Pilot Exploration of Developmental Screening in Tribal Communities
(Tribal PEDS)

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Background

Efforts are underway across the U.S. to identify young children with developmental challenges. These include *Birth to 5: Watch me Thrive* (Administration for Children and Families; https://www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive) and *Learn the Signs. Act Early* (Centers for Disease Control; https://www.cdc.gov/ncbddd/actearly/index.html). The goal of these efforts is to connect children with early intervention services, which support positive developmental outcomes. American Indian and Alaska Native (AI/AN) children, however, have not fully benefited from these efforts. One reason may be that common screening tools have not been confirmed to work well for AI/AN children. Communities use these tools because they don't have other options, but often remain skeptical of the results. Communities may also lack systems of support for children who need services. Ensuring effective developmental screening for AI/AN children requires a better understanding of both screening tools and systems of screening and intervention in tribal communities.

In 2017, the Tribal Early Childhood Research Center (TRC) assembled a group of early childhood program partners from AI/AN communities, academic researchers, and federal funding partners – a *Community of Learning (CoL)* – to design a study to better understand screening tools and systems for AI/AN children. This CoL launched the *Pilot Exploration of Developmental Screening in Tribal Communities (Tribal PEDS)* with two aims. The first aim was to explore screening systems and processes in AI/AN communities. The second aim was to pilot methods for collecting screening data on a large sample of young AI/AN children (6 months to 5 years of age), to inform a larger study to assess how trustworthy current screening tools are for these children.

What we Did

Aim 1: We used interviews and focus groups to learn from families and professionals (N=157) about early developmental screening in AI/AN communities. We talked to people in four AI/AN communities (one urban, two rural, one reservation). See Aim 1 Methods for more detail.

Aim 2: We tested methods for collecting screening data online for AI/AN children 6 months to 5 years. We partnered with the same four communities we worked with for Aim 1 to recruit families to complete online screeners about their children. A total of 240 people began the process; 157 had an eligible child, 62 consented to participate, and 39 completed the survey. See Aim 2 Methods for details.

What we Found

Aim 1: We learned about both challenges and successful approaches for screening young AI/AN children and for connecting them to services. Findings suggested priorities for effective screening efforts: (1) *intentionally building trust* among professionals and families, (2) *educating families* about screening, (3) *considering culture and context* in interpreting screening results, and (4) *enhancing training for early childhood professionals.* See Aim 1 Results for detailed findings.

Aim 2: We learned about key barriers to collecting online screener data from a large sample of families with young AI/AN children. A study to validate screening tools for AI/AN children will require strong partnerships with local programs to help recruit participants and provide feedback to families. Detailed findings are presented in Aim 2 Results.

Why our Findings Matter

Identifying developmental challenges early in a child's life can be critical to providing support for successful development and a good and healthy life. Gaps in current systems can leave some AI/AN children without the screening, assessment, and services they need. Current measures for screening young children are not necessarily appropriate for AI/AN children, interpretation of results without an awareness of culture and context can hamper the effectiveness of screening, and distrust of screening in tribal communities can prevent families from obtaining needed services to support their children's development. Lessons from listening to both families and early childhood professionals in AI/AN communities suggested strategies for enhanced and more effective screening to support better outcomes for AI/AN children (see Aim 1 Discussion for the overview of what we learned).

Better information about how trustworthy existing screening tools are for use with AI/AN children will also be critical to improving screening efforts. The Aim 2 Discussion section highlights what we learned in this study than can inform future research to understand how well these tools work with this population.

Finally, what we learned in both Aim 1 and Aim 2 have Research, Practice, and Policy Implications, which are summarized at the end of this report.

How we are Sharing Findings with Communities

To make Aim 1 findings accessible and practical for families and early childhood professionals in AI/AN communities, we created a pair of resources that we are sharing with partner communities and disseminating more broadly through the TRC. A resource we developed for early childhood professionals is included at the end of this report, in Appendix C: Partnering with American Indian and Alaska Native Families to Support Children's Development. The companion resource we created for families, to help explain the purpose and process of screening, is in Appendix D: Supporting your Child through Developmental Screening from Birth to Age Five.

INTRODUCTION

The Tribal Early Childhood Research Center (TRC) conducted a study in 2013-2014 to understand the perspectives of parents[1] and early childhood professionals[2] in American Indian and Alaska Native (AI/AN) communities on early developmental screening of children (Whitesell, Sarche, & Trucksess, 2015). In that study, we examined both broad attitudes toward screening and specific beliefs about the appropriateness of the Survey of Well-being of Young Children (SWYC) for AI/AN children, families, and early childhood programs. The goals, design, interpretation, and dissemination of that initial study, *the SWYC study,* were guided by a Community of Learning (CoL). The CoL was a group of research partners comprised of TRC researchers, AI/AN early childhood program partners (e.g., Head Start, Tribal MIECHV, and Child Care program directors), academic researchers with expertise in AI/AN early childhood, and federal funding partners (e.g., Administration for Children and Families [ACF] staff).

With the guidance of the CoL, the SWYC study included interviews and focus groups with community members in seven tribal communities. These interviews provided rich information about screening in diverse AI/AN settings around the country. While the findings provided important insights, they also led to new questions. In particular, they pointed to the importance of further examining the validity and utility of existing developmental screeners for AI/AN children. Thus, in 2017, the TRC reconvened and expanded the CoL with the goal of piloting methods for a validation study of existing developmental screeners commonly used with AI/AN children. This second study, the topic of this report, was dubbed the *Pilot Exploration of Developmental Screeners in Tribal Communities*, or *Tribal PEDS*.

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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).

Challenges for Early Screening Initiatives with AI/AN Children

Initiatives such as "*Birth to 5: Watch me Thrive*" (Administration for Children and Families, 2015) *and* "*Learn the Signs. Act Early*" (Centers for Disease Control and Prevention) have been developed to expand early childhood developmental screening in the U.S., with the goal of universal screening to identify all children with developmental needs before they enter kindergarten and connect them to services to support positive developmental outcomes. Unfortunately, the reach of such early screening efforts into tribal communities has been uneven. Challenges to screening in these contexts are complex. One critical barrier lies in the fact that the validity of existing early childhood developmental screening instruments has not been established for AI/AN children, and the lack of face validity of many of these instruments for the cultures and contexts of many AI/AN families often causes parents and early childhood professionals to question their usefulness (Whitesell et al., 2015). With no other options, however, these instruments are used, both in response to the need to screen children when concerns arise and to meet program requirements, but with little confidence.

This current state of practice poses many problems for gauging the scope of early child development needs in tribal communities, identifying needs for early childhood intervention services in tribal communities, appropriately referring AI/AN children for those services, and establishing trust for early developmental screening and intervention services in tribal communities (Whitesell et al., 2015). Decisions are made about AI/AN children and services are provided – or not provided – based on potentially inaccurate screening. The lack of information about appropriate assessment of early development among AI/AN children can result in the failure to detect early problems, allowing them to escalate without early intervention. Labeling children based on cultural or contextual variation as developmentally at risk can result in inappropriate intervention and potential harm and stigmatization (Whitesell et al., 2015).

The challenges do not stop with measurement issues, however. Many reservation, rural, and urban tribal communities lack resources (personnel and financial) to screen all children. When children are screened, resources for some developmental diagnosis and intervention may be even scarcer. Complex networks of tribal, federal, state, county, and sometimes private services vary widely across diverse AI/AN communities (Freeman, Iron Cloud-Two Dogs, Novins, & LeMaster, 2004; Gone & Trimble, 2012; Novins & Bess, 2011; Novins, Fleming, Beals, & Manson, 2000; Whitesell et al., 2015). Thus, ensuring the broad reach of developmental screening in these contexts will require a nuanced understanding of existing systems and how these systems can be leveraged to meet the needs of young children. This became very clear in discussions with the Tribal PEDS CoL as we worked to design the validation study pilot in 2017 and tribal partners expressed the need to better understand how screening works *in practice* in their programs and communities, not just how well screening tools themselves work.

EXPANDING PREVIOUS TRC WORK

As noted in the Introduction, an earlier study conducted by the TRC explored the potential utility and appropriateness of one early childhood developmental screening instrument, the SWYC, for use with AI/AN children (Whitesell et al., 2015). That qualitative study engaged tribal community stakeholders in a broader discussion of the need for early developmental screening in AI/AN communities, and more narrowly on the feasibility of using the SWYC in particular in these communities and the appropriateness of the SWYC for AI/AN cultural contexts. The CoL that guided the SWYC study was instrumental in shaping the questions we asked and how we interpreted the responses. A detailed report of that study is available in the publication, but we review key findings here because they laid the foundation for the Tribal PEDS study.

In the SWYC study, focus groups and individual interviews were conducted with 199 participants from both rural and urban tribal communities in the Midwest, Southwest, Southeast, Pacific Northwest, and Alaska. Participants represented parents; a range of tribal early childhood professionals, including pediatric health care providers; tribal Head Start, Home Visiting, and Child Care program staff; and mental health providers, and tribal government leaders and elders.

Participants reported a strong need for early screening in tribal communities due to the myriad challenges to healthy early child development that AI/AN children and their families encounter. Participants also noted important gaps in parental knowledge about child development, significant barriers that make early screening difficult in tribal communities, and insufficient resources for early intervention with AI/AN children.

Key themes that emerged in the SWYC study included those related to the process of early childhood screening, including the need to simplify screening, better engage parents in the process, incorporate Native language into the screening instruments, use appropriate providers and service settings, share screening findings across programs serving families, and better use screening results to make referrals to early intervention services when appropriate.

Another theme was related to the content of the specific screening tool, the SWYC (but also to screening tools in general). Issues related to this theme included the comprehensiveness of the instrument, the availability of appropriate norms for AI/AN children, the alignment of developmental milestones with the cultural context, and the negative wording of items.

Tribal PEDS Conceptual Framework

As noted earlier the recommendations that emerged from the SWYC study set the stage for the Tribal PEDS study, and the CoL that guided the SWYC study was expanded to become the PEDS CoL. The CoL is comprised of partners in academia and in tribal early childhood programs (Tribal Head Start and Early Head Start, Home Visiting, and Child Care) who share an interest in both screening and measurement issues.

We began conversations with this CoL with the goal of designing a study to pilot strategies for validating existing developmental screeners in common use by tribal early childhood programs. As we engaged in conversations around what such a study design would look like, program partners pushed us to make sure that the *way* screeners were collected in the validation study would reflect the way they are collected in practice in communities, rather than following a rigid scientific protocol. They were clear that validating screeners using a protocol that could not be followed in practice in community would not provide information that would be of use to them. What they need, they insisted, is *information on the validity of screeners as they are actually used.*

This contribution by program partners on the CoL caused us to pivot as a group and rethink the key questions we were asking – and to ask larger questions about systems of screening, about where and how screening instruments are used within the communities who care for young AI/AN children. We began to ask critical questions about how screening tools are used as part of "bigger picture" information parents and professionals have about children and what happens with the results of screening after it occurs. Over the course of several months of discussions with the CoL, it became clear that a shift in goals for the Tribal PEDS study was appropriate.

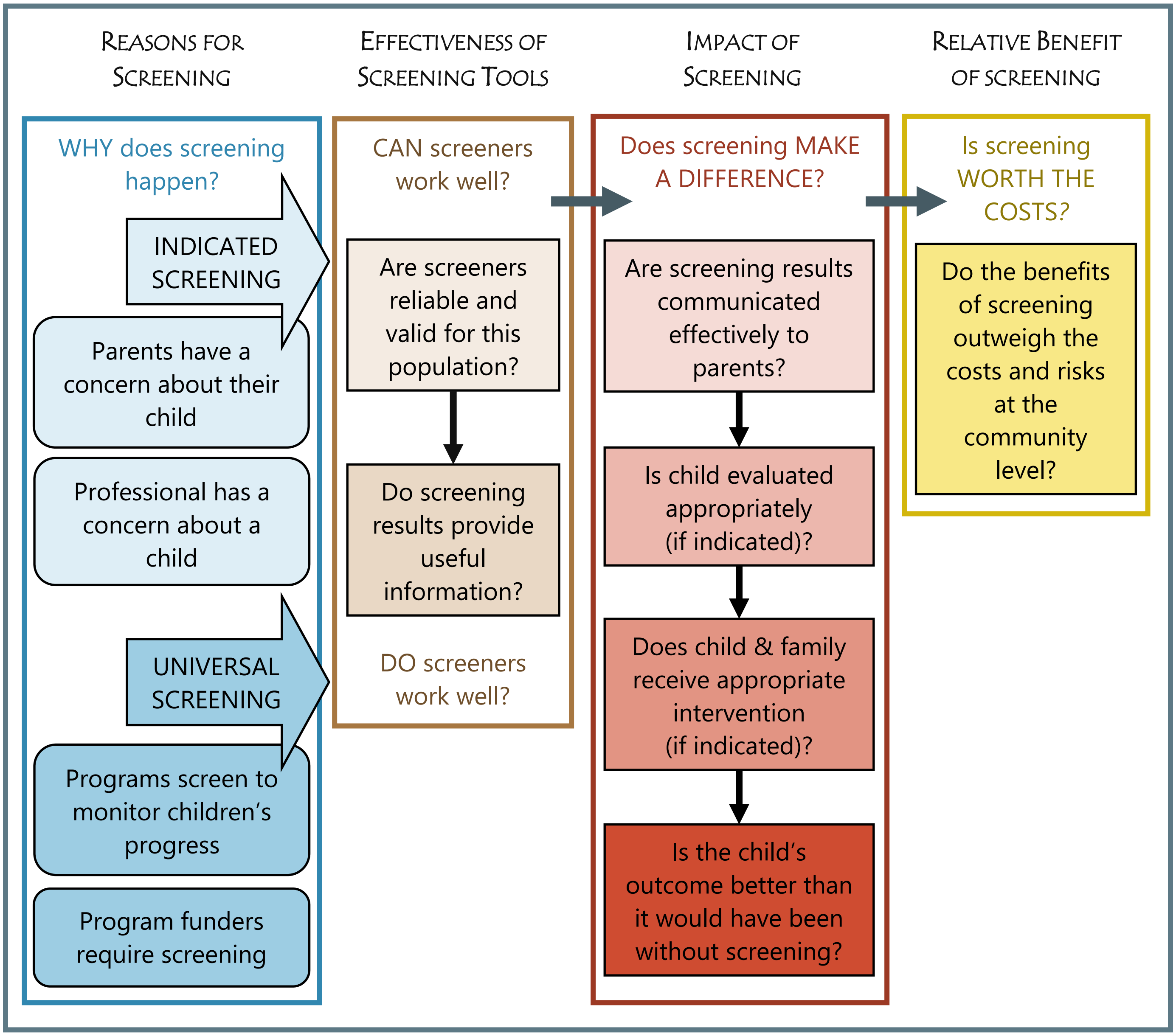
Rather than narrowly focusing on piloting methods to validate existing screeners, the CoL challenged us to take a broader view and to examine *systems* of screening in AI/AN communities and to consider how developmental screening tools operate within those systems. The CoL consulted with researchers with expertise in developmental screening (most notably, Ellen Perrin and Chris Sheldrick, creators of the SWYC), looked to the broader research literature on screening and diagnosis, and created a conceptual framework to guide the Tribal PEDS study. This framework, shown in Figure 1, draws heavily on medical screening and diagnosis work (Fryback & Thornbury, 1991) and a report by the Institute of Medicine (National Academies of Sciences, 2015). These frameworks from the medical literature highlight important questions about the ultimate value of screening in relation to improving outcomes for children. In application to early developmental screening, the ultimate goal is to support positive outcomes for children; screening itself is just one step in the process toward that goal. The Tribal PEDS conceptual framework, drawing on Fryback and Thornbury most directly, shifted the focus of screening to a *process* rather than a discrete *event* and raised key questions to consider.

With the foundation of this conceptual framework, the Tribal PEDS study was expanded to both examine screening systems and the feasibility of utilizing online data collection for validation of screeners for AI/AN children. The aims of the study thus emerged as:

1. Explore screening systems and processes in AI/AN communities through a qualitative study with parents and early childhood professionals in a small number of diverse tribal communities.
2. Pilot methods for collecting quantitative screening data on a large sample of AI/AN children 6 months to 5 years of age.

With Aim 1, we sought to gather information about how systems of early screening currently operate within and across tribal communities. We conducted interviews and focus groups with both parents and early childhood professionals about screening processes in their communities.

Figure 1. Tribal PEDS Conceptual Framework



With Aim 2, we piloted methods for effective and efficient data collection for a validation study, with the goal of informing the design of a future validation study to answer the narrower question within the framework: “Can screeners work well?” This is the validity question that originally led us into this work. It reflects the concern we have heard from many community partners that existing screening tools may not be able to validly screen their children, that the answer to this question is “no”. Valid screening tools are pivotal to screening systems working well; while the systems framework makes it clear that good tools alone are not enough, good tools are nonetheless critical. Thus, although we shifted to the larger systems framework, we did not lose sight of the original goal of validating early childhood development screeners for AI/AN children.

Tribal PEDS Partner Sites

The TRC and the CoL partnered with four early childhood programs to gather data for this study. These sites were selected from among existing TRC partners to represent different types of communities, regions of the country, and program types (Table 1). TRC research team members conducted site visits in each partner community between November 2018 and April 2019. During each visit, TRC team members provided partner program staff with tailored training on early childhood developmental screening and conducted data collection activities, including (1) key informant interviews and focus group discussions with early childhood professionals and parents (Aim 1) and (2) recruitment of parents to complete online screeners (Aim 2). Details on methods and results for each Aim are provided in the sections that follow.

Table 1. Tribal PEDS Community Partners

Site	Region	Community Type	Program Type
1	Pacific Northwest	Reservation	Tribal Head Start
2	Midwest	Rural	Tribal Behavioral Health
3	Pacific Northwest	Urban	Tribal Home Visiting
4	Alaska	Rural	Tribal Head Start

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).

AIM 1: EXPLORE SCREENING SYSTEMS AND PROCESSES IN AI/AN COMMUNITIES

Methods

Data Collection

Prior to site visits, the TRC Tribal PEDS study team worked with each partner site to identify and schedule parents and early childhood professionals for key informant interviews or focus groups about their experiences with early childhood developmental screening in their community. We completed a total of 53 interviews and 23 focus groups in the four partner communities, talking with a total of 157 individual participants (Aim 1: Table 1). We conducted 18 interviews and three focus groups with parents and 35 interviews and 20 focus groups with early childhood professionals. Each participant received a $25 gift card from a vendor identified in coordination with the partner community as most useful for local families (e.g., Walmart, Target, Amazon).

Aim 1: Table 1. Sample

Partner Site	Number of: focus groups	interviews	participants
1	5	20	46
2	5	13	34
3	5	11	33
4	8	9	44
Total	**23**	**53**	**157**

TRC research staff worked in pairs to conduct interviews and focus groups during site visits, either at the partner facilities or at other community locations arranged in collaboration with local partners and convenient to participants (e.g., at doctor's offices or locations of partner programs in the community). One team member conducted each interview using a structured guide while a second team member took notes to capture key points from the discussion. Each session was digitally audio recorded with the permission of participants. At the conclusion of each site visit, TRC research staff debriefed about common and emergent key themes across interviews.

Interview guides were developed directly from the Tribal PEDS Conceptual Framework, with questions addressing each of the four panels shown in Figure 1:

1. Reasons for screening
2. Effectiveness of screening tools
3. Impact of screening
4. Relative benefit of screening

Within each of these broad categories, a series of specific questions and probes were included to elicit experiences with different aspects of screening systems and processes within their community.

Interview guides for key informant interviews and focus groups were identical, but different sets of questions were created for parents and early childhood professionals, given their different perspectives on screening. Complete interview guides are attached in Appendix A (early childhood professionals) and Appendix B (parents).

It is important to note that 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.

Data Analysis

ATLAS.ti 8 software was used for data management and for coding transcripts. Three members of the TRC research team worked together, using the interview guides to generate a set of initial codes and create a codebook. This analytic team then independently coded all transcripts, meeting weekly to review coding questions and resolve discrepancies. A consultative and reflexive team analysis approach was followed to reach consensus on analytic methods (Krueger, 1994). A coding protocol was created and frequently updated as decisions were made about specific codes and rules for coding practices. The protocol defined and documented examples of when to use specific codes; detailed procedures for coding when text involved multiple codes or when it involved codes from both professional and parent code groups; and added a *revisit* code, defined as noteworthy text which didn't fit under existing codes. This document assured that analysts had a systematic, readily available protocol that could be referenced throughout coding.

Coding was completed in two cycles. *Cycle 1* was *structural coding* based on the topics of inquiry in the parent and professional interview and focus group guides. During this cycle, additional codes were developed to identify novel findings not yet reported in the literature.

Cycle 2 coding involved *identifying key themes* from coded transcripts and developing recommendations about best practices for early childhood 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), including 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).

Once the two coding cycles were completed, key themes were organized into topical categories related to each of the overarching questions embedded within Figure 1 (i.e., reasons for screening, effectiveness of screening tools, impact of screening and relative benefit of screening).

Results

Interviews and focus groups resulted in detailed information about systems of screening from the perspectives of both parents and early childhood professionals. Key themes that emerged in coding, organized by topical categories, are presented for each panel in the conceptual framework (Figure 1): (A) reasons for screening, (B) effectiveness of screening tools, (C) impact of screening, and (D) relative benefit of screening. Aim 1: Table 2 lists key themes within each of these topical categories. Aim 1: Table A-1 through D follow, summarizing findings related to each major theme identified within each section and providing illustrative quotes and examples. Many themes incorporated comments across discussions with both parents and professionals; comments primarily associated with one type of participant are noted in the tables. Quotes from individual participants are identified as parent or professional.

Aim 1: Table 2. Summary of themes from interviews and focus groups

A. Reasons for Screening	**Motivations for screening (Aim 1: Table A-1)** Universal screening Indicated screening **Typical screening practices (Aim 1: Table A-2)** Common screeners Screening rates **Context for AI/AN children's development (Aim 1: Table A-3)** Contextual factors influencing AI/AN children's development Historical trauma and AI/AN children's development Cultural influences on AI/AN children's development Health and developmental concerns among AI/AN children
B. Effectiveness of Screening Tools	**Effectiveness of administration strategies (Aim 1: Table B-1)** Screening methods The importance of trust **Trustworthiness of screening tools (Aim 1: Table B-2)** 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 (Aim 1: Table B-3)** **Preparedness of the screening workforce (Aim 1: Table B-4)**
C. Impact of Screening	**Communicating screening results to parents (Aim 1: Table C-1)** Approaches to providing feedback Parent preferences for receiving feedback Effectively community screening results **Referrals and resources for evaluation and services (Aim 1: Table C-2)** Availability of resources Barriers to accessing referrals and resources **Improvement in children's outcomes (Aim 1: Table C-3)**

D. Relative Benefit of Screening	**Relative benefit of screening (Aim 1: Table D)** Benefits Costs and risks Balance

A. Reasons for Screening

Three categories of responses emerged in response to questions about reasons for screening young children in their communities: (1) motivations for screening (Aim 1: Table A-1), (2) typical screening practices (Aim 1: Table A-2) and (3) the context for AI/AN children's development (Aim 1: Table A-3).

B. Effectiveness of Screening Tools

The analysis of responses to the set of questions related to the second panel in Figure 1, regarding the effectiveness of screening tools for use with AI/AN children, resulted in the identification of four key categories: (1) effectiveness of administration strategies (Aim 1: Table B-1); (2) trustworthiness of screening tools (Aim 1: Table B-2); (3) interpretation of results in the context of culture (Aim 1: Table B-3); and (4) preparedness of the screening workforce (Aim 1: Table B-4).

C. Impact of Screening

Themes that emerged regarding the impact of screening were: (1) communicating screening results to parents (Aim 1: Table C-1); (2) referrals and resources for evaluation and services (Aim 1: Table C-2); and (3) improvement in children's outcomes (Aim 1: Table C-3).

D. Relative Benefit of Screening

The analysis of interview transcripts in relation to the final panel of Figure 1, concerning the question of the benefits of screening vis-à-vis the costs and risks associated with it, are summarized in Aim 1: Table D.

Aim 1: Table A-1. Key findings, illustrative quotes, and examples related to motivations for screening

Key Findings	Illustrative Quotes and Examples
Universal screening	
Substantial screening was reported in line with requirements of Home Visiting, Head Start/Early Head Start, and Child Care programs.	*“We got to do screening because the funding says we have to do screening. So, we're going to screen everyone.”* [Professional]
Timing of screening was linked to programs (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 routinely repeat screening, some repeat only if indicated by initial positive screen.	
Screening at well-child visits, by physicians or other healthcare providers, was most often mentioned at Site 2 (where program partner was in a healthcare system), although noted across sites.	*"I understood that [screening] was, there was a way for us to know how to meet her needs, her specific needs and her development, socially and emotionally and cognitively. And you know, the things that we might need to work on with her more, such as, if she can't kick a ball, you know, start rolling the ball, showing her how to do it."* [Parent]
Lack of specialist providers for young children, including pediatricians, was often noted, but healthcare providers interviewed described active screening efforts.	
Some parents expressed frustration at being asked to repeat screening in both early childhood programs and in healthcare settings.	

Indicated screening	
Screening in response to parent or professional (usually teacher) concerns was noted in all communities, in addition to routine screening.	*"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]
Listening to parents' concerns was noted as critical: "*parents are the experts on their child*"; professional participants emphasized that parents' observations, opinions, and intuitions about children are critical to identifying problems early.	
Parents reported being relieved when screening confirmed their children were developing well - and when their concerns were validated through screening.	*"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]

Return to *Reasons for Screening*.

Aim 1: Table A-2. Key findings related to typical screening practices

Key Findings
Common screeners
The most common screeners reported in use in the communities 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, Home Visiting, or Child Care were estimated to be high (75-100% at one site); estimated rates of screening for children outside of early childhood programs were much lower, ranging from 10-50%.
Screening at well-child check-ups was also estimated to be common, although participants noted that many families do not have access to regular well-child visits, e.g., due to lack of providers in the area or lack of resources.
Screening through public health departments, health organizations, and private preschools was noted but was not generally seen to be reaching high percentages of children.
Parents refusal to participate in screening was sometimes noted as a barrier to screening.

Return to *Reasons for Screening*.

Aim 1: Table A-3. Key findings, illustrative quotes and examples related to context for AI/AN children's development

Key Findings	Illustrative Quotes and Examples
Contextual factors	
Contextual factors noted as contributing to developmental risk included exposure to stress and trauma, family disruption (e.g., due to death, incarceration, or suicide), environmental risk (e.g., family or community substance-use problems, poverty, housing instability and overcrowding, broader health inequities, isolation), and the lack of early childhood services.	*"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 pervasive trauma in some AI/AN communities was seen as potentially dulling the perception around normative child behavior; parents might see problematic behavior as normal in such contexts.	
Concern was expressed that children exposed to frequent traumas and stressors may not have basic needs met and, as a result, would be at risk for developmental delays and poor health outcomes.	*"[Trauma] is the norm in Native communities."* [Professional]
Historical trauma	
Historical trauma was also noted as impacting young children's development, as AI/AN communities continue to experience the impacts of federal assimilation policies (e.g., forced boarding schools, relocation); participants noted disrupted family structures and parenting practices.	*"[T]here is a traditional healer in the community and there is not enough of her to go around."* [Professional]

Cultural influences	
AI/AN culture was viewed as having a positive impact on children’s development; participants mentioned that very young children in their communities have a sense of pride of 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 in balancing risk for children in the face of contextual challenges and the legacy of historical trauma. Participants emphasized the importance of elders and of children learning their Native languages.	
Health and developmental concerns among AI/AN children	
Most frequently cited child health and development concerns were ADHD and autism; others noted were asthma and other respiratory issues, food scarcity (and resultant nutritional deficiencies), poor oral health, social-emotional and behavioral concerns, sensory issues, speech and language delays, and PTSD.	
Participants expressed concerns about the impact of increased technology use (e.g., cellphones) on children's development, through reduced face-to-face interaction; disrupted language development was frequently mentioned.	*“Smartphones are replacing conversations, interrupting family dinners, and opportunities for children to learn language.”* [Professional]

Return to *Reasons for Screening*.

Aim 1: Table B-1. Key findings, illustrative quotes and examples related to effectiveness of administration strategies

Key Findings	Illustrative Quotes and Examples
Screening methods	
Both online systems and paper forms were common for screening; some communities and programs reported heavy use of online screening and others relied mostly on paper tools.	"*It's 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]
Independent Screening (parents completing screening forms on their own, either online or on paper) was common. • Parents' positive comments about *Independent Screening*, particularly online screening included appreciation for the ability to complete the screeners wherever and whenever they wanted, which was helpful given their busy lives with young children. • Parents' concerns about *Independent Screening* were that they sometimes didn't know how to answer questions, would have liked to consult with their child's teacher, sometimes rushed through the screening to get it done, and worried that online screening, in particular, might not pick up potential problems.	
Collaborative Screening (parents completing screening forms together with an early childhood professional) was also common. • Parents' positive comments about *Collaborative Screening* included being able to ask for clarification of confusing questions and get professional's input about children's behavior to support accurate responses. Other advantages mentioned included literacy support, relationship building, opportunities to discuss the screening process and value of screening, and opportunities to seek guidance on supporting child development. • Parents' concerns about *Collaborative Screening* were mostly about making time for the process and 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' positive comments about *Collaborative Screening* were that screening should be conducted in a personal, private setting with a familiar, trusted individual; that parents become more receptive to screening and come to value screening as they develop familiarity and trust with a child care professional; in-person screener administration was seen as helping parents understand screener questions, supporting more accurate responses, and providing opportunity for professionals to probe for information about the context of children's behavior.	
The importance of trust	
Who administers screeners was seen to be more important than *how* screeners were administered.	*"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]
Many parents expressed fear about how screening results would be used by systems and providers (including permanently labeling children) and had concerns about disclosing information.	
A trusted relationship was noted as critical to receptivity to screening and appreciation of the value of screening.	*"Don't make me a statistic."* [Parent]
Opportunities for conversation that emerge around screening—particularly in-person screening—were also noted as important for transparency in screening and feedback, which parents said helped alleviate their anxiety and take 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]
Providing feedback to parents about screening, regardless of the outcome, was critical to trust; parents expressed frustration when they did not receive feedback and said they were left 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]

Return to *Effectiveness of Screening Tools*.

Aim 1: Table B-2. Key findings, illustrative quotes and examples related to trustworthiness of screening tools

Key Findings	Illustrative Quotes and Examples
Overall accuracy of commonly used screeners	
Screeners were seen to be working well for children in these communities.	
Most participants said cutoffs were appropriate and systematic patterns of either false negatives or false positives were not noted; participants 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).	
Sensitivity of screeners was seen as acceptable, to identify potential problems for further evaluation. Parents expressed some concern that screening might not be sensitive enough.	
Parents admitted that they sometimes rushed through screeners and that this could make results less accurate; both professionals and parents noted that some screeners were very long and overwhelming to complete.	"*[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 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 screener items raised concerns within the cultures and contexts of communities. Examples included:	• 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 Head Start classroom about the community coming together for a seal hunt to provide food, and noted how this cultural practice is at odds with social-emotional screening “red-flags” about harming animals. • Young children learning Native languages alongside English (or before English) were seen as disadvantaged in screening focused narrowly on English language acquisition.
In 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 when used among children who were, in fact, exhibiting advanced and culturally appropriate behavior.	
Some questions were seen to be too specific (e.g., whether child could cut a square with scissors); others were confusing for parents (i.e., whether or not a child could do a particular thing depended on too many factors, such as whether or not he was tired, so parents said they didn't know how to answer).	"*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]
Some questions asked about children's ability to interact with objects or opportunities that parents noted were limited in their communities (e.g., walking up a staircase when stairs were uncommon in their location).	

Participants also noted that the young AI/AN children encounter conflicting messages about appropriate behavior—within their tribal culture and within 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 parent's observations (beyond those captured on screeners) along with observations of teachers, home visitors, childcare providers, and other early childhood professionals, was noted as 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]

Return to *Effectiveness of Screening Tools*.

Aim 1: Table B-3. Key findings, illustrative quotes and examples related to interpretation of results in the context of culture

Key Findings	Illustrative Quotes and Examples
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 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 around children and parenting influence children's development and, thus, responses to screeners.	
Screening and subsequent interventions were seen by some as tools of colonization, described as attempts to acculturate AI/AN children, forcing AI/AN 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 mom and his [family] from his mom's side, 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 my side, or his dad's 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]

AI/AN children have a rich array of experiences not represented on standard screening instruments and are sometimes not exposed to the experiences measured on those instruments; concerns were raised that AI/AN children could appear to be lagging behind simply because the wrong questions are being asked. Some examples noted by participants included:	• A question asking about going into dark rooms was noted at the Alaska Native site; seasonal variation in sunlight, with long dark days in the winter and long light days in the summer, complicates the meaning of this question for young children. • Another question about understanding stoplights was pointed out in a rural community where there are no stoplights; children are thus not exposed to opportunities to know how to respond to them.

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Aim 1: Table B-4. Key findings, illustrative quotes and examples related to preparedness of the screening workforce

Key Findings	Illustrative Quotes and Examples
Most professionals reported 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]
Particular training needs mentioned included:	• Building rapport with families around 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 around developmental problems and interventions • Using information about children's circumstances to better understand screening results • Cultural awareness and using screeners in culturally appropriate ways • Ongoing training and refresher training
The lack of funding to support training in communities was noted.	

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Aim 1: Table C-1. Key findings, illustrative quotes and examples related to communicating screening results to parents

Key Findings	Illustrative Quotes and Examples
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).
Many parents reported receiving results only if their child screened positive.	Others received results in person (e.g., at parent-teacher conferences, home visits, or doctor visits).
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), that "*no news is good news*".	"*It just tells you thank you for submitting the ages and stages and that's it. I don't like that feeling, [of 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]
Parent preferences for receiving feedback	
Many parents expressed frustration with not getting results unless there was a concern; 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 were important in 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 tip sheets for 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	
Sensitivity to family background and culture is important.	*"[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]
Communicating results in the context of a conversation was noted as beneficial, providing opportunities to:	• support and encourage parents • probe for information about child's environmental context and exposures • include education about the importance and process of early childhood developmental screening and child development more generally
Tailor feedback to parents' educational level.	*"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]

Respect intergenerational child-rearing common in AI/AN communities; grandparents raising children may be unfamiliar with screening and particularly wary of it.	
Share screening results as soon as feasible.	
Offer resources and referrals, if needed.	
Use conversations about screening results as an opportunity for parents, teachers, and health care providers to be on the same page, 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]

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Aim 1: Table C-2. Key findings, illustrative quotes and examples related to referrals and resources for evaluation and services

Key Findings	Illustrative Quotes and Examples
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 specialty services only at significant distance from local families.	
Parents generally believed that adequate resources were available in their communities and they knew how to access them.	
Some parents who had received referrals, however, reported encountering long wait lists 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 services, and cited effective practices:	• 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 • 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 limited 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.	

Return to *Impact of Screening*.

Aim 1: Table C-3. Key findings, illustrative quotes and examples related to improvement in children’s outcomes

Key Findings	Illustrative Quotes and Examples
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 with children who had delays that were not identified by early screening talked about the significant challenge encountered in the absence of early intervention.	
Most professionals said they believed screening improved outcomes for children. Early services made possible through screening were believed to support better outcomes for children. Benefits noted included:	• Providing a lot of important information. • Making the process of linking children to services quicker and more efficient. • Supporting significant improvements in behavior/well-being/development when children were connected to services after screening. • Prompting discussions between health care providers and parents and helping both parents and providers become aware of a children's needs. • Identifying needs for services in the community.
Professionals said the benefits outweigh the risks as long as professionals can communicate screening results in ways that don’t alarm and alienate parents and as long as the services indicated by a screening result are available and accessible in a community.	

The value of screening was described as potentially limited by inability to provide information about knowledge and skills that are important for Native children.	*"[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 noted the need to assess the ability of systems in the community to support the needs of children.	
Professionals suggested that potential harms of screening could be reduced by avoiding or reducing redundancy in screening, sharing screening results across agencies instead of asking parents to repeat screenings.	
Professionals noted that a major factor in the ultimate effectiveness of screening is whether parents act on referrals for evaluation and services.	

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Aim 1: Table D. Key findings, illustrative quotes and examples related to Relative Benefit of Screening

Key Findings	Illustrative Quotes and Examples
Benefits	
Increasing communication between parents and professionals about children's development, allowing them to better work together to support children.	
Informing decisions about readiness for kindergarten, etc.	
Identifying children's needs earlier than they might otherwise be noticed.	*"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]
Making the process of linking children and families to needed services and resources more efficient.	
Improving children's outcomes because of facilitating early access to intervention.	
Costs and risks	
Burden on families and professionals associated with the time and resources required to complete, score, and provide feedback in the screening process.	
Parents alarmed by positive screening results (i.e. potential problems), especially when they were not communicated appropriately.	
Negative consequences of labeling children with delays or problems, especially since labels tend to be carried forward through school systems. (This was a particular concern given uncertainty over the reliability and validity of existing screening tools for AI/AN children and, thus, inaccuracy of these labels.)	
Identifying children's needs for services but not being able to provide those services due to lack of resources in the community.	
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.	

Balance	
Almost unanimously, participants responded—usually enthusiastically—that the benefits of screening outweighed the costs.	*"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 burden could be reduced by coordinating screening efforts within communities, avoiding duplication, and sharing screening results across programs and practices, although challenges with privacy were acknowledged.	

Return to *Relative Benefit of Screening*.

Discussion

We learned a great deal about screening in AI/AN communities from the four partner sites we visited. Although they represent only a very small sample of the many tribal communities around the country, they provide an important glimpse into existing approaches to screening, challenges for effectively screening and providing services for young AI/AN children, and strategies that are likely to help these efforts result in better outcomes for children and families.

In this discussion, we looked across themes and categories that emerged for the four key questions posed in Figure 1 and identified critical lessons about systems of screening in AI/AN communities.

Current Screening Efforts Vary in Reach, Administration, and Impact

Reach

We heard, across communities, that most AI/AN children enrolled in federally funded early childhood programs, including Head Start/Early Head Start and Tribal MIECHV, were being screened on a regular basis, in line with the requirements of those programs. Participants generally believed that children outside of those programs were less likely to be screened. The extent to which medical providers were routinely screening young children at well-child visits varied across communities, primarily due to uneven resources. In one community, universal early childhood screening efforts were systematic and reached most children, implemented within a large tribally run healthcare system. In another small reservation community, the local physician championed early screening and routinely screened within the tribal health clinic. In other communities, however, the lack of regular access to well-child services (in particular, the scarcity of pediatricians) was noted as a barrier to this avenue for screening young children. Robust screening systems within early childhood services (e.g., Head Start and Home Visiting) helped to fill this gap in access to screening.

Administration

The administration of screening instruments through a collaborative, in-person process or through an independent process, either online or on paper, varied across communities and, within communities, across programs. Both parents and professionals had varying perspectives and preferences for the "best" way to administer screeners. The advantages and disadvantages to each approach mentioned were quite distinct—such as ease and convenience of online administration vs. the value of the conversation around in-person assisted administration. Perhaps different approaches are best with children at different ages—such as in person for new parents with young children, online for older parents—which was consistent with the way they were being used by programs. Data on the reliability and validity of scores under these different administration scenarios is not available and is in line with a key question the Tribal PEDS CoL posed at the outset of this study. Perhaps a future study could examine the concurrent validity of screeners administered through these two approaches.

Impact

Many parents reported not getting feedback about the results of screening unless their child had screened positive for a potential problem and they expressed frustration about the lack of feedback.

Parents wanted to know the results. “No news is good news” was not enough. Not hearing anything left parents wondering how their child was doing; instead, they wanted specific feedback and guidance about their child’s development. The desire expressed by parent participants to receive screening feedback echoed the theme of trust in screening relationships and pointed to screening as an opportunity for trusted, familiar professionals to come together with parents to provide education about child development. It’s also an opportunity for professionals and parents to work together to jointly support a child.

Concerns about moving beyond screening to engaging evaluation and services for children who screen positive were raised across communities. In some communities, very limited resources were noted (i.e., no or few specialist providers); in others, parental resistance to accessing services were concerns (e.g., due to stigma). Across communities, the importance of trust and partnership with parents was emphasized to follow through from screening through referral through 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 efforts to support such efforts (e.g., initiatives such as the Tribal Early Childhood Learning Initiative at the Administration for Children and Families and Project LAUNCH at SAMSHA).

Screening of AI/AN Children can be Improved through Specific Strategies

Taken together, the findings presented here led us to conclude that early childhood screening systems in these AI/AN communities have numerous strengths, but also face challenges. What we heard from both parents and early childhood professionals in this study provided insights into strategies for addressing those challenges and strengthening early developmental screening in these communities and in other AI/AN communities.

In reviewing findings across elements in the conceptual framework, we found that the experiences of parents and providers were that screening was most effective when these key elements were present:

- parents understood the goals of screening, how screening information would be used, and what to expect in the screening process;
- parents trusted the people involved in the screening process, including assessments and referrals;
- screening scores were interpreted in the context of culture and other observations of children; and
- feedback was provided to all parents.

Ensuring 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. Transparency and trust are not easy to restore given the history in AI/AN communities, but they are essential to creating partnerships between parents and professionals for effective early screening and intervention.

Building Trust

Participants reminded us that screening AI/AN children happens within a historical context that shapes their lives today. AI/AN communities continue to experience the aftermath of historically traumatic events driven by federal policies to assimilate Native people into mainstream society and eliminate their existence as distinct cultural groups (Adams, 1995; Beiser, 1974; Campbell & Evans-Campbell, 2011; Sarche & Whitesell, 2012). Participants commented on the impacts of intergenerational and historical trauma on their families and children, through disrupted family structures and parenting practices. As noted in Aim 1: Table A-3, one professional suggested that one impact of pervasive trauma may be a dulling of perception around normative child behavior, and parents may come to see problematic behavior as normal. On the other hand, many participants cited AI/AN culture as having a positive impact on children's development, as buffering the impacts of generations of trauma. They mentioned strong cultural values, intergenerational and interdependent family structures, and community commitment to children as supports for healthy developmental outcomes. Many reflected on the importance of recognizing the protective role of these cultural factors in balancing risk for children in their communities.

Distrust of systems and policies that have, for generations, been designed to eradicate AI/AN people, however, is carried by families into the screening process and was reflected by parents who expressed fear around how screening results would be used. Parents' comments about screening as a form of colonization made this point most clearly. 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.

Considering Culture and Context

Screening tools being used in existing efforts in the communities we visited were the same tools being used in other communities around the country—standardized early developmental and social-emotional screeners created and validated without attention to their appropriateness for AI/AN populations. Nonetheless, participants generally felt that these tools worked well enough for the children in their communities, with two critical caveats.

First, participants raised several concerns about individual questions on the screeners and how the cultural or contextual misfit of those questions might impact overall scores and, thus, potentially identify a child as at risk when they were not (i.e., false positives). Participants also pointed out that available screening tools may miss important developmental milestones that are important within AI/AN cultures. Differences between developmental and social norms in Native communities and those in Western culture were discussed at length in interviews, and, as noted in the examples in Aim 1: Table B-2, where avoiding eye contact is scored negatively on existing screeners, it could be scored positively in a culture that values that behavior. Such examples, of course, highlight the complexities of children growing up to navigate dual (or multiple) cultural contexts—and participants noted this complexity.

Second, and related to the first, results highlight the importance of considering the results of screening tools in the context of other information available about the child—the culture the child is embedded within, as well as observations of teachers, home visitors, conversations with parents, etc. The contextualization of screener results was pointed out as particularly important given the increased potential for false positives.

Professionals involved with screening 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.

Providing Additional Training about Screening for Early Childhood Professionals

We learned a lot from professionals about the strategies they were using 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 needed more help. They needed more resources, and they asked for more training in how to best engage parents in the screening process, communicate results to them, and ensure successful transition to services when needed.

Many professionals reported lacking time for training, for screening, and for explaining screening to parents and sharing screening results with parents. As is typical in many AI/AN communities, resources are stretched thin and early childhood professionals are overworked.

The suggestions offered above—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 it is a complex task. It requires the professional to understand the screening score itself at a deeper level, it requires an understanding of what goes into that score, and it requires the professional to then take that deeply-understood score and embed it within an array of other information about the child. Because screening tools are not validated for AI/AN children, professionals working with these children are being asked to do a more complex task than their colleagues working with children in 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.

Screening is Worth the Effort

Each interview and focus group discussion ended with questions about the overall value of screening and, almost unanimously, participants told us that they believed the benefits outweighed the costs.

Early childhood professionals saw screening as “an educational moment”, an opportunity to start a conversation with parents about their children’s development that led to better understanding. They said screening made the process of linking children to services quicker and more efficient and they often saw significant improvements following positive screens and subsequent services.

Likewise, parents saw the value in screening. They shared that they learned a lot about their children and about what to expect in child development by completing screening questionnaires and talking to professionals about the results. Those who had children who had screened positive talked about their relief at identifying issues and the benefits of getting needed help.

Even with the imperfect screening tools available (i.e., not tailored for AI/AN children), most participants saw the tools as useful and the screening process as important for improving outcomes for children in their communities. They agreed that prevention was the key to getting children the services and resources they needed, with earlier intervention likely to result in better outcomes for children.

Resources for Communities

With the goal of taking first steps toward improving screening, we created two resources to share with AI/AN communities. These resources summarized study findings and recommendations that emerged from them. These resources were created upon the recommendation of the TRC Steering Committee, upon review of study findings, as tools for helping both parents and professionals be better informed about screening. The resources were created in collaboration with the Tribal PEDS CoL, based on findings from the interviews and focus groups.

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

The second, companion resource was designed for parents and other family members, titled *Supporting your Child through Developmental Screening from Birth to Age Five* (Appendix D). This two-page document was designed for early childhood professionals to share with families before screening begins. The document is designed to help parents understand the purpose of screening and to give them some guidance for completing screener questionnaires. It is not designed to replace a conversation between an early childhood professional and a parent before screening, but rather to begin or supplement such a conversation.

AIM 2: PILOT METHODS FOR COLLECTING QUANTITATIVE SCREENING DATA

Methods

The Aim 2 portion of the Tribal PEDS study was designed as a first step toward a future validation study of early developmental screeners for AI/AN children. It was a pilot of methods for a future study, to test the feasibility of using online data collection with families of young children in tribal communities as a way to gather a large sample of data on AI/AN children birth to five years of age. The Aim 2 pilot itself was *not* intended to gather enough data to provide meaningful information about reliability and validity of early developmental screeners, but *instead* to inform methods for a future study that could gather sufficient data to do so.

The TRC Tribal PEDS study team developed and tested an online system for collecting data on a battery of developmental screeners from the parents[3] of AI/AN children between the ages of six months and five years. The Research Electronic Data Capture System (REDCap), a secure, HIPAA-compliant web-based application (Harris et al, 2009), was used to develop the system.

Considerations in Developing the Data Collection Protocol

Providing Feedback to Families

Before describing data collection procedures in detail, it is important to describe a critical early decision made by the Tribal PEDS CoL that shaped our protocol in important ways. As we began to discuss strategies for collecting screener data for a validation study, CoL members expressed significant concern about the ethical implications of asking parents to complete screeners on their children without providing them any feedback about the results of those screenings. Community partners on the CoL voiced particularly strong concerns about this and reflected on the history of research in tribal communities that has been characterized by researchers taking information away without providing local benefit. There was also consensus that parents willing to invest the time to complete a battery of screeners, as would be required for a validation study (i.e., for concurrent validity estimates) should be given feedback about their child's progress. The standard validation study protocol of collecting data without providing direct feedback to participants was deemed unacceptable within these communities. There was also consensus that it would not be responsible or appropriate to provide screening results to participants in writing, but rather that results should be communicated by a professional who could support appropriate interpretation of results and, if indicated, connect participants to appropriate referrals or resources for their children. Thus, we decided to make individualized feedback on screening results available to all participants a part of the study protocol.

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[3] As a reminder, we use the term *parent* inclusively to refer to any adult who is raising a child; parents thus include not only biological parents but also other relatives and non-relatives who are primary caregivers to young children.

This decision had implications for the study design which were relevant to the feasibility of a large-scale validation study, notably with respect to representativeness of the sample and the complexity of the online data collection system.

Restriction of the pool of potential participants

The logistics of providing individualized feedback to all participants in a large-scale data collection effort, in multiple communities around the country, would be challenging. In addition, CoL members reasoned that feedback would best be delivered by trusted professionals from participants' own communities, rather than by outside researchers. To facilitate this, the local programs partnering in the Tribal PEDS study offered to deliver screening results to participants. All these programs routinely screened young children and had staff who were trained to deliver screening results to parents and facilitate necessary referrals. However, the capacity of these programs to take on the role of providing feedback was limited; three of the four partner programs were only able to do so for families they were already serving. Thus, the decision to make feedback available through these partnerships dramatically restricted the potential participant pool and thus limited the potential of the overall sample to be representative of all AI/AN families in these four communities. Even in the fourth community, where our research partner program had capacity to offer feedback to participant families outside their existing client base, recruitment through this program likely influenced the pool of participants.

Requirement that participants release screening data to program partners

Therefore, our recruited sample of families was restricted by connection to our study program partners. These participants, once enrolled in the study, were given the *option* to request feedback on screening results. Those who requested such feedback were required to provide contact information and sign a release to have their private information (i.e., name, contact information, and child's screening results) shared with the local program partner. Participants who were unwilling to release this information were able to participate in the study but had to opt out of receiving feedback. This requirement had the potential to further restrict the sample, and it is unclear to what extent it did so because participants could not receive feedback without releasing private information and some may have chosen to decline to participate altogether as a result.

Beyond restricting the sample, the additional step of making feedback available also added complexity to the study protocol and to the online data collection system. For online data collection, it required a complex series of extra steps to ensure consent and release of information and to ensure that protected, private information was securely kept separate from deidentified study data records. For participants who did not request feedback, we did not require submission of any identifying information (other than child birthdate to determine study eligibility and select the appropriate screener package, which was then dissociated from study data). Incorporating this complexity into the pilot study was important to understanding the feasibility of these data collection methods for this population.

Limiting Data Collection to Selected Ages

Another decision we made in designing the study protocol had to do with practical issues. Screening instruments for children at different ages from birth to five years require different versions to measure age-appropriate milestones and markers of social-emotional development. Programming online tools for data collection across multiple versions of multiple screeners is a complex task. Given the limited scope of this pilot study and limited resources available, we had to limit the number of different versions to be programmed. We did this by selecting eight discrete ages, in six-month increments from six months to five years of age, for screening. The goal was to capture the range of development in early childhood to be able to detect any challenges in online data collection reporting that might emerge at different periods. For each age selected, we included an eligibility range that corresponded to the window in which it is appropriate to use the relevant version of the screening instruments (e.g., for the six-month screeners, children five- to seven-months were eligible; see Aim 2: Table 1).

Data Collection

Participant Recruitment

Participants were recruited through flyers distributed at each of the four partner program sites. Flyers were tailored to each site and included a URL for the online data collection system as well as email addresses and phone numbers for local program contacts and study staff who could provide more information. Tribal PEDS study personnel introduced program staff at each partner site to the online data collection system during the site visits in which Aim 1 interviews were conducted and provided an information sheet for use in introducing the study to potential participants and responding to questions.

Aim 2: Table 1. Screening instruments included in Aim 2 survey, by age of child

Age of child (months)	Screener					
	ASQ-3	**ASQ: SE-2**	**SWYC**	**BITSEA**	**M-CHAT-R**	**PDQ-1**
	Ages & Stages Questionnaires, 3rd Edition[1]	*Ages & Stages Questionnaires: Social-Emotional, 2nd Edition*[1]	*Survey of Well-being of Young Children*[1]	*Brief Infant Toddler Social Emotional Assessment*[2]	*Modified Checklist for Autism in Toddlers, Revised*[2]	*Psychological Development Questionnaire-1*[2]
5 to 7	✓	✓	✓	☐	☐	☐
11 to 13	✓	✓	✓	✓	☐	☐
17 to 19	✓	✓	✓	✓	✓	✓
23 to 26	✓	✓	✓	✓	✓	✓
29 to 32	✓	✓	✓	✓	✓	✓
35 to 39	✓	✓	✓	✓	✓	✓
45 to 51	✓	✓	✓	☐	☐	☐
57 to 66	✓	✓	✓	☐	☐	☐

[1] Different versions of these screeners are used for different ages of children.

[2] A common version of each of these screeners is used across the specified age range.

Eligibility Assessment

Participants were eligible to provide screening data in this study if they were: (1) at least 18 years old and (2) a primary caregiver to an AI/AN child in one of the eight selected age groups (Aim 2: Table 1). Only one participant per family was eligible.

A public survey link provided on recruitment flyers directed interested participants to the REDCap survey that assessed eligibility for participation. Potential participants were asked: (1) their age; (2) whether they were the primary caregiver (defined as spending at least 15-20 hours per week with the child) of at least one AI/AN child between the ages of 5 and 66 months served by one of the programs participating in the Tribal PEDS study[4]; and (3) the birthdate and prematurity status of up to four AI/AN children. Birthdate and prematurity information were used to determine whether each child was within an eligible age band at the time of the assessment or would enter one of the bands during the six-month data collection period at the site. Potential participants who did not meet eligibility criteria were thanked for their interest and exited out of the survey. Potential participants who would become eligible in the future (as their child aged into an eligibility band) were given the option of providing an email address to receive a reminder email when it was time for them to complete the screeners. Potential participants who were immediately eligible were invited to continue to another screen where they could learn more about the study and provide or decline consent. Those who continued were automatically exited out of the eligibility instrument, thus keeping personal information (e.g., child's full birthdate) separated from consent and screener data. Only the age of the child (in months) was linked to the screener data collection instrument.

Consent and Feedback

Eligible participants were invited to view a pre-recorded consent video and download a written consent form from within the online system. Those who provided consent were given the option of receiving feedback about their child's screener results from the local partner program. Those who agreed were asked to complete a HIPAA form allowing their screener data to be released to the program. Participants received a $30 e-gift card.

Surveys

Prior to responding to an age-specific package of screening instruments, participants were asked to create a password that they could use if they stopped data collection and wanted to resume later.

Developmental screeners

We collected information on six screening instruments that have been validated for use in other populations. In selecting screeners to include for potential validation, we prioritized (1) screeners commonly used by early childhood program partners in AI/AN communities, (2) broad developmental

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[4] As noted earlier, one partner program (Site 3) was able to provide screening feedback to families they were not currently serving, so this eligibility criteria did not apply.

screeners as well as specific screeners for autism, and (3) tools commonly used by researchers studying early child development in AI/AN communities. The selection of screeners for inclusion was made by the Tribal PEDS CoL in consultation with other tribal early childhood program and research partners.

As shown in Aim 2: Table 1, all participants were asked to complete an age-specific Ages & Stages Questionnaire, 3rd Edition (ASQ-3), an Ages & Stages Questionnaires: Social-Emotional, 2nd Edition (ASQ: SE-2) (Squires & Bricker, 2009), and the Survey of Well-being for Young Children (SWYC) (Perrin, Sheldrick, Visco, & Mattern, 2016). In addition, participants with a child between 12 and 36 months of age were asked to complete the Brief Infant Toddler Social Emotional Assessment (BITSEA) (Carter & Briggs-Gowan, 2005), and those with a child between 18 and 36 months of age were asked to complete two autism screeners, the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R) (Robins et al., 2014) and the Psychological Development Questionnaire-1 (PDQ-1) (Zahorodny et al., 2018). The estimated time needed to complete the screeners varied from 54 to 72 minutes, depending on child age.

Demographic information

After completing the screening instruments, participants completed questions about the sex of the child screened, their own sex, relationship to the child, race/ethnicity, marital status, educational attainment, and number of children.

Process questions

A final set of questions was designed to inform an assessment of the feasibility of this online data collection strategy for a larger-scale validation study. Questions were about participants' experiences using the online data collection system. Participants were asked how much they agreed or disagreed with statements about: (1) the ease of using the online system, (2) preferences for answering screener questions on paper or online, (3) desire for assistance in answering screening questions, (4) length of the online survey, (5) utility of recruitment materials, and (6) motivations for participating. Response scales for all questions ranged from *strongly disagree* (1) to *strongly agree* (4).

Results

Participation Levels

Aim 2 was focused on assessing the viability of an online system for collecting early childhood developmental screener data on a large sample of AI/AN children birth to age 5 years. Toward that end, we first assessed participation levels among primary caregivers of age-eligible AI/AN children.[5] Participation was tracked through several key points in the enrollment and data collection process, from initial eligibility screening through consent to survey completion (see Aim 2: Figure 1).

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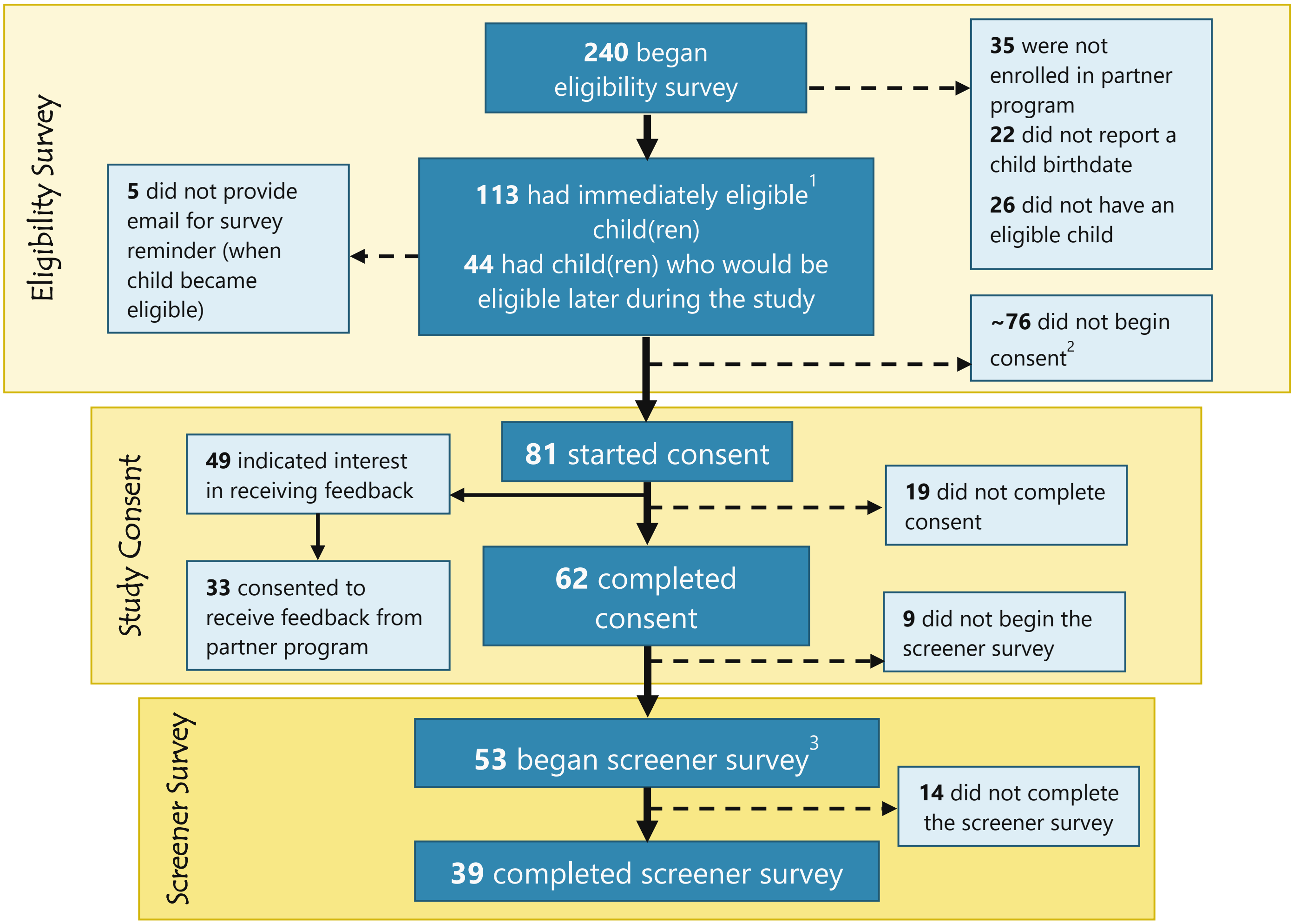
[5] The eligibility assessment was accessed through a public survey link and we could not verify that individuals did not access the link twice. Thus, eligibility data do not necessarily represent unique individuals.

Eligibility Criterion 1: Enrollment in a Partner Program

Across the four sites, 85% (N=205) of participants who completed study eligibility questions met the first eligibility criteria of being enrolled in a partner program. As noted earlier, connection to a program was critical for eligibility because of the value the CoL placed on providing screening feedback to participants who requested it and providing feedback with individualized support from programs (i.e., with interpretation and referral, if needed, rather than only providing scores).

Aim 2: Figure 1. Flow of participants through eligibility assessment, consent process, and survey completion



[1] Had a child in one of the age bands shown in Aim 2: Table 1.

[2] This number is estimated. See text for details.

[3] Setting a password for data collection was used to track starting the survey.

Eligibility Criterion 2: Child in Eligible Age Band

Among participants who met the first eligibility criterion, 89% (N=183) reported a birthdate for at least one child. Among those, 86% (N=157) were eligible based on the age of their child. Sixty-two percent (N=113) were immediately eligible; an additional 24% (N=44) had a child who would become eligible before the end of the data collection period (i.e., age into an eligibility window). Of the 44 who would become eligible at a future date, 89% (N=39) provided contact information so they could receive an email reminder to return to the site to complete the survey at the appropriate time. The remaining 14% (N=26) who reported child birthdate did not have children in the eligible age bands, either immediately or within the time frame of the study, and thus were not eligible to participate in the study.

Participant Consent

A total of 81 participants began the consent process (Aim 2: Figure 1). We cannot say for certain what percentage of eligible participants this number represents because the eligibility survey was accessed through a public survey link which could have been used multiple times by a single individual. Eligibility records do not, therefore, necessarily reflect unique individuals. If we were to assume that eligibility surveys did represent unique individuals, then the 81 participants who began the consent process would represent only 52% of all eligible participants (N=157), or 72% of those immediately eligible upon initial screening (N=113). Unfortunately, however, it is not possible to precisely quantify how many participants were lost between screening and the beginning of the consent process.

Of the 81 participants who began the consent process, 77% (N=62) agreed to participate. The majority of those who consented (79%; N=49) requested information about receiving feedback on their children's screener results. Of those, 67% (N=33) completed a release form to share screening results with the partner program so they could receive feedback through that partner. Among participants who provided consent (both those who did and did not request feedback), 85% (N=53) set a password to begin the screener survey in the online data collection system.

Survey Completion

Sixty-three percent (N=39) of consented participants fully completed data collection. Screener packages were completed on children in all eight age bands, with the largest group for the 48-month old children (26%) and the smallest group (3%) for the 24-month old children (Aim 2: Table 2).

Aim 2: Table 2. Number of completed screeners, by age of child and partner site

Partner site	Age of child (months)								**Total complete**
	5-7	**11-13**	**17-19**	**23-26**	**29-32**	**35-39**	**45-51**	**57-66**	
1	0	0	0	0	1	2	2	0	5
2	2	2	4	1	3	2	4	1	19
3	1	1	3	0	0	0	0	1	6
4	0	1	0	0	1	0	4	3	9
Total complete	**3 (8%)**	**4 (10%)**	**7 (18%)**	**1 (3%)**	**5 (13%)**	**4 (10%)**	**10 (26%)**	**5 (13%)**	**39**

Demographic Characteristics

Demographic information is provided in Aim 2: Table 3. Most participants were female (95%) and mothers (82%) to the children screened. Just over half (51%) of the children screened were male. Approximately two-thirds of participants were American Indian and 80% were married or cohabitating. Participants represented all educational levels but the majority (77%) had some college education or less. The number of children in participants' families was roughly evenly distributed across all categories ranging from one to four or more.

Aim 2: Table 3. Demographic characteristics of participants, by partner site

Characteristic	Partner Site								Total	
	1 (N=5)		2 (N=19)		3 (N=6)		4 (N=9)		(N=39)	
	n	%	n	%	n	%	n	%	n	%
Participant sex - female	4	80%	18	95%	6	100%	9	100%	37	95%
Child screened - female	5	100%	8	42%	2	33%	4	44%	19	49%
Relationship to Child										
Mother	4	80%	13	68%	6	100%	9	100%	32	82%
Father	1	20%	1	5%	0	0%	0	0%	2	5%
Grandmother	0	0%	4	21%	0	0%	0	0%	4	10%
Aunt	0	0%	1	5%	0	0%	0	0%	1	3%
Race/Ethnicity										
American Indian	4	80%	18	95%	3	50%	0	0%	25	64%
Alaska Native	0	0%	0	0%	1	17%	3	33%	4	10%
Hispanic	0	0%	0	0%	1	17%	0	0%	1	3%
White	1	20%	1	5%	1	17%	6	67%	9	23%
Marital Status										
Married/Cohabitating	5	100%	14	74%	4	67%	8	89%	31	79%
Separated/Divorced	0	0%	3	16%	0	0%	1	11%	4	10%
Never Married	0	0%	2	11%	2	33%	0	0%	4	10%
Education										
High School or Less	2	40%	6	32%	2	33%	4	44%	14	36%
Some College	0	0%	10	53%	2	33%	4	44%	16	41%
College Degree	2	40%	3	16%	1	17%	1	11%	7	18%
Post-College	1	20%	0	0%	1	17%	0	0%	2	5%
Number of Children										
1	2	40%	8	42%	1	17%	1	11%	12	31%
2	0	0%	4	21%	3	50%	4	44%	11	28%
3	0	0%	4	21%	1	17%	3	33%	8	21%
4+	3	60%	3	16%	1	17%	1	11%	8	21%

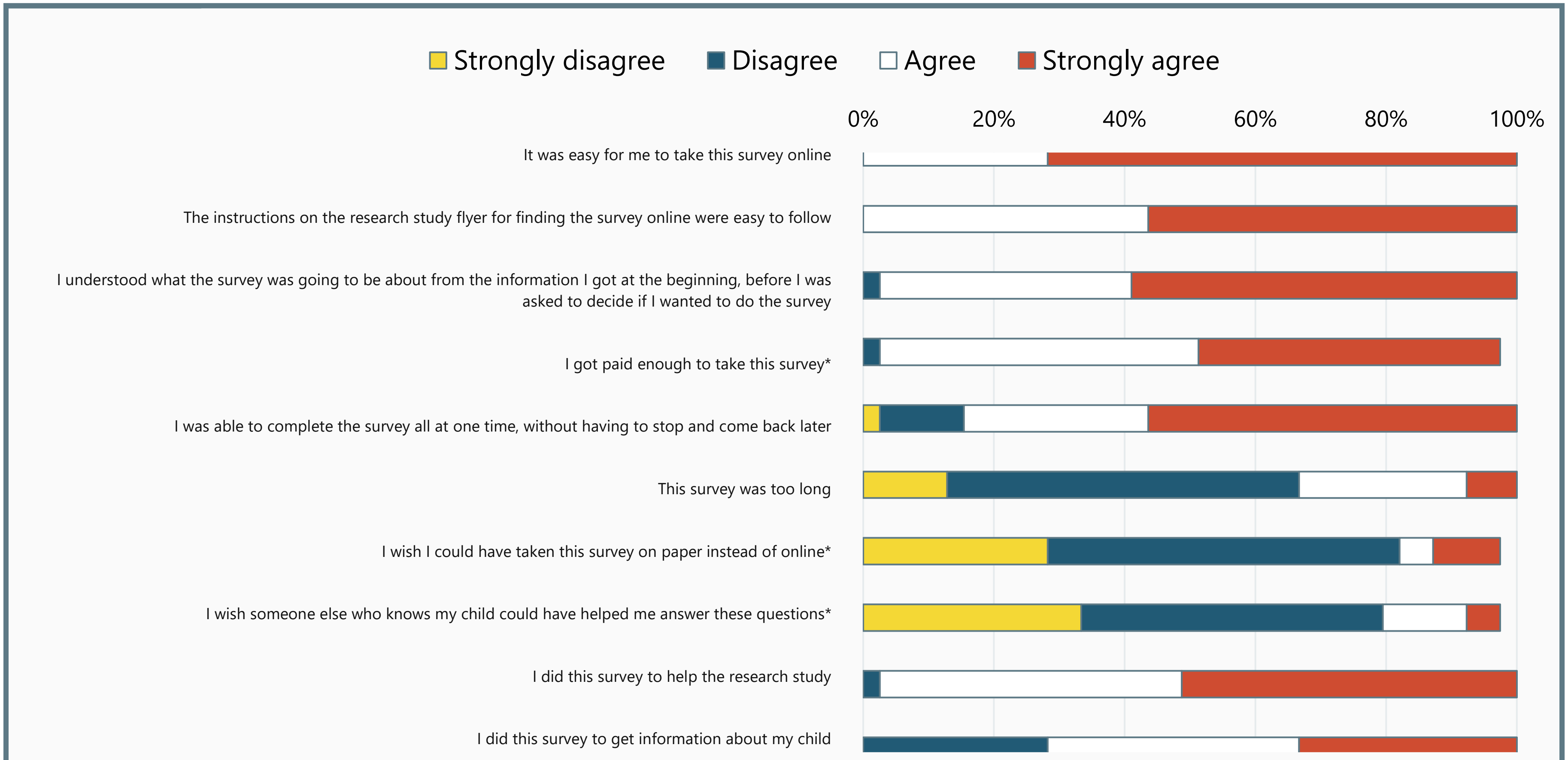
Process Assessment

Aim 2: Figure 2 shows participants' responses on the items that asked about their experience with the online data collection system. These questions were located at the end of the screener survey, so only participants who completed the survey responded to these items (N=39). All participants agreed or strongly agreed that it was easy to take the survey online and that the instructions for accessing the online system were easy to follow. Most (98%) agreed or strongly agreed that they understood the nature of the study before being asked to participate, and 95% agreed or strongly agreed that the participation incentive was sufficient. Most reported that they were able to complete data collection all at one time (85% agreed or strongly agreed).

About a third of participants reported that the survey was too long, and 15% indicated that they would have preferred to have taken the survey on paper instead of online. About a quarter agreed or strongly agreed that they would have liked to have had help answering the screener questions from someone else who knew their child well.

Finally, when asked about their motivations for participating in the study, nearly all participants (98%) reported that they completed the survey to help with the research, while 72% also said they did so to get information about their child.

Aim 2: Figure 2. Participant ratings of the online data collection process (N=39)



*One participant selected the "prefer not to answer" option.

Discussion

The goal of Aim 2 was to explore the feasibility of an online approach to data collection for a future large-scale study to examine the reliability and validity of early developmental screeners for AI/AN children birth to five years of age. The findings provide useful information about this approach.

Lessons about the Approach

First, we learned an important lesson about the feasibility of large-scale data collection with AI/AN families from members of the Tribal PEDS CoL in the process of designing this pilot study. Those partners urged us to diverge from standard validation study protocols in a critical way that restricted the participant pool and complicated the participant pool. The CoL was insistent that we not ask parents to complete screeners about their children without providing feedback about the results. There was also consensus that the written feedback would not be sufficient, but that parents should be given feedback within the context of a trusted relationship, from someone who could connect them to referrals for further evaluation or services, if needed. The concerns that pushed CoL members to insist on this feedback protocol were later reflected in what we heard from interviews with both parents and early childhood professionals in the Aim 1 interviews, namely that feedback from familiar and trusted professionals are essential components of well-functioning screening systems. The insistence on creating a validation study protocol that included feedback to parents also reflected sensitivity to a history of research in tribal communities that has taken data without returning benefit and a commitment to change that narrative (Tribal Evaluation Workgroup, 2013).

Including feedback to parents as a component of the protocol is a fundamental ethical decision for how a validation study with AI/AN children and families should be conducted, but it also places two significant constraints on the feasibility of a large-scale validation study. Such a study would require an extensive network of partnerships between the research team and partners in AI/AN communities around the country prepared to provide feedback to participating parents. Such a study could utilize existing partnerships, like those developed through the TRC network, the Multi-site Implementation Evaluation of Tribal Home Visiting (MUSE), or the AI/AN Family and Child Experiences Survey (AI/AN FACES), but these would not necessarily result in a representative sample of AI/AN children nationally. Second, participation in the study would be limited to families who have existing relationships with those programs, so as not to overextend the resources of those programs in providing feedback, thus further limiting the representativeness of the potential sample.

Moving forward, we must weigh the relative risks. We could ignore the guidance of the Tribal PEDS CoL and utilize standard validation methodology to obtain a sample of developmental screening data on AI/AN children—i.e., recruit parents of young AI/AN children regardless of their connection to local programs and provide no feedback on screening results—but if we do so, we must consider the costs, both to individual families and to AI/AN communities in terms of the legacy of distrust of research and the screening process itself.

Lessons about Implementation

When it came to collecting data using the online system, recruitment challenges, navigational difficulties, and participation burden posed significant obstacles.

Recruitment

Distribution of study flyers and announcements during parent meetings at program partner sites did not draw large numbers of potential participants to the online study portal, and, thus, this pilot effort did not draw the anticipated number of participants. Local program partner staff reported that some potential participants had challenges in accessing and using the online system, and some were confused by the eligibility criteria (e.g., child age bands). We tried to address these challenges through having local staff connect potential participants to the study team for assistance and clarification, but some were lost to initial barriers. While our process data (Aim 2: Figure 1) showed that participants who were able to navigate the system and complete the surveys reported positive experiences, those ratings were only from the select few who made it that far.

Program partners attributed some of the low participation not to confusion about how to access the online data collection system but to the lack of families' familiarity with the study and understanding of its value and purpose. All four program partners told us they believed that participation would have been higher if study staff had been able to be onsite longer to meet families, explain the study in person, introduce themselves to potential participants, and generate excitement about the importance of the study for AI/AN children and families. This approach, of course, would be much more resource intensive than introducing the study to local program staff and "deputizing" them to recruit participants, post flyers, and rely on local staff to share information about the study, but it was seen as likely to engage significantly higher participation rates.[6] Creative approaches, perhaps including engaging recruitment videos that could be shared with potential participants, would also likely be important.

Eligibility

Some of the challenges encountered here were tied to the specific limitations of this pilot study, namely that, due to resource constraints, we were only able to program the complicated surveys for eight age bands, rather than to cover the full spectrum of ages birth to five years. Thus, potential participants had to go online to find out if their child was immediately eligible (in one of the age bands). If not, they were invited to provide an email to get a reminder to return to complete the survey later. Although virtually all participants would become eligible at some point during the study, this wait-and-return process proved confusing and burdensome. For example, not all participants with a child who would be eligible at a future point during the study period requested a reminder email or returned to the online system when their child become eligible. In an actual validation study, this

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[6] We had planned to try this recruitment strategy at some sites in 2020, but the COVID-19 pandemic precluded site visits for this purpose.

barrier would be removed; children of all ages would be immediately eligible and interested participants would be able to complete the screener battery at the time of the initial attempt.

Incomplete Responses

Only a minority of all participants who qualified to complete data collection did so. Among the 157 who reported having an age-eligible child either at the time of the assessment or at some point during the six-month study period, only 39 (23%) completed the full set of screening questions for their child. Eligible participants dropped out of data collection at multiple points in the process, as shown in Aim 2: Figure 1. Not all participants who were eligible started the consent process; others started but did not complete it. Not all of those who consented went on to complete the survey.

Despite these logistical challenges, participants who *did* complete the process reported that it was a successful and positive experience. Most of these participants—the select few who made it through the screening, consent, and survey process—reported that the online system was easy to access and use. Only a minority reported that it took too long to complete data collection, that they would have liked help answering the questions, or that they preferred a paper survey over an online instrument. It is, of course, important to take these responses for what they are, namely, the reports of the successful minority of participants who completed surveys.

Fraudulent Responses

Another important challenge we encountered that will impact the feasibility of future efforts to collect a large sample of screening data online had to do with fraudulent responses attempted through the open, public link to the eligibility survey. Nearly 100 fraudulent responses, all of which were made within a two-day period, were detected in this pilot study. These responses were discovered when we noticed a rapid uptick in participants and unusual clustering of responses entered very late at night in a short period of time. We investigated further, discovered invalid email addresses and phone numbers, and were able to quickly identify fraudulent responses and remove them from the data. However, given the nature of the data collection system, namely that we made the decision to not collect identifying information to protect participant confidentiality, it is possible that other fraudulent responses were submitted but not detected.

RESEARCH, PRACTICE, AND POLICY IMPLICATIONS OF AIM 1 AND AIM 2 FINDINGS

Guidance for Systems of Screening

Strategies for improving screening of young AI/AN children (articulated on pages 37-40) included *better informing parents* about screening, *intentionally building trust* between professionals and parents, *considering the culture and context* of families at all phases, and *enhancing training for early childhood professionals.*

Research implications include studying the reliability and validity of screeners for AI/AN children (see Guidance for Validation of Screening Tools). As suggested earlier, research could also examine how guidance for tailoring screening tools (e.g., omitting culturally dystonic items or adjusting cutoffs locally) may allow flexibility for greater accuracy and acceptability of screening tools in tribal communities.

As noted earlier, there is also a gap in what we know about the reliability and validity of screening instruments under different administration scenarios that are common in early childhood programs and healthcare settings in tribal communities—broadly, *Independent* and *Collaborative* approaches. It is important to understand not just how well these tools work *as they were intended to be used* and tested in controlled conditions, but also how well they work *as they are being used in practice*, in the settings where AI/AN children are typically screened. A study examining the concurrent validity of screeners administered through different approaches may provide needed guidance.

Research could also focus on training strategies for early childhood professionals that support better implementation and interpretation of screening tools. Another avenue for research would be to examine the effectiveness of different strategies for engaging parents in the screening process, to inform efforts to expand the reach and value of screening.

The need to increase education about screening for both parents and professionals was clearly indicated in our findings, but both efforts require resources that are often scarce in AI/AN communities. It is difficult for communities and programs to find the money and time to provide training for professionals and enhance public health campaigns for parents. Priority should be given to advocating for both additional resources and developing materials communities can use to make these efforts relatively easier.

Guidance for Validation of Screening Tools

Taken together, these findings suggest that, in order to be successful, a system for collecting screener validation data on a large sample of AI/AN children may be able to utilize online tools for data collection but will require a hybrid approach with resource intensive in-person support. This support will include partnerships with local programs for in-person recruitment and to provide screening feedback to participating families.

The hybrid methodology might involve site visits to a diverse sample of tribal early childhood programs across the country during which recruitment and screening events could be held. Those events would provide an opportunity for study staff to introduce families to the data collection opportunity, orient them to the online system, provide tablets or computers for completing data collection, offer literacy support, and troubleshoot any technical or navigational difficulties that participants experience with the system.

This type of in-person support will be necessary to remove barriers that prevent participants from accessing an online data collection system altogether or from completing data collection once they have begun using the system. It may also prove useful in more precisely pinpointing the specific issues that make access or use of the online system challenging. Such issues could then be modified by the study team or clarifying guidance could be provided to participants. This information would be particularly valuable since the Tribal PEDS pilot only obtained process feedback from participants who were able to complete data collection, not those who were unable to either access the system or successfully use it. The changes resulting from user feedback may increase the accessibility of the data collection system, particularly for those who use it in the absence of in-person support. Indeed, before moving to a validation study, further development of the online data collection system would be needed, with careful testing with parents of AI/AN children and cognitive interviewing or other methods to explore usability.

In order to achieve a large enough sample of participants so that the reliability and validity of existing screening instruments for AI/AN children could be adequately assessed, it would be important to continue recruitment activities beyond the in-person events that take place during study site visits. That could involve a combination of empowering local program staff to oversee recruitment efforts and conducting those efforts remotely through social media forums and other virtual platforms. It will also be important to further consider how utilizing local programs for recruiting participants and providing screening feedback restricts the potential participant pool and, in the end, the generalizability of study findings. If we truly want to understand how well screening tools work for all AI/AN children, we cannot sample only from those served by Tribal early childhood programs.

As noted earlier, in a full validation study, AI/AN children of all ages within the birth to age five window would be eligible, removing a barrier that was unique to the limited resources of pilot study. The challenges encountered around this limitation, however, were informative in pointing to the critical importance of making the eligibility screening process as clear and simple as possible for potential participants and the losses to participation associated with complex systems of navigation.

It will also be important in future iterations of this system to build in functionality that restricts participants from reporting on the same child more than once or about more than one child within the same family. Functionality is also needed to prevent fraudulent survey responses from bots or ineligible individuals attempting to collect participation incentives. Tools such as ‘reCAPTCHA’ and ‘HTTP Referer Verification’ should be integrated, along with rigorous protocols for checking data quality.

Given that the hybrid methodology described above is significantly resource-intensive, alternative strategies for understanding how well-established screener instruments work with AI/AN children should also be considered. One such alternative is to use existing screening data from diverse samples of AI/AN children—either individually or pooled—to see what we can learn about how screening instruments are working in practice. Potential sources and analytic strategies for a secondary analysis of such data are currently being explored, including the AI/AN Family and Child Experiences Survey (AI/AN FACES) from both 2015 and 2019. Using what we already have to help inform the interpretation of screening scores for AI/AN children, while not rising to the level of gold-standard validation, can nonetheless provide critical insights on the utility of these tools for supporting the development of AI/AN children.

Finally, it is important to remember that the goals of Aim 2 are intimately connected to Aim 1 of this study. Screeners are important tools for monitoring young children's development, but they are just one set of tools within a complex system of screening and a network of monitoring young children's development within AI/AN communities. Parents and early childhood professionals use multiple sources of information about children's development and screeners should not be used in isolation. Best practice recommendations call for professionals to interpret screening scores in light of contextual information gathered from conversations with parents, conversations with teachers or home visitors, and direct observation of children in familiar settings. They also call for professionals to use their discretion in adjusting the content, administration, and interpretation of screeners to align with children's cultural and community contexts. For example, it might be appropriate to adjust a screener score for an AI/AN child by omitting information about *lack of eye contact*, if norms in that child's community are for children to avoid eye contact with their elders. Alternatively, a screener question about *climbing stairs* could be omitted if a child lives in a community where all homes and buildings are single story. Such adjustments reflect the importance of understanding the cultural and community context in which AI/AN children and families live. Research into optimal strategies for tailoring the use of existing screeners to meet the needs of AI/AN communities and training early childhood professionals to utilize existing tools with these populations is needed.

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Appendix A. Professional Key Informant/Focus Group Interview Guide

Appendix B. Parent Interview/Focus Group Interview Guide

Appendix C. Partnering with American Indian and Alaska Native Families to Support Children's Development

Appendix D. Supporting your Child through Developmental Screening from Birth to Age Five