

Fostering Partnerships to Improve
Native American Health
Sept. 16, 2015 2:00 pm Eastern Time

Speakers:

Allison Barlow, Center for American Indian Health,

Stacy A. Bohlen, National Indian Health Board

Patricia Doykos, Bristol-Myers Squibb Foundation.

A Funder's Story: Philanthropy & Native American Health



PATRICIA M. DOYKOS, PHD

BRISTOL-MYERS SQUIBB FOUNDATION

How BMSF came to focus on Native American Health

Mission – to promote health equity and improve health outcomes of heavily affected populations

Grants Program - *Together on Diabetes™* launched in 2010

- Expand Diabetes Self Management Education and Support
- Expand and strengthen community resources for diabetes self management
- Mobilize communities to take control of diabetes

Need

- Native Americans and Alaska Natives suffer the highest rates of type 2 diabetes in the nation
- 1 in 3 adults in areas of the Southwest such as AZ and NM that are home to large Native American populations
- Half of the increase in the mortality rate for Native Americans over the past two decades is attributable to type 2 diabetes
- Native American youth have the highest and fastest-increasing prevalence of type 2 diabetes of any racial group in the U.S.

Annual Focus on Population or Diabetes Self Management Issue

- 2011 African American Women
- **2012 Native Americans**
- 2013 Diabetes, Depression and Distress



How BMSF forged a partnership with Navajo and White Mountain Apache Communities

BMSF consultations with Native American Health stakeholders

- Indian Health Service Director, Diabetes Consultant, Phoenix Regional Office Director, and CDC Native Health Director
- Native American health focused associations
- Academic institutions focused on Native American Health

Key Insights from Johns Hopkins Center for AI Health consultation

- Take a multigenerational and family approach by focusing on youth living with or at risk of diabetes
- Tap into Native culture, health traditions and teachings to address the *imbalance* of diabetes
- Partner with a permanent, trusted and respected partner of the tribes
- Explore sustaining grant-created capacity and services through existing, but flexible IHS provisions, e.g. Community Health Representative positions
- Investing in youth and engaging youth in advising and delivering solutions is a key long-term sustainability strategy



NEW U.S. PARTNERS



Restoring Harmony and Valuing the Power of the Generations in a Family

While Native American youth are at high risk for developing diabetes, sustained wellness programs have been rare in schools and communities to prevent and control the disease.

That is changing. Native Americans who live in communities in the Southwestern U.S. will be supported in their diabetes journey through a pioneering program of intergenerational, family and community-focused interventions for type 2 diabetes offered by the Johns Hopkins Center for American Indian Health and its local partners. The program is supported with a \$2.25 million, two-year grant from the Foundation.

The Center is using the grant to build a diabetes education, care and support program to serve at least 250 Navajo and White Mountain Apache youths and their family members. Family health coaches are being deployed to educate youths about their disease, guide them to treatment and care and help them to make necessary changes in their diet and exercise.

At a recent home visit, family health coach Melinda Charley (pictured here) played a game with a Navajo teen living with diabetes and his brother to explain how glucose accumulates in the blood. She then had a discussion with them about what eating healthy meant to them and helped them in order to set a reachable nutritional goal. "In the Navajo way, disharmony and imbalance make one susceptible to illnesses such as diabetes," said Charley. "We tell stories and use games to convey the causes and consequences of the disharmony and also to identify the path to restoring harmony and good health."

For the Center, an added bonus of working with young people is that they often live not only with their parents but also with their grandparents. As the teen learns about living healthfully with diabetes, the family health coaches can also involve parents in adopting and promoting active lifestyles — like those of their elders and ancestors — as well as help them navigate diabetes care.



Together Diabetes

Communities United to Meet America's Diabetes Challenge

**Johns Hopkins Center for American Indian Health
Together on Diabetes Project**

*Addressing the Burden of Diabetes Among
American Indian Youth and Families*

RESULTS TO DATE

- Diabetes Case Management Program in 10 Southwestern U.S. Health Communities
- Community Health Committees meeting systematic needs, needs, and goals
- Over a year of comprehensive screening and management protocols for youth and their families, community members and providers, are underway and ready for change. New diabetes support teams are being formed.
- Screening communities with youth (over 100) and parents (over 100) attending program activities
- Home-based youth and support person centered teams, diabetes education, and support person centered teams, and diabetes management
- Diabetes case management and support person centered teams, and diabetes management
- Over 100 youth and family health coaches trained in 2014 and 17 support teams in the intervention

PROJECT GOALS

Addressing the burden of diabetes among American Indian youth and families in 10 Southwestern U.S. Health Communities. The program will address the burden of diabetes through the following goals:

- Identify and address the burden of diabetes among American Indian youth and families in 10 Southwestern U.S. Health Communities
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TRAINING & CAPACITY BUILDING

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PROJECT DESIGN/STRATEGY

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PATIENT/CLIENT RECRUITMENT & ENGAGEMENT

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PARTNERS & ROLES

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SERVICE/SUPPORT DELIVERY

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QUALITY IMPROVEMENT ACTIONS

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KEY LESSONS

Addressing the burden of diabetes among American Indian youth and families in 10 Southwestern U.S. Health Communities. The program will address the burden of diabetes through the following goals:

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Resources: www.togetherondiabetes.com



Nations within a Nation: An Introduction to Indian Country

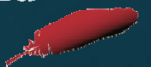
STACY BOHLEN

NATIONAL INDIAN HEALTH BOARD

GRANTMAKERS IN HEALTH WEBINAR

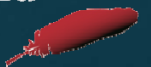
SEPTEMBER, 2015

National Indian
Health Board



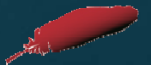
NIHB Mission Statement

One Voice affirming and empowering
American Indian and Alaska Native
Peoples to protect and improve health
and reduce health disparities.

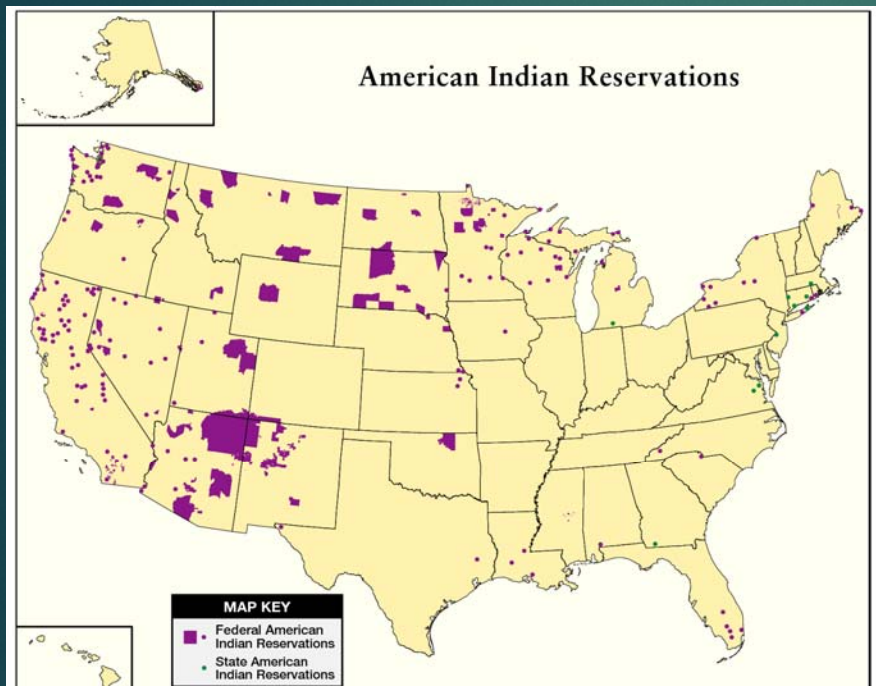


Areas of Expertise and Service

- ▶ NIHB provides a variety of services
 - ▶ Advocacy
 - ▶ Policy Formation and Analysis
 - ▶ Legislative and Regulatory Tracking
 - ▶ Direct and Timely Information Dissemination to Tribes
 - ▶ Research on Indian Health Issues
 - ▶ Program Development and Assessment
 - ▶ Public Health Infrastructure
 - ▶ Training and Technical Assistance Programs
 - ▶ Project Management

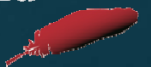


Indian Country and Tribes



- ▶ 567 Federally-recognized Tribes in 35 states
- ▶ 4.5 million American Indian/ Alaska Native people
- ▶ Approximately 56.2 million acres are held in trust by the federal government for Tribes (and AI/AN people)

National Indian
Health Board

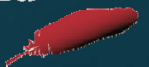


Diversity

- ▶ Difference in:
 - ▶ Tribal enrollment numbers
 - ▶ Enrollment criteria
 - ▶ Residence of Tribal members
 - ▶ Governance structure
 - ▶ Economic development
 - ▶ Relationships with state and local governments



National Indian
Health Board



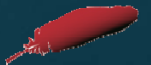
Tribal Sovereignty

- ▶ Federally-recognized Tribes have a government-to-government relationship with the federal government
- ▶ Tribes **retain** inherent authority to make their own laws and govern their own people, and others on their lands
- ▶ Tribal Sovereignty has been acknowledged and reaffirmed by the federal government in treaties, Supreme Court Case law, executive orders, and legislative actions



Trust Responsibility

- ▶ Federal government made solemn promises of protection and benefits to the Tribes in exchange for land and peace
 - ▶ Rooted in treaties, authorized by the Constitution, acknowledged and reaffirmed by Supreme Court Case law, executive orders, and legislative actions

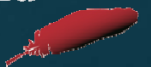


Statement of the Trust Responsibility

"The government has agreed to provide community services such as health, education and public safety, services which would presumably allow Indian communities to enjoy a standard of living comparable to that of other Americans."

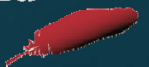
-President Richard Nixon, 1970

National Indian
Health Board



Role of non-Native Citizens

- ▶ Born into the “contract” that the United States has with American Indian and Alaska Native Nations
 - ▶ The trust responsibility is woven into the fabric of American being
 - ▶ Should not be seen as just the purview of the U.S. government





Thank you for your time and commitment to Indian health

STACY A. BOHLEN

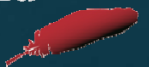
(ENROLLED: SAULT STE. MARIE CHIPPEWA INDIAN TRIBE)

EXECUTIVE DIRECTOR

NATIONAL INDIAN HEALTH BOARD

SBOHLEN@NIHB.ORG

National Indian
Health Board



Johns Hopkins Center for American Indian Health

For more than three decades,
we have partnered with American
Indian communities to co-design
programs to achieve optimal
health and well-being across the
lifespan.



Johns Hopkins Center for American Indian Health



Founded in 1991 at the Johns Hopkins Bloomberg School of Public Health by Dr. Mathu Santosham, based on 10 years' work with SW tribes



Mission: To work in partnership with American Indian and Alaska Native communities to raise AI/AN health status, self-sufficiency and health leadership of AI/AN people to the highest possible level.

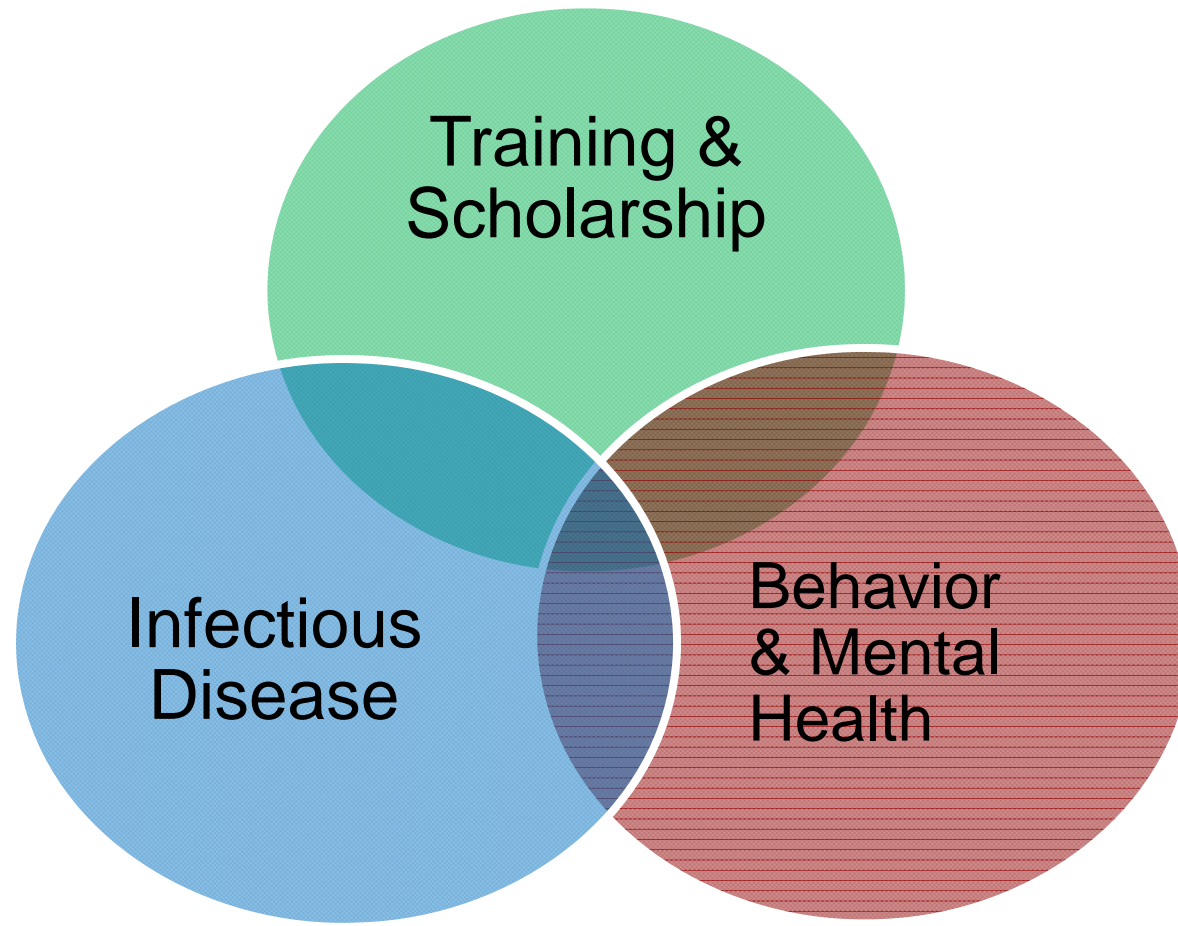


Johns Hopkins Center for American Indian Health



Director:

Mathu Santosham, MD, MPH





MOU with IHS since the Center's Founding in 1991

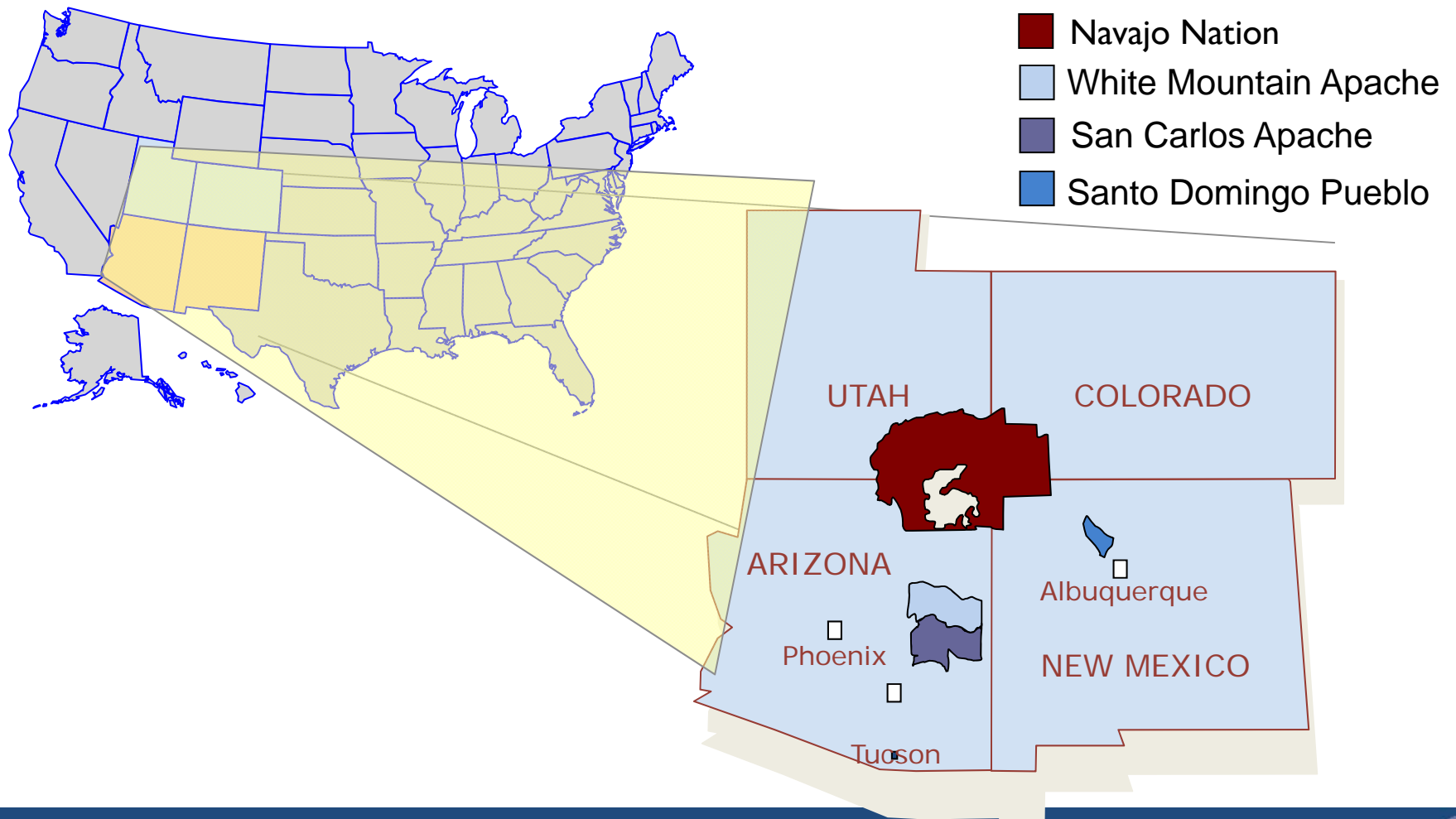


Center Director Mathu Santosham, MD, MPH signing latest IHS MOU with former IHS Director Yvette Robideaux, MD, MPH

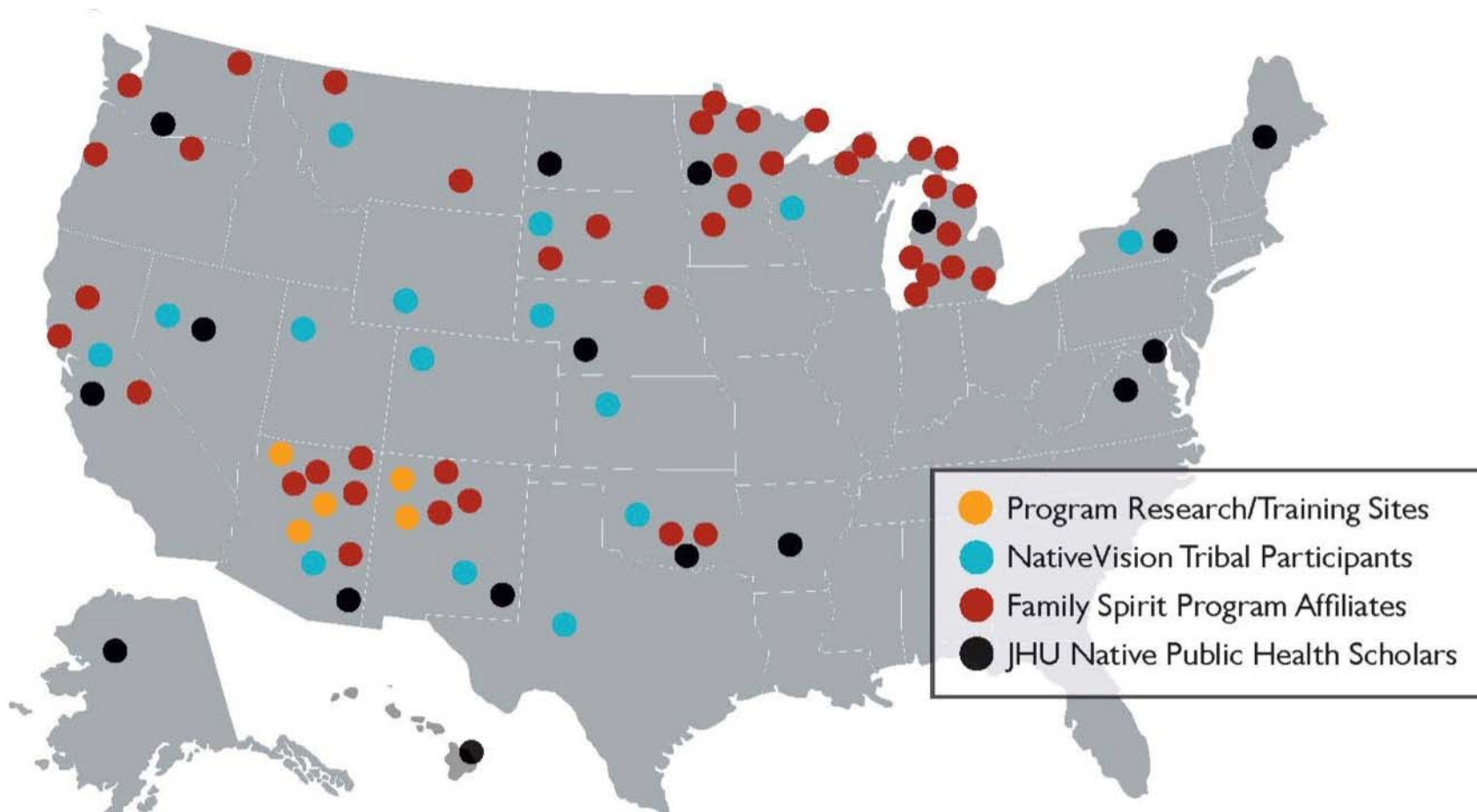
First MOU with IHS signed in 1991 with Dr. Everett Rhoades and renewed continuously to leverage assets to raise AI/AN health status to highest possible level



3 decades of partnership with Southwestern tribal communities



Johns Hopkins Center for American Indian Health



Our Center's present scope





Center now employs 125+ faculty and staff including 80+ American Indians who are doing health outreach, education and research in their communities



✓ Building local work force capacity



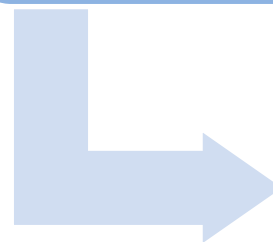
A changing landscape...



Major shift from
high infectious
disease mortality
to



Behavior and
mental health
inequalities



Low education,
employment,
modern trauma,
fractured families

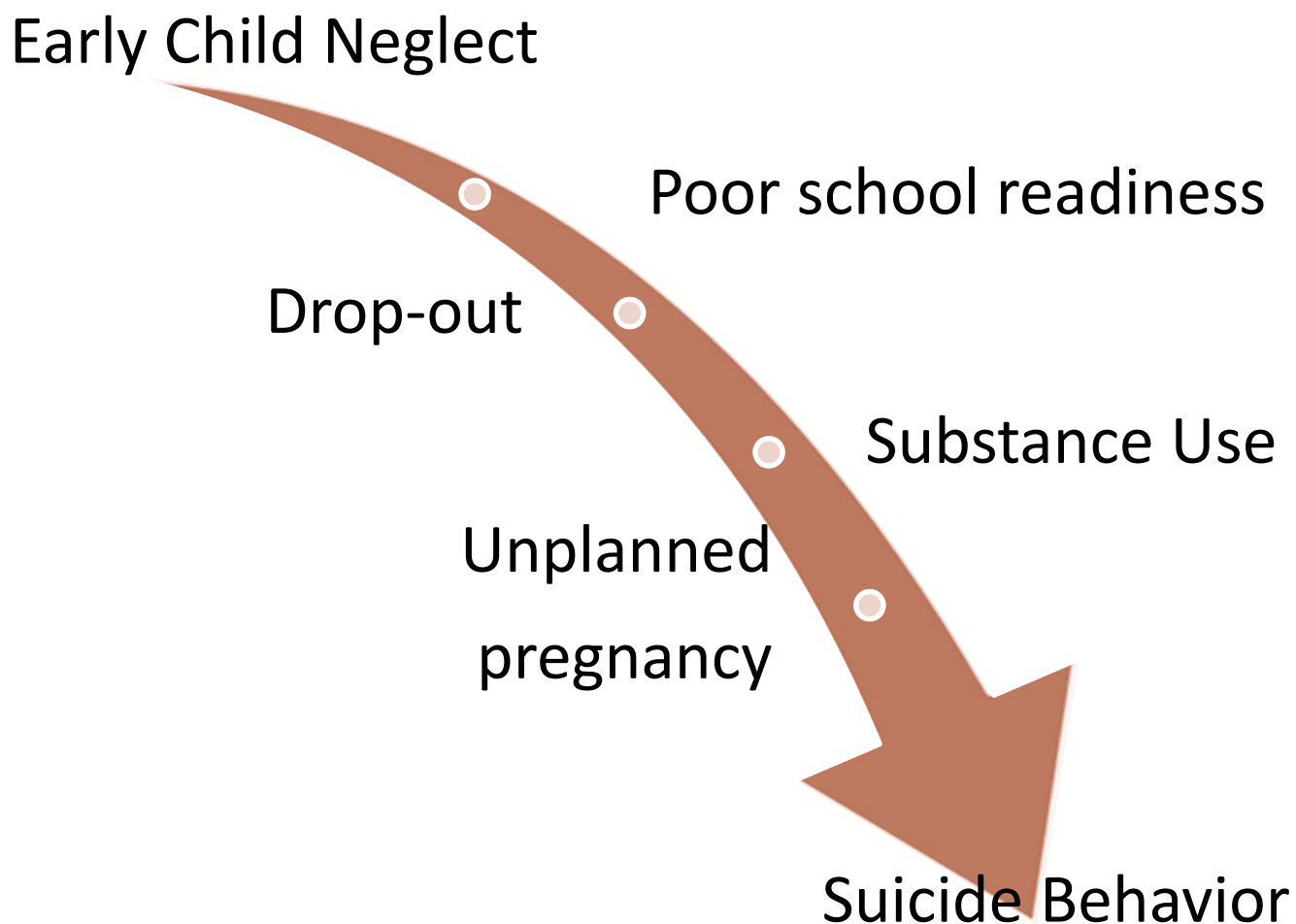


Disparities for Reservation AI/AN Youth Today

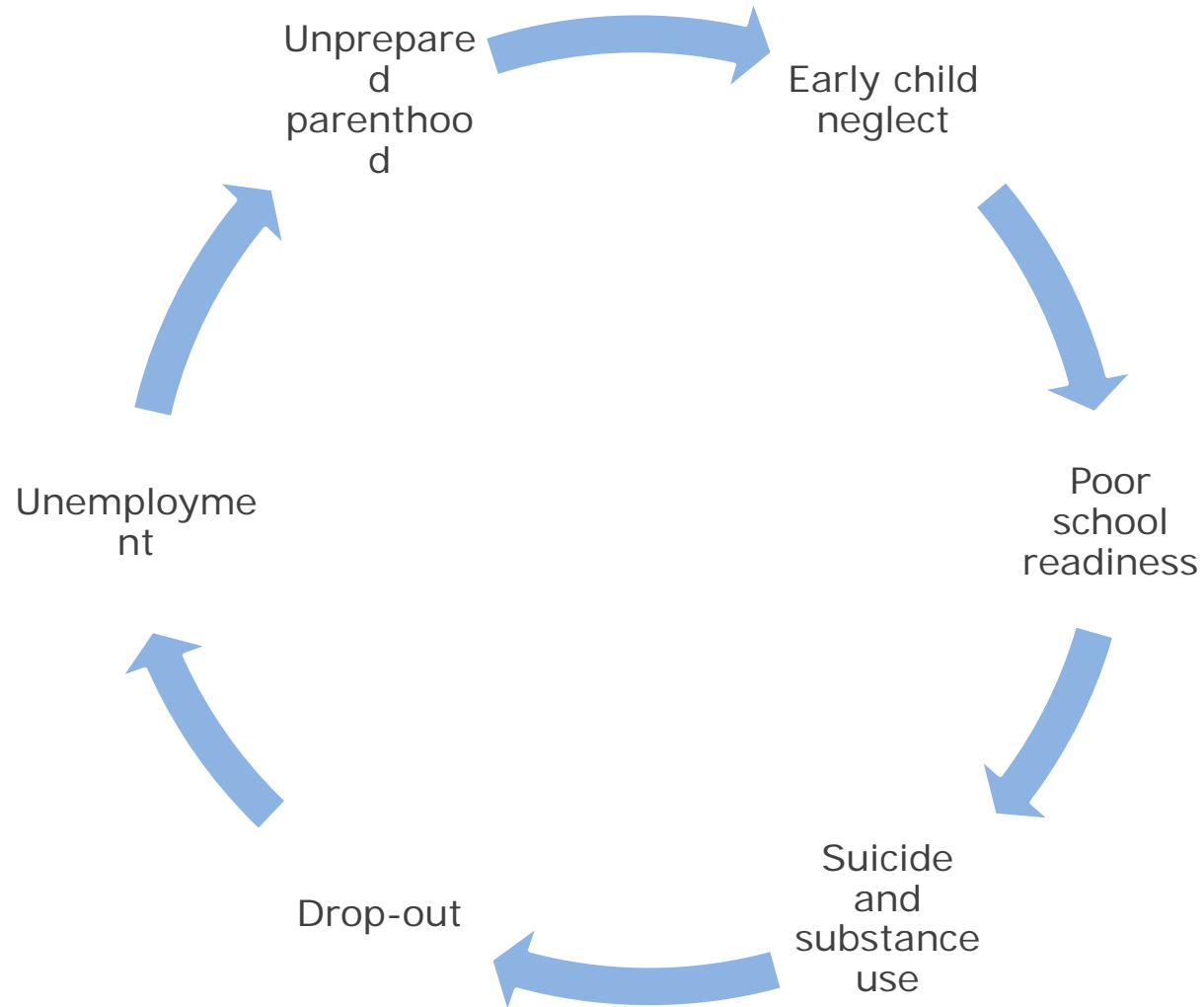
- Death Rate (0-25 yrs): 3.2x higher
- Suicide Rate (15-24): 2-3x higher
- Alcohol-related Deaths: 7x higher
- Obesity/Diabetes: 3x higher
- School Readiness <50%
- High school drop-out up to 50%
- Teen Childbearing: 2x higher
- Unemployment rates 50 to 80%



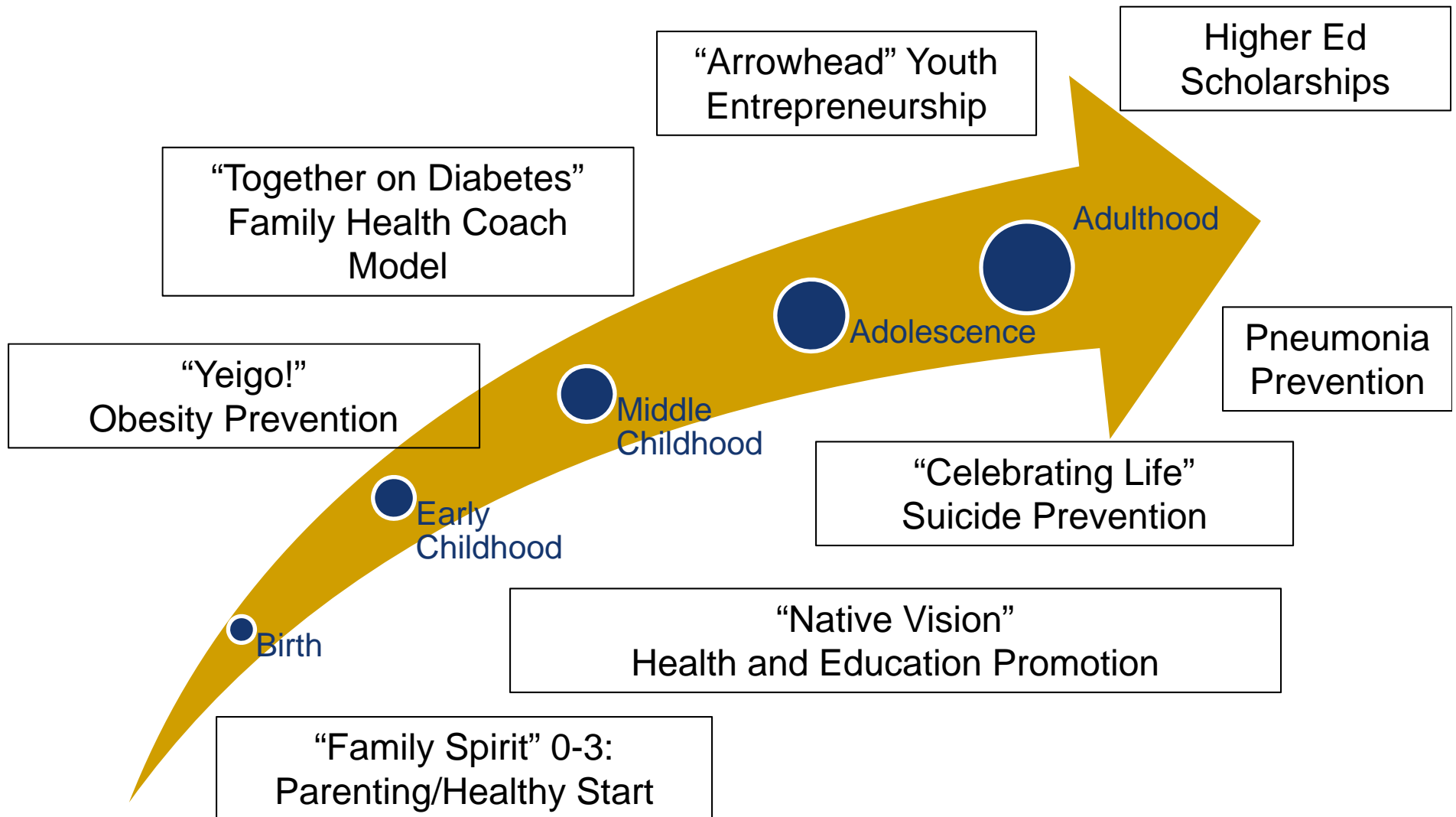
The Downward Trajectory



How do we break this cycle?



Changing the Future *Working Across the Lifespan*



**FOUNDATIONS CAN PLAY
A VITAL ROLE IN RENEWING HEALTH FOR AI/AN
COMMUNITIES**



RECOMMENDATIONS



Step 1: Importance of trust-building and relationship-building



How that translates to grant-making:

- Longer start-up time
 - Formative development
 - Planning
 - Community mobilization phase
- Multi-year commitments
 - Consider two or three stage grant-making
 - Planning, Implementation/Evaluation, Sustainability/Scaling
- Maintain flexibility—supplements, technical assistance, opportunities to amplify
- Promote simultaneous opportunities for capacity building and health education: tap into existing training grounds



Step 2: Positive Focus

Promote Approaches that Tap Cultural and Community Assets and Strengths



- Children are Sacred
- Matrilineal Societies
- Respect for Elders
- Respect for Nature

- Intergenerational Homes
- Guiding ceremonies and beliefs surrounding rites of passage



Step 3: Give and Give



- Be Generous
 - May serve fewer, but often remoteness and constellation of challenges requires more resources
 - <.4% of private philanthropy supports AI/AN needs who represent ~2% of population and have 3x health disparities
- Fill needed niche of funding for ground-up development of health interventions – with strong and trusted evaluation partners
- When starting with new communities, consider pairings with trusted partners (i.e., tribal, national AI organization, or university with track record with AI/AN populations)
- Ensure direct service to and by Native peoples (including employment/education)
- Don't forget rural areas (much to learn for many other populations)
- Consider Innovations in reporting and/or applications
 - Briefs? Photos? Audioreports? Figures/Graphs? Dialogue



Step 4: Help Train the Next Generations of AI/AN Health Workforce



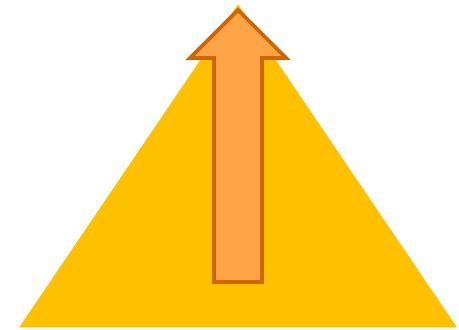
- Find and Fund Training Partners



JHCAIH American Indian Scholars Programs



- Graduate/doctoral scholarships and mentoring for AI/AN students in public health, nursing, medicine
- Public Health Certificate Program in AI/AN Health at JHU (18-credit – graduate certificate)
- Research coordinator training courses
- Educational pipeline programming
 - *Faculty development*
 - *Postdoctoral*
 - *Doctoral*
 - *Graduate*
 - *Undergraduate*
 - *High school*
- Professional development Center staff/faculty



Step 5: Leverage Partnerships



- Private-public
- Tribal-tribal (NIHB)
- Tribal-university
- Other examples
 - JHU and the NFL Players Association for Native Vision youth development program





CASE EXAMPLES



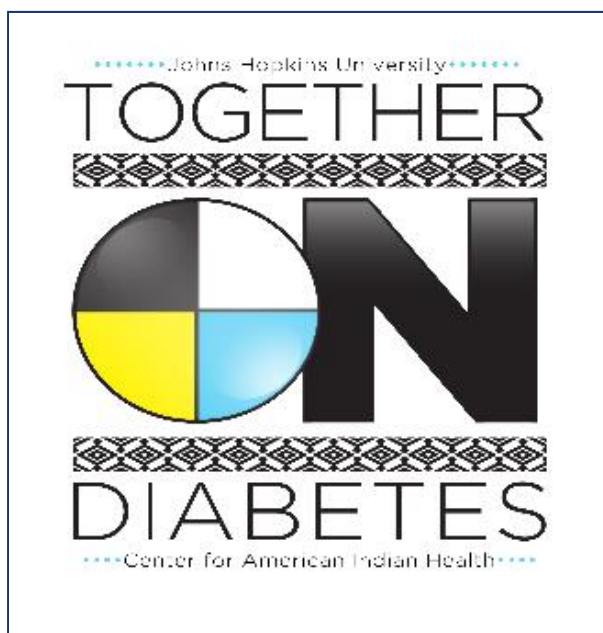
Bristol-Myers Squibb Foundation

Together  Diabetes

Communities Uniting to Meet America's Diabetes Challenge

Case Example 1

Together on Diabetes



Three Year Project Period

January 2012- December 2014*



- Engage community partners; assess assets and gaps
- Identify and adapt an Evidence Based Program
- Select program goals and evaluation measures
- Secure Tribal & IRB approvals
- Hire and train staff

- Recruit 250 adolescents/families
- Implement intervention with enrolled youth and support person
- Track process and outcome impacts
- Create knowledge base to scale up

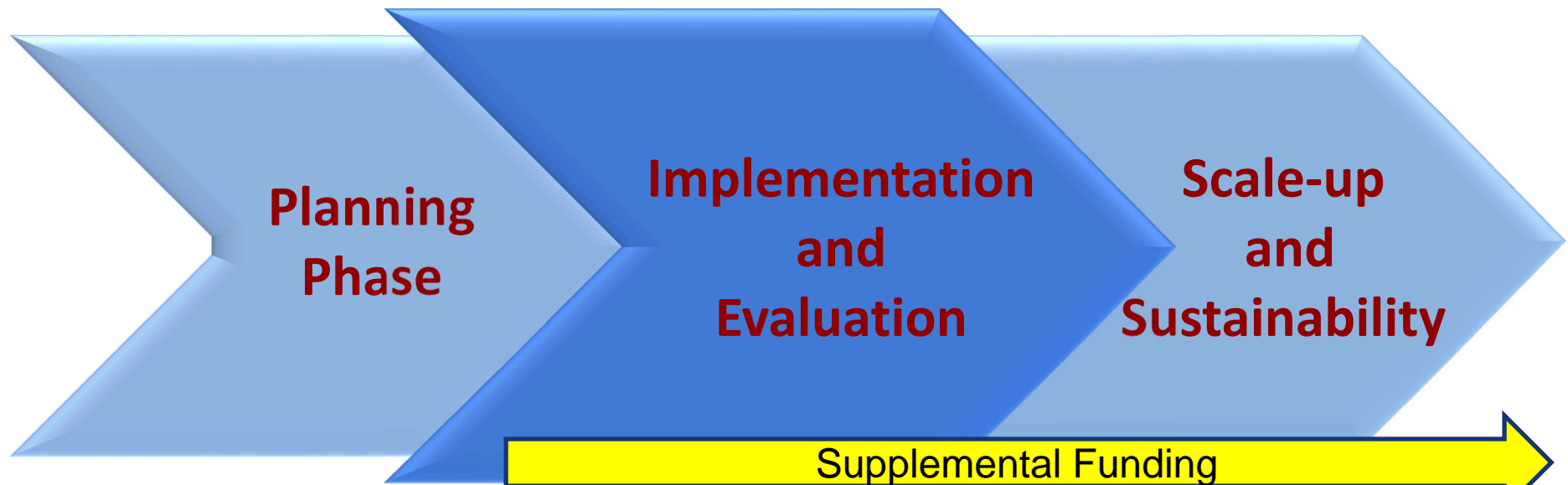
- Engage community leadership to develop strategic plan for program sustainability
- Impact local, regional and national health policy delivery

* Original Timeframe



Three Year Project Period

January 2012- January 2015*



Support to:

- Participate in Institute for Healthcare Improvement (IHI) [Triple Aim](#) training initiative
- Extend implementation phase
- Qualitative study with youth and support person for continuous model improvement

- Cost effectiveness study to prove the



Summary of Together on Diabetes



■ Accomplishments

- Enrolled 250 youth/support persons across 4 reservation sites
- Intervention and evaluation through June 2015
- 85%+ retention
- Strong preliminary results (i.e., depression↓ BMI ↓quality of life ↑satisfaction↑)
- Medical chart reviews will be conducted for 5 years following enrollment
- Launching cost effectiveness study to assist with advocacy efforts
- First youth-specific evidence-based approach to managing diabetes

■ Sustainability through IHS and Tribal Programs

- Family Health Coach criteria built to match CHR and Health Tech positions within IHS
- IHS Diabetes Director awaiting 12 month data in order to promote as best practice
- Chinle Youth Lifestyle Management iterative project -- model for sustainability through IHS

■ Continued Research and Service through Other Grant Funding

- NB3F grant in Tuba City will allow enrollment of 15 additional youth
- Navajo Area IHS – extension of curriculum to childhood obesity prevention and other risk and protective factors to prevent diabetes





Case Example 2

Family Spirit



Family Spirit Evidenced-Based In-Home Support and Education



- Created in partnership with Native communities over 18 year period
- Premise: supporting adolescent mothers is fastest path to change for community and future generations





Family Spirit Project History

Share our
Strength
Fdn

SOS Project:

- Intervention & service
- Moms/babies
- prenatal-6 months pp
(n=160 Moms/babies)

Family Strengthening:

- Moms/Dads/babies
- Prenatal to 6 mos pp
- RCT evaluation
(n= 68 moms / 48dads)

Cradling Our Future:

- * Mom/babies
- * Prenatal to 3 yrs pp
- * RCT evaluation
(n= 322 moms/children)

1998-1999

CS Mott
Ford
AE Casey
Fdns

2002-2005

NoVo Fdn
MIECHV - ACF
Tribes
IHS

Present

1995

1999-2001

2005

Fathers Project:

- Intervention design and service
- Larger curriculum to address needs of young mothers and dads

Family Spirit:

- Moms/Dads
- prenatal to 12 mos pp
- RCT evaluation
(n= 166 Moms / 75 Dads)

Program Replication

- 51 tribal sites across 15 states
- Chicago



The Secret Sauce: Indigenous Family Health Educators

- Trusted home visitors
- Compassionate role models
- Community change agents
- Work force development



Family Spirit Curriculum Package



Family Spirit Impact: Pregnancy to Age 3



Parenting

- Increased maternal knowledge ^{1,2,3,4}
- Increased parent self-efficacy ^{3,4}
- Reduced parent stress ^{2,4}
- Improved home safety attitudes³

Mothers' Outcomes

- Decreased depression. ^{1,2,4}
- Decreased substance use ⁴
- Fewer risky behaviors ^{3,4}

Child Outcomes

- Fewer social, emotional and behavior problems through age 3. ^{2, 3, 4}
- Lower risk of substance use, risky sex and behavior problems over life course



1 Barlow A, Varipatis-Baker E, Speakman K, et al *Arch Pediatr Adolesc Med.* 2006;160:1101-1107

2 Walkup J, Barlow A, Mullany B, et al. *Journal of the American Academy of Child and Adolescent Psychiatry.* June 2009.

3 Barlow A, Mullany B, Neault N, et al. *American Journal of Psychiatry.* January 2013.

4 Barlow A, Mullany B, Neault N, et al. *American Journal of Psychiatry.* February 2015.




Family Spirit: Ready to Scale



Highest **participant retention**:
91% to 1 year postpartum; 83% to
3 years postpartum

4.0/4.0 on “**Readiness for
Dissemination**”

Highest **federal rating** for
HomeVEE: effectiveness of home
visiting program models targeting
families with children 0 to 5

 **NREPP** SAMHSA's National Registry of
Evidence-based Programs and Practices





Thank you to GIH for your commitment
to renewing health for
the First Americans!



Advancing a Public Health Agenda for Native Communities

September 22, 2015 2:00 pm Eastern Time

Cosponsored by Native Americans in Philanthropy

- New topics you want to tackle or learn more about?
- Innovative work that you want to share?
- A question you want to pose to your colleagues?

Contact us at equity@gih.org