ARTICLE

THE SURVEY OF WELL-BEING OF YOUNG CHILDREN: RESULTS OF A FEASIBILITY STUDY WITH AMERICAN INDIAN AND ALASKA NATIVE COMMUNITIES

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ABSTRACT: This study examined the feasibility of the Survey of Well-Being of Young Children (SWYC), a new screener for socioemotional and developmental problems and family risk in children birth to age 5 years, for use in American Indian and Alaska Native (AIAN) communities. A Community of Learning within the Tribal Early Childhood Research Center, composed of university researchers, tribal early childhood program staff and evaluators, and federal partners, utilized a community-based participatory research approach to guide this qualitative study. Thirty-two focus groups and 20 key informant interviews ($N = 199$) were conducted with staff from Head Start, Home Visiting, and Child Care programs; pediatricians; behavioral health providers; parents of young children; tribal leaders; and other stakeholders in seven diverse AIAN communities. Three themes emerged: (a) a strong *need* to screen early for socioemotional and developmental problems and family risk; (b) the importance of a carefully designed *process* for screening; and (c) the importance of examining the *content* of the SWYC for cultural fit specific to tribal communities. Findings support two recommendations: (a) the development of guidelines for using the SWYC in tribal early childhood settings and (b) a full-scale validation study to determine appropriate use with and norms for children in tribal communities.

Keywords: American Indian, Alaska Native, developmental screening, validity, culture

RESUMEN: Este estudio examinó la viabilidad de la Encuesta de Bienestar de Niños Pequeños (SWYC) – una formulación para detectar problemas socio-emocionales y de desarrollo, y los riesgos familiares en niños entre el nacimiento y los 5 años de edad – para ser usada en comunidades indígenas norteamericanas y aquellas nativas de Alaska (AIAN). Para guiar este estudio cualitativo, una Comunidad de Aprendizaje dentro del Centro de Investigación Tribal para la Temprana Niñez, compuesta por investigadores universitarios, miembros del personal del programa tribal de temprana niñez, y socios federales, utilizó un acercamiento de investigación participativo basado en la comunidad. Treinta y dos grupos de enfoque y 20 entrevistas a informantes claves (N = 199) se llevaron a cabo con el personal de los programas Head Start, de Visitas a Casa y de Cuidados Infantiles; pediatras; profesionales de la salud de la conducta; progenitores de niños pequeños; líderes tribales; y otros interesados en siete comunidades AIAN diversas. Tres temas salieron a la luz: (1) Una fuerte necesidad de detectar temprano los problemas socio-emocionales y de desarrollo y los riesgos familiares; (2) la importancia de un proceso de detección cuidadosamente diseñado; y (3) la importancia de examinar el contenido de SWYC y cómo se adapta a la cultura específicamente en comunidades tribales. Los resultados apoyan dos recomendaciones: (1) El desarrollo de lineamientos guía para usar SWYC en escenarios tribales de temprana niñez; y (2) un estudio de validación completo para determinar el uso apropiado, y las normas, con niños en las comunidades tribales.

Palabras claves: Indígenas Norteamericanos, Nativos de Alaska, detección de desarrollo, validez, cultura

The study protocol was reviewed by the University of Colorado's Multiple Institutional Review Board (COMIRB) and determined to be exempt from IRB review (COMIRB 13–1849). The study protocol also was reviewed and approved by each participating community, in accordance with each tribe's or urban Indian community's protocol for human subjects research. This study was supported by the Administration for Children and Families 90PH0017 (D.K. Novins, PI). The Survey of Well-Being of Young Children (SWYC) Community of Learning and Tribal Research Partners: Catherine C. Ayoub, Ed.D., M.N., Harvard Medical School, Brazelton Touchpoints Center, Boston Children's Hospital; Jessica Barnes-Najor, Ph.D., Michigan State University; Cathy Ferron, Tribal Home Visiting Evaluator, Lake County Tribal Health Consortium; Hiram E. Fitzgerald, Ph.D., Michigan State University; Kate Lyon, M.A., James Bell Associates, Inc.; Charmaine Lundy, Ed. M, Kuya Qyut'anen Early Childhood Center; Aleta L. Meyer Ph.D., Office of Planning, Research and Evaluation, Administration for Children and Families; Myra Parker, JD/Ph.D., University of Washington; Melina Salvador, M.A., James Bell Associates, Inc.; Melissa Walls, Ph.D., University of Minnesota Medical School-Duluth; Shirley Williams, Fairbanks Native Association.

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RÉSUMÉ: Cette étude a examiné la viabilité du Survol du Bien-Être des Jeunes Enfants (en anglais Survey of Well-being of Young Children, abrégé en anglais SWYC)— un nouvel outil de dépistage de problèmes socio-émotionnels et du développement et le risque familial chez des enfants de la naissance à l'âge de cinq ans — afin qu'il soit utilisé par les communautés autochtones d'Alaska (AIAN) et les communautés d'indiens d'Amérique. Une communauté d'Apprentissage au sein du Centre de Recherche sur l'Enfance Précoce Tribale, composée de chercheurs universitaires, d'employés et d'évaluateurs du programme tribal de l'enfance précoce, et leurs partenaires fédéraux américains, a utilisé une approche de recherche participatoire basée sur la communauté afin de guider cette étude qualitative. Trente-deux groupes d'étude et 20 entretiens avec des informateurs clés (N = 199) ont été mis en places avec des employés du programme américain d'aide à l'enfance défavorisée Head Start, ainsi que de Home Visiting et de crêches ; des pédiatres ; des professionnels de la santé du comportement ; des parents de jeunes enfants ; des chefs tribaux ; et d'autres parties prenantes au sein de sept communautés AIAN différentes. Trois thèmes ont émergé : (1) un besoin fort de détecter très tôt les problèmes socio-émotionnels, les problèmes de développement et le risque familial ; (2) l'importance d'un processus bien conçu pour le dépistage, et (3) l'importance qu'il y a à examiner le contenu du SWYC afin qu'il corresponde culturellement au contexte des communautés tribales. Les résultats soutiennent deux recommendations : (1) le développement de lignes directrices pour l'utilisation du dans les contextes de la petite enfance tribale ; et (2) une étude de validation à grande échelle afin de déterminer sa bonne avec les enfants des communautés tribales et des normes.

Mots clés: Indien d'Amérique, natifs d'Alaska, dépistage du développemen, validité, culture

ZUSAMMENFASSUNG: Diese Studie untersuchte die Durchführbarkeit des Survey of Well-being of Young Children (SWYC) – einem neuen Screeningverfahren für sozial-emotionale Probleme und Entwicklungsprobleme sowie für Familienrisiko bei Kindern von der Geburt bis zum Alter von fünf Jahren – für den Einsatz in Gemeinden aus Indo-Amerika und Alaska (Aian). Eine Lerngemeinschaft im Tribal Early Childhood Research Center, welche sich aus Hochschulforschern, Mitarbeitern und Gutachtern des Tribal Early Childhood Programms und Partnern des Bundes zusammensetzt, verwendete einen gemeindebasierten partizipativen Forschungsansatz, um diese qualitative Studie durchzuführen. Zweiunddreißig Fokusgruppen und 20 Interviews mit Hauptinformanten (N = 199) wurden mit den Mitarbeitern von Head Start -, Hausbesuchs-, und Kinderpflege-Programmen, Kinderärzten, psychologischen Beratern, Eltern von Kleinkindern, Stammesführern und anderen Beteiligten in sieben verschiedenen Aian-Gemeinden durchgeführt. Drei Themen wurden herausgestellt: (1) ein starker Bedarf an frühen Screenings für sozial-emotionale Probleme und Entwicklungsprobleme sowie Familienrisiko; (2) die Wichtigkeit eines sorgfältig gestalteten Screeningverfahrens und (3) die Wichtigkeit der inhaltlichen Prüfung des SWYC im Hinblick auf kulturelle Passung speziell für Stammesgemeinschaften. Die Ergebnisse unterstützen zwei Empfehlungen: (1) Die Entwicklung von Leitlinien für die Verwendung des SWYC in Stammesgemeinschaften und (2) eine umfassende Validierungsstudie, um eine angemessene Nutzung mit und Normen für Kinder in Stammesgemeinschaften zu definieren.

Keywords: Indo-Amerikaner, Ureinwohner Alaskas, Entwicklungs-Screening, Validität, Kultur

抄録: この研究では、幼児の福祉調査 (the Survey of Well-being of Young Children (SWYC)) をアメリカインディアンとアラスカ原住民(AIAN)コミュニティで利用するためのフィージビリティ(実現可能性)を検証した。SWACは、誕生から5歳までの子どもの社会情緒的問題と発達問題および家族のリスクのための新しいスクリーニングである。大学の研究者、部族の早期児童期プログラムのスタッフと評価者、および連邦政府のパートナーfederal partnerから構成される、部族の早期児童期研究センターthe Tribal Early Childhood Research Center内の学習コミュニティは、この質的研究をガイドするために、コミュニティを基盤とする関与研究アプローチを用いた。32の焦点グループと、20の主要な情報提供者インタビュー(N = 199)が、Head Start、Home VisitingおよびChild Care プログラムのスタッフ、小児科医、行動的健康提供者behavioral health providers、幼児の親、部族のリーダー、および7つの多様なAIANコミュニティのその他の利害関係者stakeholderによって実施された。3つのテーマが浮かび上がった: (1) 社会情緒的および発達上の問題と家族のリスクを早期にスクリーニングすることの強い必要性、(2) 注意深くデザインされたスクリーニングプロセスの重要性、そして(3)部族コミュニティに特異的な文化に適合させるようにSWYCの内容を調査することの重要性。所見から二つの勧告が支持された: (1) SWYC を部族の早期児童期という設定で用いるためのガイドラインを開発すること、および (2) 部族コミュニティの子どもたちに適切な利用法と基準値を決定するための、本格的な妥当性研究。

キーワード: アメリカインディアンAmerican Indian, アラスカ原住民Alaska Native, 発達スクリーニングdevelopmental screening, 妥当性validity, 文化culture

摘要: 本研究探討幼兒福祉調查(SWYC)的可行性 – 一個對由出生至五歲的兒童的社會情感和發育問題及家庭風險之新篩選 – 在美國印第安人和阿拉斯加原居民(AIAN) 社區使用。在部落的幼兒研究中心內的一個學習社羣, 由大學研究人員, 部落早期幼兒教育方案工作人員和評估員及聯邦合作夥伴組成, 社羣採用基於社區的參與性研究方法, 以指導這項定性研究。本研究在32個焦點小組和20個關鍵知情人訪談(N = 199) 中, 訪問了在Head Start, Home Visiting, and Child Care方案的工作人員; 兒科醫生; 行為健康服務提供者; 幼兒父母; 部落首領; 和在七個不同的AIAN社區之其他利益相關者。三個主題出現了: (1)強烈需要早期篩查社會情感和發育問題以及家庭的風險; (2)一個精心設計的篩選過程的重要性, 和(3)檢查SWYC的內容是否適合特定部落社區文化的的重要性。研究結果支持了兩項建議: (1)發展在部落幼兒環境使用SWYC的準則; (2)全面的驗證研究, 以確定如何在部落社區兒童中適當使用及建立規範。

關鍵詞: 美國印第安人, 阿拉斯加原居民, 發展篩選, 有效性, 文化

ملخص: تناولت هذه الدراسة جدوى استبيان عن رفاهية الأطفال الصغار (SWYC) – وهى أداة استقصائية جديدة لقياس مشكلات ومخاطر النمو العاطفية الاجتماعية لدى الأطفال من الولادة وحتى عمر 5 سنوات – تم تطويرها لتستخدم فى مجتمعات آلاسكا والهنود الحمر (AIAN) . وتقوم هذه الدراسة الوصفية على مجموعة من الباحثين الجامعيين وفريق عمل من برنامج الطفولة المبكرة القبلية وبعض الشركاء على المستوى الفيدرالى حيث شاركوا جميعا فى بحث مجتمعى لتوجيه هذه الدراسة . تم تشكيل 32 مجموعة نقاش و20 مقابلة شخصية مع العاملين فى (Head Start-Home Visiting) وغيرها من برامج رعاية الطفل وأطباء الأطفال ومراكز الصحة السلوكية وبعض الآباء وزعماء القبائل وغيرهم من أصحاب المصلحة فى سبع مجتمعات مختلفة للهنود الحمر وألاسكا . وقد أظهرت الدراسة ثلاثة مواضيع هامة : (1) الحاجة القوية للكشف المبكر عن المشاكل العاطفية الاجتماعية ومخاطر العائلة , (2) أهمية وجود آلية واضحة للكشف عن هذه المشاكل , (3) أهمية مراجعة محتوى الاستبيان(SWYC) ليتناسب ثقافيا مع المجتمعات القبلية . وتدعم النتائج هذه التوصيات (1) تطوير دليل إرشادى لاستخدام الاستبيان مع صغار الأطفال فى المجتمعات القبلية و (2) القيام بأبحاث على نطاق واسع لتحديد معايير الاستخدام الأمثل مع الأطفال فى المجتمعات القبلية .

كلمات مفتاحية : الهنود الحمر , سكان آلاسكا الأصليين , فحص النمو , الصلاحية , الثقافة

* * *

EXTENDING THE REACH AND BREADTH OF DEVELOPMENTAL SCREENING

Current estimates have suggested that about 20% of children suffer from developmental delays, behavioral problems, or both (Boyle, Decoufle, & Yeargin-Allsopp, 1994; Briggs et al., 2012). Early problems include intellectual and developmental disabilities, autism spectrum disorders, speech and language impairments, learning disabilities, attention deficit disorders, and socioemotional/behavioral dysregulation (Boyle et al., 1994). There is substantial evidence that early detection, referral, and treatment can significantly reduce the long-term impact of these kinds of problems and promote better outcomes for children (Durlak & Wells, 1998; Elliot, Prior, Merrigan, & Ballinger, 2002; Gomby, Larner, Stevenson, Lewitt, & Behrman, 1995). Failure to detect problems before school entry, in contrast, is associated with the solidification or escalation of early problems that become increasingly intractable over time (Kruizinga, Jansen, Carter, & Raat, 2011).

Despite the availability of tools that can alert parents and providers[1] to the early signs of socioemotional or developmental delays, many problems go undetected until children enter school. Research has suggested that only about one third of children with developmental or socioemotional problems are identified before kindergarten and that children with socioemotional problems in particular are especially underidentified (Sand et al., 2005). Early socioemotional problems are associated with negative health outcomes later in life, including depression, oppositional defiant or conduct disorder, poor peer relationships and social skills, internalizing and externalizing problems, poor academic performance, and psychiatric problems (Briggs-Gowan & Carter, 2008; Campbell, Shaw, & Gilliom, 2000; Campbell, Spieker, Burchinal, & Poe, 2006; Fox, 2004; Hakman & Sullivan, 2009; Mesman & Koot, 2001; Shaw, Keenan, & Vondra, 1994). Increased early identification of these problems could result in more timely interventions and the reduction of problems throughout life.

Growing evidence for the importance of early detection of social, emotional, and behavioral problems has recently led the American Academy of Pediatrics to expand previous recommendations to screen for autism spectrum disorders and language, motor, and cognitive delays to include routine screening for socioemotional problems (American Academy of Pediatrics, 2001, 2006). Two recent federal initiatives have been launched to support the expansion of both the reach of early developmental screening (with the goal of *universal* screening of all American children) and the breadth of screening (with the target of *comprehensive* screening for developmental, behavioral, and socioemotional problems in early childhood). Those initiatives include *Birth to 5: Watch Me Thrive* (Administration for Children and Families 2014) and *Learn the Signs. Act Early* (Centers for Disease Control and Prevention 2004). Both programs provide resources for parents and early childhood service providers to facilitate the earlier identification of problems and to support parents in getting their children the help they need for positive developmental outcomes.

STRATEGIES FOR EFFECTIVE SCREENING IN EARLY CHILDHOOD

The success of recommendations such as those of the American Academy of Pediatrics (2001, 2006) or of initiatives such as *Birth to Five: Watch Me Thrive* 2014 and *Learn the Signs. Act Early* 2004 depends on ensuring that parents and providers have access to accurate and comprehensive screening tools to identify socioemotional and developmental problems early in life. Three critical components of this statement are highlighted here.

First, developmental screening tools must be *accessible* with respect to ease and cost of use. A valid screening tool cannot be effective if it is not accessible to parents and providers for use with young children. According to the Council on Children with Disabilities (American Academy of Pediatrics, 2006), there are four key barriers to access: (a) screening instruments that take too long to complete, (b) screening instruments that require specific props (e.g., blocks or puzzles), (c) administration or scoring procedures

[1]The term *providers* is used to refer broadly to professionals who provide services to families and children. This term includes pediatricians and other medical staff; Head Start/Early Head Start program staff; Maternal, Infant, and Early Childhood Home Visiting program staff; Child Care Development Fund program staff; social workers; WIC staff; and any other local program serving children and families.

that require specialized training, and (d) expenses such as fees for use or cost of materials. Most screening tools include at least one of these logistical barriers, and many include all four. Therefore, for screening to be done consistently, screening tools must be brief, simple to administer and score, and inexpensive. Valid, yet easy and inexpensive, screeners stand a greater chance of integration into existing services and reaching the greatest number of children. The need for screeners that are easy to use and inexpensive may be especially critical for tribal communities that often struggle with limited professional and financial resources to meet the demand for early childhood services.

Second, *accurate screening tools* are required. To be accurate, screening tools must detect problems in development with sufficient sensitivity (detecting problems when they exist) and specificity (not detecting problems when they do not exist). To do so, they must be reliable (internally consistent, consistent between raters and over time) and valid (detect true phenomena). Rigorous measure development includes careful attention to these characteristics; and screeners[2] in common use are backed by extensive psychometric analysis of data collected from large and diverse samples, which allows for generalizable conclusions about measure integrity. As screening efforts are expanded, however, research is warranted to examine the appropriateness of screening tools for use within specific diverse populations. This concern is especially relevant for tribal populations since they are rarely included in normative samples to any meaningful degree or often are not included at all. Such research will play a critical role either in documenting the psychometric soundness of existing screeners for use with specific diverse populations or in informing adaptations where needed to fit specific populations.

Third, screening tools that are *comprehensive* with respect to the areas of development and the age range with which they can be used are required. Many existing screeners are domain-specific, focusing on only one area of development and necessitating the use of multiple screening tools to comprehensively assess the full range of children's cognitive, language, motor, and socioemotional development (Sheldrick, Merchant, & Perrin, 2011). Many existing screeners also are limited in the age range with which they can be used, necessitating that providers stitch together a series of different screeners to assess children's development throughout the preschool years (birth–5 years). The lack of comprehensiveness of many screeners can necessitate the use of multiple screeners, resulting in a complex matrix of tools that must be navigated by busy providers already juggling multiple demands. The lack of comprehensive screeners is therefore a barrier to effective screening in early childhood.

RECENT INNOVATIONS IN SCREENING TOOLS: THE SURVEY OF WELL-BEING OF YOUNG CHILDREN

The Survey of Well-being of Young Children (SWYC) was developed with these challenges in mind, with the goal of providing a valid, comprehensive, and easily accessible screening tool for use with children from birth to 5 years of age. The SWYC is brief, publicly available, and easy to administer and score; it can be integrated into pediatric well-child visits and compares favorably in terms of reliability, validity, sensitivity, and specificity with longer, more specialized screeners that are widely in use (Achenbach, 1992; Squires & Bricker, 2009, 2014). The multiple, but interrelated, forms support continuity in screening from birth to 5, facilitating surveillance of children's development as it unfolds over time.

Overview of the SWYC

There are 12 SWYC forms, one corresponding to the age at each recommended pediatric well-child visit schedule between 2 and 60 months of age (i.e., 2, 4, 6, 9, 12, 15, 18, 24, 30, 36, 48, and 60 months). Each of the 12 forms includes three sections: *Development*, *Behavior*, and *Family Questions*. Items in the Development and Behavior sections are tailored to the developmental level of children at that specific age.

Table 1 provides an overview of the three SWYC sections and their component parts at each age. As detailed in Table 1, the Development section includes two parts: "Milestones" is a set of 10 items inquiring about motor, language, and cognitive milestones appropriate for the age range of the form (Sheldrick & Perrin, 2013); "Parent's Observation of Social Interactions" (POSI) is a seven-item autism screener included on the 18-, 24-, and 30-month forms (Smith, Sheldrick, & Perrin, 2013). The Behavior section includes one of two *Pediatric Symptom Checklists*: the 18-item Baby Pediatric Symptom Checklist (BPSC; Sheldrick, Henson, Neger et al., 2012) for children 2 to 18 months of age or the 25-item Preschool Pediatric Symptom Checklist (PPSC; Sheldrick, Henson, Merchant et al., 2012) for children 18 months to 5 years. Items in the Family Questions section are the same on all 12 SWYC forms and assess parent/caregiver and household substance use (i.e., tobacco, alcohol, and drug use) (Brown, Lent, Brett, Sas, & Pederson, 1996; Brown, Leonard, Saunders, & Papasouliotis, 1997, 2001; Winickoff et al., 2008), food insecurity (Black, Hager, Merry, & Quigg, 2008), parent/caregiver depression (McManus, Pipkin, & Whooley, 2005) via the Patient Health Questionnaire 2 (PHQ2; Kroenke, Spitzer, & Williams, 2003) and domestic violence risk via the Woman Abuse Screening Tool Short Form (WAST-SF; Brown, Lent, Schmidt, & Sas, 2000). Two additional items on every SWYC form assess parent/caregiver concern about the child's learning and development or about the child's behavior.

Validation of the SWYC

SWYC developers at the Floating Hospital for Children at Tufts Medical Center conducted a series of studies to validate the two

[2]The terms *screener* and *screening tool* are used interchangeably to refer to the measurement instruments used to screen for potential problems.

TABLE 1. *Components of the SWYC Included Across the 12 Forms (2–60 months)*

	Development		Behavior		Family Risk
Child Age (in months)	Milestones[a]	Parents Observations of Social Interactions (POSI)	Baby Pediatric Symptom Checklist (BSPC)	Preschool Pediatric Symptom Checklist (PPSC)	Family Questions
2	√		√		√
4	√		√		√
6	√		√		√
9	√		√		√
12	√		√		√
15	√		√		√
18	√	√		√	√
24	√	√		√	√
30	√	√		√	√
36	√			√	√
48	√			√	√
60	√			√	√

SWYC = Survey of Well-Being of Young Children.

parts of the Development section—Milestones (Sheldrick & Perrin, 2013) and the POSI (Smith, Sheldrick, & Perrin, 2013)—and the BPSC and the PPSC included in the Behavior section (Sheldrick, Henson, Merchant, et al., 2012). The third SWYC section, Family Questions, consists of items validated elsewhere (Black et al., 2008; Brown et al., 1996; Brown et al., 2000; Brown et al., 1997, 2001; McManus et al., 2005; Winickoff et al., 2008). In these validation studies, the SWYC compared favorably with existing screeners, including the Ages and Stages Questionnaire, Third Edition (ASQ-3; Squires & Bricker, 2009), the ASQ Social/Emotional (ASQ-SE; Squires & Bricker, 2014), the Child Behavior Checklist (CBCL; Achenbach, 1992), and the Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999a, 1999b; Robins, Fein, Barton, & Green, 2001). Validation studies involved families in the greater Boston area, with sample sizes ranging from 259 to 777 across the component studies.

INCLUDING AMERICAN INDIAN AND ALASKA NATIVE[3] CHILDREN IN SCREENING INITIATIVES

Universal developmental screening is important for all groups of children in the United States, including American Indian and Alaska Native (AIAN) children. The unique context of child development in AIAN communities must be considered, however, to know how screening efforts can be most effective. The broader context of children's development in tribal communities is discussed here, with a particular focus on the developmental challenges and supports for tribal children within their communities and within historical and contemporary cultural context. This section concludes by highlighting specific considerations for screening Native children.

[3]The terms *American Indian and Alaska Native* (*AIAN*), *Native*, and *tribal* are used interchangeably throughout this document, to refer inclusively to the diverse reservation and urban Native populations in the United States.

Developmental Challenges and Supports in Tribal Communities

AIAN children come from diverse tribal nations across the United States. With more than 600 federally or state-recognized tribes, and a large percentage of the population living in urban areas, there is tremendous diversity in cultural and community supports for young children's development and in the challenges that young AIAN children and their families face. A review of the limited national data indicates that as a whole, AIAN children are more likely to experience poverty, child abuse and neglect, accidental injury and death, out-of-home placement, family and community violence, and parental/caregiver substance abuse than are their non-Native peers (Duran et al., 2004; Koss et al., 2003; LaFromboise & Graff Low, 1989; Lujan, 1989; Patel, Wallace, & Paulozzi, 2005; Piasecki et al., 1989; Robin, Chester, Rasmussen, Jaranson, & Goldman, 1997). AIAN communities are the poorest in the nation, with low rates of academic achievement and high rates of unemployment (Kilborn, 1992; National Center for Education Statistics, 1997; U.S. Census Bureau, 2000). Rates of violent victimization and domestic violence are higher than those in other groups (Amnesty International USA, 2006; Bachman, 1992; Bohn, 2003; Manson, Beals, Klein, Croy, & The AI-SUPERPFP Team, 2005; Rennison, 2001; Tjaden & Thoennes, 2000), and health disparities are large (Indian Health Service, 2015). Poverty, abuse, out-of-home placement, and parental substance use are well-documented risk factors for development, especially given the impact of these early adversities on brain development across the life span (Shonkoff & Bales, 2011; Shonkoff, Boyce, & McEwen, 2009). Some of the few studies of AIAN children's early socioemotional and cognitive development have suggested early delays in language and cognitive development and early behavior problems in the populations sampled (Sarche, Croy, Crow, Mitchell, & Spicer, 2009). Early intervention services for AIAN children are extremely limited, reflecting both an overall shortage of mental and other health services in AIAN communities (Duran et al., 2005; Gone, 2004; James,

Schwartz, Berndt, & Foundation, 2009; Johnson & Cameron, 2001; Katz, 2004; Manson, 2000; Novins, Beals, Sack, & Manson, 2000; U. S. Commission on Civil Rights, 2003) and extremely limited research into culturally informed intervention models for Native children and their families (Sarche & Spicer, 2008).

In these contexts, sources of developmental risk are greater, making the call for universal developmental screening all the more urgent. It is critical, however, that developmental screening efforts take into account the historical, cultural, community, and familial contexts in which AIAN children develop. First, AIAN communities in the United States continue to experience the repercussions of historically traumatic events driven by past federal policies to assimilate Native people into mainstream society and eliminate their existence as a distinct cultural group. Children were targeted for removal from their families and communities into government- and missionary-run boarding schools that severely limited their contact with families and communities and forbade them from practicing their culture or speaking their language (Adams, 1995; Beiser, 1974; Campbell & Evans-Campbell, 2011; Sarche & Whitesell, 2012). Boarding schools devastated not only the boarding school children and their families but future generations as well, through disrupted parenting and destabilized culture passed down through the generations. The effects remain in familial and social struggles in tribal communities today (Beiser, 1974; Giago, 2006).

Family and community structures were further undermined by high placement rates of AIAN children into foster and adoptive families by social service systems that were poorly informed about Native parenting practices and more likely to remove Native than non-Native children from their homes (LaFromboise, Trimble, & Mohatt, 1993; Suina & Smolkin, 1994). Native children removed from their homes, particularly those placed into non-Native homes, suffered long-term consequences such as substance abuse, depression, and higher rates of losing their own children to out-of-home placement (Brave Heart & Spicer, 2000; Spicer, 1998; Westermeyer, 1977).

Despite the tremendous hardships faced by AIAN communities, both historically and today, their rich cultural heritage is a source of support and strength for children and families. AIAN communities of diverse tribal backgrounds view children as sacred gifts from the creator (Brave Heart & Spicer, 2000; Jacobs, 1995; Lee & Armstrong, 1995; Spicer & Sarche, 2007). Children grow up surrounded by extended kin networks where interdependence, reciprocity, and obligations to care for one another are emphasized (LaFromboise et al., 1993). Intergenerational relationships in AIAN families provide opportunities for elder members of the family to pass down tribal stories and practices that convey values by which to live (Suina & Smolkin, 1994). Through participation in traditional ceremonies, AIAN children gain a further sense of belonging and identity not only within their families but within their communities and culture as well. These cultural assets are thought to buoy AIAN children against developmental challenges, and evidence in the literature to support such cultural resiliency is emerging (Jumper-Reeves, Dustman, Harthun, Kulis, & Brown, 2014; Pewewardy, 2002).

Developmental Screening of Native Children

Understanding the unique context of child development in AIAN communities raises important considerations for screening efforts. First, it highlights the need for screeners that are attuned to this unique context. While researchers are working with localized tribal communities to ensure that assessments are culturally appropriate, reliable, and valid (Barlow et al., 2013; Barlow et al., 2015), these efforts are more the exception than the rule. Very little is known about how measures work with children in diverse tribal communities around the country. No screening measures—or measures of early development of any kind–to our knowledge have been created or validated specifically for use with tribal children. Measures are typically standardized with ethnically and culturally diverse samples to increase generalizability. These standardization samples rarely include many AIAN children, however, and when they do, they do not include sufficient numbers of AIAN children to support conclusions about the reliability, validity, sensitivity, or specificity of screeners for this population. As a result, evidence is lacking about whether the established measures currently being used in tribal communities contain content that is appropriate for use with AIAN children or whether scoring guidelines and norms are appropriate (Beals, Manson, Mitchell, Spicer, & AISUPERPFP-Team, 2003). Rigorous measurement studies are needed before developmental screening of AIAN children can proceed with confidence.

In addition to the lack of validated measures, access to developmental screening is another challenge in tribal communities. The service ecologies of many reservation, rural, and urban tribal communities are often underfunded relative to need; struggle to recruit and retain providers (particularly those with specialized training); and include multiple contract service providers delivering care that may or may not be coordinated (Freeman, Iron Cloud-Two Dogs, Novins, & LeMaster, 2004; Gone & Trimble, 2012; Novins & Bess, 2011; Novins, Fleming, Beals, & Manson, 2000). As a result, individuals may face difficulties in accessing these services due to long wait times to see the appropriate provider, the lack of coordination among providers, and challenges of their own (e.g., transportation). Ensuring the broad reach of developmental screening in this service ecology can therefore be challenging despite the tremendous need to do so. Efforts to broaden the reach of developmental screening must therefore take these factors into account.

THE SWYC TRIBAL FEASIBILITY STUDY

Given the promise of the SWYC in general and the lack of any systematic data on developmental screening in tribal contexts, the current study explored three issues: (a) the perceived need for early screening in tribal communities, (b) the feasibility of implementing the SWYC in tribal early childhood service settings, and (c) the cultural appropriateness of the SWYC in tribal communities. The study was conducted by the Tribal Early Childhood Research Center (TRC), at the request of and with support from the Administration on Children and Families (ACF). The TRC is funded to (a) engage in a participatory process of consultation with key

stakeholders and collaboration with tribal Head Start/Early Head Start (HS/EHS), Maternal, Infant, and Early Childhood Home Visiting (MIECHV), and Child Care Development Fund (CCDF) programs to foster a community of learning; (b) support and conduct research and measurement development; (c) enhance program evaluation and research-to-practice activities; (d) broadly disseminate the findings of the TRC; and (e) train the next generation of researchers to work effectively with HS/EHS, MIECHV, CCDF, and other early childhood programs in AIAN communities. Integral to these efforts has been the creation of Communities of Learning (CoLs) composed of TRC researchers, tribal community partners, other university researchers, and ACF program staff; one of these CoLs guided the SWYC Tribal Feasibility Study (discussed next). To our knowledge, this work was one of the only efforts (if not the only effort) to systematically engage tribal communities nationally in assessing the appropriateness of a developmental screener for use with tribal populations before recommending that it be used broadly in these contexts. This exploratory groundwork was critical to providing guidance on how the SWYC might be used in tribal communities, informing adaptations that might be necessary, and assessing the need for a validation study in this population.

METHOD

This study was funded by the ACF Office of Planning Research and Evaluation, under Grant 90PH0017 to the TRC (D.K. Novins, PI). The study protocol was reviewed by the University of Colorado's Multiple Institutional Review Board (COMIRB) and determined to be exempt from COMIRB review. The study protocol was reviewed and approved by each participating tribal community, in accordance with each tribe's or urban Indian community's protocol for human subjects research.

The TRC CoL

As noted earlier, the TRC's CoLs are a cornerstone of our tribal early childhood research. The creation of CoLs is consistent with a statement by the National Congress of American Indians that the responsible conduct of research with tribal nations includes education around interpreting and understanding data and research (NCAI Policy Research Center and MSU Center for Native Health Partnerships, 2012). It also is consistent with guidelines published by the Children's Bureau regarding effective evaluation practice in tribal communities, guidelines that are equally relevant to research with tribal communities and that prioritize efforts to support tribal capacity for research through mentoring and collaborative projects (Tribal Evaluation Workgroup, 2013).

The SWYC CoL was one of the three active TRC CoLs and was dedicated to the collaborative design and implementation of the current study as well as to the writing of this report. It is composed of partners in academia and in tribal HS/EHS, MIECHV, and CCDF programs that share an interest in both screening and measurement issues. The SWYC CoL played a central role in study development, implementation, and analysis. Monthly CoL meetings were held via telephone conference, with the lead research team providing updates to members about project progress and soliciting input on next steps in the data-collection process and, eventually, interpretation of the findings and report writing. CoL members whose communities participated in the study served as key contacts, facilitating tribal approval processes as well as data-collection logistics. A draft of the final report and key themes was reviewed with the CoL; the final report included revisions based on their feedback.

Sample

Drawing on the relationships within the TRC, and the SWYC CoL in particular, seven tribal communities were purposively recruited to participate in this study; all shared an interest and willingness to contribute to our knowledge of developmental screening in tribal communities. All participating communities were HS/EHS, MIECHV, and/or CCDF grantees, and all had existing ties to the TRC because of these programs. Two communities were in the upper Midwest (reservation); two in the Southwest (reservation, urban); and one each in the Southeast (rural), Northwest (urban), and Alaska (rural). As a part of our confidentiality agreements with participating tribal communities, individual tribes or tribal organizations are not named; participating communities are referred to by regional descriptors (Norton & Manson, 1996).

In all, 199 individuals in these seven tribal communities participated in a total of 32 focus groups (FGs) and 20 key informant interviews (KIIs). Within each community, participants were purposively selected in consultation with community research partners to represent a range of early childhood stakeholders including pediatricians, nurses, nurse practitioners, mental health providers, teachers, school principals, child welfare workers, social workers, dentists, emergency medical technicians, tribal government officials, parents, and staff from a variety of programs such as HS/EHS, CCDF, MIECHV, tribal court, Indian Child Welfare, Indian Health Service, health boards, human services, behavioral health, family services, and Women, Infants, and Children (WIC). Interviews in communities included both Native and non-Native participants; in some communities, the vast majority of participants were tribal members; in others, a substantial number were non-Native service providers living and working in the community. Tribal elders participated in interviews and focus group discussions; elders did not meet separately as a group in any of the communities. Not all of these stakeholders were involved in every community; rather, the kinds of stakeholder groups included in a given community depended on the relevance of a given stakeholder group within the service ecology of each community, as determined by our local research partners.

Across all communities, participants welcomed the opportunity to share their perspectives on a new developmental screening tool that had potential applications in their communities. Participants often expressed appreciation for the opportunity to do so, given the more typical experience of new tools being promoted, or even imposed, without consideration for the relevance, reliability,

TABLE 2. *Participants by Community*

Community	Region	Type	Participants	Focus Groups	Key Informant Interviews
1	Midwest	Reservation	29	5	3
2	Midwest	Reservation	29	5	4
3	Southwest	Urban	5	0	3
4	Southwest	Reservation	33	6	0
5	Southeast	Rural	31	6	5
6	Alaska	Rural	54	8	2
7	Northwest	Urban	18	2	3
Total			199	32	20

or validity within tribal contexts. Table 2 shows the distribution of participants across communities and type of interview.

Procedures

In each community, a local research partner assisted the TRC research team in recruiting participants and scheduling the FGs and KIIs. In some communities, the local research partner took the lead on scheduling and arranging all interviews; in other communities, the local research partner made initial contacts with potential participants and introduced them to the TRC team, who then made follow-up contacts and scheduled interviews. In all communities, the local research partner also was a participant in at least one FG or KII. Recruitment letters explaining the purpose of the study and background information on the SWYC and sample SWYC forms (12- and 24-month versions) were sent via e-mail or hand-delivered to prospective participants.

FGs and KIIs were held in central locations in the participating communities, such as community halls, health clinics, HS or Child Care centers, social services offices, or the participants' own workplaces. FGs and KIIs were conducted by three members of the TRC team at the University of Colorado Anschutz Medical Campus (Drs. Sarche and Whitesell, Ms. Trucksess) with assistance from a TRC colleague at Michigan State University (Dr. Jessica Barnes-Najor). With the FGs, the goals of the study were explained to all participants. Participants were informed that participation was voluntary, that individual-level responses would be kept confidential, and that their tribal community would not be identified by the research team in presentations or reports. Participants were given an opportunity to ask questions about the study and about their participation. All participants gave the research team verbal permission to record the interviews. Written documentation of consent was not required by COMIRB review (exempt status) nor in most participating communities; written consent was obtained in one community according to tribal approval stipulations.

For KIIs, participants were given copies of the 12- and 24-month SWYC surveys at the beginning of each interview; copies of all 12 forms were made available for those who wished to review the entire set. Research team members began each session by explaining the goals of the study, reviewing the SWYC instrument and explaining its components and purpose, and then asking for participants' impressions about the measure. Facilitators followed Interview Guides (see Appendix A for providers and Appendix B for parents) to ensure that a core set of questions about the SWYC were addressed in each interview. KIIs and all FGs included a lead facilitator and at least one note-taker, except in three interviews where a designated note-taker was not present. In that case, digital recordings were reviewed by a research assistant who created additional notes of those discussions.

Data Analysis

Notes-based analysis was used in this study, which included notes from FG and KIIs; debriefing sessions; and summary reports from moderator, assistant moderator, and other study team personnel (Krueger, 1994). A qualitative constant comparison analysis was employed (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987). The three major stages of this type of analysis included open coding, axial coding, and selective coding (Strauss & Corbin, 1998). The third author took primary responsibility for initial analysis and determination of codes along with consultative and reflexive team analysis. The analysis process was systematic and verifiable (Krueger, 1994). A systematic, three-step process was followed at the culmination of each community visit. First, the facilitator and note-taker(s) debriefed within a couple hours after the interview to share observations and highlight key topics. Second, the third author created an initial summary report of key points and main topics discussed in each interview. Third, all notes were compiled for each FG or KII. Audio files were spot-checked and reviewed systematically to ensure that notes from each session were complete with respect to key themes.

Following this initial review and compilation of notes, a spreadsheet was created to organize all codes by community. The first step of the analysis was done with open coding, and data were sectioned into small units along margins of notes pages. The second stage of axial coding was an iterative process, which was conducted after the first two community visits and revisited after data-collection visits in each subsequent community. At this stage, small units were collapsed into categories. Also at this stage, all authors reviewed emerging categories and arrived at mutually agreeable themes and subthemes; these themes were reviewed and revised based on new data collected at each site. After all site visits were complete, the final stage of analysis consisted of selective coding in which all categories were condensed into main themes and subthemes.

RESULTS

As stated, the goals of this study were to assess (a) the need for early socioemotional and developmental screening in tribal communities, (b) the feasibility of implementing the SWYC in tribal early childhood service settings, and (c) the cultural appropriateness of the SWYC for use with tribal children. Our analysis of the

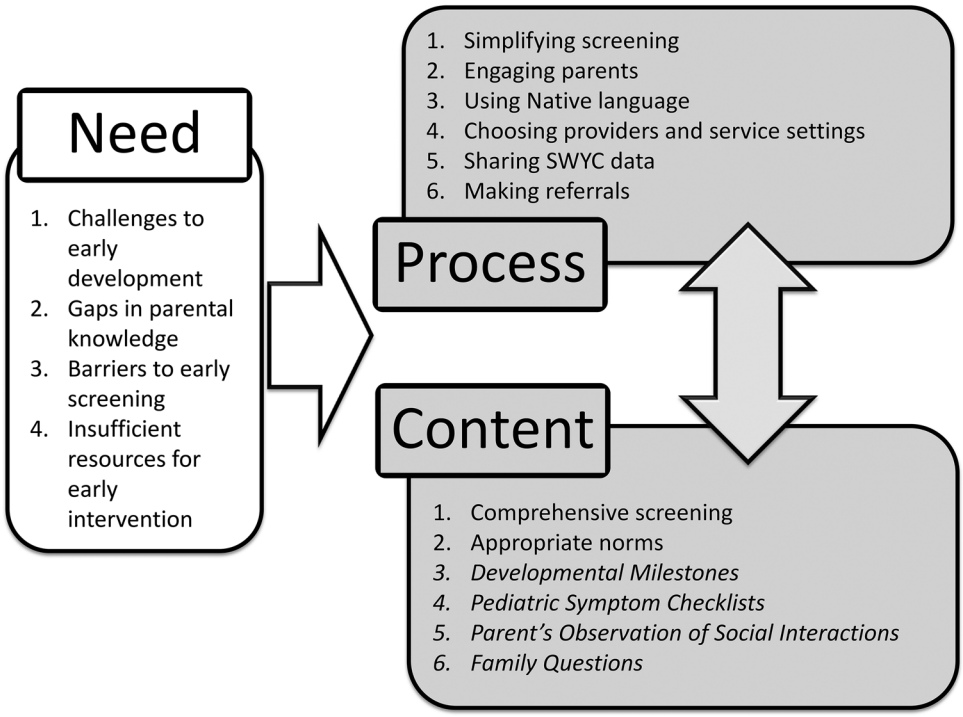

FIGURE 1. Key themes and subthemes from analysis of focus group discussions and key informant interviews in seven tribal communities.

FG and KII discussions resulted in three broad themes related to the study goals: (a) There is a need for developmental screening in tribal communities; the SWYC is promising for meeting that need, but (b) process considerations will be important in implementing the SWYC (or any other developmental screener) in tribal contexts, and (c) content considerations will be critical to interpreting the SWYC when used with Native children. As depicted in Figure 1, these three key themes were strongly interrelated. As a result, subthemes were often difficult to place within a single theme. For example, some subthemes within the Need theme are later revisited in relation to Process (i.e., addressing Barriers) or contextualized in reflections on *Content*. In addition, some themes that emerged under both Process and Content spoke directly to the ways the SWYC was seen potentially meeting *Need* (e.g., Simplifying screening under Process and Comprehensive screening under Content).

Need for Developmental Screening in Tribal Communities

Participants in all communities were in agreement regarding the need for increased developmental screening and early intervention in tribal communities. Four subthemes related to Need included challenges to early development, gaps in parental knowledge about child development, barriers to early screening, and insufficient resources for early intervention (described next).

Challenges to early development. The first subtheme under Need echoed what the literature has documented about the developmental challenges that children in tribal communities face. While variation existed across communities regarding the nature of specific concerns and the frequency with which they were mentioned, several common concerns emerged: lack of economic resources, family disruption, housing instability and overcrowding, family and community substance-use problems, exposure to stress and trauma, health disparities, isolation, and the lack of early childhood services. Reflecting on the importance of addressing problems early, adult mental health care providers shared a long view of socioemotional and behavioral problems, observing that many of the adults with whom they worked had difficulties that began early in life and that early intervention might have prevented lifetimes of struggle.

Common sources of support for child development in tribal communities also were shared, including strong cultural values, intergenerational and interdependent family structures, and community commitment to children. Many participants reflected on the importance of recognizing these strengths and the important role that they play in balancing risk for children in their communities.

Gaps in parental knowledge about child development. The second Need subtheme emerged as both providers and parents noted that parents of young children often did not know what to expect developmentally and lacked a frame of reference for what was normal relative to other children. The gaps in parental knowledge were often raised with regard to young, first-time parents. In some communities, gaps in parental knowledge were attributed to the fact that families living in more isolated areas had less

interaction with other children and families. Many participants suggested that screening would provide a structured opportunity for dialogue about developmental milestones and about age-appropriate behavior, emotional expression, and social interaction. Others noted the potential for the Family Questions to make parents aware of how their behavior might affect their children, suggesting that even if parents would not answer these questions honestly because of their sensitive nature, being asked about these risk factors as a part of developmental screening might plant seeds that would encourage them to consider seeking help.

Barriers to early screening. Another subtheme related to Need for screening concerned barriers that make screening difficult in tribal communities. The first type of barrier noted was limited access to services, which in turn meant fewer opportunities for screening to take place. In many communities, limited access was the result of few pediatric specialists (particularly in behavioral health). In other communities, the geographic distance between services and families coupled with transportation challenges posed a barrier to access services. Environmental risk for developmental or socioemotional problems combined with service access barriers made it less likely that screening would have a broad reach. As a result, participants said that identification of children with developmental or socioemotional problems was often delayed until children entered school at age 5 or 6 years of age. Many participants noted the importance of screening children early in life and, if indicated, connecting them with services to support optimal development.

Another barrier to developmental screening concerned the screening tools themselves. The most common screener that participants reporting using was the ASQ, sometimes along with the ASQ:SE; other commonly used screeners included the Learning Accomplishment Profile (Chapel Hill Training Outreach, 2004), the Strengths and Difficulties Questionnaire (Goodman, 1997), the Developmental Assets Profile (Search Institute, 2004), the Developmental Indicators for the Assessment of Learning (Mardell-Czudnowski & Goldenberg, 1983–1998), the Devereux Early Childhood Assessment (LeBuffe & Naglieri, 1999a; LeBuffe & Naglieri, 1999b), and the M-CHAT. In discussing their experiences with these screeners, participants expressed frustration with the length of time that they required, the cost of the materials necessary, the need to use multiple tools for comprehensive screening and across service settings, and uncertainties about the appropriateness of standardized measures and scoring criteria for tribal children. Participants noted that the ASQ in particular took parents more than 1 hour to finish and that providers often had to follow up with parents to ensure its completion. Parents complained about not having enough time to complete all the forms required of them, especially when multiple screeners were used to assess different developmental concerns (e.g., the ASQ, the ASQ-SE, the M-CHAT) or across different service providers (e.g., HS and Indian Health Service). Participants noted that the cost to purchase screening materials and train providers in their use can be prohibitive for tight program budgets. Finally, a few providers noted that the screeners that they were using had not been validated with tribal children, and they were therefore uncertain about how much to trust the scores within this population.

Despite concerns about screening tools in use, participants often reported general satisfaction with the screeners that they were using. One participant noted how administration of the ASQ during a home visit offered the chance to discuss a child's development in a detailed way with parents and that the length (and comprehensiveness) of the tool therefore was a strength in this regard.

Insufficient resources for early intervention. The fourth subtheme within Need highlighted the lack of resources for intervention available to children who might screen positive. In some communities, providers were confident that resources were available for referral and intervention when needed; in others, however, participants expressed concern that early screening would identify problems that could not be addressed due to limited intervention resources. Many suggested that screening in the absence of resources to address the concerns that could be raised by screening would be worse than not screening at all. One participant emphasized this point when stating "with screening comes responsibility." Some participants, however, felt that screening, even without the resources to fully address the problems that would be identified, could be important for documenting need and arguing for resources.

Process Considerations

Discussions with both providers and parents across all communities were rich with insights into how the SWYC should (or should not) be administered for maximal effectiveness. These insights included reflections on how the SWYC generally fits well within their communities as well as how some administration procedures may need to be adapted. These reflections on how the SWYC should be administered were encompassed under the broad theme of Process Considerations for detailing who should administer the SWYC, where (i.e., in what setting) it should be administered, how it should be presented to parents, and what should be done with SWYC findings. These considerations were critical because effective use of the SWYC would result in more children being screened, more parents being informed, and earlier treatment of developmental and socioemotional problems to maximize the potential for optimal development. While our discussions were about the SWYC specifically, the considerations raised by participants can be applied to the implementation of almost any developmental screener in tribal communities. Six subthemes emerged within the broader theme of Process Considerations.

Simplifying screening. Participants in every community were enthusiastic about the SWYC's ease of use relative to other screeners. Both providers and parents appreciated the SWYC's brevity, which promised to help overcome one of the barriers to developmental screening that they had noted. Participants noted that parents often did not complete existing screeners carefully or at all because of their length. The fact that the SWYC was free to use also was important, brought up most often in communities where concerns

about limited resources also were mentioned. Several providers across communities also noted the advantage of having a screener that is easy to administer and score, did not require advanced training for providers, or did not involve lengthy scoring procedures. Some participants also commented that the visual graphing of scores could be useful in communicating the scores both to parents and providers and in tracking development over time. Note that the SWYC's extreme ease of use also may be a liability. Some providers were so enthusiastic about its ease of use that they were ready to rush to its use without thinking through the process and content considerations raised by other participants. The SWYC's ease of use therefore makes it vulnerable to being used inappropriately. A widely disseminated set of detailed guidelines for the SWYC's use in tribal contexts will therefore be critical to mitigate this risk.

Engaging parents. One Process Consideration that was shared in every tribal community and almost every FG or KII was the critical importance of ensuring that parents were full partners in screening efforts. This concern was reflected in a variety of comments that essentially reflected a lack of parental trust and hesitance to share information. Many participants emphasized the importance of telling parents how the SWYC results would be used before asking them to complete it. They were concerned that parents would not answer SWYC questions honestly due to fears about who would see the information and how it could impact them or their children. Parents expressed concerns that their responses on the SWYC would make them or their child "look bad." One parent stated, "Putting this on paper is scary"—meaning that there would be written documentation of their concerns that could be used in ways that they could not foresee. For example, many participants expressed concerns about Indian Child Welfare becoming involved and children being taken away based on SWYC responses. This fear reflected the painful history of child welfare in tribal communities and the reticence of parents to trust a system that has too often resulted in children being removed from their homes and their communities.

Participants also stressed that the SWYC should be introduced in such a way that parents are not put off by the nature of the questions—many of which are worded negatively and ask about sensitive topics. Considerable concern arose both about the negativity of items on the BPSC, the CPSC, the POSI, and the Family Questions and the lack of items about positive behaviors and family strengths. For example, several participants thought that the word "symptom" in the heading of the BPSC and the PPSC could cause concern among parents. They also worried that asking only about problems in development would cause parents to have heightened concerns about their children's development even when none were warranted.

Even though they expressed concerns about how SWYC information would be used, participants also noted the need for developmental screening and the importance of including the family risk questions as part of screening. Many suggested steps that could be taken to both retain these questions (and thus gather critical information) and address parents' concerns about answering them. First, participants suggested that parents should be told why questions were being asked—to help identify needs their children might have that could be addressed. Second, participants suggested that parents should be well-informed that they did not have to answer any questions that they were uncomfortable answering, particularly those in the family risk section. Finally, participants suggested that both providers and parents should be well-informed about the limits of the SWYC—in other words, that it is a screener rather than a diagnostic tool, and that a positive screen means that further evaluation is indicated, but not necessarily that a problem exists.

Many participants noted that the SWYC provided opportunities for dialogue with parents about child development—*teachable moments* when providers could share information and help fill the gap in parent knowledge of early development. Several parents said that they wished they had been asked the SWYC questions when their children were younger, noting that it would have provided an opportunity for them to better reflect on and understand their children's development.

Effective dialogue with parents and providing education as part of screening requires, however, that the provider administering the SWYC be knowledgeable about child development and be prepared to answer questions accurately and with sensitivity (see Subtheme 4). Professionals can offer either reassurance of normal development or guidance and referral when challenges are suspected. Note that while assuming that this kind of provider skill is reasonable in the pediatric settings in which the SWYC has been validated to date, it should not be assumed in many underresourced tribal settings.

Several participants commented that offering parents information and suggestions for what they can do to support their children's development is an important outcome of screening that could potentially avert the need for referral and services by empowering parents to be more proactive in addressing their own children's needs. Furthermore, given the potential for repeated administration of the SWYC across early childhood (from 2–60 months), participants felt that even if parents were not ready to report concerns at a given time, the conversation started with the SWYC might prompt parents to consider sharing more or seeking help in the future.

Another theme that recurred in conversations with providers was questions about who should complete the SWYC and provide information about a particular child's development. The SWYC was designed and validated as a parent-report screener. Many participants expressed concerns that parents would report only some of the concerns about their child or in their family and that a provider (e.g., a home visitor) may see things differently and perhaps more objectively. To this end, participants suggested that there be room on the SWYC for provider comments and observations. Participants also remarked on the number of children in tribal communities who are raised in extended family and multigenerational homes. In these contexts, adults other than the child's biological parents may be better or equally important reporters of the child's

development. Participants suggested that there be ways for other important caregivers to weigh in on SWYC questions about the child's development and the family context.

Using Native language. One theme that emerged in different ways across different communities was the issue of Native language in the SWYC. The diversity in comments related to language use reflected the diversity in language use itself across communities. In some contexts where the tribal language was widely used, much discussion arose about the translation of the SWYC (where written tribal language is appropriate) or the need for a translator (for communities where tribal language is only oral) to be involved in administration. In communities where the tribal language was less prevalent or where language revitalization efforts were recently under way, many commented on the need to at least recognize the extent to which tribal language is used and to appropriately accommodate language in screening efforts.

Choosing appropriate providers and service settings. Two other broad themes that emerged were related to who should administer the SWYC and where it should be administered. In terms of *who* should administer it, the theme of trust emerged again, with participants in every community stressing that the SWYC should be administered in the context of a trusting relationship. Without that relationship, respondents felt that parents would not answer honestly and that the information gathered on the SWYC would be compromised (or that parents would refuse to complete it at all). As noted earlier, many felt that the SWYC should be given in the context of a dialogue with parents and that this dialogue must be in the context of a relationship with a trusted provider.

The question of *where* the SWYC should be administered was complicated. The service ecologies for young children and families in tribal communities are quite distinct from the service ecology in the United States more generally and very different from the greater Boston area where the SWYC was initially developed and validated. In addition, across tribal communities there are a broad array of service ecologies ranging from very sophisticated and well-funded systems to systems that include only very basic or underfunded services. Many conversations with participants focused on identifying the places where children and families were most likely to come into contact with providers and which of those service settings might provide natural opportunities for screening. In all communities, participants reported that parents rarely bring children in for all recommended well-child visits (the visits where the SWYC was designed to be administered). Many noted that children were not brought in for well-care until they were required to get immunizations at school entry; once immunizations were complete, visits dropped off again. Perceived barriers to these visits included lack of financial resources, distance to travel and lack of transportation, and distrust of providers and healthcare systems (especially Indian Health Service systems, where turnover among providers was reported as high). Thus, while most participants agreed that a well-child visit would be an optimal opportunity for screening, especially if there is a strong relationship between a parent and a provider, many were skeptical about the reach of screening in this context alone.

Many alternative sites for SWYC administration were suggested. Some similar suggestions were made across many communities while others were unique to particular settings. Pediatricians were often mentioned as being appropriate providers to administer the SWYC, although participants in many communities suggested alternative service providers who might have more opportunity to administer the SWYC. The WIC program came up in a number of communities as a promising setting for screening; participants often noted that even families who have little or no contact with other providers will come to WIC for support. In communities with MIECHV programs, participants often suggested home visits as opportunities for screening. HS/EHS and CCDF programs also were named as promising venues for screening. Child welfare providers suggested using the SWYC at intake for children referred to their system. Similar suggestions were made for children referred into behavioral health systems. Concern was raised, however, that existing providers in these systems may be too overloaded in their current duties to take on the added burden of administering the SWYC.

Sharing SWYC Data

Another process consideration related to where and with whom SWYC data might be shared. Participants suggested that sharing SWYC data across service settings or providers could minimize the burden on parents (who would not have to complete the same form twice) and could help in coordination of services. For example, HS/EHS providers thought that having access to SWYC results collected before age 3 years (perhaps by home visitors or pediatricians) could help them prepare to meet the needs of children and families coming into their system. Others suggested that having ways of sharing developmental screening information between providers (akin to an electronic medical record) would minimize the burden on both parents and providers Some communities were on the cusp of such a system through the use of an integrated cross-program electronic medical record system whereas others noted disconnects among local programs that hampered efforts to serve children and families. Participants expressed some concerns about breaches of patient confidentiality that are inherent in more open and integrated systems, and noted that efficiency and integration must be weighed against these risks.

Making referrals. Resources to help children and families in need of behavioral health interventions varied across communities. Participants in some communities reported that they had adequate resources, with appropriately qualified providers and systems available for further evaluation and intervention. But in most communities, participants reported that behavioral health resources were lacking. As noted earlier, many participants were opposed to screening when options for referral and services were insufficient, citing ethical concerns about identifying potential problems without offering services for individual families. Others suggested,

however, that screening data could be used to support requests for additional resources and would be useful on a community level.

Even in communities where referral resources were available, participants mentioned access barriers. Across communities, distance to services was a barrier. In many rural tribal communities, families are dispersed across large geographic areas and have limited access to reliable transportation, often with no public transportation options. Urban communities also face these challenges, with urban Indian populations dispersed across neighborhoods that are often far from centralized tribal health centers and services. Another barrier often noted concerned distrust. In some communities, participants felt that families might not want to access services, even when they were easily available. Services are sometimes seen as interference by outsiders and a continuation of years of acculturation policies and programs that interfere with tribal culture and family structures.

Finally, participants suggested that challenges within families would interfere with successful linkage to services for children who screened at risk. Many noted the prevalence of domestic violence and substance use within families and thought that these factors would impact the likelihood that parents would follow up on referrals and access services. Participants suggested that children in these contexts might be especially in need of developmental intervention and that attention would need to be paid to support such families through the referral process.

Content Considerations

Participants generally responded positively to the content of the SWYC items and felt that they were appropriate for the children and families in their communities, further reflecting general enthusiasm about this instrument for use in tribal contexts. Nonetheless, several specific items were identified as potentially inappropriate in tribal contexts; these deserve further examination, as they may impact the validity of the SWYC for future use with Native children.

In reviewing the feedback provided on the content of the SWYC items, note that while the seven tribal communities in this feasibility pilot were selected to represent different regional, cultural, and urban/rural contexts, they represent only a small portion of the diversity among tribal groups in the United States. With this diversity in mind, participants questioned whether the SWYC could be equally reliable and valid across *all* tribal contexts. Some suggested that an AIAN version of the SWYC would be needed, adapting some items to better reflect the natural course of child development in Native populations. Others suggested that adaptation would need to go further, given the level of diversity across Native communities; to this end, many recommended multiple AIAN versions of the SWYC, each tailored to specific cultural groups (e.g., Northern Plains, Pueblo, Northwest, Alaska).

Intertribal diversity is therefore important to consider when reviewing the content considerations summarized next. Two themes cut across the different sections of the SWYC and were raised across communities; within each are specific subthemes, some of which emerged in multiple communities and others in just one or two.

Comprehensive screening. Participants appreciated the value of the SWYC as a comprehensive screener with greater breadth than they did screeners that were currently being used in their communities, often noting, in particular, the value of including the family risk questions. Many participants talked about the links between family substance use, mental health, financial strain, conflict, and children's developmental struggles, suggesting that this information would be useful to providers serving children. They also noted the sensitive nature of these questions, the responses to which could elicit social services or child welfare involvement, and therefore advised caution in collecting these data (discussed earlier).

Participants appreciated the inclusion of both the autism and socioemotional and behavioral screening items. Several providers, across different communities, reported observing recent increases in both autism spectrum disorders and behavioral problems among young children in their communities and emphasized the need to identify these children early and connect them with resources.

Appropriate norms. Participants expressed concerns about the appropriateness (or inappropriateness) of existing norms across all sections of the SWYC. Participants were concerned that children in their communities might erroneously be deemed "deficient" for failing to meet milestones or exhibit particular behaviors. On one hand, there was concern that the prevalence of developmental and behavioral problems in early childhood actually might be high among tribal children, due to challenges such as lack of economic resources, geographical isolation, exposure to trauma, and parental substance use. In a context where developmental and behavioral problems are high, participants wondered if parents would see behavior that is actually problematic as "normal." In other words, if many children in the community are at risk, at risk becomes what is seen as normal.

On the other hand, participants also were concerned that the particular items on the SWYC might falsely inflate concerns, flagging children as having problems when they are, in fact, on course developmentally. Specific examples of items that were seen as problematic are discussed next, followed by a summary of feedback on each of the specific sections of the SWYC. The discussions made clear that some items might need to be adapted to reflect local contexts or that scoring and cutoffs might need to be realigned to reflect the experiences of tribal children.

One example of this was evident in participants' concerns that high rates of poverty in tribal communities might influence responses on SWYC items and result in underestimates of development progress. For example, families who cannot afford to have books in their home are not able to provide as many opportunities for children to interact with written language. Children in these homes would be more likely to screen positive for developmental delays. However, these families, especially those in communities with rich oral traditions, may be supplementing children's experience with language in other ways. These children may be very

much on track developmentally, particularly with regard to local values around oral language development, but appear delayed on the standardized SWYC rating system. Positive screens in such instances risk unnecessarily raising concern for parents and taxing scarce intervention services.

Developmental milestones. Concerns with the Milestones section aligned with two subthemes: The first related to language, and the second related to cultural and environmental context. Recommendations about the use of Native language varied greatly across communities. Some participating communities were characterized by widespread use of Native language where children were exposed extensively to their Native language in their homes and throughout the community (including in early childhood programs). In other communities, Native language use was far less common. In those communities, language-revitalization efforts may have been under way, but use of Native language may have remained limited to basic words (e.g., greetings, relationship terms) or to particular contexts (e.g., ceremonies). Across these contexts, participants sometimes questioned how children would be rated on language milestone items. For example, on the 12-month form, there is an item "Calls you 'mama' or 'dada' or similar name;" participants suggested including tribal words for those relationships or adding "in your tribal language" to this item. Another suggestion was to add "in English or in your Native language" to the item "Names at least 5 body parts—like nose, hand, or tummy." Still other participants suggested collecting information about the languages to which children are exposed; this would help contextualize their responses on language-related items and adjust interpretations of scores accordingly.

Another set of concerns reflected the environmental and cultural contexts in which children grow up and how those contexts impact the expression of development, as captured on the SWYC. In one community, participants noted that the item "Walks up stairs with help" would be infrequently endorsed because there are no stairs in their community since traditional homes and other buildings are single-story. They were concerned that children's motor development would be underestimated because of this environmental constraint and suggested substituting other indicators of gross motor development (e.g., "Climbs up on the couch or chair"). This concern was echoed across communities in relation to specific Milestones items that represented a misfit to environmental contexts.

Participants also expressed some concern that the content of Milestones items did not adequately reflect local values around child behavior. One example was the use of the language item "Looks around when you say things like 'Where's your bottle?' or 'Where's your blanket?'" on the 15-month form, at an age where use of a bottle was considered developmentally inappropriate in the particular culture. Another was the item "Uses words like 'me' or 'mine.'" This item was considered problematic in communities where children are taught early to think more about communal values (e.g., *our* and *ours*). One participant noted that use of the term *me* is egocentric and inconsistent with Native cultural values. "Plays games like 'peek-a-boo' or 'pat-a-cake'" was suggested as another example of cultural mismatch; not playing these games was seen as consistent with local culture rather than reflective of failed development.

BPPS checklists. Participants across many communities were concerned that both the BPSC and the PPSC items were worded negatively. Participants worried that this frame of reference would be anxiety-provoking to parents by focusing their attention only on problems. Some participants reacted negatively to the use of the word *symptoms* in the section header and suggested calling this section something else to dilute the emphasis on deficits. One participant suggested offsetting this possibility by first asking parents to reflect on a child's strengths before turning to questions about problems. Many commented that socioemotional and behavioral strengths were overlooked on the SWYC, but noted that such strengths were related to resilience in the face of hardship and were thus important developmental markers for children in tribal communities. These comments generated discussions about the purpose of screening, the need to keep screening brief, and the sacrifice of balance for brevity. However, some participants remained concerned that including only negative items could send a message to parents that only problems are important, missing an opportunity to help them identify and foster their children's strengths. One participant stated that "Resiliency factors are most important to focus on and teach with our children; specifically, we need to teach them about hope, positivity, and empathy."

Some participants felt that questions on the BPSC and the PPSC were too vague or subjective. One example raised was the item "Does your child cry a lot?" Participants asked about what constituted "a lot" and about the time frame (Today? Last week? All the time?). Some suggested that the response options should be expanded to capture the range of potential responses.

Participants shared that several items had a different meaning in tribal contexts (and different meanings across different tribal contexts). Participants noted that the item "Is your child aggressive?" might be problematic, suggesting that behavior that might be considered appropriately assertive in the United States more broadly might be seen as aggressive in many tribal communities. In one community, participants noted that the concept of aggression is so culturally discordant that the Native language had no word for it.

Another example of cultural and contextual disconnect was the item "Is it hard to keep your child on a schedule or routine?" In some communities, participants noted that schedules and routines are not valued in the same way as they are in mainstream communities; parents do not generally try to establish schedules with their children. In the Alaska Native community, participants pointed out the widely varying hours of daylight across seasons and noted that families' schedules and routines, to the extent that they exist, vary widely during the year.

Participants not only questioned the fit of some SWYC items but also suggested that important items reflecting culturally relevant values for young children were missing. One example related

to the importance of self-sufficiency in many tribal communities. Across communities, participants pointed to the importance of listening and observation skills and noted that no questions on either the BPSC or the PPSC addressed the emergence of those skills. Other important skills noted as missing included self-control and interdependence (e.g., evidenced by early efforts to help family members).

Participants in almost all communities suggested that the context in which tribal families live—both in terms of culture and context—would affect the interpretation of SWYC scores. They insisted that only a provider who is familiar with the context should interpret the scores. They also suggested that the person administering the SWYC should have an opportunity to add their observations (e.g., "This child exhibits adequate gross motor development, but has no experience with stairs") and that parents completing the SWYC should have an opportunity to provide additional detail (e.g., "My child cries all the time lately, but he/she has been sick").

Th POSI. This screener engendered less discussion than did other sections of the SWYC, but comments from both parents and providers were generally positive. Some noted the importance of including an autism screener, given the perception that autism rates were increasing in tribal communities. Some teachers noted more children with autism spectrum disorders in their classrooms and that earlier identification would be useful in supporting the best outcomes for these children. One parent shared that her own child was not diagnosed until adolescence and that critical time was lost for intervention.

Some items on the POSI did generate discussion of cultural context, however. For example, the item "Does your child look at you when you call his or her name?" engendered concern that the item would be confounded with cultural values around avoiding direct eye contact. Others suggested that the question "What are your child's favorite play activities?" should include "listening to stories you tell" (along with "reading books with you"), given strong oral traditions in many tribal communities and the similar social functions of these two activities. Some participants reacted negatively to the item "Does your child look if you point to something across the room?" because pointing is considered unacceptable within some tribal cultures.

Family Questions. The content of the Family Questions section generated the most discussion across all sections of the SWYC. Participants had both positive and negative reactions. Speaking to the importance of these questions, one participant stated "To get anywhere with the child, you have to address these family issues." Across all communities, and in almost every FG and KII, participants commented on the importance of family risk factors in early development and the need to identify risk and intervene to promote positive development.

Just as often, however, participants expressed strong concerns about the sensitive and intrusive nature of these questions. Many participants said they would not expect parents to honestly answer these questions. Others thought that parents would refuse to answer these questions, and some suggested that their inclusion on the SWYC would lead to the refusal by some parents to complete the survey, resulting in a lost opportunity to screen for developmental problems entirely. Parent participants worried that they would be judged to be a "bad parent" if they admitted to family risk factors, and were concerned that child welfare services might become involved and that their children might be taken away from them.

Several participants suggested that it might be difficult for parents to answer the family risk questions because of the complex family environments associated with the multigenerational homes common in their communities. It is common in tribal communities for primary caregivers to be someone other than biological parents; grandmothers, grandfathers, aunts, uncles, and other adult relatives often step in to care for children because the traditional parenting structure relies on extended family and/or because parents are unable to do so. Participants noted that the effects of family risk factors might be difficult to predict when multiple adults lived in the home. For example, parents may not abuse substances or smoke cigarettes, but children might be exposed because other adults in the household do so. In contrast, participants also noted the strengths of multigenerational and extended family homes; multiple adult caregivers provide different resources, create different relationships with children, and fulfill different caregiving roles in support of children's growth and development. Many participants felt that these sources of resilience were overlooked by the focus on family *risk*.

The particular content of some family risk questions also was seen as problematic. For example, the item "Does anyone smoke tobacco at home?" raised concern in communities where ceremonial use of tobacco is common and quite distinct from regular use of tobacco. Ceremonial tobacco use has very different potential implications for young children's development: (a) It can be associated with strong cultural and spiritual practices, and (b) it is rarely done in ways that would extensively expose children to second-hand smoke. Another issue that came up with this particular question was the interpretation of the word *home*. One participant noted that *home* is typically used to refer to someone's home tribal community as a whole, rather than to his or her particular household or dwelling. In that context, "Does anyone smoke tobacco at home?" was interpreted as a very broad question asking about tobacco use among people in the community.

In addition to the comments about how well items on the SYWC fit with local contexts and culture, many of the comments offered by participants were about items *not* on the SWYC, important family risk factors that they thought should be included. Most notably, participants suggested adding questions about exposure to trauma, which is all too common in many tribal communities. Participants emphasized the importance of understanding this context for child development. Other recommendations were to include questions about anxiety, prescription drug use, and housing/homelessness.

Participants also noted the absence of questions that focused on valuable family strengths that they saw as critical to

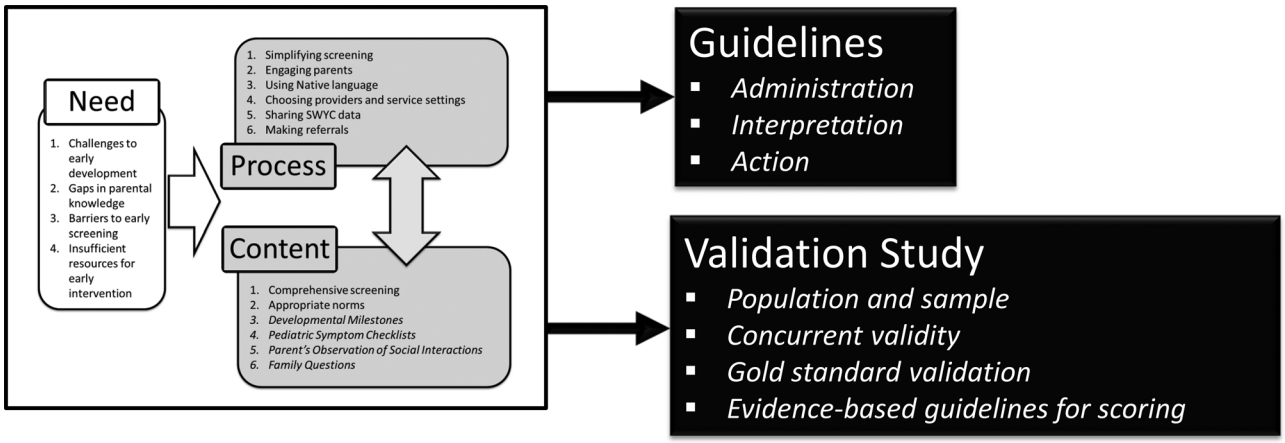

FIGURE 2. Recommendations for next steps.

promoting resilience among young children and felt would be important information for providers working with children and families to promote successful development. Recommendations were to add questions about parents' community connections and support, cultural values and engagement, and resilience factors such as hope.

DISCUSSION AND RECOMMENDATIONS

The findings of this study have important implications for use of the SWYC in tribal communities and support tempered enthusiasm for moving forward to use the SWYC with tribal communities. The findings need to be understood within the limitations of the study, as detailed later, but they suggest two critical next steps, as depicted in Figure 2.

The first recommendation is to develop *Guidelines for Use of the SWYC in Tribal Communities* that can inform the process of implementing and interpreting the SWYC in its current form. Excitement about the SWYC was a common theme that cut across all the participating communities, and both providers and parents often asked where they could access forms, learn the scoring, and get started. The SWYC already has been adopted by some tribal MIECHV grantees and is being considered for use in some tribal HS/EHS programs. The best outcome for these early adopters will be realized if they have some guidance in using the SWYC in tribal contexts, informed by what has been learned from tribal partners in this study and urging caution in interpretation of SWYC scores in the absence of data on their meaning for tribal children and families.

The second step critical to successful and meaningful implementation of the SWYC will be to conduct a validation study of the SWYC in tribal communities. Such a study is needed to carefully explore the reliability and validity of the instrument for use with AIAN children and to establish appropriate norms, scoring procedures, positive screen cut points, and to address implementation issues such as whether its use indeed results in earlier identification and referral of children with developmental problems.

Recommendation 1: Guidelines for Use of the SWYC in Tribal Communities

Guidelines for use of the SWYC should include recommendations of three types: *administration*, *interpretation*, and *action*. This discussion is organized around these three areas.

Guidelines for administration. Guidelines for administration should begin with recommendations about who should administer the SWYC to parents, reflecting the concerns outlined earlier about the importance of a trusting relationship between the parent and the provider receiving the SWYC data. Recommendations about who should administer the SWYC will need to be determined within each community and need to reflect the particular ecology of the community and the existing relationships between parents and providers.

It also will be important to create guidelines for preparing providers to administer the SWYC. Although the SWYC was developed for general use without specialized training, use of the SWYC in tribal contexts before it is validated will require at least orientation to its strengths, limitations, and unknown characteristics for tribal populations. Training guidelines might include ensuring that providers understand the purpose and appropriate use of the SWYC—in particular, the distinction between the SWYC as a screener and lengthier diagnostic measures. Training also should focus on appropriate follow-up and referral procedures and how they can be tailored to particular communities. In addition, providers might need training in how to administer the SWYC, particularly to ensure a nonjudgmental screening process given the context of negative judgments rendered toward tribal communities. A commitment to confidentiality also should be fostered among those administering the SWYC as well as a respect for balancing the needs for privacy within families with the need for sharing information across systems and providers to ensure the most effective services for families. In this vein, participants suggested that some providers would be appropriate for asking the Family Questions (e.g., where the provider has a direct relationship with

the parent: primary care physicians or home visitors) and others where this section should be excluded (e.g., where the provider's relationship is more through the child: HS teachers).

Administration guidelines also should include recommendations around confidentiality of SWYC data, particularly which providers should have access to data and how data shared across providers can be protected from being seen by unauthorized individuals. These issues will have to be thoughtfully addressed within community service systems in which the SWYC is administered, but guidelines can be developed to help communities navigate these concerns.

Related to confidentiality concerns is the need to inform parents about the SWYC in advance and to be transparent about the purpose of the screening, potential outcomes, and how data will be shared and protected. Proper guidance for communities in this regard will help parents feel comfortable about completing the SWYC and providing accurate information. Clarity also should be achieved within communities about how data will be shared across providers and service settings. This will involve careful discussions within communities; but guidelines could be drafted to inform how those conversations might take place, the important stakeholders to include, and the right questions to ask. It will involve not only sensitivity to parent concerns about confidentiality but also technical issues around shared data systems and protection of electronic data. Many participants noted the importance of parents' being assured that they have a say in how SWYC results will be used and are informed about who will see their information and how it will be used.

Guidelines for interpretation. Appropriate administration of the SWYC will be critical to ensuring quality responses that can form the foundation of good screening, but no data yet reveal whether the SWYC instrument itself is a reliable and valid tool for use with tribal families. It has not been validated for use with tribal children, and the validation samples in the Northeastern United States represent a population that is likely quite different from the AIAN population. Guidelines should make it clear that any use of the SWYC at this point should be approached with caution, and scores—and particularly cut points for positive screens—interpreted with caution and with a thorough understanding of the particular tribal context in which they are being used. Guidelines could highlight specific considerations and some of the concerns raised by focus group participants with respect to the validity of the SWYC for tribal children, most notably regarding the sensitivity and specificity of the measure. These guidelines should provide broader information on the strengths and limitations of screeners, both in general and for the SWYC in particular, and the strengths and limitations of the screening process, both for all children and for tribal children in particular.

Guidelines for action. Finally, conversations with community members made it clear that the effectiveness of the SWYC as a screener will be enhanced by guidance around what to do with SWYC data. This guidance will include suggestions about how to process SWYC scores with parents and how to provide immediate feedback on how their child is doing and what they, as parents, can do to support successful development. This guidance also could incorporate recommendations to share existing resources with parents, such as those provided by the *Birth to 5: Watch Me Thrive* and *Learn the Signs. Act Early* initiatives, taking the opportunity to educate parents on different aspects of early development as a part of the screening process.

Recommendations also should be provided about what scores trigger a referral for further evaluation and/or intervention versus what scores suggest that the child should be followed closely, but not referred immediately for evaluation or intervention. This ties into broader issues about what the scores mean for AIAN children and how to thoughtfully consider scores in the absence of data on the reliability and validity of these scores.

Guidelines also should be provided about how to identify appropriate referral resources within the community, both for further evaluation and for intervention services. If evaluation and intervention services are not available in the community, guidelines should suggest strategies for evaluation and intervention options outside the community and/or consider the pros and cons of gathering SWYC information to support bids for additional resources.

Finally, guidelines should be provided for use of SWYC data beyond the individual relationship between a parent and a provider (e.g., considerations for systems that could benefit from shared SWYC data, strategic plans for using data shared across these systems to inform intervention for children and families). These guidelines also should include recommendations for ensuring that infrastructure is in place to securely store and utilize data, or if unavailable, for how such infrastructure might be built to meet community needs.

Recommendation 2: A Nationally Representative Validation Study of the SWYC in Tribal Communities

The creation of guidelines for using the SWYC as is with tribal children would support the most informed use for the immediate future. An essential longer term goal, however, will be the validation of the SWYC for use with AIAN children. Such validation will enable recommendations for administration, interpretation, and referral based on rigorous scientific information about how the SWYC actually performs. While the feasibility study reported here was qualitative in nature, intended to gather essential perspectives from tribal stakeholders, a validation study necessitates a quantitative design at its core. Even so, a validation study will benefit from a mixed-methods approach, utilizing qualitative data to inform both the identification of key questions and the interpretation of quantitative findings, particularly in relation to cultural differences in both markers of successful child development and parenting strategies to support development. Some parameters for the design of a validation study within the broader AIAN population are suggested next.

Population and sample. An essential challenge in validating the SWYC for use with AIAN children lies in the diversity of the population. Although AIANs make up less than 2% of the U.S. population, they represent over 600 distinct tribal nations. As noted earlier, participants in the current study often commented on this diversity and on the importance of understanding how the SWYC performs for children across distinct tribal communities. This concern brings to the forefront the importance of defining the AIAN sample for a validation study and determining the best approach for including a sample that could be adequately representative of the overall population of AIANs across the country. While the value in validating the SWYC within individual tribes, or at least in cultural regions, is apparent, it would not be feasible to conduct such a validation study given limited resources for research and limited sample sizes in many small tribes.

Thus, our recommendation for a validation sample would be a nationally representative sample of AIANs that could inform guidelines for use of the SWYC with tribal populations in general. Although such a sample would not allow analysis of the psychometric properties of the SWYC within a particular tribe or cultural group, it would support the creation of guidelines for scoring and use of SWYC data that are at least informed by data on Native children, which would be much more relevant than would existing data. The creation of a nationally representative sample of AIAN children, however, presents a significant challenge given the relatively small size of the population (<1.5% of the total U.S. population) and the extreme diversity of the populations (>600 tribes). A thoughtful and systematic approach to sampling will be required, one that ensures a diverse and broadly representative sample (Novins et al., 2012).

One major hurdle to building a nationally representative sample of AIANs is raised by the difficulty of identifying a sampling frame. One study successfully created representative samples of AIANs in two tribal groups by relying on tribal rolls to delineate the populations from which to sample (Beals et al., 2003; Novins et al., 2012). To emulate this approach in obtaining a national sample, researchers would need access to tribal rolls for all tribes (federally recognized and state-recognized) and to information on which tribal members have children in the zero- to 5-year age range. This is not likely a viable sampling approach, practically speaking, because of the complexities involved in building partnerships with individual tribal communities and gaining their participation in a study and commitment to sharing tribal rolls with researchers. This approach also would limit the population of interest to enrolled tribal members, effectively excluding any families who may identify as AIAN and live within AIAN communities but do not meet enrollment criteria. Careful thought needs to be given to delineating the population of interest.

Assuming that the population could be defined and the sampling frame identified, the appropriate sampling strategy would need to be identified. This phase can build on work done in planning the development of an AIAN Family and Child Experiences Study (FACES) of Head Start programs in Region XI. Many alternative sampling strategies have been considered by the federal partners, study contractors, and planning workgroups made up of tribal program directors and university researchers experienced in partnering with tribal communities around research. The FACES workgroups have settled on a stratified random sampling approach to ensure a representative sample of diverse AIAN communities. Conversations such as those that have been occurring in the AIAN FACES workgroup will be necessary to refine the population and sampling strategy for a SWYC validation study.

Validation studies require large sample sizes to enable the psychometric statistical analyses necessary to inform decisions about the performance of the measure. The different versions of the SWYC pose additional challenges in terms of sample size, necessitating sufficient numbers of children for each of 12 age forms (2–60 months). Our preliminary estimate is that an overall sample size of 500 would be required, with SWYC data on 40 children at each age. This sample size is comparable to the sample used by the SWYC developers in the initial validation studies (Perrin & Sheldrick, 2013; Sheldrick, Henson, Merchant et al., 2012; Sheldrick, Henson, Neger et al., 2012; Sheldrick & Perrin, 2013; Smith et al., 2013).

Concurrent validity. The first part of a validation study of the SWYC for AIAN children would parallel the design of the original SWYC validation study, examining the comparability of the SWYC to screeners currently in widespread use (Perrin & Sheldrick, 2013; Sheldrick, Henson, Merchant et al., 2012; Sheldrick, Henson, Neger et al., 2012; Sheldrick & Perrin, 2013; Smith et al., 2013). SWYC data would be collected on children along with screening data using other instruments, and comparisons would be made to determine the extent to which the SWYC and other screeners agree on the identification of children as either at risk (i.e., in need of additional evaluation or intervention) or not at risk (i.e., developing normally). The concurrent screeners to be used would be the same ones used in the original SWYC validation study, as shown in Table 3.

An important caveat should be noted to the plan for replicating the original SWYC validation study within the AIAN population. The foundation of the original SWYC evidence of concurrent validity was the reliance on previously validated screeners (the ASQ-3, ASQ-SE, POSI, PHQ-2, CBCL, and M-CHAT). None of these screeners has been validated for use in tribal populations, so the criteria against which the SWYC would be evaluated in the proposed study are tenuous. Unfortunately, the complete lack of validated screeners for this population leaves no option for assessing concurrent validity. It does, however, point to the importance of going beyond the design of the original SWYC validation study to include a second phase in an AIAN SWYC study that would allow concurrent validity vis-à-vis a gold standard clinical assessment.

Gold standard validation. In addition to being necessary because of the lack of previously validated screeners for AIAN children, a clinical assessment in the context of tribal communities will provide critical and refined diagnostic information that recognizes local context and development and utilizes culturally sensitive assessment. A tailored approach to clinical assessment can provide

TABLE 3. *Criterion measures*

	SWYC Component			
Criterion Measure	Milestones	Parents Observations of Social Interactions (POSI)	Baby Pediatric Symptom Checklist (BSPC)	Preschool Pediatric Symptom Checklist (PPSC)
Ages and Stages Questionnaire (ASQ-3)	√			
Ages and Stages Questionnaire: Social/Emotional (ASQ-SE)			√	√
Parenting Stress Index (PSI)			√	
Parent Health Questionnaire (PHQ-2)			√	
Child Behavior Checklist (CBCL)				√
Modified Checklist for Autism in Toddlers (M-CHAT)		√		

SWYC = Survey of Well-Being of Young Children.

valid diagnostic information that can then be used to validate (or invalidate) the SWYC screening results. It will have the added benefit of providing validation information regarding the measures collected for concurrent validity, the ASQ-3, ASQ-SE, PSI, PHQ-2, CBCL, and M-CHAT, which, as noted earlier, are lacking validation data in tribal communities as well.

Completing clinical assessments on the full 500 children recruited into the larger validation study would be prohibitive in terms of both investigator time and resources, but clinical interviews on a subsample of 100 children would provide important validity data. Half of this sample, 50 children, would be randomly selected from children who screened positive on the SWYC (estimating a 20% positive screen rate, comparable to national estimates of developmental delays and disorders, and thus approximately 100 children). To sufficiently test for the sensitivity and specificity of the screening, a matched sample of 50 additional children would be selected at random from the approximately 400 children not screening positive for problems. These 50 children also would receive clinical assessments.

Evidence-based guidelines for scoring. A critical outcome of an SWYC validation study would be the identification of evidence-based guidelines for scoring and cut points for identifying children at risk and in need of additional evaluation and perhaps intervention. Data provided by the validation study will allow us to examine whether differential weighting of items is called for, based on cultural variation in the fit of items, and whether cut points need to be adjusted to reflect different contexts of development. Item response theory techniques for analysis will be particularly useful in identifying differential item functioning across tribal groups and that comparing these findings to the original SWYC validation study will inform scoring guidelines.

Study Strengths and Limitations

Despite a number of important strengths, this study has limitations, and findings should be interpreted with these in mind. First, although participating communities were selected strategically to represent diverse tribal contexts, they cannot fully represent the array of AIAN communities across the country. Some selection bias occurred in that participating communities already had some relationship or connection with the TRC; this was not a random sample across tribal communities. Interviews across communities raised many common themes; however, unique themes also emerged within each community, and there are likely other unique considerations relevant to communities that did not participate.

Given the goals of this feasibility pilot and the resources and time allocated to its completion, the decision was made to include as many tribal communities as possible and as many stakeholders as possible in each. This strategy included extensive travel to meet in person with participants in all seven participating communities. The resulting allocation of resources precluded the completion of costly transcription of all interviews, which in turn precluded the use of qualitative analytic software such as NVivo or AtlasTi. A trade-off of this approach was that the level of detail analyses could include was limited and did not allow for full quantification of the frequency of themes and subthemes in a detailed way both within and across communities.

Finally, plans to gather actual SWYC data from a small pilot sample of parents were not completed due to challenges in the timeline of the participating tribal partner. However, home visitors who were beginning to administer the SWYC were debriefed about their experiences administering the SWYC with parents, and their comments are reflected in the analyses summarized here. It will be important in future work to review SWYC data directly or debrief with parents about their experience in completing the SWYC; these steps will be critical in a validation study to fully understand the utility of the SWYC for tribal families.

In conclusion, this study has provided critical information about the usefulness of the SWYC in supporting efforts to expand early childhood screening into tribal communities. The consultation with tribal stakeholders as a first step in exploring the feasibility of the SWYC was, to our knowledge, unprecedented and

was met with enthusiasm by participants. The input received from individuals in tribal communities who provide services to young children and families and/or who are parents themselves is invaluable in guiding how to most effectively use this new tool in AIAN communities.

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