

# Towards a Culturally-Informed Approach to Assessment and Research Participation Among Native Children and Families: Supporting the Navajo Birth Cohort Study

LEND Capstone Project

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# Mentors

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# Problem Framing

- Historic and current social, political, and cultural circumstances in the US have contributed to disparities based on social determinants of health, including race, income, and immigrant status
- Inadequately addressed disparities exist in:
  - mental and physical health outcomes
  - educational outcomes
  - access to assessment and treatment
  - treatment participation

(Lasser et al., 2006; Saffran et al., 2009; Taylor, 2006)

# Problem Framing

- Native communities in the US represent one underserved community in which there is evidence of unaddressed health and access disparities (Duran et al., 2004; Duran et al., 2005; National Center for Education Statistics, 1997)
- There is a dearth of research on Native children and families
- Historical context reasonably impacts current research participation for Native children and families, including a history of previous researchers not working closely and collaboratively with community members and not adequately protecting privacy (e.g., naming data collection sites in a way that decreased anonymity of participants and brought stigma to the community) (Davis & Reid, 1999)

# LEND Capstone Project Goals: Big and Small

Contributing to research efforts that:

- 1) Aim to reduce health disparities, especially in participation in clinical assessment and treatment
- 2) Increase meaningful community participation

Objective 1:

Inform best practices for culturally competent administration, scoring and interpretation of the Vineland Adaptive Behavior Scales for the NBCS

Objective 2:

Inform an enhanced participatory and culturally-informed data collection plan for the NBCS

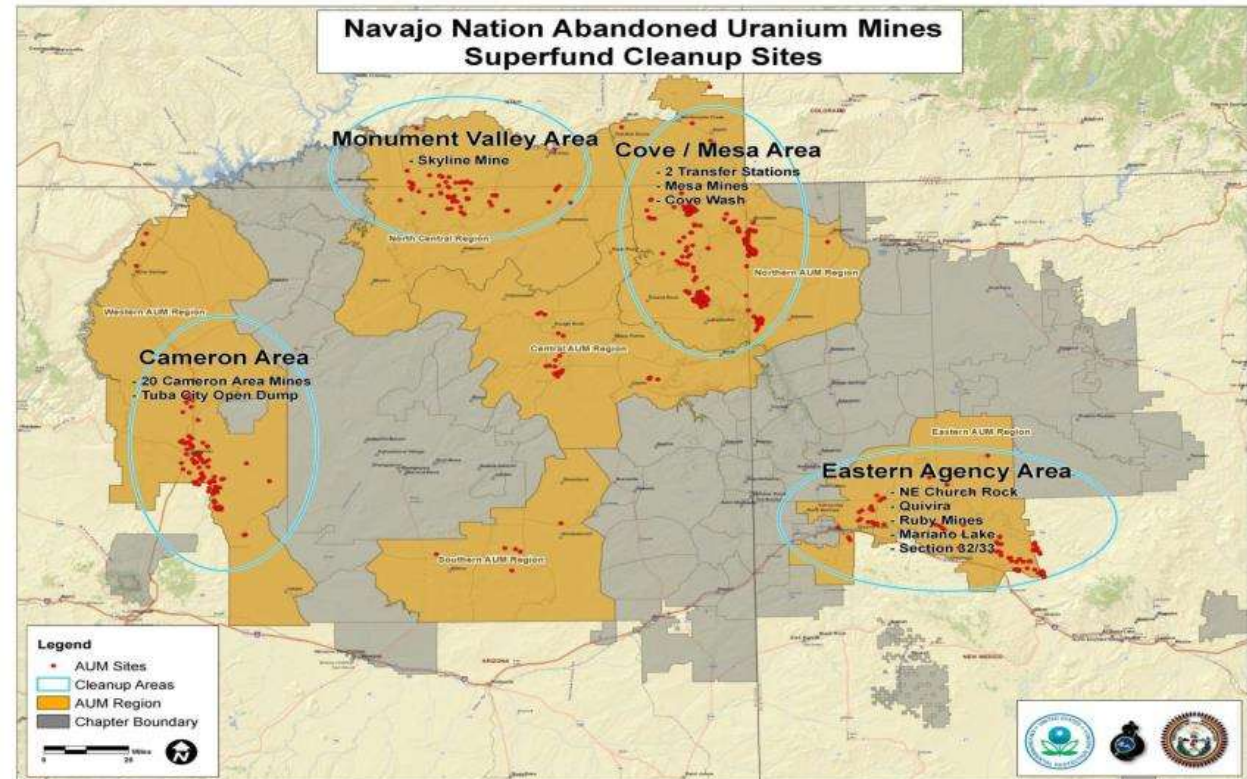
# LEND Competencies

- 1) demonstrate attitudes/behaviors required for successful family-professional partnership
- 2) demonstrate sensitivity and responsiveness to diverse families in various settings
- 3) identify family-centered practices in the community and services systems
- 4) critically review literature (evidence, design, sample size, CI's, statistical tests)
- 5) demonstrate skills in access/utilization of electronic information and resources and database
- 6) demonstrate basic competencies in professional writing

## Background: The Navajo Birth Cohort Study (NBCS)

- Arose from a congressional mandate to study exposures to uranium wastes among residents of the Navajo Nation
- Began in 2010 as a collaboration between UNM, the Navajo Nation, and other government agencies
- Primary Goal: To better understand the relationship between uranium exposures and birth outcomes and early developmental delays

# Background: The Navajo Birth Cohort Study (NBCS)





## Background: The Navajo Birth Cohort Study (NBCS)

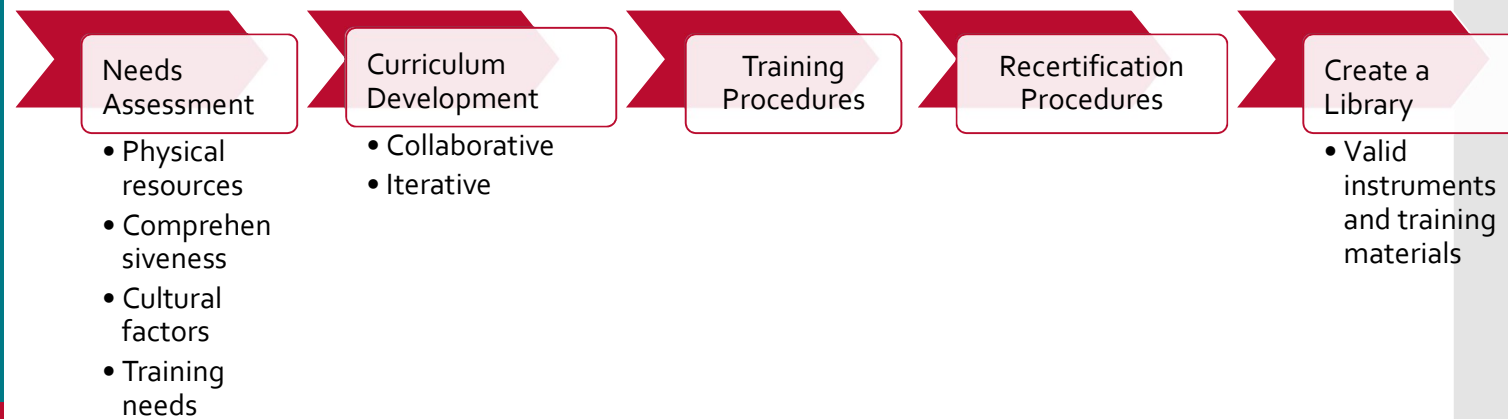
Measures collected over time:

- Prenatal and postnatal metal exposure monitoring
- Early childhood developmental assessments
- Comprehensive 4-year-old assessments (see table below)

<b>Domain</b>	<b>Measure</b>
Cognitive	DAS-II
Language	OWLS-2
<b>Adaptive skills</b>	<b>Vineland</b>
Social-Emotional	CBCL, SRS-2 (questionnaires)
Behavioral Observation	TOF, CARS-2
Medical	Medical and Developmental History, Physical Exam
Social cognitive functioning	Eye tracking measure

## Background: The Navajo Birth Cohort Study (NBCS)

# Echo Distant Indigenous Training System (EDITS)



Objective 1: Inform best practices for culturally competent administration, scoring and interpretation of the Vineland Adaptive Behavior Scales, Third Edition (VABS-3)

- The VABS-3 is an assessment of a child's adaptive functioning administered via semi-structured interview
- Adaptive functioning = “performance of an individual in daily activities pertaining to personal and social functioning” that are relevant for their age and include skills across a variety of developmental domains (Tan et al., 2014)
- Domains of functioning covered on the VABS-3:
  - Communication (Receptive, Expressive, Written)
  - Daily Living Skills (Personal, Domestic, Community)
  - Socialization (Interpersonal Relationships, Play and Leisure, Coping Skills)
  - Motor Skills (Gross and Fine Motor)
  - Adaptive Behavior Composite (Communication + Daily Living Skills + Socialization)

## Objective 1: Guiding questions for literature review

- How can existing research inform considerations for the administration, scoring, and interpretation of the VABS-3 in the NBCS?
  - Has the VABS-3 or other measures of adaptive functioning been used previously with Native children and families?
  - Does the VABS-3 or other measures of adaptive functioning appear to be valid and reliable with Native children and families?
  - What do we know qualitatively about the response of Native families to the VABS-3 or other measures of adaptive functioning (e.g., cultural acceptability and relevance of items)?

## Objective 1: Literature review results

- Only one published study has used the VABS-3 with Native children-this study only used the gross and fine motor domains and did not report on the psychometric properties of the measure in the sample (Kalberg et al., 2006)
- The normative sample for the Vineland did not (explicitly) include Native children in the sample (there was a small undefined “other” category) (Sparrow, Cicchetti, & Saulnier, 2016)
- Within the US, one study found some slight differences in aspects of adaptive functioning between rural versus urban populations of young children (Bornstein et al., 2005)

## Objective 1: Literature review results

- Some studies have highlighted the process of adapting and translating the VABS-3 for use in different non-Western countries (Goldberg et al., 2008; Tan et al., 2012) and have supported that:
  - Adaptive functioning is defined by one's cultural and environmental context
  - VABS-3 items are not culture-neutral and wording was changed and some items were eliminated as part of the adaptation process
  - One study found that the adapted VABS-3 showed similar and adequate internal consistency reliability, construct validity and distinguished between those with and without an intellectual disability
  - Another study found a different relationship between the construct of adaptive functioning and cognitive ability and achievement
    - US: Adaptive and cognitive functioning overlapping, but distinct constructs that both predict academic achievement
    - Zambia: Adaptive functioning was not related to cognitive functioning, but did predict reading achievement

## Objective 1: Product and Dissemination

- Product = Literature review conclusion and process recommendations:
  - There is very limited research on the assessment of adaptive functioning in Native children
  - Culture and environment play an important role in defining and shaping adaptive functioning and should be explored further both quantitatively and qualitatively in the NBCS
  - More information about the cultural acceptability and relevance of the VABS-3 by community stakeholders (e.g., field staff members) is needed to guide administration, scoring, and interpretation in the NBCS
- Dissemination = these process recommendations were translated into content that was added to a VABS-3 training for field staff members as part of the Echo Distant Indigenous Training Systems (EDITS)

Objective 2: Inform an enhanced participatory and culturally-informed data collection plan for the NBCS

Guiding questions for literature review:

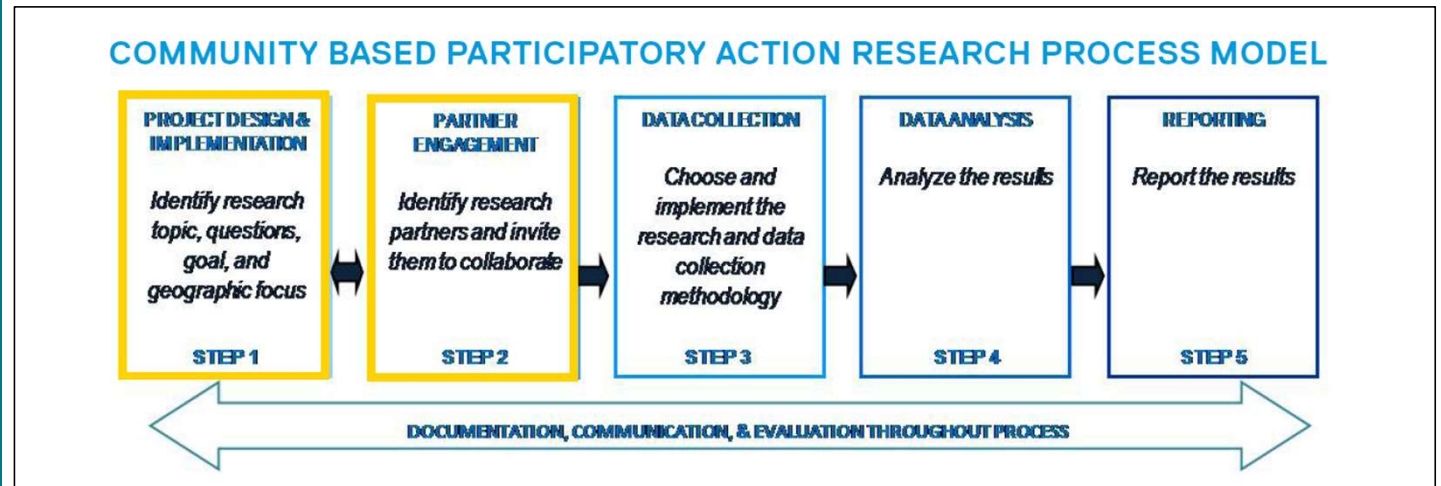
- What are the common components of a participatory action research approach?
- How is a participatory approach used across the phases of a research project?
- How is this approach already being followed in the NBCS and how can it be further enhanced?



## Objective 2: Literature review results

- Participatory action research (PAR) is a philosophy and model that applies to the act of conducting research at all stages of the research process
- Defining characteristics of PAR (Baum et al., 2006):
  - 1) focuses on research with the purpose of enabling action and social change (e.g., with groups or communities)
  - 2) careful attention to power dynamics with the goal of sharing power in democratic process
  - 3) research participants are active in the process instead of passive as in more traditional research models

Objective 2: Literature review results



(Burns et al., 2011)

## Objective 2: Product and Dissemination

- Product = Literature review conclusion and process recommendations:
  - Increase opportunities for field staff participation in NBCS evaluations
  - Increase opportunities for field staff to give feedback about the effectiveness and cultural appropriateness of the NBCS measures and evaluations **AND** incorporate this feedback into practice with families
  - **Use language and actions to support collaboration between the research team and field staff members as full and equal partners**
- Dissemination = these process recommendations were translated into content (e.g., language and discussion questions to encourage collaboration during trainings) that was added to a VABS-3 and other trainings (e.g., how to share referrals with families) for field staff members as part of the Echo Distant Indigenous Training Systems (EDITS)

## Lessons Learned

- Unique considerations for dissemination given project goals (e.g., inform processes of project) and context (e.g., complex project- multiple research teams, research sites, established processes, I am a new team member in a long standing project)
- Appreciation of the complex nature of effecting change within a team within a system
- Reflections on creating meaningful changes (e.g., opportunities for participation and feedback  $\neq$  increased participation and feedback)

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# Product

Excerpt of slides contributing to the EDITS based on the two literature reviews completed

- We know that adaptive skills are sensitive to a child's:
  - Culture: if a family values parents feeding children and a child is not expected to feed herself/himself, they will have less opportunities to learn independent feeding skills)
  - Environment: if a child does not go to school yet or play with children outside of the home, they likely have more experience using social skills with parents and siblings, but not with other children their age)
- This means that some items on the Vineland may not apply as well to a family or a community

(Goldberg et al., 2008; Tan et al., 2012)



- Very few other published research studies have used the Vineland with Native communities in the United States (Kalberg et al., 2006)
- Some research has found differences in adaptive skills between samples of rural versus urban children in the United States (Bornstein et al., 2005)
- This means that we currently do not have a lot of information about the use of the Vineland with Native communities
- This also means that we have an opportunity to better understand some of the ways in which the Vineland is effective and appropriate as well as where it may not be as effective and appropriate for Navajo children and families

- Since you all have expertise in your communities and will be completing the Vineland with parents, we want to learn from you about your evaluation of questions from the Vineland
- For example:
  - What questions do not seem appropriate given your knowledge of your community's culture, values, and environment?
  - What items would you recommend adapting or rewording to be more culturally appropriate?
  - How might you adapt or reword these items?

# Break Out Group Activity

- Each group will be assigned to one subdomain (e.g., Daily Living Skills, Communication)
- Review the items in your assigned subdomain with your group and decide on a list of items that you think require more discussion or adaptation, including:
  - Items that you think are less appropriate or would need to be adapted
  - Items that are confusing for you or might be confusing for families