It’s Never Too Early to Start: Special Diabetes Program for Indians Renewal Efforts

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Learning Objectives

• Understand the Special Diabetes Program for Indians (SDPI) legislative history and process for legislative renewal.

• Implement three different techniques for sharing SDPI success stories.

• Have increased confidence in ability to provide outreach and education about the SDPI and its impact on diabetes treatment and prevention in Indian Country to policymakers.
  • Local impact storytelling
  • State- and Tribal-specific data reporting
  • Hosting site visits for policymakers
National Indian Health Board

• Core Mission: To advocate on behalf of all federally-recognized Tribes to ensure the federal government upholds its trust responsibility to deliver health and public health services as promised in treaties, and reaffirmed in legislation, executive orders and Supreme Court cases.
• Founded by the Federally Recognized Tribes in 1972

• Purpose: Elevate the unified voice of Indian Country for the improvement of our Peoples’ health delivery systems, health care and health outcomes

• Advocate to ensure the Federal Government upholds its Trust Responsibility for our Peoples’ health

• 12 Members through the 12 IHS Service Areas – one from each

• Members appointed through regional Tribal Health organizations
Group Discussion

• What is the impression of your community on Congress?

• Why do you think Congress fails to enact legislative priorities from Tribes?

• What do you think you can do to help?

• How many of you have advocated before? What barriers do you encounter when advocating?
Two Houses of Congress:

U.S. House of Representatives

- 435 voting Members of Congress (MOCs) apportioned by population (Delegates and Commissioners Participate But Do Not Vote.)
- 2 – Year Terms
- Rules – Majority will always prevail!
Two Houses of Congress:

U.S. Senate

- Two per each of 50 States = 100
- 6 Year Terms
- Rules - Deference to minority.
  Filibuster.
Only 5% of bills introduced made it to the floor of either the House or Senate, a marker that the bill enjoyed serious deliberation.

Analysis

- The vast majority of bills (97%) introduced in the 113th Congress failed to become law, and most never even came close; only 5% of bills introduced passed at least one chamber.
- While there has been a recent trend of unproductivity in Congress, GOP leaders hope to pass more legislation in the 114th Congress.
Political Context

• Congress’ overall productivity is diminishing over time:

The 113th Congress
Second Least Productive since WWII
Number of Public Bills and Joint Resolutions Enacted into Law by Congress
80th-113th Congresses (1947-2014)

1,028 Laws
The 84th Congress passed more
laws than any other post-WWII
due to unified Dem control of
both chambers

337 Laws
The 104th Congress reached a then-
low due to partisan division
following the 1995 government
shutdown

296 Laws
The 113th Congress passed only 72
laws in 2013 and 324 laws in 2014,
making this Congress the second last
productive on record

Analysis

• By historical standards, the 113th Congress was incredibly unproductive; it enacted over one-half as many laws (296) as the average number of laws passed by the past 33 Congresses (653)
• Budget fights exacerbated unproductivity, as the time spent resolving impasses detracted from other priorities
• Even with budget struggles temporarily resolved for the 2015 fiscal year, the number of bills enacted remains below historic norms, as Congress now passes more legislation in omnibus form; many bills in the 84th Congress might be included in one
today, for example

Political Context The Federal Budget

- Discretionary as a percentage is going down over time
WHY EDUCATE CONGRESS?
Why Advocate/ Educate?

- Duty as a U.S. citizen, but especially as an advocate for your people
- Congress won’t know what issues are important to you if you don’t tell them
- Many (most) Members of Congress don’t know about the American Indian / Alaska Native issues
- Most Members of Congress want to help you
WHO SHOULD WE BE TALKING TO?
Your own Senators and Representatives

- You should always establish a good relationship with your own Senators and Representatives
  - Invite them to events you have including council meetings; cultural events; facility tours
  - Make sure you know the district staff in your area.
  - Call local office to set up meetings
- Visit www.senate.gov or www.house.gov to find your representatives
- It is recommended to know all representatives from your state – especially if they are on the relevant committees (Senate Finance; House Ways and Means; House Energy and Commerce)
Tribal Leaders

It is important that your Tribal leadership knows why SDPI is changing your community so that they can be informed when they visit Capitol Hill or other federal offices.

Make sure that they have talking points on the main components of your program:
- What do you do?
- What results have you gotten?
- How is it changing lives?
- What are your challenges?
  - Is funding a problem? Why? How much do you need?
But what if you can’t get to Washington DC??
Write!

- If you can’t get a meeting with a Congressional Office at home or in the district write a letter from your Tribe.
- Email is the best way – Find out who handles the issue at the staff level and send directly.
- Organize a letter-writing campaign.
- Pass a Tribal Resolution.
  - NIHB can help with sample letters and Resolutions.
SDPI Legislative History

• Established through the Omnibus Reconciliation Act of 1997

• The Special Diabetes Program and the Special Diabetes Program for Indians were typically renewed as part of the “Medicare Extenders” which attached to the “DocFix”
  • Governed the rate that physicians are paid by Medicare
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>Congress extends SDPI an additional two years at current funding level of $150 million per year</td>
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<tr>
<td>2014</td>
<td>Congress extends SDPI for an additional year at current funding level of $150 million per year</td>
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<tr>
<td>2012</td>
<td>Congress extends SDPI for an additional year at current funding level of $150 million per year</td>
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<tr>
<td>2010</td>
<td>Congress extends SDPI for an additional three years at current funding level of $150 million per year</td>
</tr>
<tr>
<td>2008</td>
<td>Congress extends SDPI for an additional two years at current funding level of $150 million per year</td>
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<tr>
<td>2007</td>
<td>Congress extends SDPI for an additional year at current funding level of $150 million per year</td>
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<tr>
<td>2004</td>
<td>Congress directs SDPI to initiate demonstration projects focused on diabetes prevention &amp; cardiovascular disease risk reduction</td>
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<tr>
<td>2003</td>
<td>NIH Diabetes Prevention Program (DPP) Study results provided scientific evidence that type 2 diabetes can be prevented or delayed</td>
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<tr>
<td>2002</td>
<td>Congress extends SDPI for an additional five years and increases funding to $150 million per year</td>
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<tr>
<td>2000</td>
<td>IHS establishes Best Practices based upon SDPI data</td>
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<tr>
<td>1998</td>
<td>Congress extends SDPI for an additional three years and increases funding to $100 million per year</td>
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<tr>
<td>1997</td>
<td>Tribal Leaders Diabetes Committee (TLDC) created by Congress to guide IHS in development and consultation of SDPI</td>
</tr>
<tr>
<td>1997</td>
<td>Special Diabetes Program (SDP) consisting of the Special Diabetes Program for Indians and Special Type 1 Diabetes Research Program created by congress - $30 million provided for each program for five years</td>
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<tr>
<td>1996</td>
<td>American Diabetes Association created Awakening the Spirit (ATS) national advocacy team</td>
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<tr>
<td>1986</td>
<td>Indian Health Service Standards of Care developed</td>
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<tr>
<td>1976</td>
<td>Indian Health Service National Diabetes Program created by Congress</td>
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<tr>
<td>1974</td>
<td>Diabetes Mellitus Interagency Coordinating Committee (DMICC) established by Congress</td>
</tr>
<tr>
<td>1963</td>
<td>National Institutes of Health (NIH) Pima Indian Study recognized diabetes epidemic among American Indians</td>
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Special Diabetes Program For Indians

• Special Diabetes Program for Indians received a 2-year extension in the Medicare Access and CHIP Reauthorization Act of 2015 (P.L. 114-10)
  • Will expire on September 30, 2017

• NIHB/ Tribes still seeking long-term renewal - $200 million / 5 years or permanent renewal
  • SDPI has not been increased since 2002. Calculating for inflation (non-medical) this represents a 23% decrease
Special Diabetes Program For Indians

• Program is popular with lawmakers

• 2013: Congressional Letter had over 75% of Congress!
  • 336 House Members
  • 76 Senators

• For more information visit www.nihb.org/sdpi
The Future of the Special Diabetes Program for Indians

• Future reauthorization path unclear, but likely to get renewed
• Will do Congressional Support letter in 2016/2017
• In the meantime…
  • Continue site visits / outreach and education with Congress
  • Continue to share success stories
  • Develop a case for funding increase – SPECIFICS
“Through the oral tradition, story becomes both a source of content as well as a methodology”. –George Cajete
Local Impact - Alaska

Charlotte McConnell, Tlingit

SouthEast Alaska Regional Health Consortium (SEARHC) Lifestyle Balance and Diabetes Prevention Program

“We seriously need the Diabetes Prevention Program in our community. The longer it is here the more people it will help to prevent diabetes.”
- Charlotte McConnell

Through the Diabetes Prevention Program I found out I had pre-diabetes. I had also been told I had high cholesterol and blood pressure and they wanted to put me on pills but I didn’t want to take their pills. I wanted to lower my blood sugar, blood pressure and cholesterol with food and exercise. The Diabetes Prevention Program was there to help me get my blood sugar back to normal and improve my health without having to take pills, so I joined the program and started going to classes. The classes have really helped keep me on track. I’ve learned ways to eat less fat and how to cook and prepare my meals in a more healthy way. I really like the positive changes that are now evident in my overall health. When I completed the program I stopped going to classes and found my cholesterol and blood pressure were stable to go up again. So, I came back to the program and I’m doing better now and my blood sugar is back in the normal range.”
Storytelling Formats

• Written
• Verbal
• Digital Storytelling
• Site Visits
Local Impact - Minnesota

Arne Vainio, MD - Mille Lacs Band of Ojibwe
Fond du Lac Human Services Diabetes Prevention Program

“We have an Ojibwe saying, “We do these things to keep our traditions and language alive.” The only way to do this is to keep our elders alive and the best way to do that is through our diabetes prevention efforts and everything that goes with it.”
- Arne Vainio, MD

My mom endured multiple complications from diabetes including, amputations of both her legs and a kidney transplant. On the night of my graduation from residency she passed away from congestive heart failure. Then at age 46 my brother had a stroke which started me on my personal journey to look at my own health risks. That journey has evolved into writing health articles for a variety of Native publications and a video-documentary that has gone viral in Native communities.

Along the way, I was diagnosed with pre-diabetes, enrolled in the Fond du Lac Diabetes Prevention Program, lost 17 pounds and today my blood sugar is no longer in the pre-diabetic range. I think it was strange for others in the classes when I first started attending, but I learned a lot in the 16 week Lifestyle Balance curriculum and 3 year commitment. I felt it was extremely helpful that the program was a team effort with clinicians, diabetes educators, lifestyle coaches, dietitians, fitness coaches, and support staff. I especially appreciated the sharing and being at the table with the other participants who were also focused on diabetes prevention and improving their overall health. The education and support from both the staff and participants was invaluable. We are a sharing community. That is our heritage and that’s how we learn our language and culture.
## Formats: Verbal

<table>
<thead>
<tr>
<th><strong>DO</strong></th>
<th><strong>DON’T</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Plan beforehand</td>
<td>“wing it”</td>
</tr>
<tr>
<td>Know the issue your story relates to</td>
<td>Exaggerate statistics</td>
</tr>
<tr>
<td>Tell (only) your truths</td>
<td>Make promises you can’t deliver</td>
</tr>
<tr>
<td>Be specific when asking for action</td>
<td></td>
</tr>
<tr>
<td>No more than 3 asks per story shared</td>
<td></td>
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</tbody>
</table>
Formats: Digital Storytelling

https://www.youtube.com/watch?list=PLAgsmx6PTMkOJdFzOXTfDrT2JGG6l&v=EdKdjIlk7tb8
Formats: S.H.O.W. SDPI

- *S.H.O.W. Congress SDPI in action by hosting a site visit:*
  - **S**chedule a time to reach out to your member of Congress
  - **H**ost your member at your SDPI site
  - **O**rganize the community to participate
  - **W**itness the change when your member goes back to D.C.
Why pair data with your stories at all?
Kinds of Data

Data is a collection of facts such as numbers, measurements, observations or even a description of things.

• **Quantitative** – counts, measurements, answers how much?
  • A1c levels, blood pressure, BMI (risk factors for diabetes/related chronic disease)
  • Disease prevalence (how many people have diabetes)
  • Dialysis rates, Death rates (to what extent diabetes causes disability/death)

• **Qualitative** – opinions, attitudes, perceptions, answers why?
  • Interviews
  • Focus groups
  • Open-ended survey questions
  • Testimonies or personal stories
Using Data in your Stories

• Surveillance data
  • Used to estimate the health status and behavior of populations
  • Used to provide information for planning, implementing and evaluation public health practices
  • Purpose is to empower decision-makers to lead and manage more effectively by providing timely, useful evidence.
Example of Surveillance Data

Number (in Millions) of Civilian, Non-Institutionalized Persons with Diagnosed Diabetes, United States, 1980-2014

Diabetes is becoming more common in the United States. From 1980 through 2014, the number of Americans with diagnosed diabetes has increased fourfold (from 5.5 million to 22.0 million).
Common Data Topics for Diabetes Stories

• Data topics and/or research topics that may work well with SDPI stories
  • Obesity
  • End stage renal disease/dialysis
  • Cardiovascular disease
  • High blood pressure
  • HbA1c levels
  • Lower limb amputations
  • Economic burden of diabetes
  • Social support
  • Eating behaviors
  • Physical activity
3 “R”ules for Using Data

• Recent
• Reputable
• Relevant
Is it RECENT?

• Most recent is ideal
• Within the past 3 years
  • Exceptions:
    • Landmark studies such as ACE Study, Strong Heart Study
    • Nothing else is available
• What is more impactful?
  • Point in time data vs. trend data
Is it RELEVANT?

Heart Attack Hospitalization
Rates by Year: New Mexico, 2000 - 2005

<table>
<thead>
<tr>
<th>Year</th>
<th>Rate per 10,000 Standard Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>34.1</td>
</tr>
<tr>
<td>2001</td>
<td>32.1</td>
</tr>
<tr>
<td>2002</td>
<td>30.5</td>
</tr>
<tr>
<td>2003</td>
<td>29.5</td>
</tr>
<tr>
<td>2004</td>
<td>28.3</td>
</tr>
<tr>
<td>2005</td>
<td>25.4</td>
</tr>
</tbody>
</table>

NOTE: Hospital admission rates are among resident adults ages 35 and over and are age-adjusted per 10,000 standard population. Data are based on primary, or first-listed, diagnosis for acute myocardial infarction (ICD-9 codes 410.0 - 410.92). State resident admissions to the Veterans Administration Hospital, any Indian Health Service (IHS) Hospital, or an out-of-state hospital are not collected by the Health Policy Commission. Although Native Americans can be admitted to an IHS Hospital for heart attack, they are typically transferred to non-IHS Hospitals for care. Therefore these admissions can be counted. Transfers from acute-care facilities have been excluded.

SOURCE: Data provided by the New Mexico Health Policy Commission; analysis by the New Mexico Environmental Public Health Tracking Network, New Mexico Department of Health. Population estimates provided by the Bureau of Business and Economic Research, University of New Mexico.

Explanatory Text: Similar to the National trend, heart attack hospitalization rates are declining over time in New Mexico.
Is the Data from a Reputable Source?

• Is the source cited?
• Is the source trusted?
• Cite your sources in your story
**Examples**

*Age-adjusted* percentage of people aged 20 years or older with diagnosed diabetes, by race/ethnicity, United States, 2010–2012

- Non-Hispanic whites: 7.6%
- Asian Americans: 9.0%
- Hispanics: 12.8%
- Non-Hispanic blacks: 13.2%
- American Indians/Alaska Natives: 15.9%

*Based on the 2000 U.S. standard population.
Examples

Percentage of Youth Overweight or Obese
BIE School, location: xxxx

- Linear (K-5th grade)
- Linear (6th-8th grade)
- Linear (High school)
AI/AN rate was 2.6 times higher in X counties than the state rate in 2010.

### Table 24. Percentage of AI/AN within Counties who reported having diabetes (REACH)

<table>
<thead>
<tr>
<th></th>
<th>AI/AN Total</th>
<th>AI/AN Men</th>
<th>AI/AN Women</th>
<th>NC Men</th>
<th>NC Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (sample size)</td>
<td>% (sample size)</td>
<td>% (sample size)</td>
<td>%</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td>23.9% (952)</td>
<td>20.5% (422)</td>
<td>26.8% (530)</td>
<td>6.8%</td>
<td>6.7%</td>
</tr>
<tr>
<td>2010</td>
<td>27.2% (946)</td>
<td>24.6% (405)</td>
<td>29.4% (541)</td>
<td>9.2%</td>
<td>10.0%</td>
</tr>
<tr>
<td>2011</td>
<td>30.6% (900)</td>
<td>28.2% (495)</td>
<td>32.5% (495)</td>
<td>9.5%</td>
<td>10.0%</td>
</tr>
<tr>
<td>2012</td>
<td>26.3% (910)</td>
<td>24.9% (409)</td>
<td>27.8% (501)</td>
<td>10.8%</td>
<td>10.8%</td>
</tr>
</tbody>
</table>
Since SDPI Programs Began:

43% Decrease in ESRD

• End-stage renal disease due to diabetes declined for AI/AN more than any other racial group between 2000-2011.*

** IHS Special Diabetes Program for Indians. 2011 Report to Congress: Making Progress Toward a Healthier Future
Some Design Considerations

• Keep it simple
• Readability
• Attractive
• Show dramatic impact
Some Sources of Quantitative data

- EHR/RPMS System – locally or TEC
- Diabetes Registry – locally, IHS
- Tribal Health Assessments, Community Health Assessments – locally, TECs
- Tribal Epidemiology Centers
- America’s Health Rankings [http://www.americashealthrankings.org/states](http://www.americashealthrankings.org/states)
- CDC Diabetes Report
- IHS Report to Congress
Pairing Data with Stories Activity
Questions?
Michelle Castagne  
*Public Health Project Coordinator*  
(202) 507-4083  
mcastagne@nihb.org

**Diabetes In Indian Country:** [www.nihb.org/sdpi](http://www.nihb.org/sdpi)