Challenges of Using Existing Measures of Early Development in Tribal Contexts

Jessica Barnes*, Ann Belleau^, Hi Fitzgerald*, Michelle Sarche+

*Michigan State University
^Inter-tribal Council of Michigan
+University of Colorado Denver
Overview

- Conceptual framework for understanding measurement challenges and solutions
- Case example: Wiba Anung
- Case example: The Survey of Well-Being of Young Children (SWYC)
CONCEPTUAL FRAMEWORK
**What is child development?**

- Child development refers to the biological, physical, cognitive, and social-emotional that occur in human beings between birth and the end of adolescence, as the individual progresses from dependence to increasing independence.

- Development is shaped by the interaction of what the individual brings and the environments in which s/he is developing.
Bronfenbrenner’s Ecological Model: Adaptation of Context Examples
To understand what normative development looks like
To understand the factors that shape development
To know when development does not proceed as expected, or falls off track
To know what to do to keep development on track...what to do when it falls off track
To determine whether or not what we are doing is making a difference
A given measure does not account for the multiple contexts in which children develop, and does not account for other aspects of development.
Multiple Pathways in Development
Measures are based on the assumption that development manifests similarly in all children.

- **Domain**: Core aspects – some variation across cultures
- **Construct**: Dimensions or elements of the core – more variation across cultures
- **Item**: Specific indicators – most variation across cultures
**Example: The Infant Toddler Social Emotional Assessment**

- **Social Emotional Development**
  - **Competence**
    - Mastery Motivation
    - Prosocial Peer Relationships
    - Imitative Play
  - **Dysregulation**
    - Sensory Sensitivity
    - Sleep
  - Likes to figure things out
  - Wants to do things for self
  - Enjoys challenging activities
  - Must be held to go to sleep
  - Sleeps through the night
  - Wants to sleep in someone else’s bed
Why do existing measures fall short in tribal contexts?

- An important construct for the local context is missing entirely, or is underemphasized.
- A construct is there but the item used to operationalize the construct has a different meaning or no meaning in the local context.
- Construct is there but at odds with local context.
- Important aspects of the local context that shape development are not considered.
- Important aspects of the local context that shape the process of gathering measurement data are not accounted for.
- Virtually no norms for American Indian or Alaska Native children.
When is adaptation needed?

- When a measure doesn’t include important questions, ask questions in a way that doesn’t make sense, etc., the measure may not be **reliable or valid** for your population
  - Validity – measuring what you intend to measure
  - Reliability – measuring it consistently
  - A measure can be reliable but not valid, but an unreliable measure cannot be valid
- It is important to remember that even though there are problems with some measures, many measures work quite well across populations and contexts
**WHAT TO DO? ADAPT CONTENT**

**Content:** How the constructs is operationalized
- What the questions need to be reworded?
- What questions need to be added?
- What questions need to be taken out?
**What to Do? Adaptation of Process**

**Process** – How or where the measure is administered, or who administers it, may need to be adapted, e.g.:

- Trained lay assessors from within the tribal community v. outsiders
- Assessment protocol that involves animated conversation to engage child may need to be tempered to reflect cultural protocols for more reserved interaction
- Consideration of cultural protocols for what is appropriate to discuss with whom, based on gender, age, etc.
Interpretation – Scores on measures may need to be interpreted within the cultural context

- Understanding the process and content of measures within the cultural context is critical, even more so for measures that are used as is (un-adapted)
Difficult-to-adapt Measures

- Standardized and norm-referenced measures may be difficult to adapt
  - **Standardized** measures depend on strict protocols for administering the measure – the kinds of questions that are asked, the way the questions are asked, and how the overall measure is scored, and may also depend on those who administer the measure to be deemed “reliable”
  - **Norm-referenced** tests are standardized but also “norm-referenced” with respect to how the scores are interpreted

- These kinds of measures – particularly those that are also proprietary – may not be amenable to adaptation
Temper the *interpretation* of standardized or norm-referenced tests within the context of tribal communities.

Consider *supplementing* standardized or norm-referenced test with other measures to provide a fuller/more accurate picture of outcomes in your community.

Mixed methods – including *qualitative data* – may be particularly helpful here

- Interviewers notes
- Observations
- Debriefing interviews
- Focus groups
What to do? Design a New Measure

- What are the key constructs?
- How are those constructs expressed in specific behaviors?
- What are the norms for this context?
- Potentially time-consuming and expensive process
Challenge the notion of “best” practice that can be universally applied

Culture is a moving target
  - Within groups
  - Between groups
  - Over time

So what to do?
Researchers must work with Tribal communities and Tribal research partners in meaningful ways from planning to implementation to dissemination

- Community-Based Participatory Research
- Tribal Participatory Research

Consider the use of qualitative data to give meaning to numbers
Wiba Anung: A Community-Specific Case Example
Wiba Anung Partners

Michigan State University
The Inter-Tribal Council of Michigan, Inc.
Bay Mills Community College

Bay Mills Indian Community
Grand Traverse Bay Band of Ottawa and Chippewa Indians
Huron Potawatomi Nottawaseppi Band of Potawatomi
Hannahville Potawatomi Indian Community
Keweenaw Bay Indian Community
Lac Vieux Desert Band of Chippewa
Little Traverse Bay Band of Ottawa Indians
Pokagan Band of Potawatomi Indians
Sault Ste. Marie Tribe of Chippewa Indians
Wiba Anung: Timeline

Year 1: Conducted large and small group meetings to identify the focus of the research partnership

Year 2: Conducted focus groups to determine community perspectives, Worked in large and small groups to develop the research plan

Year 3-6: Conducted the research together
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<tr>
<th>Stage in Engaged R/E</th>
<th>Degree of Engagement</th>
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<tbody>
<tr>
<td>Identify issue of importance</td>
<td>Community</td>
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<tr>
<td>Decide on research question(s)</td>
<td>Research/Evaluation</td>
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<td>Select research design</td>
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<td>Develop instrument/process</td>
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<td>Collect data</td>
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<td>Analyze data</td>
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<td>Interpret data</td>
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<td>Disseminate of findings</td>
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<td>Create academic products</td>
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<td>Create public products</td>
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Adapted from Stanton, 2008
Small group met weekly: planning large group meetings, discussing various plans to present to the large group, talking about concerns of fit

Large group met four times that year: reviewing plan options, reviewing measurement options
Wiba Anung: Benefits of Co-Creation for the Project

- Through the process of co-creation, we were also promoting co-learning
  - Trust was developed and strengthened
  - The process was improved

- Our ability to collect and interpret quality data was heightened
Wiba Anung: Interpreting with Caution

- Academic school readiness competencies
- Differences in parent and teacher perception of child behavior
Professional development as a result of academic school readiness data

Continuation of data collection after the conclusion of the research project
The SWYC: A Cross-Community Case Example
What is the SWYC?

- **Brief, parent-report screener** for developmental, social-emotional, and family risks in young children between birth and 5 years of age
- **Surveillance tool** designed to be administered at each of the 12 pediatric well child visits
- **Sensitivity > specificity**
- **Validated** in 2013 among a diverse sample in the Northeastern US
- Available **online for free**
- Developed by Tufts University researchers
  - Ellen Perrin, M.D & Chris Sheldrick Ph.D
Domains Assessed with SWYC

- Preschool Pediatric Symptom Checklist (PPSC)
- Baby Pediatric Symptom Checklist (BPSC)
- Behavior: Internalizing, Externalizing
- Development: Delays, Autism
- Milestones
- Parent Observation of Social Interactions (POSI)
- Family Risk
- Family Risk Factors
An Assessment of the SWYC in Tribal Contexts

- Supported by ACF
- Planned by a TRC Community of Learning
- Carried out in 7 tribal communities
- Focus groups and key informant interviews
  - Pediatricians, other physicians, physician assistants, nurses
  - Mental health providers
  - Head Start administration, teachers, staff
  - Child Care administration, providers, staff
  - Tribal Home Visiting administration, home visitors, staff
  - Child welfare and family services staff
  - Parents
Questions for Focus Groups and Key Informants

- Is the SWYC an **acceptable** tool for screening tribal children? Is it culturally appropriate?
- Is a screening instrument like the SWYC **needed** in tribal communities?
- Is it **feasible** to administer the SWYC in tribal communities? In what settings within communities?
- Are **resources available** for children who are identified as having potential delays or problems?
WHAT’S PROMISING ABOUT THE SWYC FOR USE IN TRIBAL CONTEXTS?

- People appreciated being asked
- The SWYC is brief
- The family risk questions are important
- There is a need to identify children early
- Repeated administration may make some parents more comfortable reporting concerns
- Completing the SWYC can be educational
WHAT ARE SOME CONCERNS ABOUT THE SWYC IN TRIBAL CONTEXTS?

1. Lack of trust limits how truthful people will be – especially for fear of losing children
   1. Who administers the SWYC, in what setting, and in what format?
2. Family risk questions are too sensitive
3. Duplicates exiting assessments
4. Referral resources inadequate if delays are detected
5. Focus on “symptoms” – not many positive items
6. Cultural concerns
7. Is it possible to have “an” American Indian/Alaska Native version?
### Examples of Cultural Concerns

- Important constructs for the local context are **missing entirely**
  - Self-sufficiency
  - Self-control
  - Learning through observation
- Construct is operationalized in a way that has a **different (or no) meaning** in the local context
  - Gross motor – use of stairs
  - Fine motor – draws with crayons
  - Social-emotional – acts aggressive
  - Autism screener – listens to story being read
- Construct is there but **at odds with local context**
  - Autism screener – makes eye contact
- Important **aspects of the local context** that shape development are not fully considered
  - Family risk – multigenerational homes in many tribal communities
  - Family risk – isolation in very rural communities
Next Steps for the SWYC in Tribal Contexts

- Adaptation of process, content, norms, and interpretation all on the table
- Process/interpretation: More training in appropriate use of the SWYC in tribal contexts
- Content/Norms: Design and conduct a validation study
  - What items would we change?
  - What items would we add?
  - What are the statistical properties of the SWYC when used with tribal children?
Questions? Comments? Take aways?