

# ***It's Never Too Early to Start:***

## *Special Diabetes Program for Indians Renewal Efforts*

2106 National Tribal Public Health Summit  
Atlanta, GA  
April 11-13, 2016

Presented by:

**Stacy A. Bohlen**, Executive Director, NIHB

**Michelle Castagne**, Public Health Project Coordinator, NIHB

**Karrie Joseph**, MPH, Public Health Program Manager, NIHB

National Indian  
Health Board



# 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.

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

# National Indian Health Board

- 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

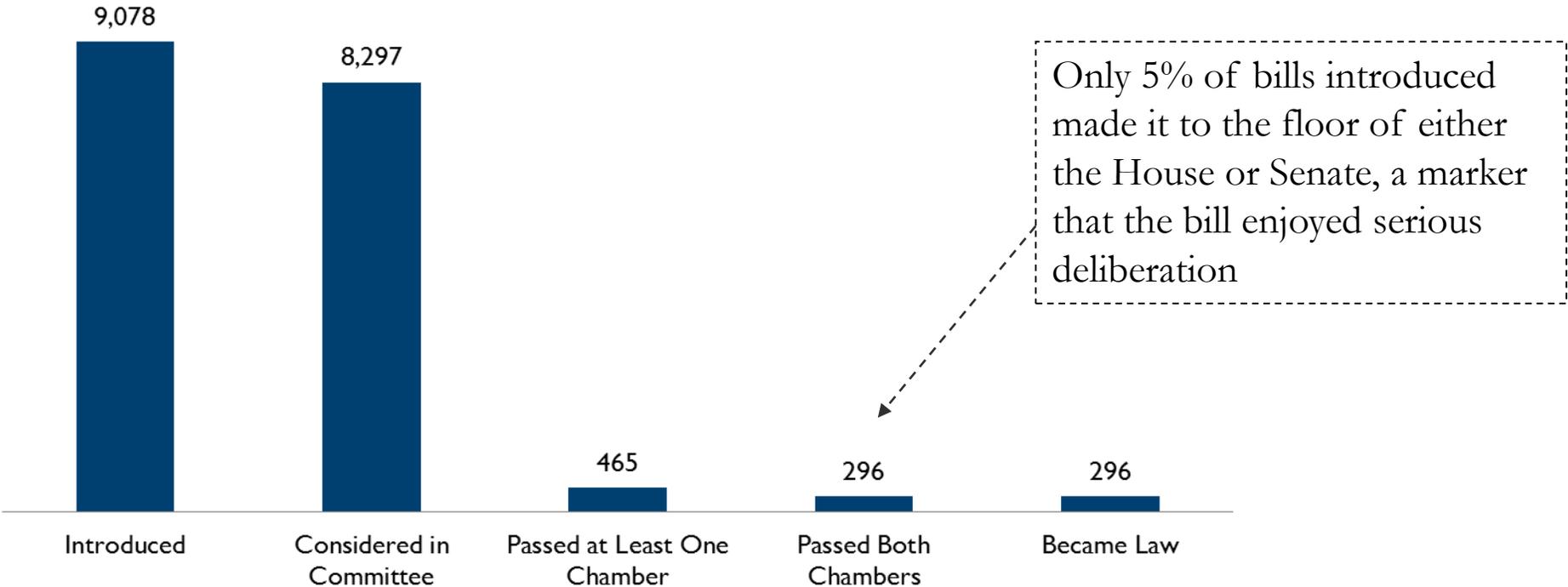
- Two per each of 50 States = 100
- 6 Year Terms
- Rules - Deference to minority.

Filibuster.



# ONLY 3% OF BILLS INTRODUCED IN 113TH CONGRESS BECAME LAW

Number of Bills and Joint Resolutions, by Stage of Consideration (113th Congress)

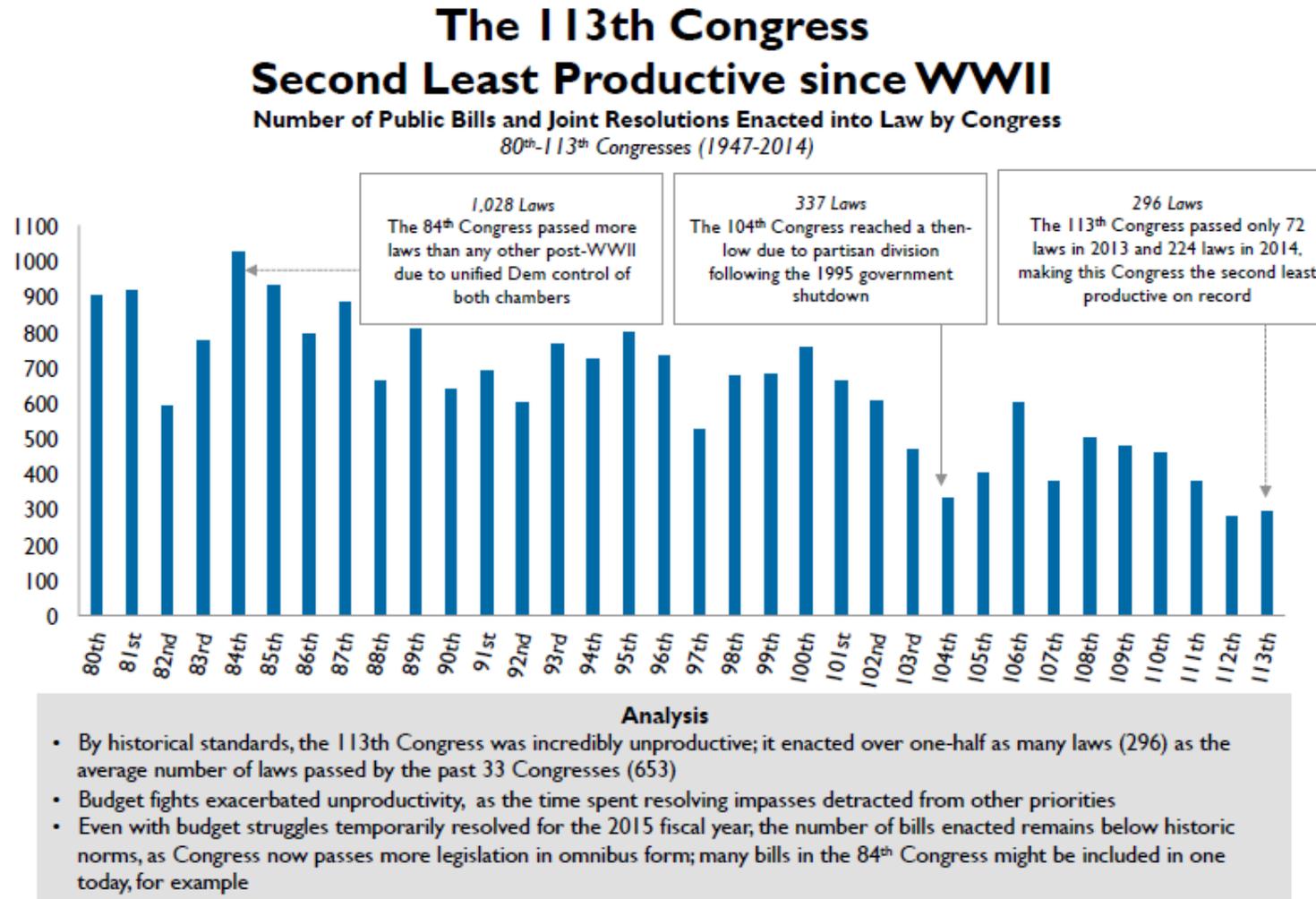


### Analysis

- 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 114<sup>th</sup> Congress

# Political Context

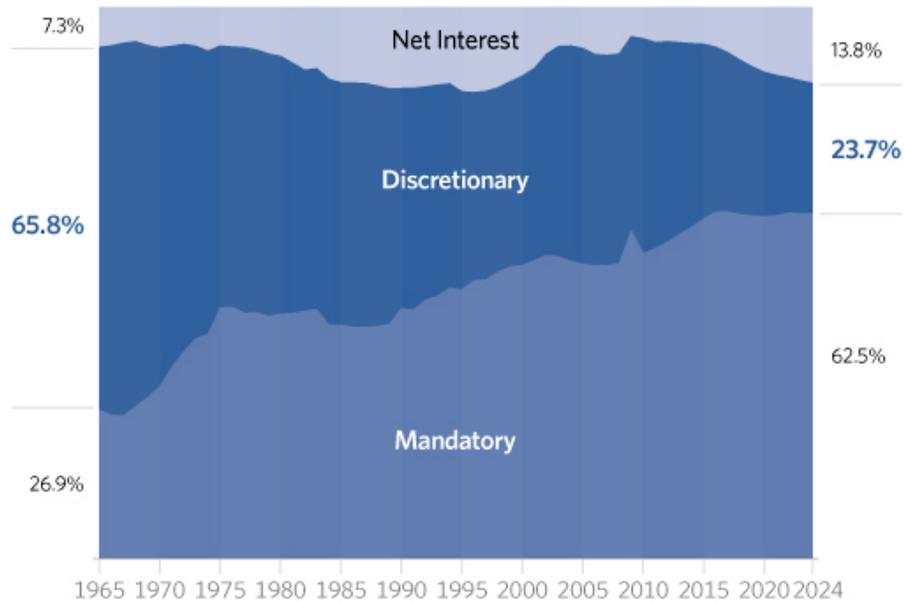
- Congress' overall productivity is diminishing over time:



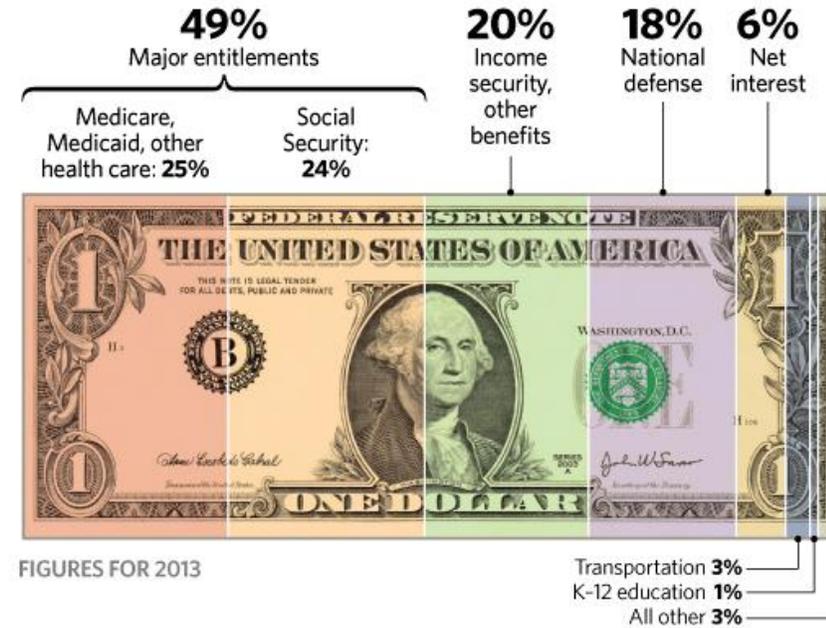
# Political Context The Federal Budget

## As Entitlement Spending Grows, the Discretionary Share of the Budget Falls

SHARE OF TOTAL FEDERAL SPENDING



## Where Did Every Dollar in Spending Go?



- 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](http://www.senate.gov) or [www.house.gov](http://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

**Renew the Special Diabetes Program for Indians this Year**



The Special Diabetes Program for Indians (SDPI), created by Congress to prevent and treat type 2 diabetes in tribal communities, expires in 2014. The Native American death rate due to diabetes is 1.6 times higher than the general U.S. population.

SDPI is getting real results and saving taxpayer dollars: the risk of cardiovascular disease has decreased and the incident rates of diabetes related kidney disease fell 28% - greater than for any other racial group. This means significant cost savings for Medicare, Medicaid and the Indian Health Service. SDPI draws on locally-driven, culturally-appropriate programming. It is one of our nation's most effective federal efforts in combating diabetes and results in significant long-term health care savings.



# 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



# SDPI Legislative History

2015	Congress extends SDPI an additional two years at current funding level of \$150 million per year
2014	Congress extends SDPI for an additional year at current funding level of \$150 million per year
2012	Congress extends SDPI for an additional year at current funding level of \$150 million per year
2010	Congress extends SDPI for an additional three years at current funding level of \$150 million per year
2008	Congress extends SDPI for an additional two years at current funding level of \$150 million per year
2007	Congress extends SDPI for an additional year at current funding level of \$150 million per year
2004	Congress directs SDPI to initiate demonstration projects focused on diabetes prevention & cardiovascular disease risk reduction
2003	NIH Diabetes Prevention Program (DPP) Study results provided scientific evidence that type 2 diabetes can be prevented or delayed
2002	Congress extends SDPI for an additional five years and increases funding to \$150 million per year
2000	IHS establishes Best Practices based upon SDPI data
1998	Congress extends SDPI for an additional three years and increases funding to \$100 million per year Tribal Leaders Diabetes Committee (TLDC) created by Congress to guide IHS in development and consultation of SDPI
1997	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
1996	American Diabetes Association created Awakening the Spirit (ATS) national advocacy team
1986	Indian Health Service Standards of Care developed
1976	Indian Health Service National Diabetes Program created by Congress
1974	Diabetes Mellitus Interagency Coordinating Committee (DMICC) established by Congress
1963	National Institutes of Health (NIH) Pima Indian Study recognized diabetes epidemic among American Indians

# 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](http://www.nihb.org/sdpi)

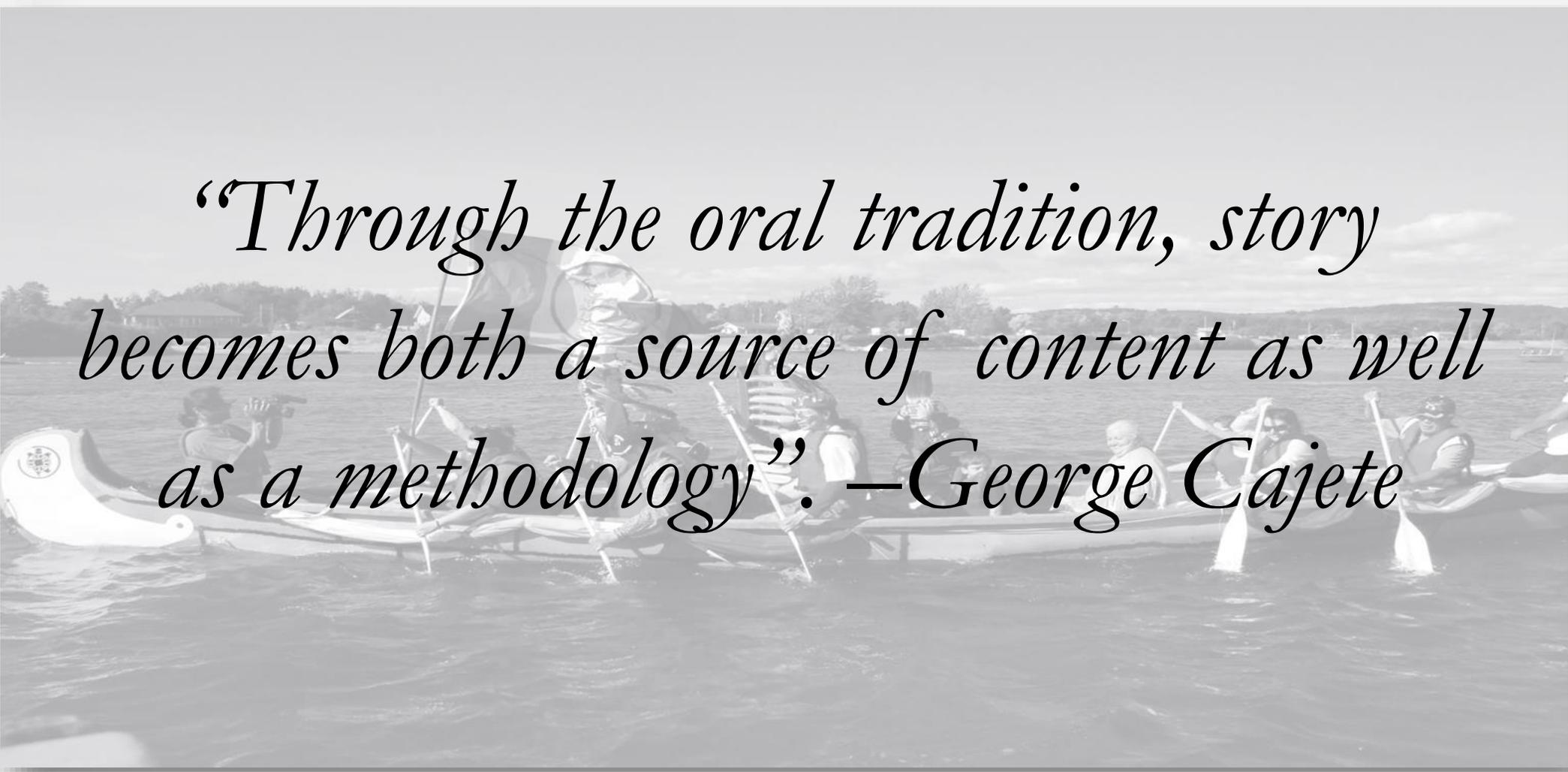


# The Future of the Special Diabetes Program for Indians

- 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



# Storytelling

A black and white photograph of a group of people in a canoe on a body of water. The image is semi-transparent, serving as a background for the text. The people are wearing life jackets and using paddles. The background shows a shoreline with trees and buildings under a cloudy sky.

*“Through the oral tradition, story becomes both a source of content as well as a methodology”. –George Cajete*

# Local Impact Stories

www.nihb.org/sdpi/local\_impact\_charlotte\_mcconnell.php

Diabetes in Indian Country

National Indian Health Board

Home For the Community About the Special Diabetes Program for Indians For Advocates

## 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 starting 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.

### Stories & Programs

**Diabetes Program Participants**  
[Tell us more about your journey with Diabetes by filling out this form](#)

**Diabetes Care Providers**  
[Share how SDPI funding has changed your community by filling out this form](#)

**Alabama**  
**NEW!**  
[The Poarch Creek Indian Community](#)  
Community Diabetes Support Group

**Alaska**  
[Charlotte McConnell](#)  
SouthEast Alaska Regional Health Consortium (SEARHC) Lifestyle Balance and Diabetes Prevention Program

[Bristol Bay Area Health Corporation](#)  
Annual Diabetes Walk



# Storytelling Formats

- Written
- Verbal
- Digital Storytelling
- Site Visits



# Formats: Written



## 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.

### Stories & Programs

**Diabetes Program Participants**  
[Tell us more about your journey with Diabetes by filling out this form](#)

**Diabetes Care Providers**  
[Share how SDPI funding has changed your community by filling out this form](#)

**Alabama**  
**NEW!**  
[The Poarch Creek Indian Community Community Diabetes Support Group](#)



**Alaska**  
[Charlotte McConnell](#)  
SouthEast Alaska Regional Health Consortium (SEARHC) Lifestyle Balance and Diabetes Prevention Program



[Bristol Bay Area Health Corporation](#)  
Annual Diabetes Walk



[Southcentral Foundation Special Diabetes Program for Indians](#)



# Formats: Verbal

<i>DO</i>	<i>DON'T</i>
Plan beforehand	“wing it”
Know the issue your story relates to	Exaggerate statistics
Tell (only) your truths	Make promises you can't deliver
Be specific when asking for action	
No more than 3 asks per story shared	



# Formats: Digital Storytelling



<https://www.youtube.com/watch?list=PLAgarmx6PTMkKOJdFzOXpztDrT2JGG6Ib&v=EdKdjlK7tb8>

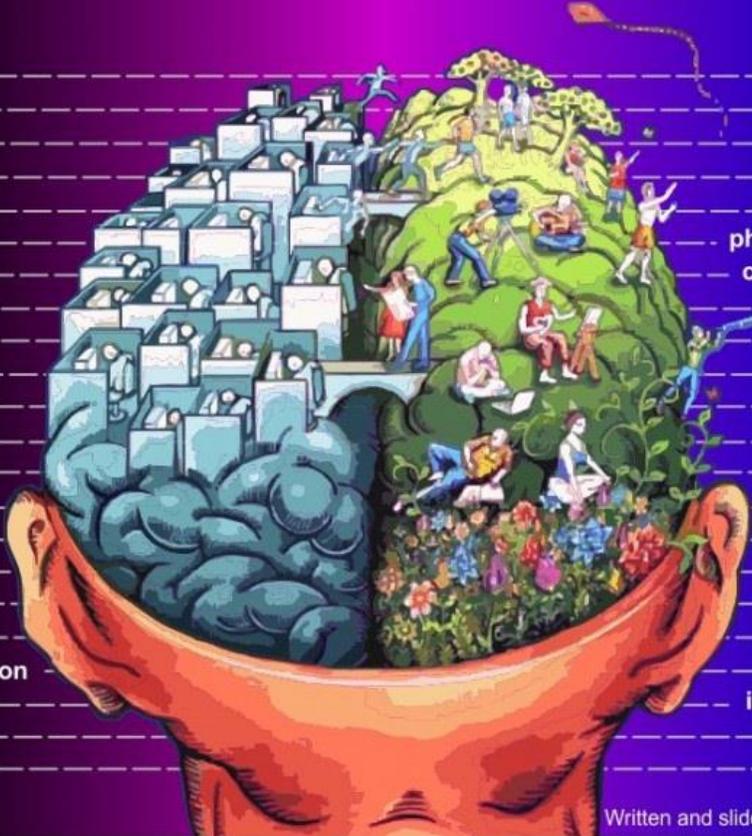


# Formats: S.H.O.W. SDPI

- *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?



**Left brain expression  
(Academic)**

- detail oriented  
(Looks at parts)
- Logical
- Sequential
- Rational
- math and science
- can comprehend
- Analytical
- Objective
- uses logic
- facts rule
- words and language
- present and past
- knowing
- acknowledges
- knows object name
- reality based
- forms strategies
- order/pattern perception
- practical/planned
- safe
- cautious

**Right brain expression  
(Creative)**

- 'big picture' oriented  
(Looks at wholes)
- Random
- Intuitive
- Holistic
- philosophy & spiritualism
- can 'get it' (the meaning)
- Synthesizing
- Subjective
- uses feeling
- imagination rules
- symbols and images
- present and future
- believes
- appreciates
- knows object function
- fantasy based
- presents possibilities
- spatial perception
- impetuous/spontaneous
- adventurous
- carefree/risk taking

Illustration by: VaXzine

Written and slide design by Dr C Daniels 2008



# 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**



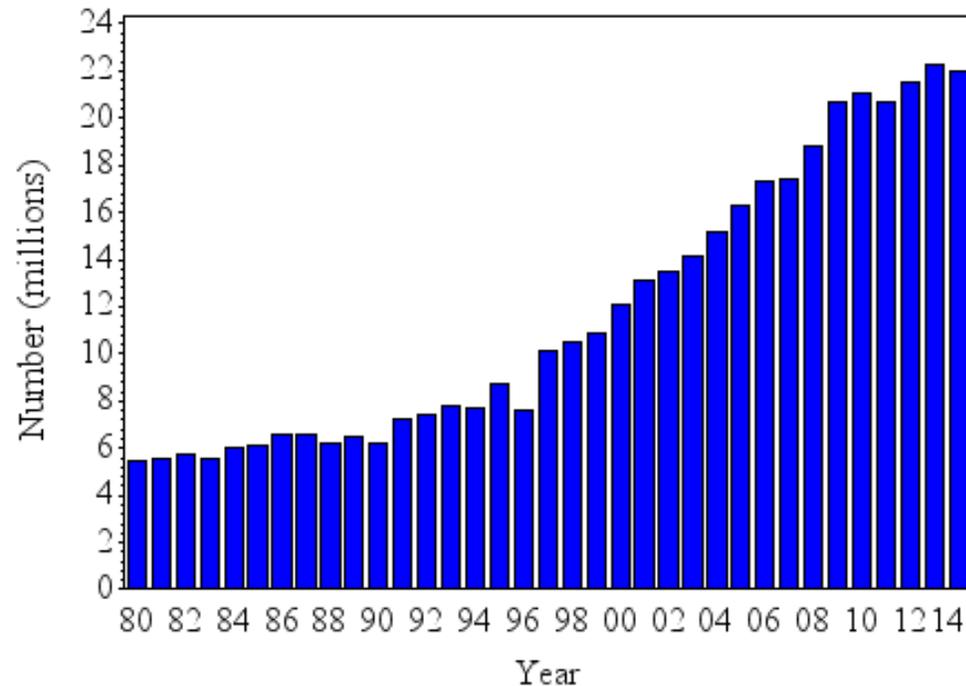
# Using Data in your Stories

- 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



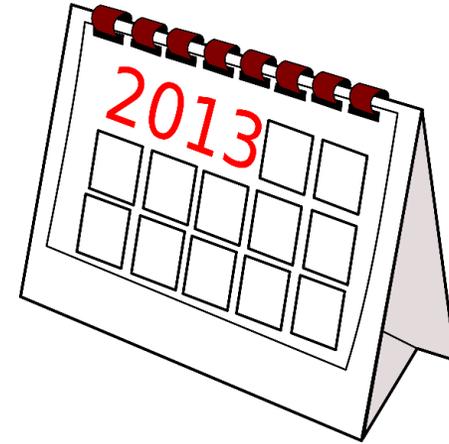
# 3 “R”ules for Using Data

- **R**ecent
- **R**eputable
- **R**elevant

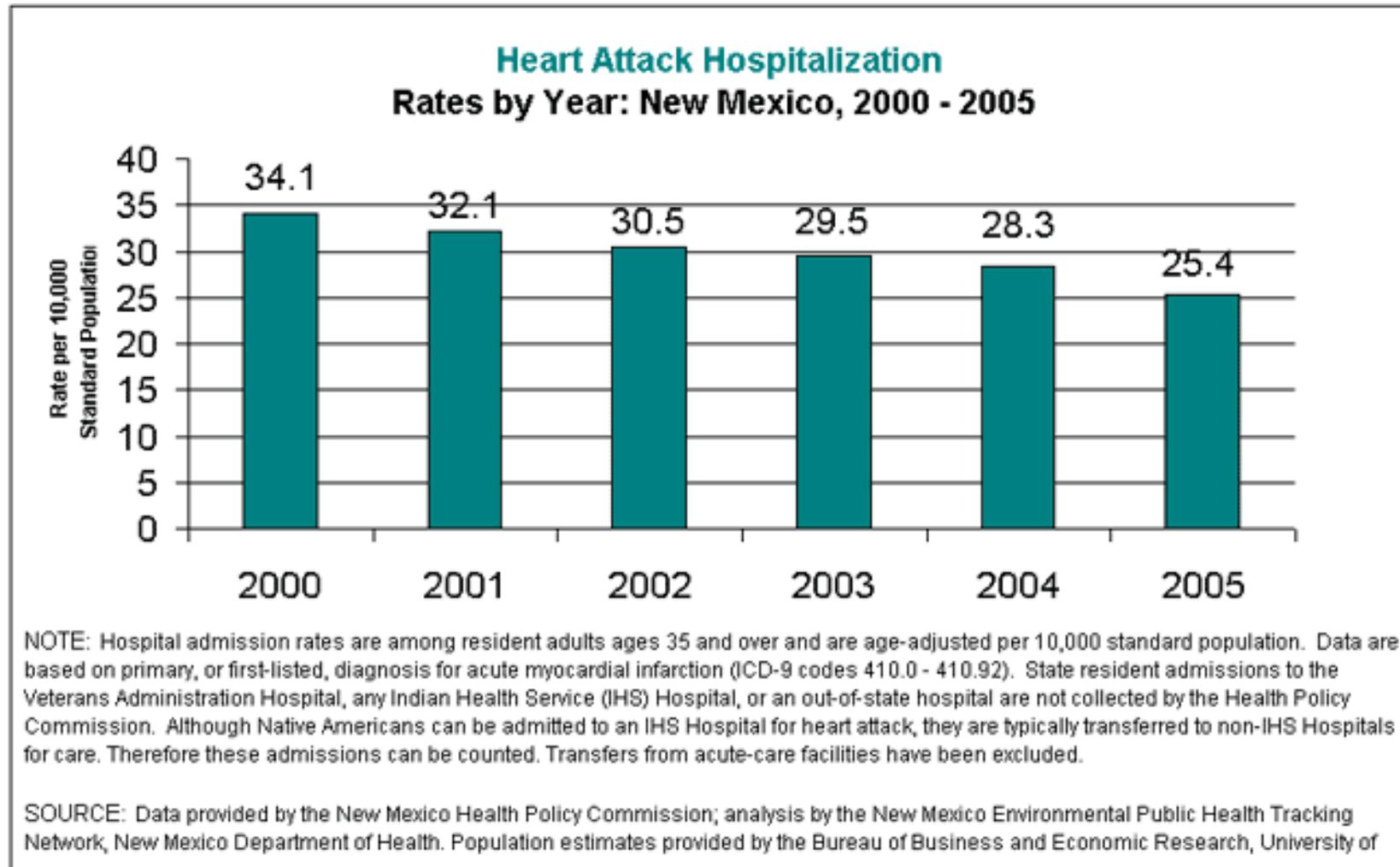


# Is it RECENT?

- 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?



Explanatory Text: Similar to the National trend, heart attack hospitalization rates are declining over time in New Mexico



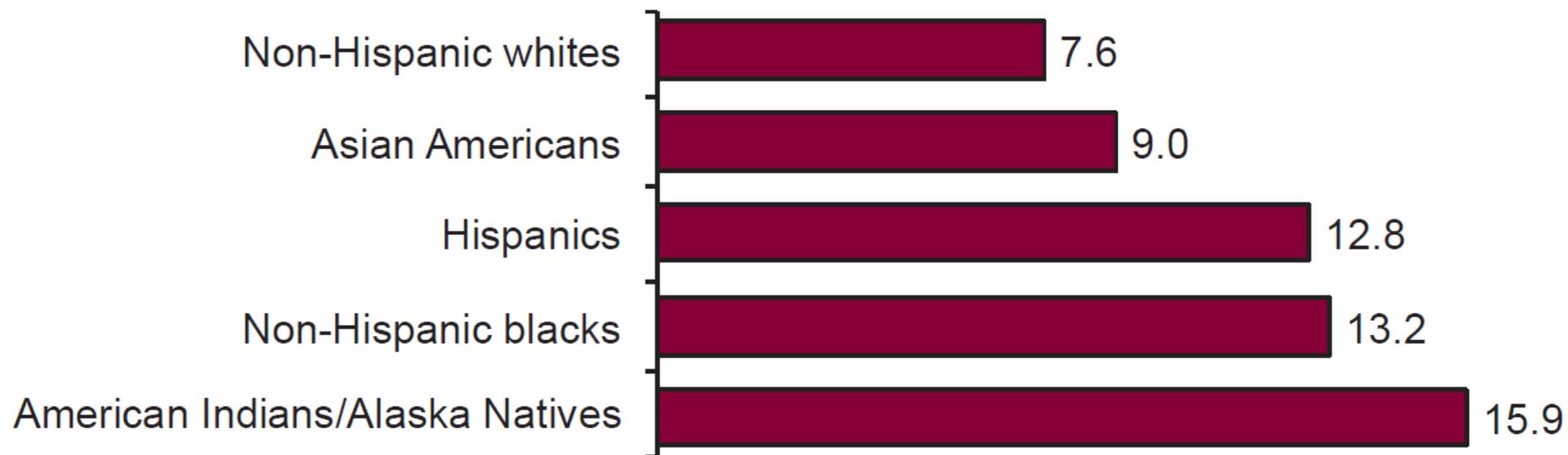
# Is the Data from a Reputable Source?

- 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**

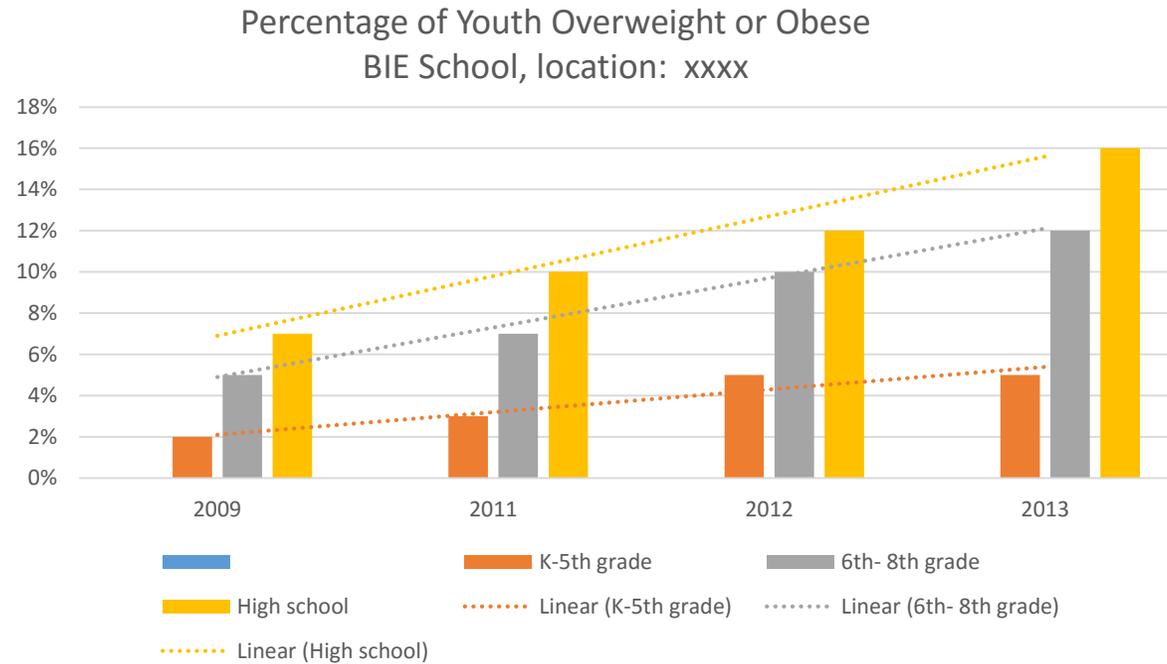


\*Based on the 2000 U.S. standard population.

Source: 2010–2012 National Health Interview Survey and 2012 Indian Health Service's National Patient Information Reporting System.



# Examples



# Examples

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

	AI/AN Total	AI/AN Men	AI/AN Women	NC Men	NC Women
	% (sample size)	% (sample size)	% (sample size)	%	%
2002	23.9% (952)	20.5% (422)	26.8% (530)	6.8%	6.7%
2010	27.2% (946)	24.6% (405)	29.4% (541)	9.2%	10.0%
2011	30.6% (900)	28.2% (405)	32.5% (495)	9.5%	10.0%
2012	26.3% (910)	24.9% (409)	27.8% (501)	10.8%	10.8%

AI/AN rate was 2.6 times higher in X counties than the state rate in 2010.



# Examples

## 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.\*

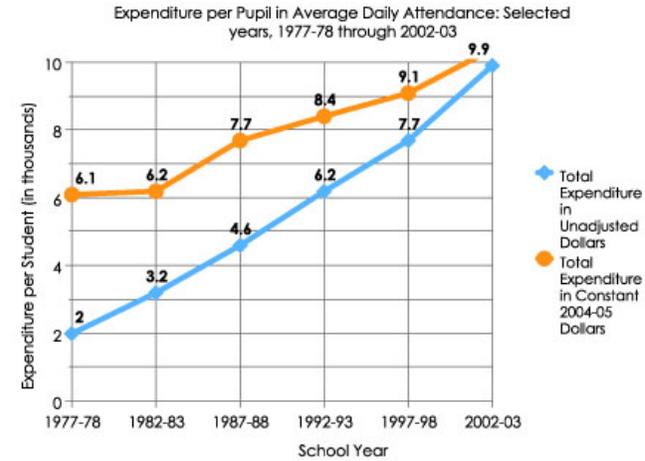
\*U.S. Renal Data System. *USRDS 2013 Annual Data Report* <http://www.usrds.org/atlas.aspx>

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

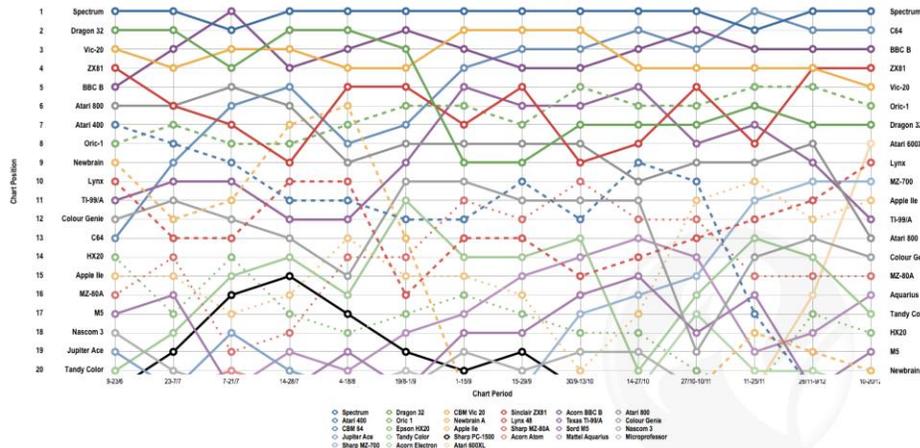


# Some Design Considerations

- Keep it simple
- Readability
- Attractive
- Show dramatic impact



The NCES Common Core of Data (CCD) 2004-2005



# 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  
[https://www.ihs.gov/epi/index.cfm?module=epi\\_tec\\_tecs](https://www.ihs.gov/epi/index.cfm?module=epi_tec_tecs)
- County Health Rankings <http://www.countyhealthrankings.org/>
- America's Health Rankings <http://www.americashealthrankings.org/states>
- CDC Diabetes Report  
<http://www.cdc.gov/diabetes/pubs/statsreport14/national-diabetes-report-web.pdf>
- IHS Report to Congress  
<http://www.ihs.gov/MedicalPrograms/Diabetes/index.cfm?module=programsSDPIRTC>



# Pairing Data with Stories Activity



# Questions?



Michelle Castagne

*Public Health Project Coordinator*

(202) 507-4083

[mcastagne@nihb.org](mailto:mcastagne@nihb.org)

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

