

National Indian Health Board



Special Diabetes Program for Indians (SDPI)
Think Tank

August 23, 2018

Table of Contents

Introduction	1
Considering the Success of SDPI Over the Past 20 Years - Summary	2
Demonstrating SDPI Success to Others	5
Additional Evidence Needed to Demonstrate SDPI Success	5
Evaluative Efforts that Might Be Undertaken to Develop the Evidence.....	6
Impact of SDPI on Adjacent Areas of Chronic Disease	6
Securing Feedback on SDPI from a Broader Audience	7
Appendix A- SDPI Think Tank Participants	8
Appendix B - Notes Considering the Success of SDPI over the Past 20 Years.....	9
Elements of SDPI that Have Made It Successful - Notes	9
What We Could Do Better - Notes	11
Critical Issues Facing SDPI – Next 3-5 Years - Notes.....	12
Defining Future Success – Key Elements of SDPI Discussion - Notes	15
Appendix C - Notes From Additional Evidence Needed to Demonstrate SDPI Success	16
Appendix D – Notes from Evaluative Efforts that Might Be Undertaken to Develop the Evidence	18

INTRODUCTION

The National Indian Health Board advocates that the Special Diabetes Program for Indians (SDPI) is the nation's most strategic, comprehensive and effective effort to combat diabetes and its complications in Indian Country. Since 1997, when SDPI was first established by Congress, remarkable outcomes in diabetes have been realized in diabetes treatment and prevention, including reductions in average blood sugar levels, reductions in the incidence of heart disease and cholesterol levels; a significant increase in the promotion of health lifestyle behaviors; and a 54 percent decline in the incidence rate of end-stage renal disease (ESRD).

The purpose of the SDPI Think Tank was to identify, discuss and to try to reach consensus on specific elements of SDPI which have made it a successful and viable program for the past 20 years. Once identified, these elements can inform the future of SDPI as well as inform other chronic disease program efforts that wish to model its design and implementation to maximize success.

Think Tank invitees were identified through recommendations by primary members of the Tribal Leaders Diabetes Committee, who themselves were also invited to participate. Twenty-one attendees, including elected Tribal leaders, members of the Tribal Leaders Diabetes Committee, Indian Health Service (IHS) or Tribal SDPI program representatives, an IHS Area Diabetes Consultant and others affiliated with the work of the SDPI participated in the facilitated small and large group discussions (See [Appendix A](#) for the participant list).

To begin, Stacy A. Bohlen, Executive Director of the National Indian Health Board (NIHB), welcomed participants to the meeting and thanked them for their participation. Stacy made the following opening remarks:

- We owe a huge debt to those who initiated this effort [SDPI] and those who have kept it alive over the past 20 years.
- There have been significant reductions in diabetes and its complications among our people.
- SDPI has received ongoing funding driven by strong advocacy and demonstration of results.
- The Tribes make it work, and the program is recognized for its successes.
- NIHB will continue to support SDPI in partnership with the Tribes.

Stacy then introduced Laurie Schulte of The Clarion Group and invited her to facilitate the session. Laurie outlined the agenda for the day:

- Consider the success of SDPI over the past 20 years.
- Reach consensus on the key elements of SDPI that are essential for future success.
- Consider how to continue to demonstrate SDPI success to others.
- Consider the impact of SDPI on adjacent areas of chronic disease.
- Develop questions for securing feedback on SDPI from a broader audience.

Laurie also suggested the following as “ground rules” for the day:

- All have an equal share of voice.
- All may speak freely.
- All are asked to be open and constructive.
- All are welcome!

CONSIDERING THE SUCCESS OF SDPI OVER THE PAST 20 YEARS - SUMMARY

Participants met in small groups to consider the success of SDPI over the past 20 years. They addressed the following:

Elements of Success: What are the elements of SDPI that have made it successful?

What Could We Do Better: What, if anything, could we do better?

What are the *Critical Issues* facing SDPI over the next three to five years?

Six important themes emerged throughout these discussions, which are listed below. The detailed notes are included in [Appendix B](#).

- Funding and Advocacy
- Grantee-Directed and Culturally Adaptable Program
- Holistic Approach that Emphasizes Prevention
- SDPI Practice Characteristics
- Workforce
- Data Capture, Use and Infrastructure

Funding and Advocacy

Congressional SDPI authorization and funding were identified as *Elements of Success*. Three of the four breakout groups identified the 20 years of mandatory Congressional funding as affording the program longevity and stability and SDPI has become well-established in Tribal communities. Diversified support from Tribal councils, community members and elders as well as early champions, such as Kelly Acton and Buford Rolin were identified as contributing to the program's early establishment and long-term success with Congress. Other elements of success included a unified Tribal voice for advocacy and an agreed strategy for funding.

Congressional authorization and funding were likewise identified as *What We Could Do Better* and *Critical Issues* by the majority of the breakout groups. As SDPI funding has only been reauthorized in 1 and 2 year increments since 2008 as well flat funding of \$150 million/year during the same time period, Think Tank participants stressed longer term authorizations such as permanent funding are critical in the upcoming years. Increased funding to account for inflation and to help stabilize the SDPI workforce, critical to the program's success, were also stressed. Factors such as outreach and guidance to Tribal leaders and stronger consultation will contribute to SDPI advocacy. Participants identified that it is always essential to get the "voice of the people" when advocating on their behalf. It was noted that historically, SDPI caucuses were well-attended and voting provided a mechanism for an agreed upon strategy. A system by which all Tribes weigh in on the future of SDPI is needed and NIHB can be the mechanism for this. Also noted was that Tribes and urban Indians are well-connected and this relationship should continue.

One issue that surfaced in the discussion was preparing for the future and how to move to self-governance/sustainability, such as what would be an alternative funding plan if IHS is no longer the keeper nor funder of SDPI.

Grantee-Directed and Culturally Adaptable

Think Tank participants identified the grantee-directed element of the SDPI program as essential to its success. Other terms that arose describing this element were “Tribally-driven” and “community-directed”. By design, the SDPI grant program allows individual grantee communities flexibility in program decision-making such as determining needs, setting priorities and choosing best practices. Participants also identified that the SDPI program is culturally adaptable and can support the use of traditional ways, like fostering the use of traditional foods. Cultural sensitivity is another element identified, which in practice, for example, the SDPI program staff, due to their connection with the community, were instrumental in assisting new providers learn about the population they serve, resulting in better care for patients. Tapping into traditional knowledge and ways of teaching was identified as *What We Could do Better*. Promoting traditional foods and Tribal practices were identified as *Critical Issues* as well as the use of traditional health workers.

A Holistic Approach that Emphasizes Prevention

A holistic approach aligns with the worldview that everything is connected and approaching diabetes from multiple angles honors that view. Participants cited that SDPI was successful due to the SDPI program allowing for clinical interventions to treat diabetic patients and prevent complications as well as allowing population interventions (e.g. community events, education and outreach) and providing infrastructure for wellness and prevention of diabetes (e.g. fitness centers). It was noted that one-time funding for wellness infrastructure was a boost to the program years ago and that boost to infrastructure is needed again. Other elements such as patient-centered care, case management, a team approach and the integration of other services such as pharmacy and behavior health were all cited as *Elements of Success*. As one group identified, “The model moves us into other areas of health care for success.”

On the population level, SDPI was indicated as being part of community work and plays a part or has the potential in addressing the social determinants of health (i.e social factors that influence health typically defined as education, economic status, housing etc.). It was stressed that AIAN can define their own social determinants.

Under this theme, a *Critical Issue* was to cast the net of diabetes prevention further and look for ways to expand beyond SDPI, such as into behavioral health and food insecurity. A few areas identified in which SDPI is already impacting adjacent areas of chronic disease are colorectal cancer screening, oral health, behavioral health, childhood obesity and maternal and child health.

SDPI Practice Characteristics

Although SDPI programs vary widely, this theme captures some of characteristics of the work of SDPI, either by design or by practice, identified by the Think Tank as *Elements of Success*. The use and the sharing of best practices was a recurring theme in several of the discussions. SDPI best practices are “focused areas for improvement of diabetes prevention and treatment

activities/services and related outcomes in communities and clinics.”¹ The educational component of SDPI, which is also one of the best practices and it’s relation to health literacy was mentioned several times and identified as an important element of success. Networking, partnering with nearby programs, and focusing on prevention were likewise identified as *Elements of Success*.

The successes of the Healthy Heart and Diabetes Prevention Initiatives (specific SDPI funding set-asides from 2004–2016) and related resources were noted as an area *Where We Could Do Better* as those resources were described as being “lost” and “hard to find”. These initiatives have documented positive results and toolkits were created to sustain their implementation.

One idea was the formation of a SDPI Center of Excellence. A center of excellence is described as a team, a shared facility or an entity that provides leadership, best practices, research, support and/or training for a focus area.²

Workforce

The SDPI workforce was also identified as a Key Element of Success by three of the four breakout groups. SDPI’s longevity has supported the ability of programs to hire and maintain long term staff which contributes to patient trust and supports continuity of care. SDPI affords programs the ability to hire qualified staff such as Certified Diabetes Educators and specialists in the communities that may not otherwise be accessible. That the program is composed of professionals and paraprofessionals was cited as a strength. Also contributing to the program’s success due to workforce is that SDPI offers professional development opportunities. Through the network of Indian Health Service, Tribal and Urban programs, as well as SDPI resources and technical assistance available through the IHS Division of Diabetes Treatment and Prevention, the SDPI workforce has access to specialized trainings, networking opportunities through in-person meetings and conferences, and the opportunity to earn Continuing Education Units. The Area Diabetes Consultants (ADCs) were mentioned several times as important components of the SDPI workforce, especially when they were engaged and provided support and networking opportunities to the programs.

What Could We Do Better in terms of workforce, participants suggested standards for qualifications of health educators as well as consistent ADC support including smooth transitions between departing and new ADCs.

As programs have seen the value and benefit of long term dedicated and qualified employees, workforce recruitment and retention was identified as a *Critical Issue* in the next 3-5 years, due to high turnover and vacancy rates. Uncertain funding, competitive salaries, geographical remoteness and burnout were cited as contributors to turnover rates. Many Tribal programs have supported professional development of individuals from within their Tribes and “growing your own” was identified as critical to SDPI success and also supportive of Indian self-determination. The increased inclusion of traditional health workers as well as community health aides were additional SDPI workforce *Critical Issues* identified.

¹ <https://www.ihs.gov/sdpi/sdpi-community-directed/diabetes-best-practices/>

² https://en.wikipedia.org/wiki/Center_of_excellence

Data Capture, Use and Infrastructure

Data capture was identified by all four groups as an element of success for SDPI however improvement in types of data captured and the processes for capturing and using data were recommended. Participants cited the required annual diabetes audit, the SDPI Outcomes System, and the Government Performance Results Act data as a means for accountability, as well as identifying needs and contributing to demonstrating SDPI success. While the value of data was acknowledged as vital to SDPI success, acquiring data from IHS was cited as difficult and the majority of the breakout groups cited issues with Tribal level data and Tribal data infrastructure as *Critical Issues* and *Where We Could Do Better*. It was also noted in the discussion that some would like to see a transition toward a Tribally-managed SDPI data collection system.

Additional *Where We Could Do Better* suggestions included enhancing the SOS system, using comparison groups such as capturing data from non-diabetics to demonstrate the [primary] prevention aspects of SDPI, capturing Tribal traditional practices in the data, building in evaluation and being able to demonstrate return on investment. Note that capturing prevention data was a recurring theme throughout the Think Tank. The audit data is clinical and patient care focused and participants stressed the need to demonstrate the prevention impacts of SDPI. On a larger scale, it was suggested an epidemiology team composed of members across entities and specific to SDPI could be beneficial.

DEMONSTRATING SDPI SUCCESS TO OTHERS

Participants met in small groups to consider how to best demonstrate SDPI success to others. They considered the following:

What additional evidence is needed to demonstrate SDPI success?

What evaluative efforts might be undertaken to develop the evidence?

Below is a consolidated, yet not exhaustive list. The detailed notes are included in [Appendix C](#).

Additional Evidence Needed to Demonstrate SDPI Success

- Policy changes (systems and environment, such as junk food tax, grocery store environments, employee wellness policies, walking paths, gardens)
- Effects of diabetes education on health literacy/Diabetes Education outcomes
- Continuity of Care
- Obesity rates/Physical activity and nutrition
- Return on Investment/cost effectiveness
- Impact on employment
- A1c
- Life expectancy (related to diabetes management complications)
- Quality of Life
- Effects on family
- Holistic approach
- Impact of SDPI on other programs
- Changing of norms (that affect behavior)

- Collaborations

Evaluative Efforts that Might Be Undertaken to Develop the Evidence

Building upon the previous discussion on what additional evidence is needed to demonstrate success, participants outlined potential sources of data. Below is a consolidated, yet not exhaustive list. The detailed notes are included in [Appendix D](#).

- Tribal resolutions, laws and policies, and MOUs
- Compliance data
- Participation numbers
- Cultural practices data
- Uptake of traditional foods
- Biometrics
- Diabetes education data
- Referral rates
- Continuity of care
- Hospitalization rates, medications, dialysis
- Workforce data – length of employment, level of training

A few methods were offered in general to help demonstrate success and collect data. Those included qualitative methods such as digital stories, testimonies, focus groups and success stories. Other methods, more qualitative in nature, included a national SDPI survey as well as community surveys.

IMPACT OF SDPI ON ADJACENT AREAS OF CHRONIC DISEASE

In considering the current and potential impact of SDPI on adjacent areas of chronic disease, participants shared examples from their programs where their efforts are having such an impact. A summary of these examples follows.

- Connecting colorectal screening and SDPI
 - Access to names
 - Ability to leverage SDPI infrastructure
 - Inpatient and prevention sites
- Training practitioners on diabetes standards of care
 - Training on “how we do things”
 - Spreads to other areas (hypertension, chronic pain)
 - Particularly useful if SDPI pre-dates clinical sites
- Childhood obesity prevention via CATCH – Coordinated Approach to Child Health
- Behavioral health referrals
- Connecting SDPI with oral health
- Supporting maternal and child health as SDPI monitors pregnant women

- Healing our Spirits Worldwide: international “decolonization” program with indigenous peoples that SDPI (via NIHB) will contribute to this fall

SECURING FEEDBACK ON SDPI FROM A BROADER AUDIENCE

The input from this “Think Tank” is extremely valuable for the future success of SDPI. At some future point, NIHB may also be able to secure input from a broader audience on what is necessary for the sustainable success of SDPI. The group considered what questions it would want NIHB to ask if it is able to secure this feedback. A list of potential questions follows.

- To be asked of program directors/staff:
 - What has worked in the implementation of your SDPI program? What would you do more of?
 - What data elements for your program does Congress need to fund SDPI? To increase funding?
 - If you were going to hire your ideal person for SDPI, what would that person be like?
 - What types of staff are funded by your SDPI program (in relation to the best practice)?
 - What kind of professional development is needed for success? Retention? (Examples: boot camps, Centers of Excellence)
 - After 20 years of success, do you need a refresher on SDPI?
- To be asked of patients: who helped you the most with your diabetes?
- To be asked of Tribal leaders: what difference has SDPI made in your community?
- To be asked of those who didn’t participate in SDPI: why not?

APPENDIX A- SDPI THINK TANK PARTICIPANTS

IHS Service Area	Name	Affiliation
Alaska	Judy Thompson	Alaska Area Diabetes Consultant
Albuquerque	Beverly Coho*	Albuquerque Area Indian Health Board
Albuquerque	Benelda Cohoe-Belone	Ramah Navajo School Board, Inc.
Bemidji	Christine Daugherty	Gun Lake Band Potawatomi Diabetes Program
Billings	Karen Duboise	Ft. Peck Diabetes Program
California	Rosemary Nelson*	Councilmember, Astariwi Band of Pit River Indians
Great Plains	Eddie Johnson*	Councilmember, Sisseton-Wahpeton Oyate
Great Plains	Connie Brushbreaker	Rosebud Sioux Diabetes Program
Nashville	Edie Baker*	Health and Elder Services, Poarch Band of Creek Indians
Nashville	Kay Thomas	Poarch Band of Creek Indian Diabetes Program
Oklahoma	Shondra McCage	Chickasaw Nation Diabetes Care Center
Oklahoma	Tammie Cannady*	Choctaw Nation Health Services
Phoenix	Kristy Klinger	San Carlos Apache Healthcare Corporation
Phoenix	Cindy Nahee*	Councilmember, Yavapai-Apache Nation
Portland	Sharon Stanphill*	Cow Creek Band of Umpqua Tribe of Indians
Portland	Sarah Sullivan	Health Policy Analyst, NW Portland Area Indian Health Board
Tucson	Daniel Preston*	Councilmember, Tohono O'odham Nation
Tucson	Jennie Mullins*	Pascua Yaqui Tribe Diabetes Prevention and Treatment Program
	Stacy A. Bohlen*	CEO, National Indian Health Board
	Karrie Joseph	Deputy Director, Health Policy and Programs, NIHB
	Spero Manson	Director, Centers for American Indian and Alaska Native Health, University of Colorado

*Members of the Tribal Leaders Diabetes Committee

APPENDIX B - NOTES CONSIDERING THE SUCCESS OF SDPI OVER THE PAST 20 YEARS

Elements of SDPI that Have Made It Successful - Notes

GROUP 1

- Structure
 - Grant accountability
 - Audit
 - Flexible grant requirements
- Programs can be culturally adapted to each community; provision of services is Tribally driven.
- Includes preventative aspect of diabetes and its complications
- Choose best practice/community-directed reporting for grants; data capture is part of success.
- Community/clinical directed
- Congressional support
- DDTP/IHS technical assistance

GROUP 2

- Ground work, early advocates
 - Kelly Acton
 - Buford Rolin
- Ability to hire qualified diabetes educators: specialists to focus on diabetes
- Community director
 - Grass roots input
 - Tribal Council support
- Vision and mission-driven work
- 20 years of funding
- Equalized playing field
 - Adequate funding
 - Ability to hire and retain educated professionals
- Ability to network, share best practices
- Accountability due to data submission through SOS, annual audit
- Area Diabetes Consultants (ADCs) help make it successful.

GROUP 3

- Tribal Council support and community response
- Community-directed; flexible (e.g., prevention focus and intervention focus depending on needs)
- Ability to hire and retain staff; supports continuity of care
- Able to use SDPI to leverage other resources
- Partnerships with other programs nearby; share resources
- Network of support from Area (ADCs)
- Tribes advocate – SDPI a necessity for the Tribe
 - Community members support

- Elders involved
- Longevity of the program; stability
- Jobs
 - Self esteem
 - Self determination
- Training for community members
- Infrastructure for wellness, prevention
- Awareness and community hold each other up.
- IHS website
 - CEUs
 - Information
 - Resources
 - Training
- Science translated to programs (best practices)
- SDPI is culturally sensitive.
 - Helped new providers learn
 - Better care for patients
- Fosters the use of traditional foods, ways
- Influenced a holistic approach to diabetes management care (diabetes management registry)
- Use of registry and GPRA:
 - Gives bigger picture
 - Helps identify needs

GROUP 4

- Long-term staff; patient trust
- Education which is constantly evolving
- Case-managed care
- Team approach
- Grant requirements
 - Audits
 - Updates every six months
- Community work; involvement and commitment
 - Traditional
 - Foods/nutrition
 - Walks/runs/bicycle workshops
- Social determinants
- Community at large
 - Universities
 - Legislators
 - Community clinics
 - Governments
- The model moves us into other areas of health care for successes.
- Tribal ability to design the framework and expand for their specific community
- Changed the message to overcome stigma
- Patient centered: tailoring to patient schedule, wants, needs

- It is more acceptable now to learn from educators and coaches.
- Getting providers into the community
- Lifestyle coaches/educators
- Overcame other issues such as transportation, child care
- Change from intensity/scare tactics of providers to become more supportive and cultural (more self-governance)
- Family focused
- The curriculum is fluid.
- Integration of pharmacy and behavioral health
- More follow up
- Specific to the Area they are from with cultural appropriation

What We Could Do Better - Notes

GROUP 1

- Consistent funding – mandatory/permanent
- Employee retention
- Decreased attrition
- Accept AADE/ADA DSME recognition for accreditation (don't do twice).
- Enhance SOS data capture.
- Expand national diabetes SDPI conference opportunities.
- Enhance IHS Tribal relationships.
- Referral system
- Improve communication and care coordination between clinic and community-based programs.
- Build in evaluation funds for SDPI at the program and national levels.
- Use data infrastructure funding in a fair and transparent way.
- We need more standardization among all IHS areas; we all operate differently.

GROUP 2

- Qualifications: standardization for qualification of health educators
- Full funding, predictability of funding
- Consistent ADC support
- Discretionary vs. mandatory funding: know the pros and cons well before recommending
- Support programs with staff turnover (grants, data).
- Strategies to build relationships between ADCs and Tribal Leader Diabetes Committee (TLDC) representatives
- Mechanisms to retain qualified staff

GROUP 3

- More funding and thus more staff
- It has been a long time since the one-time infrastructure set aside; it is needed again.
- More opportunity to meet with other Tribes (e.g., SDPI poster session)

- Tap into traditional knowledge and ways of teaching.
- Data infrastructure
 - Do better to meet the needs of programs.
 - The current way creates competition and conflict.
- The audit only captures certain things (clinic); we need to better measure best practices (e.g., physical activity).
- Longer-term funding including inflation adjustments
- Planning for the next level

GROUP 4

- Workforce development to train dieticians
- Need for IHS DST facilities to change intensity with patients
- Tribal-focused long-term stability
- Billable restrictions (especially through Medicare/Medicaid)
- Hard to find Healthy Heart/DPP resources, best practices
 - Need a Center for Excellence
 - Need Healthy Heart/DPP as best practice
- Need best practices list/resource guide between Areas
- More quantitative data/data infrastructure from Tribes
- Difficulties getting data from IHS
- Healthy foods questionnaire to get quantitative data
- Online data bank needed
- Need for inclusion of prevention in audit
 - The audit is structured around people with diabetes.
 - SDPI has a lot of prevention programming.
 - This needs to be better quantified.
- Need for inclusion of tribal traditional best practices

Critical Issues Facing SDPI – Next 3-5 Years - Notes

GROUP 1

- Securing SDPI funding
- Education/advocacy
- Agreed strategy for funding
- Improved data infrastructure for Tribes to report
- Better capture of data in diabetes-related education
- Looking for ways to expand beyond SDPI, e.g.:
 - Behavioral/integrated health
 - Food insecurity
- Certification/accreditation of diabetes education programs (CDC)
- Promoting traditional foods and tribal practices

GROUP 2

- How is IHS assisting Tribes in developing sustainability if SDPI funding goes away?
- Funding
- Data
- Understanding Tribal constitutional provisions; Tribal leaders visiting Capitol Hill should know these well
- We need to be able to do long-term planning which requires predictable funding.
- Looking at data to show ROI
- Educate as many people as possible about SDPI.

GROUP 3

- Mandatory funding
- Be more proactive, less reactive.
 - Determine where we want to go.
 - Prevention
 - Educating young people
 - Vs. looking at data and filling gaps
- Identifying/understanding what the trends are, including at the Tribal level
- Establish a unified Tribal voice for advocacy efforts.
- Outcome of this year's elections and the impact on Congress
- Stabilizing staff, need dedication
- Growing our own experts

GROUP 4

- Data infrastructure
 - Online data entry?
 - A national system that can interface with multiple EHRs
 - SDPI specific
 - Epi team supported by NIHB/TECs/Tribes
 - Statisticians
 - Data coordinator
 - Support staff for each Area
 - Transition toward this Tribally-managed data collection while still including IHS data; there is so much history there.
- Workforce
 - Traditional health workers
 - Aides
- Funding
 - Mandatory
 - Multi-year authorization
- High turnover rate
- Healthy Hearts/DDP got lost.
- Intensity
- EHR modernization: need to include prevention
- Data is vital.

- Not through the government
- Tribally run
- Team epi center
- Transparency and collaboration

Discussion included the following points.

- SDPI turnover has a number of causes, including:
 - Funding and its uncertainty from year to year
 - Better compensation elsewhere
 - Geographical remoteness which limits access to services
 - Burnout
- Workforce development, including “growing our own,” is critical for ongoing SDPI success.
 - Staff members need the skills to work with our people.
 - They need a heart for making a difference.
 - Some models exist for supplementing SDPI staff by orienting laypeople to contribute.
 - Some support the notion of “Centers of Excellence” that include didactic as well as immersive, practical experiences for professionals and laypeople.
- Relationships between SDPI staff and Area Diabetes Consultants vary.
 - The role is very useful when fulfilled well.
 - Transitions between departing and new ADCs need to be smooth.
- While IHS data has historic value, it:
 - Is difficult to access
 - Only captures clinical information – not prevention
 - Some would like to see a transition to Tribally-managed SDPI data collection.
 - Expanded IT infrastructure would provide job opportunities at home.
- In addition to funding for staff, training, and IT, in some Tribes funding is needed to strengthen “brick and mortar” infrastructure.
- There is opportunity to do more to manage the system of care.
 - The quality of care coordination depends on the SDPI grantee and how the relationships are managed. An understanding of best practices would be helpful.
 - Communication and collaboration are key.
 - Communication is typically lacking when facilities are IHS-funded.
 - Tribal support for SDPI also makes a difference.
 - Staff turnover impacts success – which makes the relationships even more important.
 - One unique collaborative approach is to incorporate the SDPI team/diabetes-related metrics into provider metrics.
- We need to be able to consolidate more comprehensive data at the national level.
 - The IHS audit does this for treatment.
 - There is no mechanism for prevention.
 - Demonstrating outcomes from prevention initiatives is difficult – even though we know they work. This is not unique to SDPI or diabetes.
- Using associations via qualitative evaluations is one way to demonstrate the value of prevention, e.g.:
 - Other evidence shows that event A leads to outcome B.
 - SDPI is doing event A. Thus, it will cause outcome B.

- Examples of these “prevention markers” include reducing soda consumption, access to healthy food, fitness centers, etc.
- The “big win” with legislators who control funding is data supplemented by anecdotal evidence about their constituents – impacting their voters is a big motivator.

Defining Future Success – Key Elements of SDPI Discussion - Notes

Based on the output above, the group worked together to identify those elements of SDPI that are essential for its future success – whether existing or desired. A summary follows.

- Funding and its structure
 - Mandatory, multi-year authorizations, inflation adjustments
 - Including an alternative funding plan if IHS is no longer the keeper nor funder of SDPI; how to move to self-governance/sustainability
 - Clinical and outreach is ideal.
 - Grantee-directed
 - Whether clinical or community
 - Flexible and can be tailored
 - Culturally appropriate and Tribally driven
 - Unified Tribal voice for advocacy (outreach to Tribal leaders, stronger consultation)
 - Education and health literacy
 - Patient engagement and self-management
 - Sufficient numbers of qualified staff
 - Professionals and paraprofessionals
 - Standardized human resources
 - Engagement of ADCs
 - Data infrastructure and use
 - Build in evaluation.
 - Improve continuity of care.
 - A holistic approach that emphasizes prevention
 - Communities of practice: networking, sharing best practices, advocacy
-
- Discussion included the following points.
 - Tribal leaders need guidance and support regarding advocacy so that they are able to successfully fulfill their responsibilities.
 - There needs to be a system by which all Tribes weigh in on the future of SDPI.
 - Historically, SDPI caucuses were well attended and voting took place.
 - NIHB can be the mechanism for this.
 - Tribes and urban Indians are well-connected regarding SDPI; this should continue.
 - As an alternative to “social determinants of health,” “holistic” is a better way of characterizing the notion that diabetes prevention and treatment should include housing, social services, mental health, etc. American Indians/Alaska Natives can define their own “social determinants.”
 - SDPI needs to connect clinical efforts and outreach; it must continue to be:
 - Connected with providers
 - Connected with/in the community
 - It is always essential to get the “voice of the people” when advocating on their behalf.

APPENDIX C - NOTES FROM ADDITIONAL EVIDENCE NEEDED TO DEMONSTRATE SDPI SUCCESS

GROUP 1

- Policy changes (system and environment) in Tribes/on reservations
 - Junk food tax
 - Memoranda of understanding with grocery/convenience stores on sugary drinks
 - Replace soda machines in schools with healthy drinks and snacks.
 - Employee wellness policies for Tribal employees
 - Community and family gardens
 - Walking paths
- Documenting community event participation
- Success stories
- Diabetes education results
- Community health literacy skills for diabetes and other chronic diseases taught in schools – for all ages
- Improve continuity of care.

- **GROUP 2**
- ROI data: if dialysis and amputations, complications go down, how much money does this save IHS?
- Sharing health policy changes, e.g.:
 - Not serving soda in hospitals
 - Grocery stores on reservations changing the location of less healthy foods so they are not at eye level
- Some measure of prevention success
- Life expectancy: are diabetes management-related complications, causes of death decreasing?
- Quality of life data, perhaps via a survey of Tribal members

- **GROUP 3**
- Prevention
- Translation to other minority groups (African Americans, Hispanics) to support SDPI
- Family effects
- Qualitative evidence
- Financial distribution effect on outcomes
- SDPI indicators
- Measure holistic approach.
- Quantitative data
- Impact of SDPI on other programs
- Cost effectiveness
- Impact on employment
- People without diabetes management included in data
 - Awareness
 - Reducing stigma

- Health behaviors
- GROUP 4
- Testimonials
 - Digital stories
 - Posters
 - News articles
 - Pre and post (8- to 12-year olds)
 - “Make a change camp”
 - “Show of hands with kids” (documenter is counting hands)
- Sales data
 - Reductions in sugar-sweetened beverage purchases
 - Increases in water purchases
- Financial savings
 - Elders love to save money for the Tribe.
 - No wasting
- Changing normative values
 - Kids walking more
 - Changing “want a ride?” to “is something wrong because I didn’t see you walking?”
 - Numbers of people in a community running/walking
 - It’s normal to see women in the fitness center.
- Family involvement
- Number of collaborative partners
 - One-pagers
 - “How did our program benefit your program?”
 - ”What was the quality?”
 - Letters of appreciation
 - Earned media
 - Free/newsworthy stories
 - Recognition of when the program provides a service
 - Examples of collaborative partners:
 - Hospitals
 - Schools
 - Doctors’ offices
 - Community programs/Tribal programs
 - Big public events
 - Employers
 - Churches
- Health reports
 - Obesity rates/Consumption of healthy foods/Amounts of activity/Fitness testing
 - Tools to measure life skills/coping/budgeting
- A1C-lowering data specific to the SDPI program
 - Numbers of patients on at least three times
 - Baseline A1C
 - Lowest A1C within 12 months of baseline

APPENDIX D – NOTES FROM EVALUATIVE EFFORTS THAT MIGHT BE UNDERTAKEN TO DEVELOP THE EVIDENCE

GROUP 1

- Policy changes
 - Community surveys
 - Money collected and reallocated to health and wellness
 - Collect resolutions, laws and policies, and MOUs.
 - Track compliance.
 - Focus groups
 - Use of policy and data collection
 - Numbers participating, numbers of gardens, farmers’ markets
 - Increased physical activities
 - Cultural practices
 - Uptake of traditional foods
 - Qualitative assessment
- Documenting community event participation
 - Evaluation efforts
- Success stories
 - Pre/post tests and biometrics
 - Portion control
 - Qualitative assessment
- Diabetes education results
 - Increase knowledge, understanding, and skills.
- Community health literacy skills for diabetes and other chronic diseases taught in schools – for all ages
 - Completion rates
 - Retention rates
- Improve continuity of care.
 - Track completed referral rates.

GROUP 2

- Data collection infrastructure
- Universal collation of data from the 300 SDPI sites
- Compare SDPI to a similar program in the private sector.
- Consider a national SDPI survey:
 - People living with diabetes management
 - Tribal members
 - Health care staff

GROUP 3

- Digital stories
- Evaluating clinical and outreach continuity of care

- Process evaluations (e.g., data)
- Information back to participants (e.g., GHWIC)
- Live testimonies
- Change the audit.
- Best practices measures
- Hospitalization rates, medications, dialysis
- Qualitative and quantitative
- SDPI workforce
 - Length of employment
 - Level of training
- Compare SDPI and non-SDPI tribes.
- Compare self-governance and non.

GROUP 4

- A standardized – but still individualized – way of reporting data elements, e.g.:
 - Of these 20, pick five for your program.
 - Or – required to answer these three, but able to report on other things, too
- An SDPI-specific epidemiology center
 - To guide all programs
 - Data goes into the University of Colorado but based out of SDPI instead of being contracted out.
- SDPI programs need to have an evaluation piece within each program.
- SDPI programs need access to Congressional reports.