first-time mom, you kind of freak out whenever the questions come up and your child's not at that spot. If they're like nine months, not rolling over, sitting up, you know, more to be alert I guess or you know, something's wrong."* [Parent]

Parents' past experiences with screening influenced how they approached screening and how open they were to accepting screening results.

> *"I was 20, 21 years old and it was my first child. I don't remember having home visits and they're saying, you know, oh, well she's a little delayed and this and this. And being the young mom not knowing if I was doing everything right, I remember it really affected me. I remember I cried like, oh no, what am I doing wrong? You know, now that I've had three kids, I'm just like, eh. So, I'm not worried about it. I[v'e] become a little more experience[d]."* [Parent]

Parents expressed interest in getting additional information along with screening feedback, such as information about what their child should be doing, age-appropriate parenting strategies, and activities to support child development.

> *"It'd probably nice to see, at least for autism, more support-group type things. There's no easy way to lift that stigma of having a child in special ed or not knowing exactly what to do at home to work on those things. As a single parent, you get overwhelmed, there's always barriers."* [Parent]

Effectively communicating screening results.: Professionals' shared many ideas for facilitating the provision of screening feedback to families. An important theme was ensuring sensitivity to family background and culture.

> *"[Share feedback] with mutual respect that helps to facilitate beyond whatever language, and then they're very receptive because they realize you're not trying to take anything away. You're just trying to add to their tools*." [Professional]

> *"Some doors are really scary to walk into [laughter]. And some doors you really connect with. But it's just about finding how to connect with that family the best and support their kids."* [Professional]

Participants also reflected on the benefits of communicating results in the context of a conversation that provided opportunities to support and encourage parents, probe for information about a child's environmental context and exposures, and include education about child development and the importance of early childhood developmental screening. Tailoring feedback to a parent's educational level was also noted as critical.

> *"Just be kind and respectful and hope that they will do the same and that their child will benefit from that. But, yeah, don't talk down to them, don't teacher-talk, don't put words in their mouth."* [Professional]

Participants emphasized respect for intergenerational child-rearing, which is common in AIAN communities. Sensitivity to grandparents raising children was encouraged, noting that these caregivers might be unfamiliar with screening and particularly wary of it.

Professionals and parents agreed that sharing screening results as soon as possible and offering resources and referrals (if needed) were important in the screening process. Discussions about screening results were viewed as an opportunity for parents, teachers, and health care providers to work toward the same goals and reinforce each other's efforts to support children.

> "[Y]our role is based off a relationship. You're not just going into the home to teach the kids, you're not the teacher, you're the partner with the teacher, you're not the shining star, you're there to support the parent as the first and primary teacher of their child." [Professional]

> "Screening can be a teachable moment - the parent is there, they are ready for the conversation, ready to take action." [Professional]

Referrals and resources for evaluation and services

Availability of resources.: Professionals' reports of available resources varied across the four partner communities; some had interconnected networks of services while others had sparse networks or noted that specialty services were available only at significant distances

from local families. Parents generally believed that adequate resources were available in their communities and they knew how to access them. However, some parents who had received referrals reported encountering long waitlists or having to travel long distances to see specialists (e.g., 2-hour drives).

Barriers to accessing referrals and resources.: Availability of resources did not always result in *access* to resources; several barriers were described that kept parents from following through on referrals. Parents shared that obtaining an evaluation or accessing services could be anxiety-provoking and overwhelming.

> *"Do I want to know? Do I want to put my kid through this kind of thing?"* [Parent]

Professionals noted the value of a '*warm hand-off'* to effectively connect parents to service. They cited effective practices that included having a community champion for screening, free screening for all children, relationships and connections to create formal referral pathways between organizations, liaisons to coordinate hand-offs between screening and referral organizations, and secure funding for screening and intervention (e.g., Title I money).

Lack of familiarity, trust, and relationship were noted as barriers to effective referral. Long distances to specialty providers posed barriers for families with limited access to reliable transportation and little or no public transportation options. Professionals noted the lack of funding for specialty providers (e.g., with expertise in autism, sensory issues, or ADHD) as well as difficulty in recruiting such providers to remote communities.

Improvement in children's outcomes.: Parents reported improvements as a result of services provided after screening, or as a result of guidance they received on what they could do at home to support development. Parents of children with developmental challenges not identified by early screening talked about the negative consequences of the lack of early intervention.

Most professionals said they believed screening improved outcomes for children. Benefits noted included providing important information, prompting discussions between professionals and parents about children's strengths and needs, facilitating the process of linking children to services, supporting significant improvements in behavior and development when children were connected to services, and identifying needs for specific types of services in the community. Professionals unanimously believed the benefits outweigh the risks, as long as professionals can communicate screening results in ways that do not alarm or alienate parents, and as long as the services indicated by a screening result – e.g. further assessment and, if indicated, intervention – are available and accessible in the community. The value of screening was described as potentially limited by an inability to provide information about knowledge and skills that are relevant to AIAN children and their lives. Some professionals described tailoring items they saw as inappropriate or irrelevant for AIAN children, replacing them with relevant wording or examples to ensure that accurate screening.

> *"[There is] a question about compassion and [it] did not fit. I would change names to be people that the [children] knew. I would change things that were in the story. I made up a story about clams. I was consistent about clams because the kids all [knew]. And so, for compassion, I did a horse clam hole in the bottom of the bay because it was summer. The story that they had in [the screener] was irrelevant, and none of our kids could identify with the story in there. So, I changed it and made my own. And I would mark 'yes' because they did understand it. They took the time to help that littleneck clam out of that horse clam hole. Some of the tools just have such a lack of cultural sense, cultural relevancy, or sensitivity or even meaning."* [Professional]

Professionals suggested a need to assess the ability of systems in their communities to support the needs of children. They also indicated that potential harms of screening could be reduced by avoiding or reducing duplicating screening, for example, by sharing screening results across agencies instead of asking parents to repeat screenings. Professionals also noted that a major factor in the ultimate effectiveness of screening is whether parents act on referrals for further evaluation and services.

Relative Benefit of Screening

The analysis of interview transcripts in relation to the *Relative Benefit of Screening* identified themes of *benefits*, *costs and risks*, and *balance* between the two.

Benefits—Participants cited increased communication between parents and professionals about children's development as an important benefit of screening, which allowed them to work collaboratively alongside families to support children. They noted that screening identifies children's needs earlier than might otherwise be recognized and that screening results were useful for informing decisions about kindergarten readiness.

> *"I'm definitely thankful for it. Without it, I'm not sure I would've been able to catch that two of my kids needed extra therapy services."* [Parent]

Costs and risks—The costs of screening shared by participants included burden on families to complete the screeners and professionals associated with the time and resources required to complete, score, and provide feedback about screening.

A risk that concerned participants was that parents might be unduly alarmed by positive screening results (i.e. potential problems), especially when the meaning of a positive screen (i.e., indicating further evaluation but not necessarily a diagnosis) was not communicated appropriately. Potential for false-positive screens due to cultural and contextual misalignment of existing screening tools and overreliance on these tools to the exclusion of other observations of a child amplified this concern.

The negative consequences of labeling children with delays or problems were also seen as a significant risk associated with screening, especially since labels tend to be carried forward through school systems. This labeling was a particular concern given uncertainty over the reliability and validity of existing screening tools for AIAN children and, thus, inaccuracy of these labels. Another risk noted was that parents might be alerted to a need

for early intervention but then not be able access intervention due to lack of resources in the community.

Balance

Almost unanimously, participants responded that the benefits of screening outweighed the risks.

"Really grateful for the screening because I feel like my kids' generation is the first generation to really have this in place, consistently. And uh, I feel like if it's, I feel like if it was around kind of in the past the[n] certain kids could have really benefited from that early screening. Um, so I'm really grateful [that] my kids have had it, that they can take advantage of it. And then all the resources that come with it. It's been a really great experience for my family, so it's good, it's wonderful." [Parent]

Participants suggested that the burden of screening could be reduced by coordinating efforts within communities, avoiding duplication, and sharing results across programs and practices, although challenges with privacy – especially in such tightly connected committees - were acknowledged.

Discussion

Taken together, the findings presented here revealed that developmental screening systems in the AIAN communities surveyed have numerous strengths, but also face challenges. Parents and early childhood professionals provided insights into strategies for addressing those challenges and strengthening early developmental screening in these and other AIAN communities. We heard from both parents and providers that screening was most effective when four key elements were present:

1. parents understood the goals of screening, how screening information would be used, and what to expect in the screening process;
2. parents trusted the people involved in the screening process, as well as in the follow-up assessment and referral process;
3. screening scores were interpreted in the context of culture and other observations of children; and
4. feedback was provided to all parents, regardless of screening results, by trained early childhood professionals.

In response to these lessons, we propose four parallel strategies to enhance screening (detailed below): *Ensure that parents understand screening*; *build trust before screening; consider culture and context in the screening process, interpretation and action; and train early childhood professionals in culturally sensitive screening.* It is notable that these strategies align with key Principles for Assessment articulated in guidance for early childhood practitioners working with Indigenous children half a world away (Māori in New Zealand), namely ensuring that the *purpose is clear*, being mindful that *assessment is not a static process*, building *partnership informed by professional judgement and the family's*

expert knowledge of their child and family circumstances, and remembering that *assessment does not take place in a vacuum* (Ministry of Health, 2013).

Ensure that parents understand screening

Parents who shared positive screening experiences talked about understanding the goals of screening and benefiting from strong relationships with professionals who worked with them to access services. Parents who were fearful of screening worried about how they or their child would be judged, who would see screening results, and whether their children would be taken away from them if problems were identified. Taking the time to provide parents with information about the entire screening process was seen as essential to addressing these fears and help parents feel comfortable engaging in the screening process so they are more likely to complete questionnaires honestly and accurately.

Build trust before screening

Participants explained that screening AIAN children happens within a historical context that continues to shape their lives today. Transparency and trust are not easy to restore given the history of betrayal experienced in AIAN communities, but they are essential to creating partnerships between parents and professionals for effective early screening and intervention. Conversations with parents made it obvious that screening could not be effective without a foundation of trust in the screening process – including trust in the purpose of the screening and trust in the people and institutions involved. Early childhood professionals described their efforts to build trust by taking time to get to know families before engaging in screening activities with them, providing screening feedback regardless of the nature of the results, and using screening as an opportunity to support parents in activities that promote their child's development. Doing so helped make it clear that screening was one component of a partnership dedicated to supporting a child's development rather than an attempt by institutions to identify deficits in a child's development. Across communities, the importance of trust and partnership was emphasized, in screening and also through referral and connection to services (creating a warm hand-off). Communities that had established integrated systems across programs (e.g., Head Start, Home Visiting, healthcare, schools) reported the greatest success in accomplishing this, pointing to the importance of more investment to support such efforts (e.g., initiatives such as the Tribal Early Childhood Learning Initiative funded by the Administration for Children and Families and Project LAUNCH funded by the Substance Abuse and Mental Health Services Administration).

Consider culture and context in the screening process, interpretation and action

Results highlight the importance of considering the results of screening tools in the context of other information available about the child. Screening results should be interpreted with knowledge of the culture the child is embedded within. They should also be interpreted in the context of information provided by teachers, home visitors, and others who know the child. Discussions with parents are also important in interpreting screening results and adding depth to what screening tools provide. The contextualization of screener results is particularly important given the increased potential for false positives using screeners not normed for AIAN children or developed with AIAN child development, culture or language

in mind. Professionals who are familiar with the local community and culture are best poised for interpreting screening results for children in context and working with their families to support evaluation and intervention plans, if appropriate. These professionals could address mistrust by being a continued supportive, empathic presence in the community.

Train early childhood professionals in culturally sensitive screening

We learned a lot from professionals about the strategies they used to screen young children in their communities, share screening results with families, and connect them to needed resources. Tremendous efforts were underway and amazing work was being done. But we also heard that they need more help. Resources are in short supply in many communities, and professionals specifically requested more training in how to best engage parents in the screening process, communicate results to them, and ensure successful transition to services when needed.

Despite the desire for more training, many professionals also noted the lack of time for it, and for screening. As is typical in many AIAN communities, resources are stretched thin and early childhood professionals are overworked. As noted earlier, returning screening results only when a concern was often attributed to lack of time and resources. This means that a crucial opportunity for positive parenting feedback or sharing extra knowledge with families is then missed, making screening more problem-focused than strengths-based and increasing parents' reticence to engage in the process.

Suggestions to interpret screening results in the context of other information, including the cultural context of children and families, may sound simple enough on the surface. But these are complex and time-intensive tasks. They require professionals to understand the screening score itself at a deeper level, to understand what goes into that score, and to embed that score within an array of other information about the child. It also requires professionals to identify culturally inappropriate questions and to tailor such questions to make them appropriate without undermining the integrity of the measure itself or rendering overall scores uninterpretable. This is a sophisticated task, beyond the scope of what most early childhood professionals are prepared to do. Because screening tools are not validated for AIAN children, professionals working with these children are being asked to do a more complex task than their colleagues working with other populations (who can take those screening scores more at face value). Teachers, home visitors, childcare workers, pediatricians, nurse practitioners, and other early childhood professionals need guidance for this complex task.

Action Steps

Resources for communities—With the goal of taking first steps toward improving screening, we created two resources to share with parents and early childhood professionals in AIAN communities (see Appendices 1 and 2). These resources summarized study findings and practical recommendations that emerged from them. These resources were created upon the recommendation of the CoL with the goal of returning findings to AIAN communities in ways that actionable steps could be taken – in this case, by providing guidance to both parents and professionals for making screening processes more effective.

The first resource was designed for early childhood professionals (see Appendix 1): *Partnering with American Indian and Alaska Native Families to Support Children's Development.* This resource outlines actionable strategies for working with parents for effective screening and follow-up. It is designed to provide guidance on preparing parents and other family members for screening, following through with them to provide screening results, and helping families navigate referrals to resources, if needed.

The second, companion resource was designed for parents and other family members raising young children (see Appendix 2): *Supporting your Child through Developmental Screening from Birth to Age Five.* This two-page document was designed to be shared with families before screening begins, as a concrete tool for early childhood professionals to use in conversations with parents and families. The goal is to facilitate better understanding of the purpose of screening and to provide guidance for completing screener questionnaires.

Research to validate screening tools—It was clear from our conversations with both parents and providers that approaches to screening in Tribal communities ranged from collaborative in-person screening to online independent screening. Consistent with the initial guidance from the CoL, it will be important to understand the reliability and validity of screening results under these different administration scenarios – as they are used in practice. Future research should examine the concurrent validity of screeners administered through these different approaches and thus provide guidance on how to use existing tools most effectively.

Limitations

The findings reported here were drawn from interviews with parents and early childhood professionals in only four communities. Although these communities were strategically selected to represent different types of AIAN communities, they nonetheless represent a very small sample of the many Tribal communities throughout the country. Across these four very different communities, however, we heard very similar themes; thus, we believe findings are likely generalizable to other AIAN communities.

The questions we asked of parents and professionals were based on the Tribal PEDS conceptual framework. While these questions broadly queried multiple aspects of the screening process, reliance on that framework may have constrained what we heard from participants.

The COVID-19 pandemic precluded us from returning to partner communities in person to share study findings and gather input on the meaning of findings. While we were able to share back with program partners using virtual platforms, this likely limited the amount of feedback we received and, therefore, the integration of community perspectives into our interpretation of findings.

Conclusion

The appropriateness of existing developmental screeners for use with AIAN children – and with other racially and ethnically diverse and Indigenous children more broadly – has

been questioned for some time, both by researchers and communities. Very few studies have explicitly addressed this concern, however, or tried to identify feasible ways to ensure accurate screening. This study expanded the focus beyond questions about the validity of screening measures alone to understand screening *processes* more broadly, including the ultimate value of screening for supporting children's development. Important contextual and historical factors relevant to AIAN children and families emerged as important in these processes, and this study illustrated the central value of community-based research in furthering scientific knowledge. As the dominance of measures normed on Western populations continues, this study provides important insights into community perspectives and the potential risks and benefits of screening with imperfect tools, and provides guidance for practitioners and those designing screening interventions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Relevance and Key Findings

Key findings suggest that early developmental screening of AIAN children can be enhanced by (1) improving education for both parents and professionals about the goals of screening and the screening process, (2) building trust between parents and professionals conducting screening, and (3) considering cultural context in interpreting and acting on results of screening.

Improving screening for AIAN children is critical for creating equity in early intervention and has the potential to significantly improve health and developmental outcomes for these children.

Diversity and Anti-Racist Scholarship

This study was grounded in a deep appreciation for diversity and employed an anti-racist approach with implications for equitable policy and programming. The study was led by a Community of Learning (CoL) comprised of Native and allied researchers with expertise in Tribal early childhood development partnering with early childhood practitioners from diverse Tribal communities and cultures, including those where the data for this study were gathered. CoL members collaborated to develop the conceptual framework that guided the study, identify study questions, design study protocols, and interpret findings. Informed by Indigenous research methodologies (Smith, 2021), this study was driven by a commitment to ask questions prioritized by Indigenous communities and develop research strategies in collaboration with community partners. Knowledge gained was shared with communities, with an emphasis on practical application, to support positive outcomes for Native communities, advance practitioners' knowledge, and foster community development.

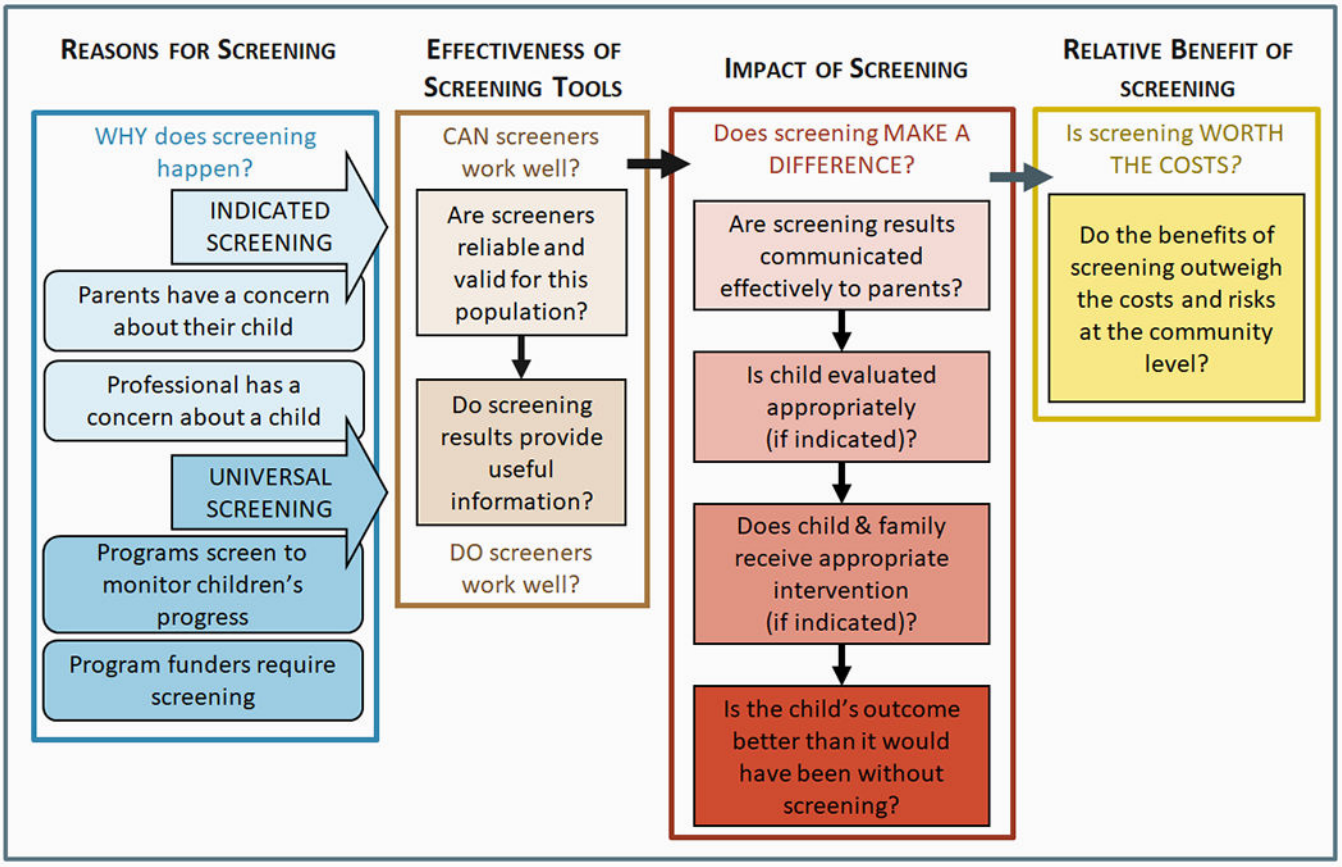

Figure 1.
Conceptual Framework of Screening Systems

Table 1.

Tribal PEDS community partners and sample[1]

Partner	Region	Community Type	Program Type	Focus Groups	Interviews	Participants
1	Pacific Northwest	Reservation	Tribal Head Start	5	20	46
2	Midwest	Rural	Tribal Behavioral Health	5	13	34
3	Pacific Northwest	Urban	Tribal Home Visiting	5	11	33
4	Alaska	Rural	Tribal Head Start	8	9	44
Total				23	53	157

[1]Out of respect for community confidentiality at the participating sites, and in accordance with research protocols approved by those partner sites, we do not provide specific identifying information.

Table 2.

Summary of themes from focus groups and key informant interviews

Framework Component	Key Themes	Subthemes
Reasons for Screening	Motivations for screening	Universal screening
		Indicated screening
	Typical screening practices	Common screeners
		Screening rates
	Context for AIAN children's development	Contextual factors influencing AIAN children's development
		Historical trauma and AIAN children's development
		Cultural influences on AIAN children's development
	Health and developmental concerns among AIAN children	
Effectiveness of Screening Tools	Effectiveness of administration strategies	Screening methods
		The importance of trust
	Trustworthiness of screening tools	Overall accuracy of commonly used screeners
		Concerns with appropriateness of specific screener items
		Screeners as only one of many sources of information
	Interpretation of results in the context of culture	
	Preparedness of the screening workforce	
Impact of Screening	Communicating screening results to parents	Approaches to providing feedback
		Parent preferences for receiving feedback
		Effectively community screening results
	Referrals and resources for evaluation and services	Availability of resources
		Barriers to accessing referrals and resources
	Improvement in children's outcomes	
Relative Benefit of Screening	Benefits	
	Costs and risks	
	Balance	