

The Need for Measurement Validation for AIAN Children: Example from the Survey of Well-Being of Young Children

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The Way Forward II: Measurement Validation, Tribal Sovereignty, and
Community Participation



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Topics

- ∞ Imperative for this work: The Importance of Validated Measures for Young AIAN Children
- ∞ Seeking Community Input: Example from the SWYC for AIAN Communities Feasibility Study
- ∞ Challenges for Validating Measures for AIAN Children

Challenges we will discuss today - things to think about throughout this meeting

- Sampling
- Tribal sovereignty and local oversight of research
- Cultural diversity across AIAN communities
- Costs

The Importance of Validated Measures for Young AIAN Children



Imperative for this Work

Collecting data using faulty measures - or even just measures we don't *know* whether or not we can trust - undermines the quality of evidence.

- ∞ This is true for evaluations - putting resources into evaluations using existing measures that don't appropriately assess outcomes is unlikely to be a good investment.
 - In the end, faulty measures undermine the quality of evidence on intervention effectiveness and can lead to erroneous conclusions.
- ∞ It is also true for service provision - using screening measures with uncertain validity make it difficult to appropriately refer children for services.

Early Developmental Screening

- Identifying children with developmental needs early and connecting them with services can help foster best outcomes.
- New initiatives to expand screening efforts are underway nationally (*Birth to 5: Watch me Thrive; Learn the Signs. Act Early*)

Screening of AIAN Children

- Early screening is equally important in tribal communities – perhaps more important, given contextual risk factors for developmental challenges.
- New initiatives to expand screening should reach tribal communities so that AIAN children share equally in programmatic efforts to support early development.

The SWYC

- The SWYC was developed to help make universal screening more feasible.
- It is brief, publicly available, and easy to use – and it screens for a variety of challenges in early development.



Validation of the SWYC

The SWYC has gone through a **rigorous process of validation** – confirming that it is appropriately sensitive and specific

- **Sensitive** – it (usually) detects developmental concerns that are present in children
- **Specific** – it does not (usually) suggest concerns when none are present

The SWYC was constructed to enhance sensitivity; not all children who have SWYC scores suggesting concerns will actually have developmental problems. The goal is to prompt further evaluation and to *not miss* problems than could benefit from early intervention.

Validation for AIAN Children

- Screening is useful only to the extent that screening tools (such as the SWYC) actually do a good job of identifying children who may have developmental challenges (appropriately sensitive and specific).
- The rigorous validation of the SWYC has
 - not included systematic samples of AIAN children
 - nor included screening in the context of AIAN communities.*

**This is true for the validation of virtually every screener or assessment tool for early childhood.*

Need for Validation

Providers and parents in tribal communities need good tools to screen and assess children.

- They use the best tools available to them
 - despite the lack of reliability and validity data for AIAN children
 - and despite the concerns they have, from their own experience, that the tools are actually not providing trustworthy information about AIAN children.
- Often they have to use tools that are required by funders or program developers.
- **The lack of information about the validity of these tools for AIAN children results in decisions being made about children and the services provided to them on the basis of incomplete and potentially incorrect information**

Consequences of mis-measurement and “false truths”

- ∞ Mismeasurement in early childhood assessment:
 - Health problems go unnoticed and progress without treatment
 - Children don't get early services and problems escalate
 - Children get mislabeled as having problems when they are actually on track developmentally
- ∞ Mismeasurement in research and program evaluation - if targeted outcomes or program implementation are not measured well . . .
 - the effects of an intervention are impossible to determine
 - misleading conclusions may be drawn about a program's effectiveness - either underestimating or overestimating impact

Seeking Community Input: Example from the SWYC for AIAN Communities Feasibility Study

Purpose of the study

In exploring the potential usefulness and appropriateness of the SWYC for AIAN children, we first sought to engage community stakeholders in the discussion of:

1. the need for screening,
2. the feasibility of using the SWYC in AIAN communities, and
3. the appropriateness of this tool for these cultural contexts.

The study was guided by the Tribal Early Childhood Research Center **SWYC Community of Learning** , a partnership of researchers and tribal program leaders from tribal Head Start, Home Visiting, and Child Care.

Whitesell, N.R., Sarche, M., & Trucksess, C. (2015). The Survey of Well-Being of Young Children. Results of a feasibility study with American Indian and Alaska Native communities. Infant Mental Health Journal, 36(5), 483-505.

Participant Communities

Community	#1	#2	#3	#4	#5	#6	#7	Total
Region	Midwest	Midwest	Southwest	Southwest	Southeast	Alaska	Northwest	
Rural/Urban	Rural	Rural	Urban	Rural	Rural	Rural	Urban	
Participants	29	29	5	33	31	54	18	199
Focus groups	5	5	0	6	6	8	2	32
Key informant interviews	3	4	3	0	5	2	3	20

Participants represented a range of tribal early childhood stakeholder groups, including: Pediatric health care providers, Tribal Head Start, Home Visiting, and Child Care program staff, Mental health providers, Parents, Tribal government leaders, and Elders.

Approvals were obtained from all participating tribes and communities; approval was obtained from the Colorado Multiple Institutional Review Board at the University of Colorado.

Key Findings

Need

1. Challenges to early development
2. Gaps in parental knowledge
3. Barriers to early screening
4. Insufficient resources for early intervention



1. Simplifying screening
2. Engaging parents
3. Using Native language
4. Choosing providers and service settings
5. Sharing SWYC data
6. Making referrals

Process

Content

1. Comprehensive screening
2. Appropriate norms
3. *Developmental Milestones*
4. *Pediatric Symptom Checklists*
5. *Parent's Observation of Social Interactions*
6. *Family Questions*





12 months

12 months, 0 days to 14 months, 31 days

Birth Date:

Today's Date:

DEVELOPMENTAL

These questions are about your child's skills and abilities. If your child does not do these things, please be sure to tell us.

No stairs? No peek-a-boo?

- No opportunity for child to demonstrate development
- Child scores lower than she "should", gets a score below the cut-point and gets flagged as potentially having a developmental delay.

Picks up food

Pulls up to standing

Plays games like "peek-a-boo" or "pat-a-cake"

Calls you "mama" or "dada" or similar name

Looks around when you say things like "Where's your bottle?" or "Where's your blanket?"

Copies sounds that you make

Walks across a room without help

Follows directions - like "Come here" or "Give me the ball"

Runs

Walks up stairs with help

	0	1	2
	0	1	2
	0	1	2
	0	1	2
	0	1	2
	0	1	2
	0	1	2
	0	1	2
	0	1	2

Note: Culture or context? What is the distinction?

BABY PEDIATRIC SYMPTOM CHECKLIST (BPSC)

These questions are about your child's behavior. Think about what you would expect of other children the same age, and tell us how much each statement applies to your child.

	Not at all	Somewhat	Very Much
Does your child have a hard time being with new people?	0	1	2
Does your child have a hard time in new places?	0	1	2
Does your child have a hard time with change?	0	1	2
Does your child mind being			
Does your child cry a lot?			
Does your child have a hard time calming down?	0	1	2
Is your child fussy or irritable?	0	1	2
Is it hard to comfort your child?	0	1	2
Is it hard to keep your child on a schedule or routine?	0	1	2
Is it hard to put your child to sleep?	0	1	2
Is it hard to get enough sleep because			
Does your child have trouble staying as			

Hard time with new people because they are so rare?
Hard time with schedule or routine because of seasonal variation?

Any "aggression" is viewed negatively in the culture so what might not be noted as aggressive by mainstream parents "flags" a child in a Native community.

Is your child... Aggressive?

❑ In contrast - "any" aggression might be important to flag in some cultural contexts as a cause for developmental concern

Recommendations

- ☞ **Screening efforts should be enhanced in tribal communities**
 - as in other communities – to better meet the needs of young families and support better developmental outcomes for children.
- ☞ **Guidelines are needed** to support tribal communities in utilizing the SWYC in ways that will be most effective, including recommendations for:
 - Administration
 - Interpretation
 - Action
- ☞ **A validation study is needed** to determine the psychometric soundness of the SWYC for use with tribal children. This study will require:
 - Careful attention to defining the population and engaging an appropriate sample
 - Examination of concurrent validity with existing screeners*
 - Gold standard validation using culturally sensitive assessment
 - The creation of evidence-based scoring guidelines for use with tribal children

Moving forward with early childhood screening in tribal communities

Whether the SWYC or other screeners are used, more study is needed to determine how accurately these tools reflect developmental problems among AIAN children.

This will not be easy work, but without it, AIAN children will remain marginalized in the screening and early intervention efforts underway nationally.

Challenges for Validating Measures for AIAN Children

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The Challenges - for Discussion

- **Sampling:** Large, representative samples are needed for measure development and validation.
- **Tribal sovereignty and local oversight of research:** Challenges to recruiting “national” AIAN samples.
- **Cultural diversity across AIAN communities:** Reservation, urban; distinct cultural traditions; does a national sample even make sense?
- **Cost:** Validation studies are expensive. They involve collecting a lot of data from a large, carefully-selected sample and require significant time and research effort. Funders are reluctant to invest, especially given pressing calls for immediate intervention.

Contact Information

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