



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK



INTERDISCIPLINARY TECHNICAL ASSISTANCE CENTER
ON AUTISM AND DEVELOPMENTAL DISABILITIES

MCH Leadership Competency 11: Working with Communities and Systems

Division of Maternal and Child Health Workforce
Development Grantee Virtual Meeting

October 3, 2019

Agenda Overview

- ▶ Agenda of the meeting:
 - ▶ Framing delivered by Dr. Jackie Stone
 - ▶ Presenters:
 - ▶ South Dakota LEND
 - ▶ University of Minnesota Nutrition Training Program
 - ▶ University of Alabama at Birmingham LEAH
- ▶ Closing and Evaluation
- ▶ Notetaking Template

	Relevant takeaways and/or lessons learned that can be applied to my program's efforts	Relevant takeaways and/or lessons learned that can be applied to my program's efforts
South Dakota LEND		
Competency skill addressed:		
Competency skill addressed:		
Minnesota Nutrition		
Competency skill addressed:		
Competency skill addressed:		
Alabama LEAH		
Competency skill addressed:		
Competency skill addressed:		

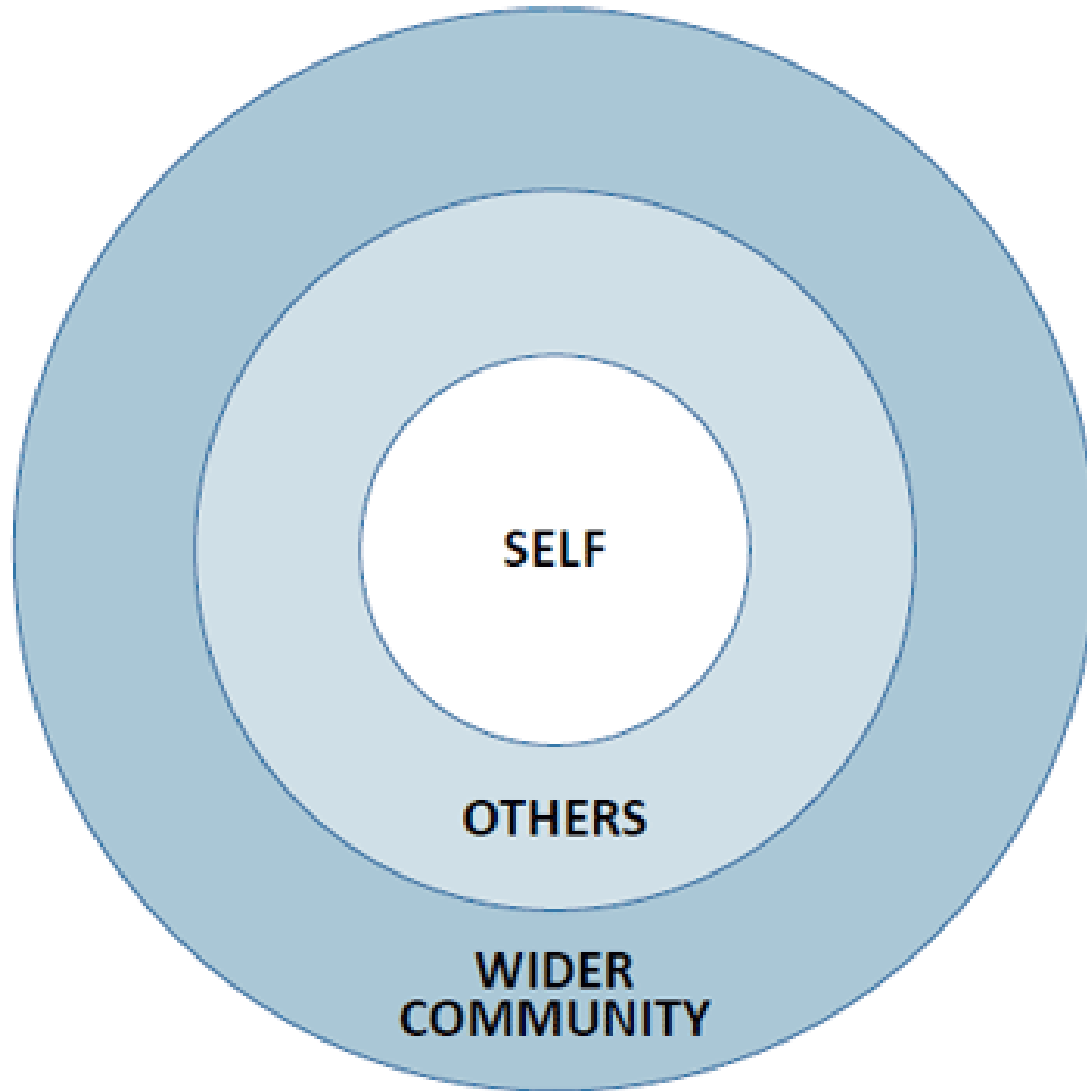
Dr. Jackie Stone

Kennedy Krieger Institute (MD)

Competency 11: Working with Communities and Systems

- ▶ Improving the health and well-being of children, youth, families, and communities is a complex process because so many:
 - ▶ *Communities*
 - ▶ *Stakeholders*
 - ▶ *Systems*
 - ▶ *Intersecting factors*

Applying the competency



Building and Sustaining Partnerships with Tribal Communities in SD

Eric Kurtz, Ph.D.

Executive Director

Center for Disabilities (SD UCEDD/LEND)

Associate Professor of Pediatrics

University of South Dakota

Sanford School of Medicine



Center for Disabilities

South Dakota LEND



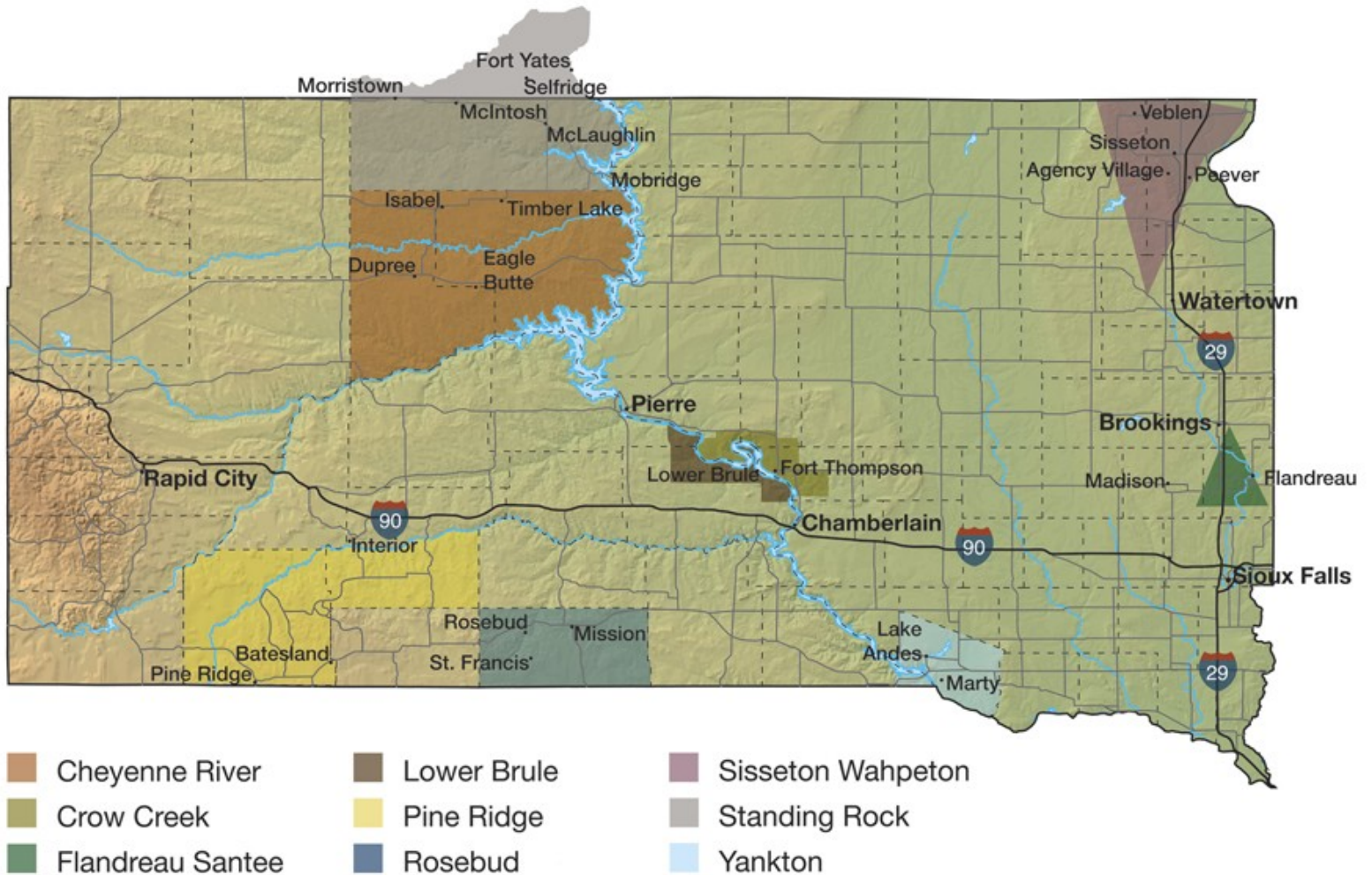
Purpose:

- ▶ Increase the number of health professionals serving individuals with ASD, NDD, and DD
- ▶ Bridge continuing education and TA across healthcare, education, and human services systems on ASD, NDD, and DD
- ▶ Engage in research and information dissemination on issues related to ASD, NDD, and DD especially in underserved and underrepresented populations.

Program Challenges:

- ▶ Rural and reservation communities are geographically isolated
- ▶ High poverty rates, health disparities, ACES, etc.
- ▶ Achieving trainee and faculty diversity that reflects our state's demographics

South Dakota Tribes



National Training Initiative: Diversity Fellowships

- ▶ Partnered with Sinte Gleska University - a tribal higher education institution chartered by the Rosebud Sioux Tribe in Mission, SD.
- ▶ Developed a collaborative-experiential-immersion (CEI) learning approach (began 2015-2016)
- ▶ Engaged faculty and students from USD-SD LEND and SGU in shared learning experiences:
 - ▶ Clinical rotations
 - ▶ Didactic courses
 - ▶ Leadership development
 - ▶ Boards and committees
 - ▶ Capstone projects
 - ▶ Site visits



Center for Disabilities

Fellow Profile: Whitney Jones



News

- Stories
- Share Your Story
- Archived News
- Press Releases

Find Network Members

UCEDD's | LENDs' | IDORCA's

AUCD Technical Assistance

URC UCEDD Resource Center

TAC Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities

AUCD Emerging Leaders Community

AUCD Diversity & Inclusion Toolkit

NIRS National Information Reporting System

Login

Search for Network Projects and Products

AUCD Federal Partners

Maternal and Child Health Bureau	Administration on Developmental Disabilities
CCC: National Center on Birth Defects and Developmental Disabilities	National Institute of Child Health and Human Development

Becoming a Leader on the Rosebud Indian Reservation (SD UCEDD/LEND)

July 11, 2016

In September of 2015, the USD Center for Disabilities was one of 14 centers across the country to receive a National Training Initiative (NTI) grant from the U.S. Department of Health and Human Services Administration for Community Living. This grant gives the Center an opportunity to partner with Sinte Gleska University on the Rosebud Indian Reservation to design a Diversity Fellowship opportunity. The Center's project focused on supporting a collaborative, immersion, experiential learning approach for two Sinte Gleska University students. The selected fellows are Whitney Jones and Vanessa Sully, both Human Services majors from Mission, SD. They were selected, and receive support and guidance from tribal elder Burdette Clifford, M.S., Human Services Department Chair at Sinte Gleska University. Principal Investigator and Project Director for the NTI program, Eric Kurtz, Ph.D., states that while many current efforts are being pursued to promote the values of diversity and inclusion, there is still much work to be done and much to learn from the perspectives of those residing in reservation communities.



Pictured are the students Vanessa Sully and Whitney Jones.

"It is critical that we bring people together and establish relationships so that we can learn from one another, and truly integrate our shared vision for working together to improve access to services and supports," says Kurtz.

For one fellow, this experience was another way for him to give back to his community. Whitney Jones was born and raised in Sioux Falls, S.D. and then moved to Mission, S.D. as an adult. He then had to adjust to the very different environment and the unique needs present on the Rosebud Reservation.

"When I heard about the challenges faced on the reservation, I knew I had to step up and show them that there are opportunities out there that can make a difference in our lives," says Jones.

Once he heard about the NTI program through Clifford, he jumped at the opportunity. As a fellow, his experiences ranged from learning about policy and advocating for disability issues in Washington D.C. and South Dakota state capital, Pierre, S.D. to attending conferences, clinics, and community events that the USD Center for Disabilities holds. He has even made new friends with the SD LEND trainees and has started a Facebook page to keep in touch.

"This experience has opened my eyes to the world of disability, the struggles, and the laws and regulations that affect people with disabilities on an everyday basis," says Jones.

His advice on prospective students wanting to participate in the NTI program in the future, is to go into it with an open mind. "It is a great opportunity for students to see the world differently than back home and it is a great stepping stone for students, like myself that want to go into counseling or who want to work with people with disabilities as a career," says Jones.

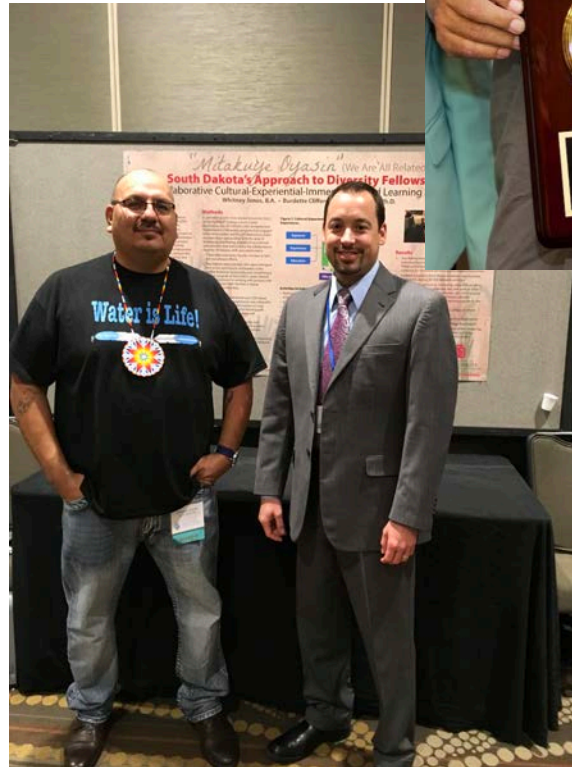
When he finishes the fellowship in September, he will also be graduating from Sinte Gleska University with a bachelor's degree in counseling with an emphasis in chemical dependency. His career goal is to stay in Mission, SD and work at an agency in which helping people is their top priority. He will still continue to have ties to Sinte Gleska as he will develop a video promoting the NTI program and collaborate with Clifford on starting up a transition clinic on the Rosebud Indian Reservation.

"There is a greater need for this type of clinic on the reservation because some of our youth don't realize that there are people out there that want to help you succeed beyond high school," says Jones.

Throughout the internship, Clifford also points out that not only do students gain knowledge and experience in the disability field but also develop their own ideas to bring back to their communities and their future careers. "It gives students the hands-on experience and a broader knowledge of what an institution (i.e. USD Center for Disabilities) would offer such as services and programs that they otherwise may not be aware of," says Clifford.

Equally as important as the fellows learning from experiences that were provided to them through the Center for Disabilities, the trainees, faculty, and staff of the Center have learned critical information and have been able to see important issues through perspectives and viewpoints not otherwise provided in their training.

Both Clifford and Kurtz agree that former students will serve as role models and mentors for new students going into the program which will enhance the motivation and interest in being current and future leaders.



Mutual Benefit

USD

- ▶ Increased relationships/trust
- ▶ Enhanced program's ability to enhance cultural and linguistic competency
- ▶ Increased understanding of SDH and Health Disparities/ Health Equity
- ▶ Increased experience with underserved and underrepresented areas
- ▶ Pipelines established for future trainees/faculty

SGU

- ▶ Increased knowledge in ASD, NDD, and DD
- ▶ Access to undergraduate and graduate coursework
- ▶ Leadership development opportunities
- ▶ Enhance professional networks
- ▶ Access to policy and advocacy activities
- ▶ Exposure to health and related careers
- ▶ Ongoing collaboration and support

Sustainability

- ▶ Continued and expanded activities even after funding did not
 - ▶ Formal Faculty role in SD LEND (Tribal Liaison)
 - ▶ Numerous intermediate-term trainees
 - ▶ Expanded cultural immersion activities
 - ▶ Expanded collaborative offering of coursework
- ▶ Collaborated on obtaining grants to build capacity in tribal communities across SD
- ▶ Have extended to all nine Tribes in SD



Skills addressed

- ▶ **Foundational Skill 1:** Relate the mission, vision, and goals of an organization to the broader system in which it belongs to facilitate shared understanding, responsibility, and action.
 - ▶ Strategy 1: Didactic (Courses, seminars, conferences)
 - ▶ Strategy 2: field experiences, cultural immersion activities
- ▶ **Advanced Skill 11:** Maintain a strong stakeholder group with broad-based involvement in an environment of openness, inclusion, and trust.
- ▶ **Advanced Skill 13:** Use community collaboration models and leverage existing community improvement efforts to define a meaningful role for MCH
 - ▶ Strategy 1: Collaborative-experiential-immersion (CEI) learning approach
 - ▶ Strategy 2: Sustainability plan

Questions for South Dakota LEND

Moderated Q&A

The background features abstract, overlapping geometric shapes in various shades of green, ranging from light lime to dark forest green. These shapes are primarily located on the left and right sides of the frame, creating a modern, dynamic feel. The central area is a clean, white space where the text is placed.

Break

10 minutes

University of Minnesota Nutrition



Jamie Stang, PhD, MPH, RDN

University of Minnesota, School of Public Health, Division of Epidemiology & Community Health

Director, Public Health Nutrition Training Grant

Director, Center of Excellence in MCH Education, Science & Practice Training Grant

Former Nutrition and LEAH Trainee



Kate Franken, MPH, RD

Minnesota Department of Health, Child and Family Health, WIC Program Director

Incorporating a Positive Deviance Perspective in Minnesota WIC



Using a Positive Deviance Approach to Improve Child Obesity Prevention Messages, Programs and Services

- ▶ Primary aim to create collaborative training and experiential learning opportunities for trainees, graduate students, faculty, Title V staff and other organization staff in using positive deviance approaches in child obesity prevention efforts
- ▶ Secondary aim to increase our shared understanding of strategies associated with lower risk of obesity in at-risk children and communities
- ▶ Third aim to share asset-based, community-derived, promising strategies with MCH programs, service providers and community agencies
- ▶ Funded through a Child Obesity Enhancement from HRSA

Using a Positive Deviance Approach to Improve Child Obesity Prevention Messages, Programs and Services

- ▶ The Positive Deviance Model
 - ▶ Why do some individuals/families/groups thrive while peers with access to the same knowledge and resources do not?
 - ▶ Used to identify community-specific, accessible/affordable, adaptive behaviors
 - ▶ Relies heavily on qualitative or mixed-methods approaches
- ▶ Many public health and MCH professionals have received formal training in biostatistics and epidemiology
 - ▶ Predominantly quantitative methodologies
- ▶ Fewer have been formally trained in qualitative methods or mixed methods approaches to research
 - ▶ Required to gather types of data most useful in positive deviance research

Using a Positive Deviance Approach to Improve Child Obesity Prevention Messages, Programs and Services

- ▶ Collaboration between UMN faculty and trainees and MDH staff and consultants
- ▶ Utilize the “See One, Do One, Teach One” approach
 - ▶ Joint trainings to “see” how positive deviance work is conducted
 - ▶ Joint research project to “do” an investigation using positive deviance approaches
 - ▶ Joint dissemination to “teach” our colleagues, trainees, mentees, and MCH service providers about the approach and our findings
- ▶ On-going UMN-MDH meetings to identify question, methods, where to recruit participants, populations to focus on
 - ▶ Chose to focus on preschool-aged children from populations showing changes in obesity rates over past 7-8 years



Faculty, Trainees and Partners

Core Collaborative Partners:

Zobeida Bonilla, Jamie Stang, B Alex Foster, Laura Hooper, Junia Nogueira de Brito, Marcia McCoy, Joni Geppert, Rebecca Gruenes, Kate Franken

MPH Trainees:

Somadee Cheam, Yetundi Akingbemi, Noelle Yeo, Kalia Thor, Toluwani Awokoya, Lauren Pringle, Marianna Colucci, Ashley Ansolabahar, Laura Villarreal, Elizabeth Stanczyk



Incorporating a Positive Deviance Perspective in Minnesota WIC

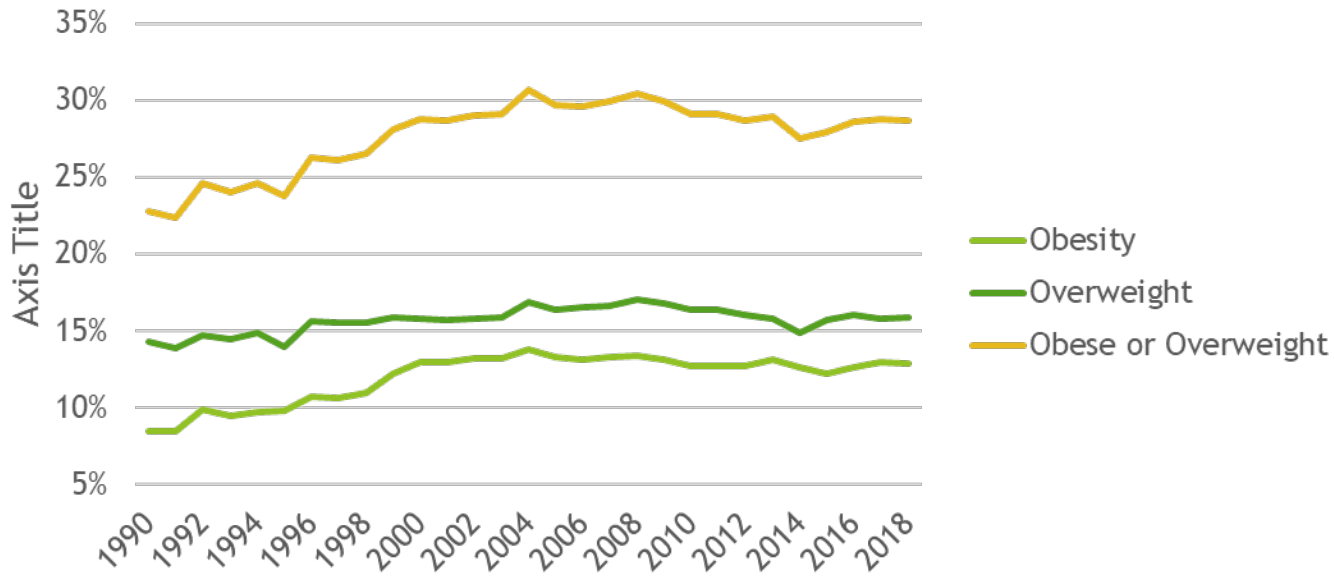


Minnesota WIC

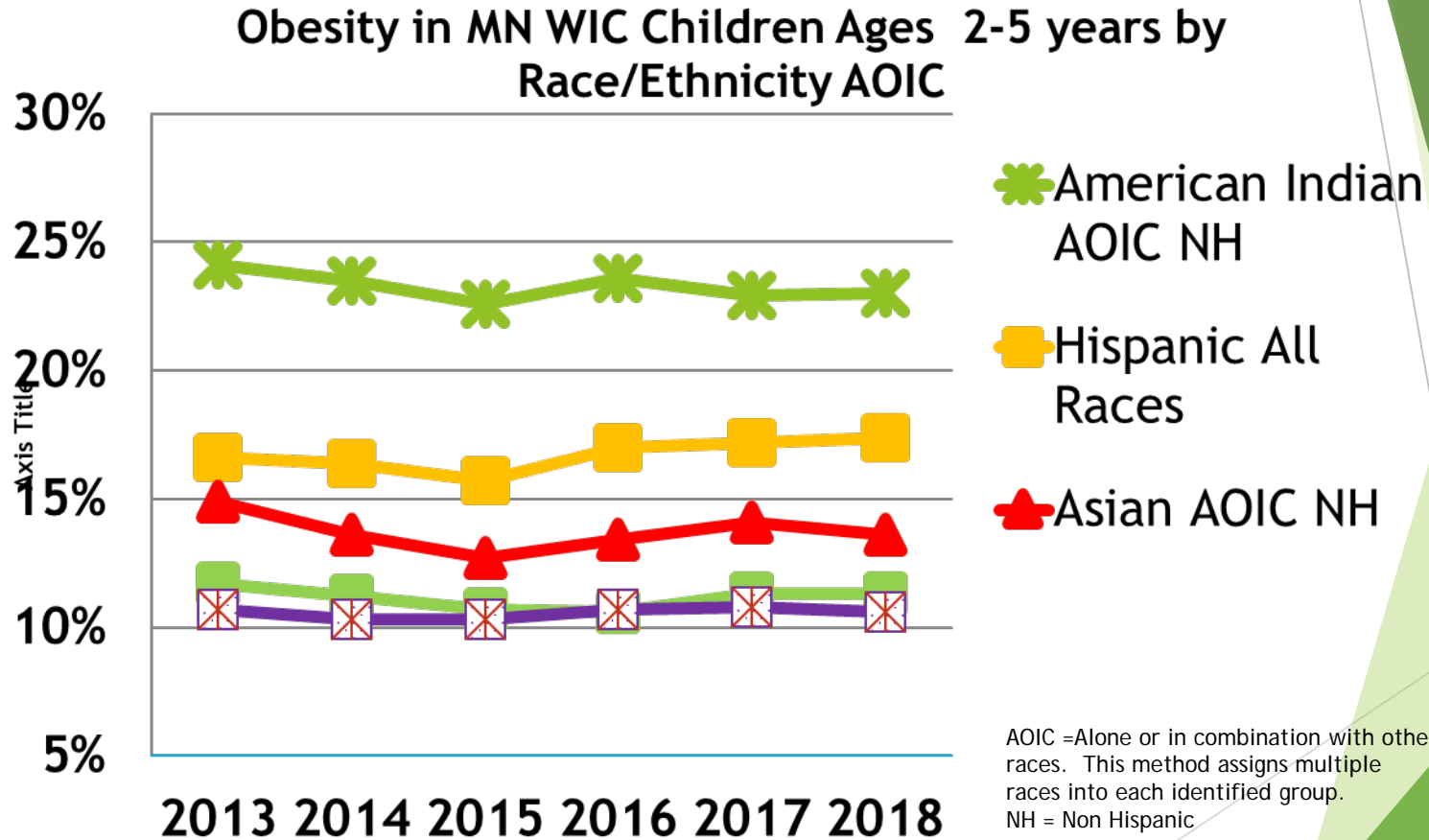
- ▶ Each month serves 58,000 children.
- ▶ Top four states nationwide in serving percent of those eligible for WIC.
- ▶ HuBERT WIC Information System collects individual level data on weight status, participation, breastfeeding and other health indicators.
- ▶ Collect information on race/ethnicity and cultural identity.
- ▶ WIC services include individualized nutrition education and counseling to improve health status

Obesity in MN WIC

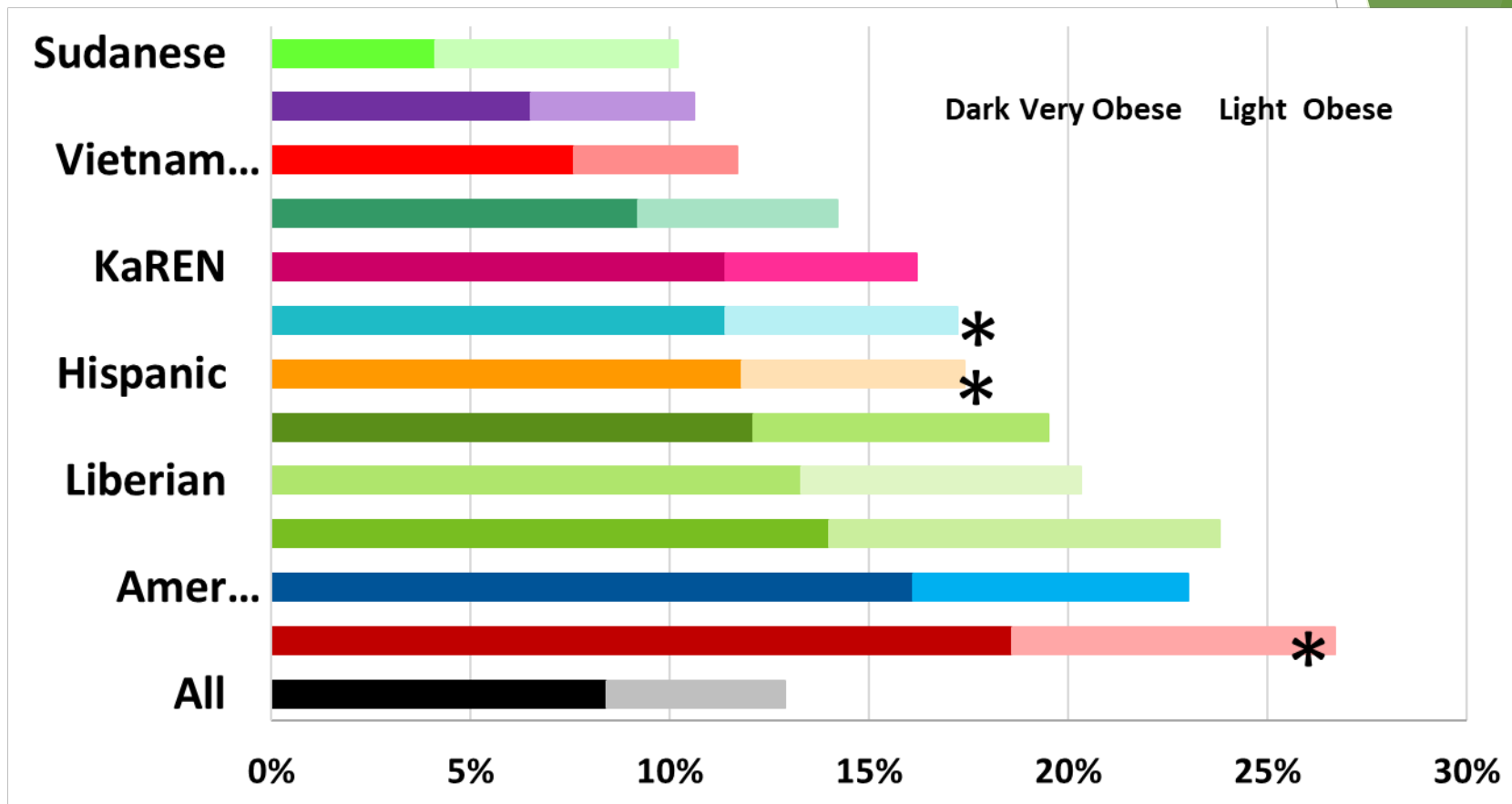
Obesity and Overweight Status in MN WIC
Children Ages 2-5 years



Obesity by Race/Ethnicity



Obese and Very Obese by Cultural Identity



WIC Nutrition Services - Opportunities

- ▶ Better understand cultural practices related to early feeding practices
- ▶ Improve our nutrition education messages
- ▶ Build confidence in providing information to diverse populations
- ▶ Build knowledge of what works and what doesn't work for different cultures
- ▶ How to target messages? Do the same messages work for all?
- ▶ Provide examples of successful strategies in communities
- ▶ "Could I share with you what other parents have found to be helpful for promoting healthy eating and physical activity?"

Positive Deviance in Child Obesity Collaborative Project

- ▶ Why do some individuals succeed in the face of adverse circumstances?
 - ▶ Mixed methods models with strong qualitative component
- ▶ Recruiting 90 families from MN WIC Program
- ▶ Three target racial/ethnic groups
 - ▶ African American (including US born and immigrant families)
 - ▶ Southeast Asian (including US born Hmong)
 - ▶ Hispanic (including US born and immigrant families)
- ▶ Half of families in each group with child on obesity trajectory, half on stable weight trajectory
 - ▶ Matched for demographics, zip code and family and community characteristics
- ▶ In-home interviews and WIC data
- ▶ Inductive qualitative and mixed methods analyses
 - ▶ Models for overall group and within each racial/ethnic group



Focus Group Session 3- Recruiting Participants

Using a Positive Deviance Approach to Improve Child Obesity Prevention Messages, Programs and Services

- ▶ Held series of trainings and professional consultations on positive deviance research & qualitative research methods
 - ▶ Attended by 89 individuals from the UMN and MDH
 - ▶ Conducted by faculty from UMN and OHSU
- ▶ Future trainings written into both the Nutrition and CoE grant plans to sustain the collaborative training model
- ▶ Developed the “Bright Spots: Positive Deviance Approaches to MCH Research” mini-lab
 - ▶ Specific space for UMN faculty, students, trainees and MDH staff and consultants to utilize for collaborative work in positive deviance
 - ▶ Online training resources for other students, faculty, programs and agencies to view

Positive Deviance Qualitative & Mixed Methods Mini-Lab



UMN-MDH Collaborative Training and Working Groups

Ten collaborative training sessions

- Qualitative/mixed methods software
- Interviewing and focus group methods
- Positive deviance model development
- Mixed methods analysis techniques



Bright Spots Mini-lab Kits

MDH Partners

- Child & Family Health
- WIC
- Birth Defects Monitoring/Analysis
- Office of Statewide Health Improvement
- Diabetes Prevention Program
- Cancer Control Unit
- Title V Consultants



Skills addressed

- ▶ Skill 12: Build effective and sustainable coalitions to address specific outcomes.
 - ▶ Strategy 1: Developed project jointly from the very beginning in true collaboration form
 - ▶ Shared vision and priorities, joint ownership
 - ▶ Strategy 2: On-going, dedicated support and resources
- ▶ Skill 8: Manage a project effectively and efficiently, including planning, implementing, delegating, sharing responsibility, staffing, and evaluating.
 - ▶ Strategy 1: On-going review and brainstorming, sharing successes/barriers
- ▶ Skill 4: Identify stakeholders and the extent of their engagement in the collaborative process
 - ▶ Strategy 1: Periodic check-ins
 - ▶ Strategy 2: Celebrations of milestones

We have been challenged by...

- ▶ **Withdrawal of one community that had agreed to participate**
 - ▶ Important to remember that community wishes regarding research need to be respected
 - ▶ Adaptability is key with community partnerships
- ▶ **Turnover in staff and trainees**
 - ▶ Slow administrative processes resulted in inability to recruit all families within the academic year
 - ▶ Changes in staff and trainees
- ▶ **Competing priorities**
 - ▶ Community-based, in-home interviews are time consuming
 - ▶ Qualitative research is time consuming

Minnesota WIC's Role in Positive Deviance Research with U of M

- ▶ Identified caregivers of children on the trajectory towards obesity and not on the trajectory and worked with students to randomly recruit study sample
- ▶ Worked with U of M to develop study questions.
- ▶ WIC analytic staff attended trainings sponsored by the U of M on qualitative data analysis, mixed methods research, data triangulation and presentation of results
- ▶ Working with U of M to analyze and interpret data.
- ▶ Will disseminate findings to local WIC agencies statewide and use information to target nutrition interventions.

Minnesota WIC Benefits of Partnership

- ▶ Learning about positive deviance and its potential implications for improving WIC services.
- ▶ Exploring the feasibility of positive deviance and qualitative research within WIC.
- ▶ Gaining internal capacity to analyze, report and use qualitative data.
- ▶ Access to students that provide the time and effort needed for labor-intensive qualitative research.
- ▶ Developing our future work force of professionals.

We are excited about...

- ▶ **Strong collaborations** with MDH
 - ▶ MDH and UMN have shared vision for future work in child obesity
 - ▶ Streamlined process for integrating trainees into MDH projects
 - ▶ Ability to “give back” to MDH
- ▶ **Qualitative mini-lab** has created stronger ties among training grant programs
 - ▶ MN Obesity Prevention Center is handling logistics
 - ▶ CoE grant will share resources to support mini-lab
- ▶ **Developing strong ties and more trust within our communities**
 - ▶ Identified community leaders who share our interests in improving health of MCH populations
- ▶ Assisting with development of **asset-based counseling messages** for families that we can share with WIC, MIECHV, Head Start, Healthy Start and other programs

Questions?



Focus Group Session 5 Demonstration

Questions for Minnesota Nutrition

Moderated Q&A

University of Alabama at Birmingham



Tina Simpson, MD, MPH
UAB LEAH Project Director



Hannah Hulsey, MD
UAB LEAH Medical Fellow

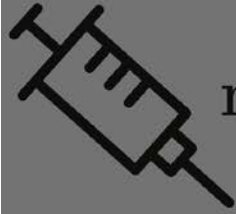


Michelle Brown, PhD, MS
Program Director
Healthcare Simulation



MCH Skills

- ▶ Identify stakeholders and the extent of their engagement in the collaborative process
- ▶ Build effective and sustainable coalitions to address specific outcomes.



130+ people die of opioid
related overdoses each day

The U. S. Opioid Epidemic



2.1 million



Addressing the Opioid Crisis

- ▶ Clinician education on prescribing practices, nonopioid pain management
- ▶ Addressing stigma
- ▶ Treatment options for opioid use disorder
- ▶ Patient family and caregiver education
- ▶ Transitions of care
- ▶ Collaborating with communities
- ▶ Advocacy and policy

UAB LEAH + UAB OIPS Collaboration



Innovative Response

- ▶ Born out of a Hack-a-thon
- ▶ Office of Interprofessional Simulation for Innovative Clinical Practice
- ▶ Content experts in addiction psychiatry, treatment counseling, pharmacy, simulation
- ▶ Needs assessment



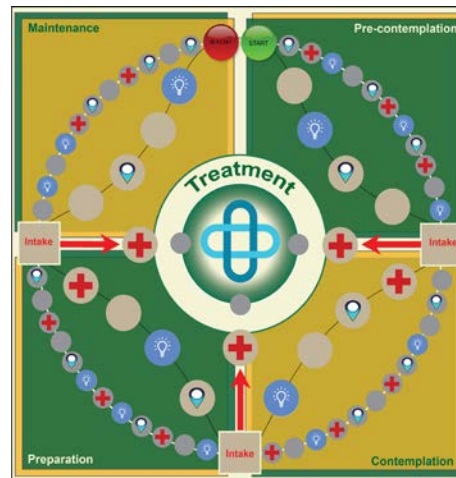
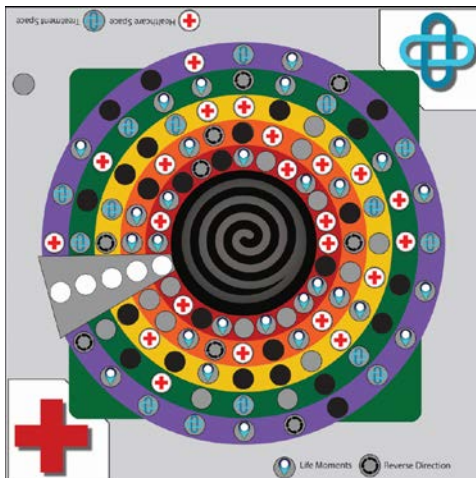
Goals of the Simulation

- ▶ The Opioid Simulation focuses on
 - ▶ Opioid use disorder as a chronic, relapsing disease for which there is treatment and recovery.
 - ▶ The impact of personal resiliency on opioid use.
 - ▶ The role of stigma in the opioid epidemic.



Design of the Simulation

- ▶ Tabletop format
 - ▶ The Opioid Simulation tabletop concept is similar to that of a board game.
 - ▶ Navigate life as someone with an opioid use disorder
 - ▶ Obtained stakeholder feedback through piloting the simulation



Interaction during Simulation

- ▶ Prebrief
 - ▶ Orientation to roles
 - ▶ Progress around the board
- ▶ Simulation
 - ▶ Life cards
 - ▶ Healthcare provider interactions
 - ▶ Opportunity to enter treatment (for some)
- ▶ Debrief
 - ▶ Structured
 - ▶ Stigma exercise
 - ▶ Connect participants to community resources

Partnering with LEAH

- ▶ Polish the Simulation
- ▶ Additional stakeholder feedback
- ▶ Prompted next step -measuring impact



Trainee Perspective

- ▶ Insight into the complexities and challenges of substance abuse disorder
- ▶ Effects of opioid use on the individual, interpersonal, and community levels
- ▶ Increased compassion and understanding as a health provider
- ▶ Broader perspective of how we can address the opioid crisis in our health systems and at a policy level

Questions for UAB LEAH

Moderated Q&A

Conclusion

Next Steps

- ▶ Meeting will be archived
- ▶ Tip-sheet will be disseminated
- ▶ Please take our evaluation

The background features abstract, overlapping geometric shapes in various shades of green, ranging from light lime to dark forest green. These shapes are primarily located on the left and right sides of the frame, creating a modern, layered effect. The central area is a plain white space where the text is located.

Thank you!