

Title V Maternal and Child Health (MCH) Block Grant 2011-2015 Needs Assessment

Planning Retreat
February 2, 2010
ND State Capitol, Pioneer Room
Bismarck, ND
8:00 a.m. - 4:30 p.m.



NORTH DAKOTA
DEPARTMENT of HEALTH

Welcome

*Celebrating 75 Years of Title V
2011-2015*

Michael Fraser, Ph.D.
Chief Executive Officer
Association of Maternal
and Child Health
Programs (AMCHP)



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

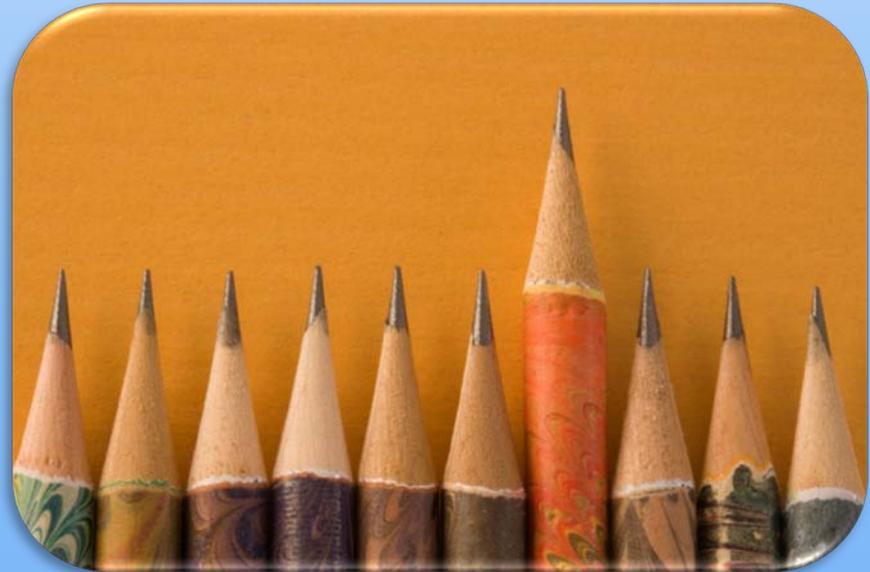
Title V Maternal and Child Health Then ...

- In the face of the Great Depression, President Franklin D. Roosevelt signs into law new legislation to promote and improve maternal and child health nationwide.
- Title V of the Social Security Act is born (1935).



Title V Maternal and Child Health Today ...

- Leadership
- Performance
- Accountability



Requirements for State Allocation

Grants to states are based on the proportion of low-income children that a state bears to the total number of children for all the states

- Annual Report and Plan
- 30 percent of funds must be allocated for children with special health care needs
- 30 percent of funds must be allocated for preventive and primary care services to children
- A fair method of allocation
- Coordination of activities with other MCH-related programs (WIC, EPSDT)
- **Statewide Needs Assessment to be conducted every 5 years**
- And many others

Note: 4:3 match is required of states

Needs Assessment Process

Title V legislation requires that the state prepare a statewide needs assessment every five (5) years that shall identify (consistent with health status goals and national health objectives) the needs for:

- Preventive and primary care services for families, pregnant women, mothers and infants up to age one;
- Preventive and primary care services for children (ages 1 to 24); and
- Services for children and youth with special health care needs (ages birth to 21).

Needs Assessment Goals



- Improved outcomes for MCH populations
- Strengthen partnerships

Needs Assessment Process

- Engage stakeholders
- Assess needs and identify desired outcomes and mandates
- Examine strengths and capacity
- Select priorities
- Seek resources

Needs Assessment Process

- Set performance objectives
- Develop an action plan
- Allocate resources
- Monitor progress on outcomes
- Report back to stakeholders

Title V/MCH Block Grant: What We Are Required to Monitor

- Title V/MCH Block Grant:
 - Federal performance measures
 - State performance measures – selected by needs assessment process every five years
 - Health systems capacity indicators
 - Health status indicators
 - Numbers served

North Dakota State Mandates: Funded by Title V/MCH

- Testing and Treatment of Newborns
NDCC 25-17 (Newborn Screening Program
NDAC 33-06-16)
- Sudden Infant Death Syndrome (SIDS) Program
NDCC 23-01-05
- Medical County Coroner (related to SIDS)
NDCC 11-19.1-07
- Children with Special Health Care Needs
NDCC 23-41.01-07

Needs Assessment Process: Getting Started

- Title V MCH Needs Assessment Survey – perceived needs
- Focus groups – youth ages 14-17, young adults ages 18-24, and parents of CSHCNs
- Review of the data – and there's lots!
- Presenting the data to our partners – that's you!



State Overview: Challenges



- **Growing elderly population**
(46 of the 53 counties will have 22% or more of their population age 65 and older by 2020)
- **Expanding minority population**
(13.8% increase from 2000, primarily occurring on Indian reservations)
- **Significant decline in the number of youth** (15% decline from 2000 to 2005)

Limited Access to Health Services

- Geographic distances
- Health professional shortage areas
- Lack of adequate insurance coverage
- An imbalance between reimbursement and cost

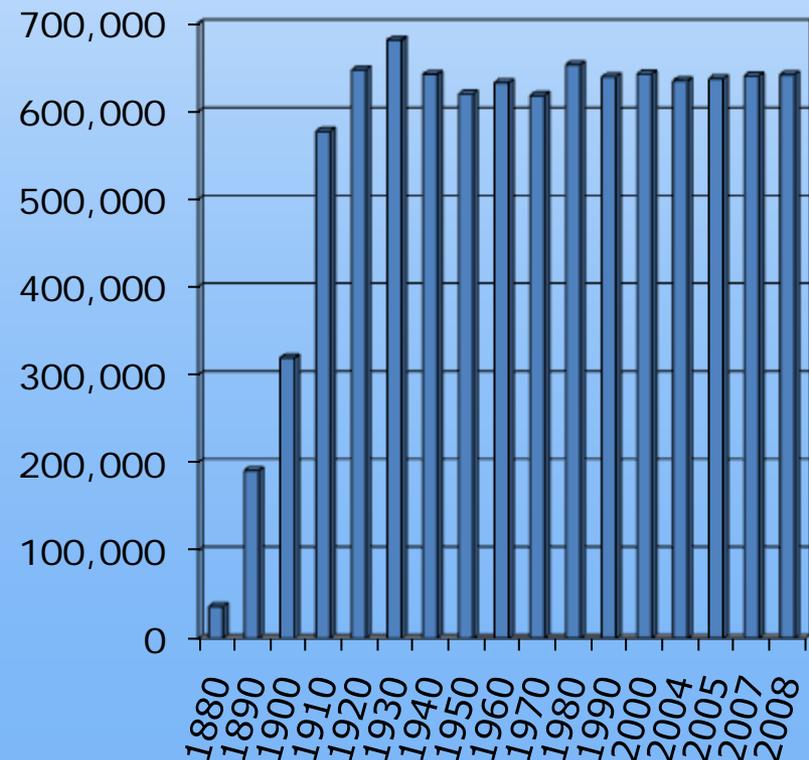


State Overview: Population

- North Dakota's population peaked in 1930 at 680,845.
- The July 1, 2008 population estimate for North Dakota totaled 641,481, an increase of 3,577 persons from 2007.

Source: U.S. Census Bureau, Decennial Census and the Population Estimates Branch
<http://www.census.gov/popest/estimates.php>

North Dakota State University, IACC Building,
Room 424, Fargo, ND 58105 Phone: (701) 231-8621
URL: <http://www.ndsu.edu/sdc>

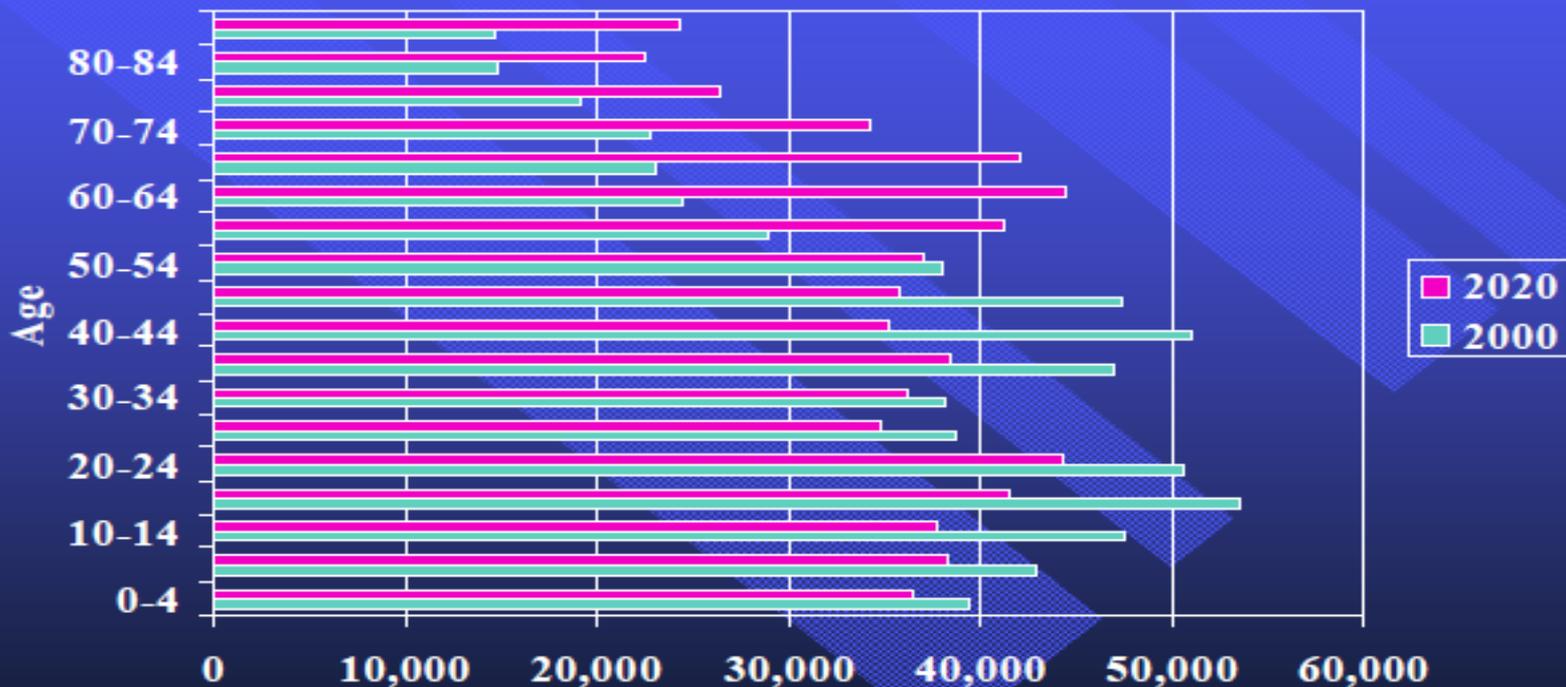


■ North Dakota Population

State Overview: Population

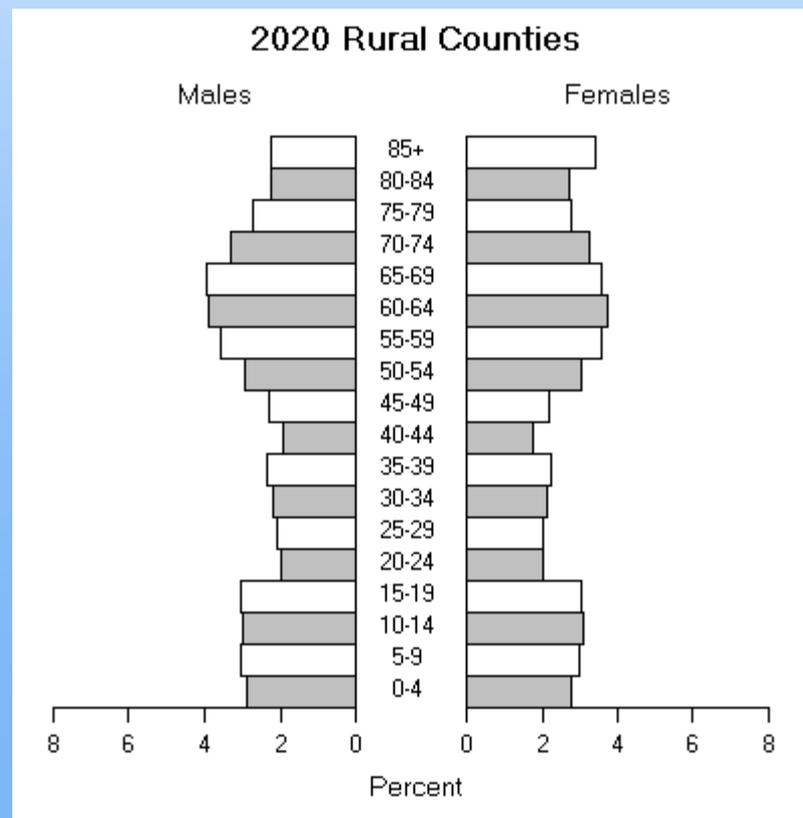
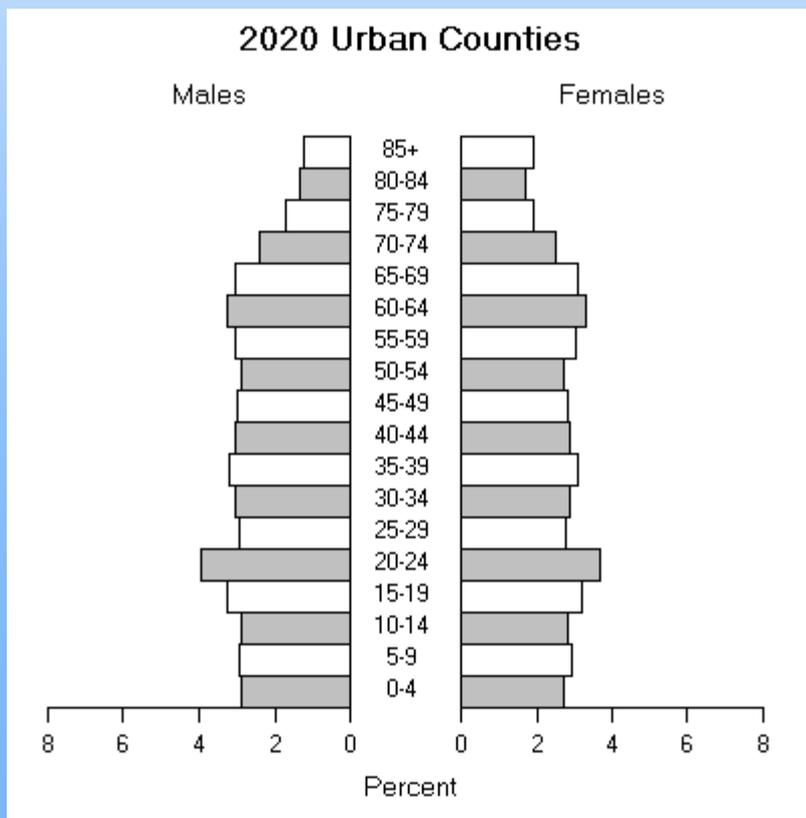
North Dakota

Population by Age, 2000 and 2020 (Projected)



Source: North Dakota State Data Center

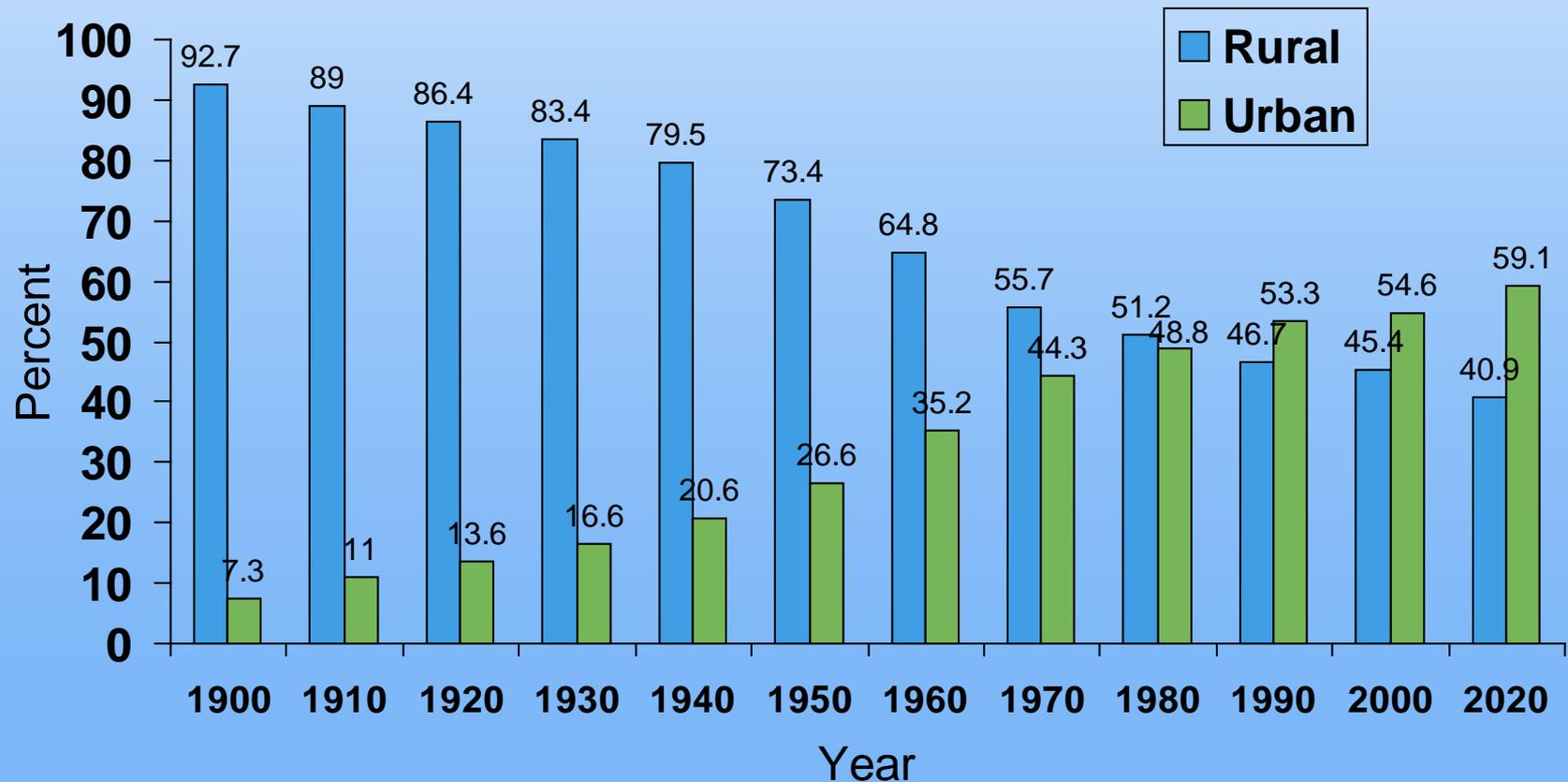
Rural and Urban Population Distributions



Age and Gender for North Dakota

State Overview:

Population Urban-Rural Distribution

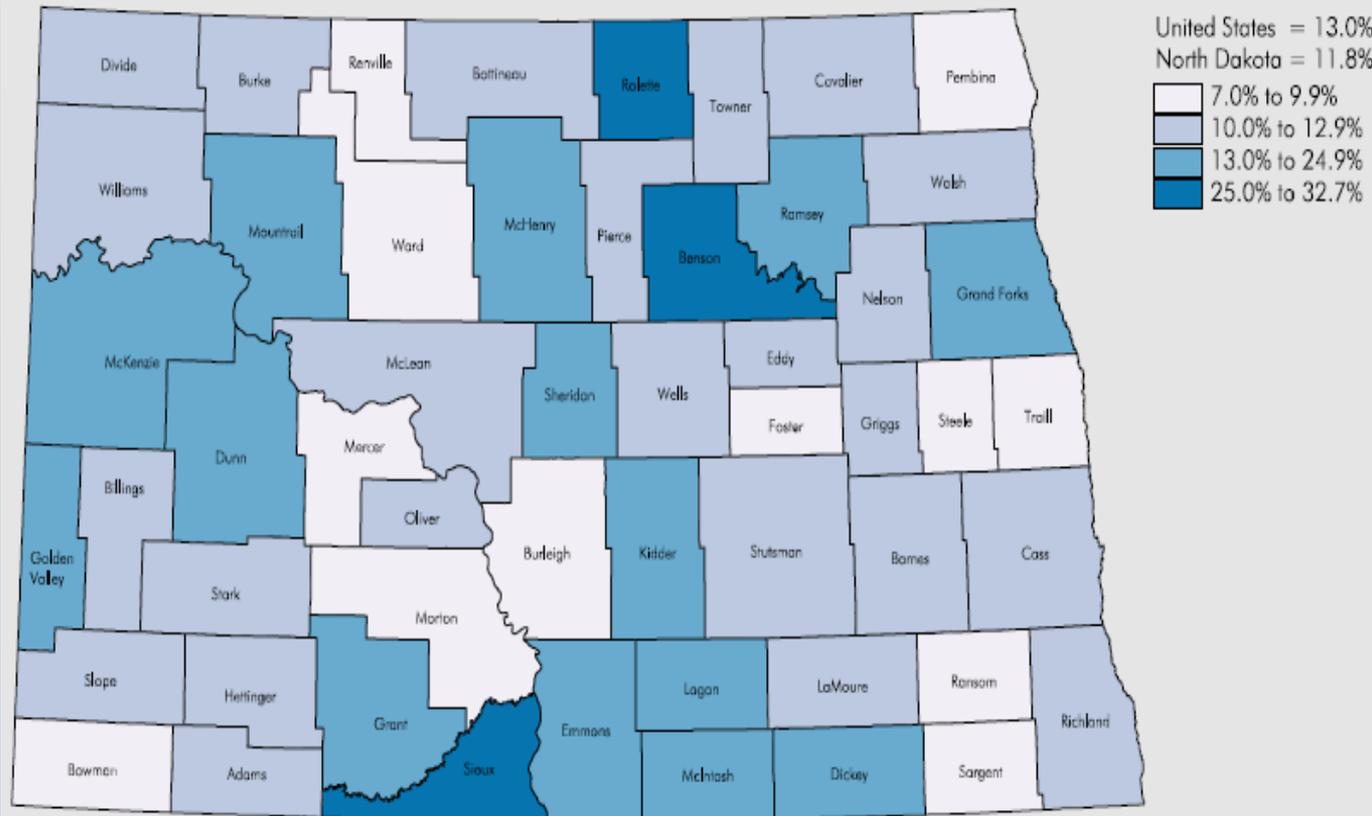


Source: U.S. Bureau of the Census, Decennial Censuses.

North Dakota State University, IACC Building, Room 424, Fargo, ND 58105 Phone: (701) 231-8621

URL: <http://www.ndsu.edu/sdc>

State Overview: Poverty



An estimated 11.8 percent of North Dakotan's lived in poverty in 2007, or about 75,000 people.

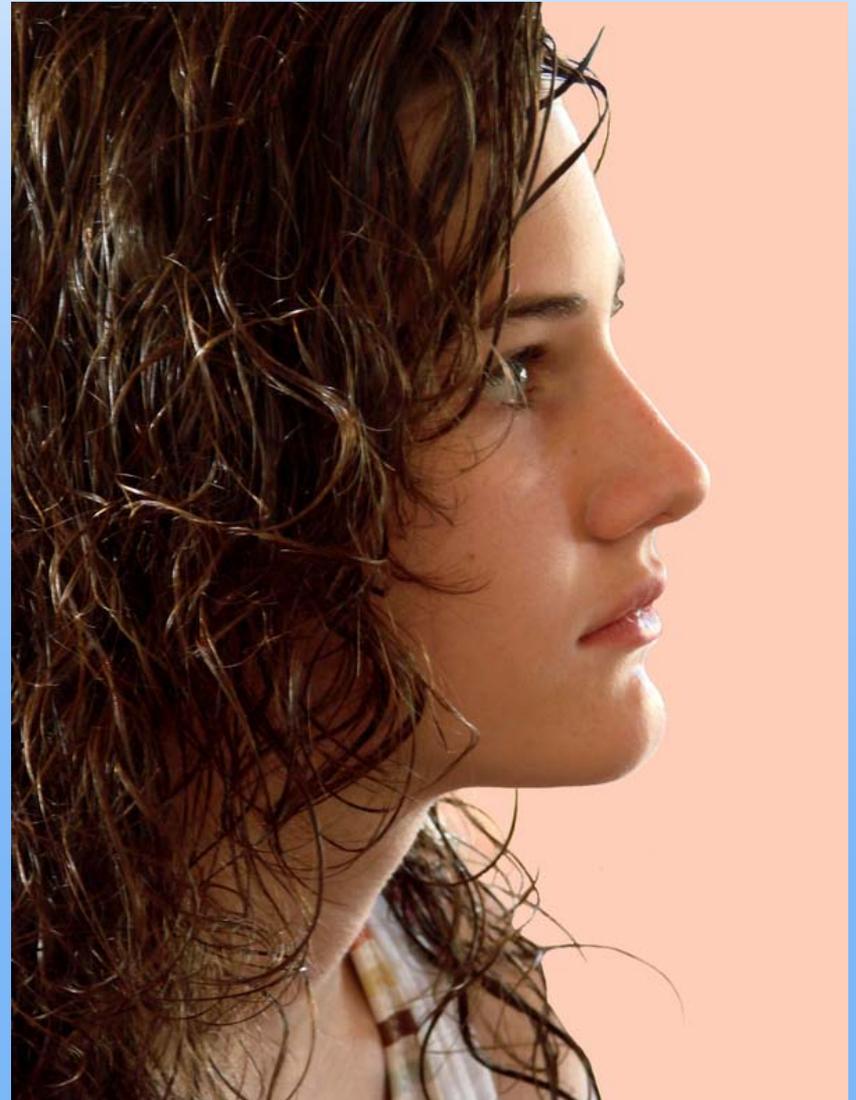
Nationally, 13 percent of all persons lived in poverty in 2007.

Source: US Census Bureau, Small Area Income and Poverty Estimates Program

Prepared by the North Dakota State Data Center, May 2009

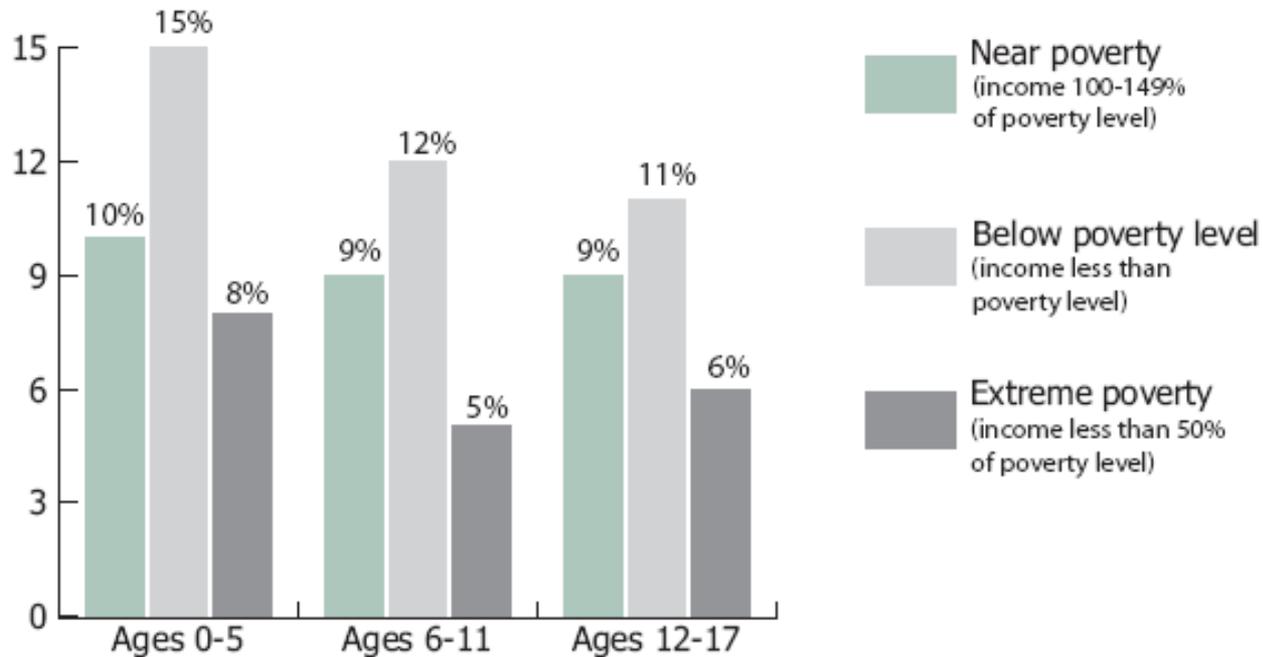
State Overview: Poverty

- In 2007, **14 percent of North Dakota children ages 0-17 lived in poverty** – this rate has not changed in nearly a decade.
- Children living with a single mother and American Indian families have higher percentages.



State Overview: Poverty

Figure 18. Poverty Status in North Dakota by Age of Child, 2006



Children ages 0-5 have the highest poverty rates in North Dakota, including the highest rates of **extreme poverty**.

Health Insurance

- North Dakota's 2006-08, 3-year average of uninsured children (ages 0 to 17) was 8.7 percent, or approximately 13,000 children (North Dakota Data Center, NDSU).
- North Dakota's 2007-08 uninsured adults (ages 19-64) was 14.4 percent (Kaiser Family Foundation).

Health Insurance

2004 ND Household Survey

- Overall uninsured rate – 8.2% of the population
- The majority of uninsured adults above age 17 were employed (71.7%)
- Those significantly more likely to be uninsured:
 - Males
 - Those ages 18-24, as compared to those between the ages of 25-54
 - American Indians, as compared to Caucasians and other races
 - Those residing in a household that earned less than 200% of the FPL
 - Those living in rural areas



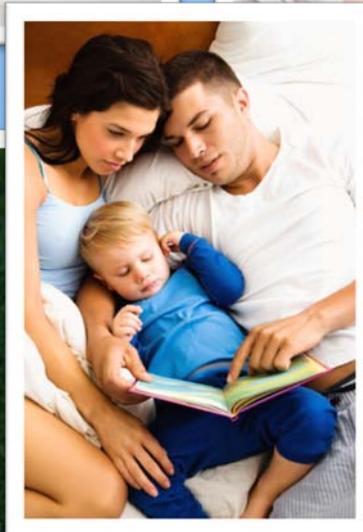
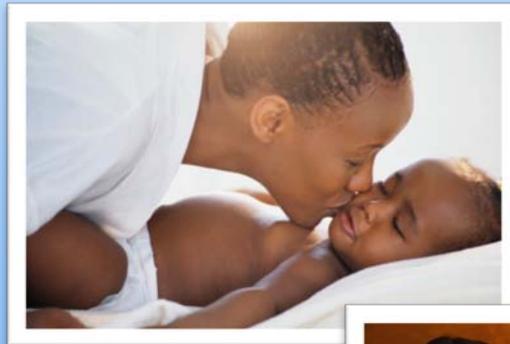
Characteristics of North Dakota's Underinsured

- Self-employed, PT employees, and FT employees of small companies
- Aged 19-24 and 55-64
- Fair/poor health status
- Ethnic minorities
- Below 200% of poverty level

Presentations: Population Specific Data

Pregnant Women,
Mothers and
Infants to Age One:

- Kate Black
- Kjersti Hintz



Pregnant Women, Mothers and Infants to Age One

Population Overview: 2008

- ND population: 641,481
 - ND racial population breakdown:
 - White 91.4%
 - American Indian/Alaskan Native 5.6%
 - ND women 18-44 years 112,825
 - ND infants 0-12 months 8,998
- } 19% of entire ND population

Title V MCH Block Grant Needs Assessment Survey Results

Top 10 Perceived Needs	Percent
Parenting education	47.7%
Access to care	38.8%
Early and adequate prenatal care	36.7%
Childcare/Daycare for infants	36.0%
Uninsured or under insured	32.6%
Substance/Alcohol use during pregnancy	27.5%
Screening, assessment, treatment (e.g., developmental, social, emotional, hearing, metabolic, etc.)	26.5%
Infant abuse and neglect	26.1%
Immunizations	21.4%
Maternal mental health screening, assessment and treatment (e.g., emotional, behavioral or mental disorders)	21.2%

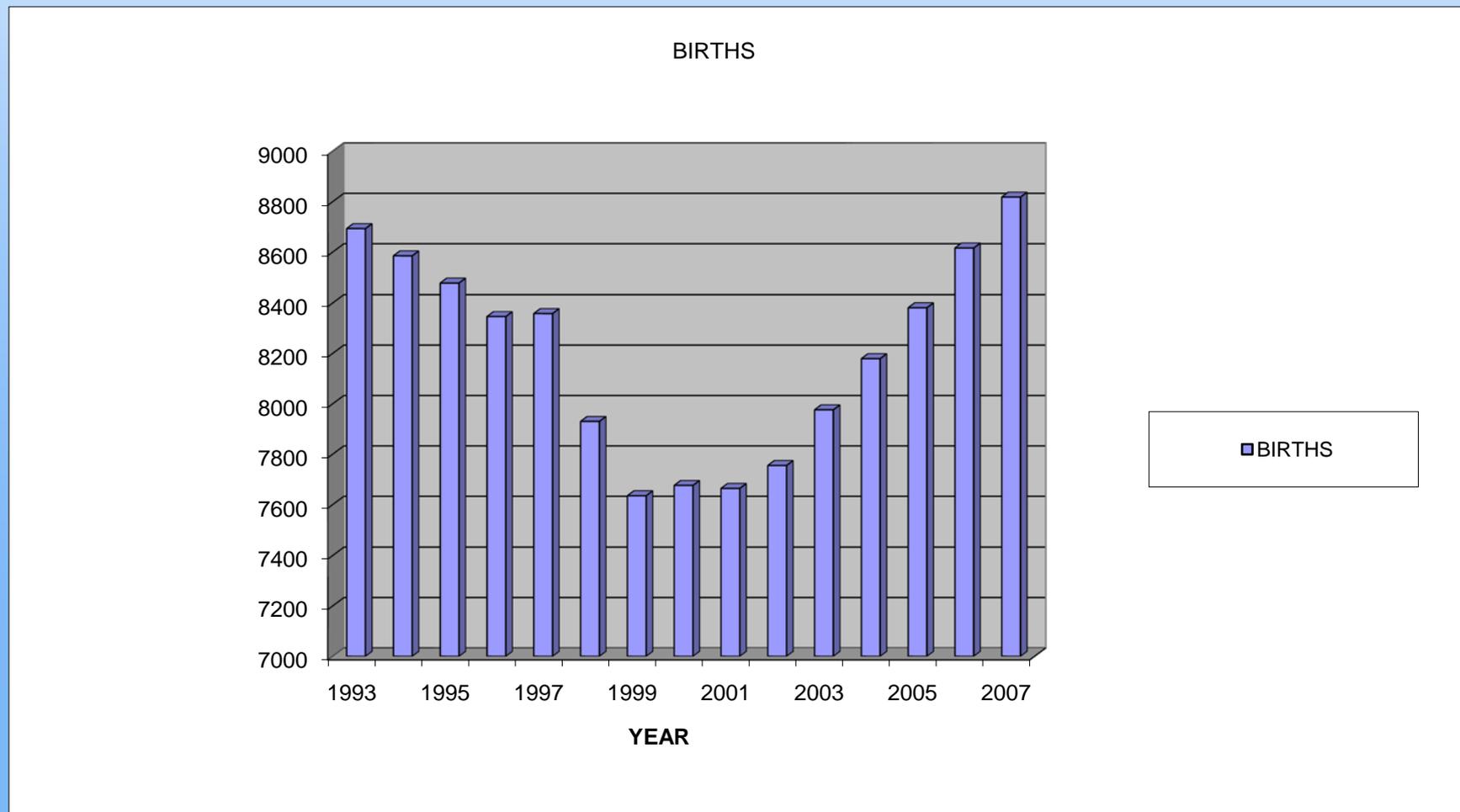
Needs Addressed

These areas include:

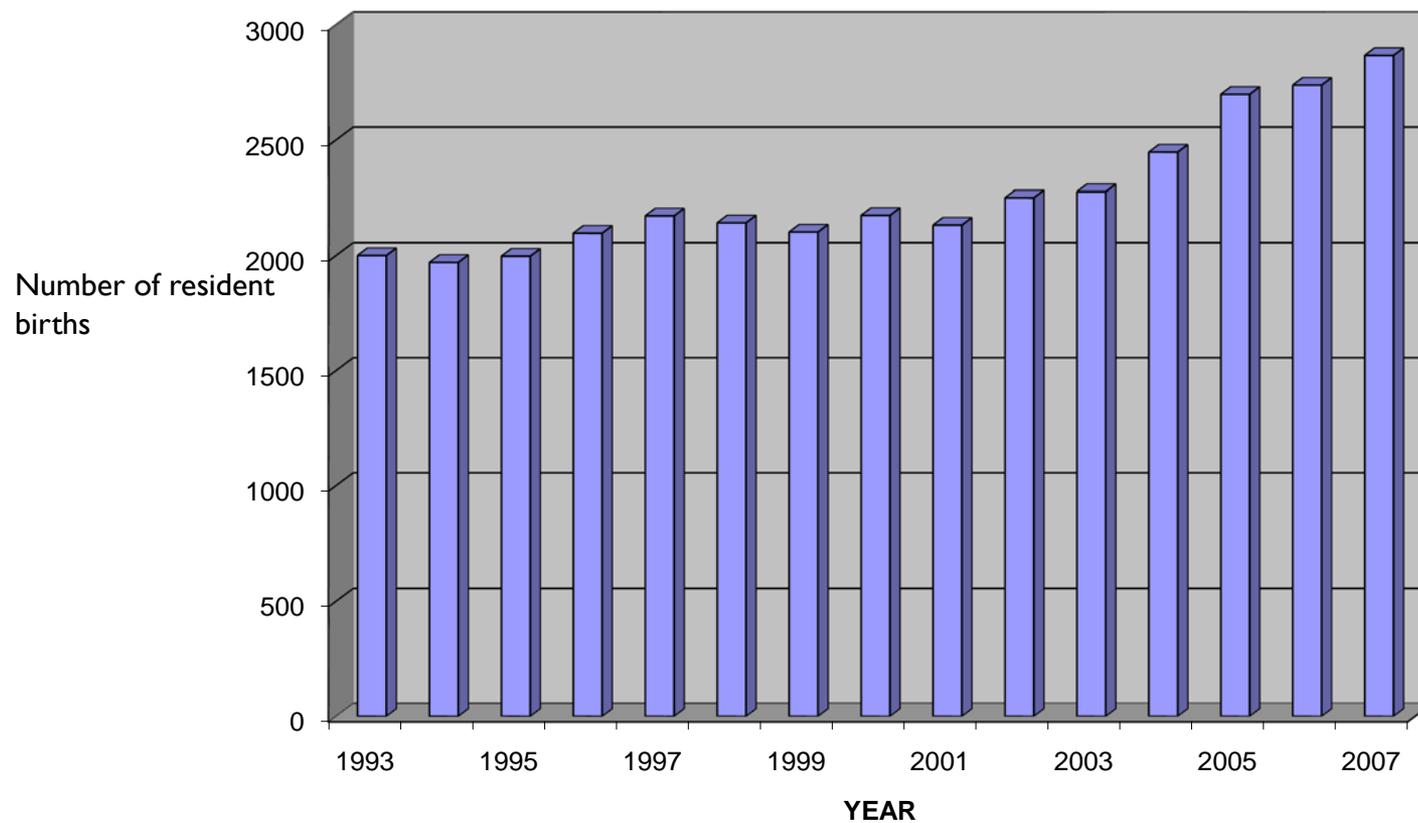
- Family Planning
- Lack of Health Insurance
- Smoking
- Binge Drinking
- Prenatal Care
- Preterm Births/LBW
- Infant Death
- Child Care
- Parenting Education



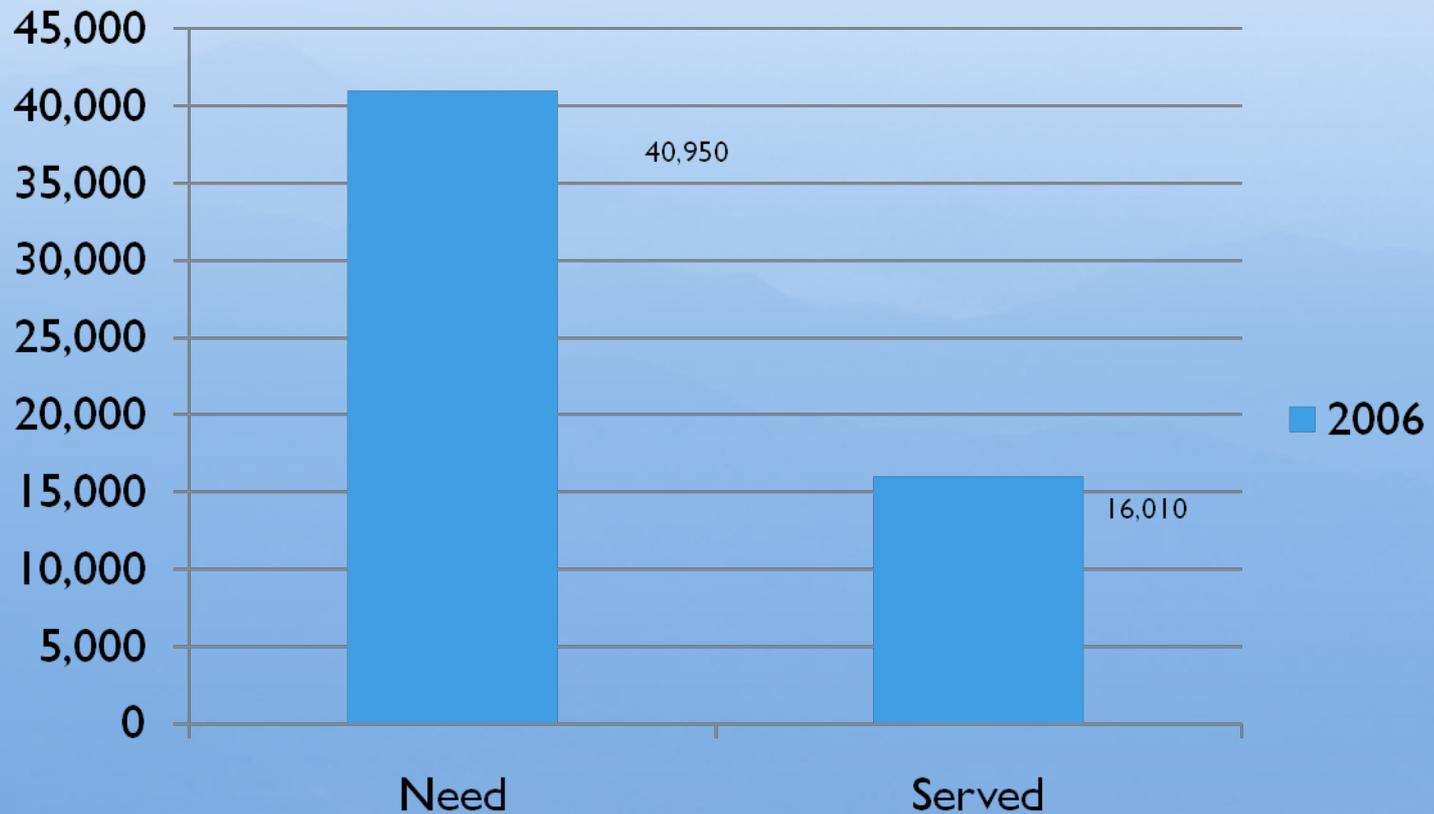
ND Births



ND Out of Wedlock Births



Family Planning Services



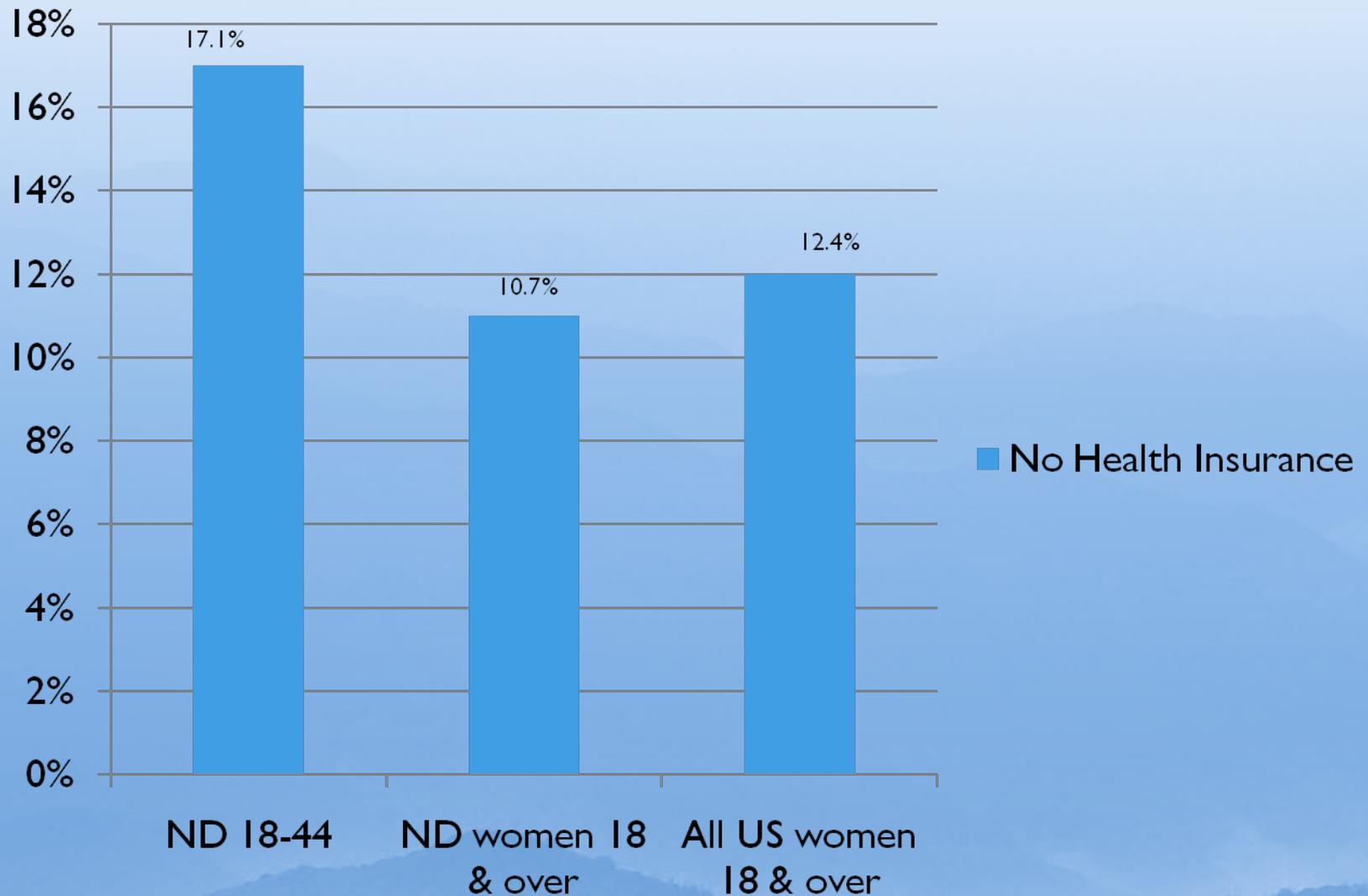
ND Contraceptive Services

Among the 50 states and the District of Columbia, North Dakota ranked:

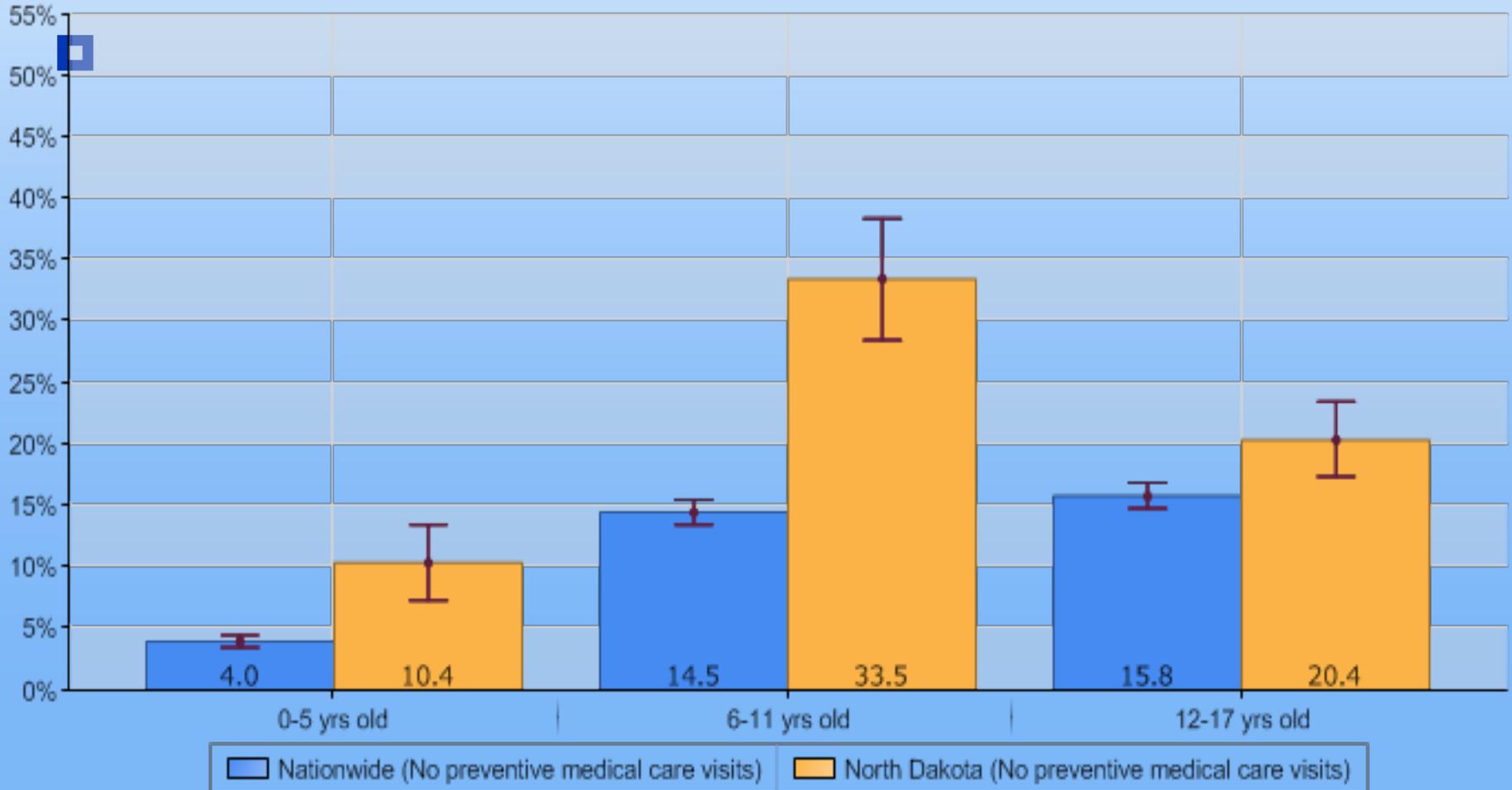
- 50th in service availability;
- 34th in laws and policies;
- 46th in public funding; and
- 50th overall.



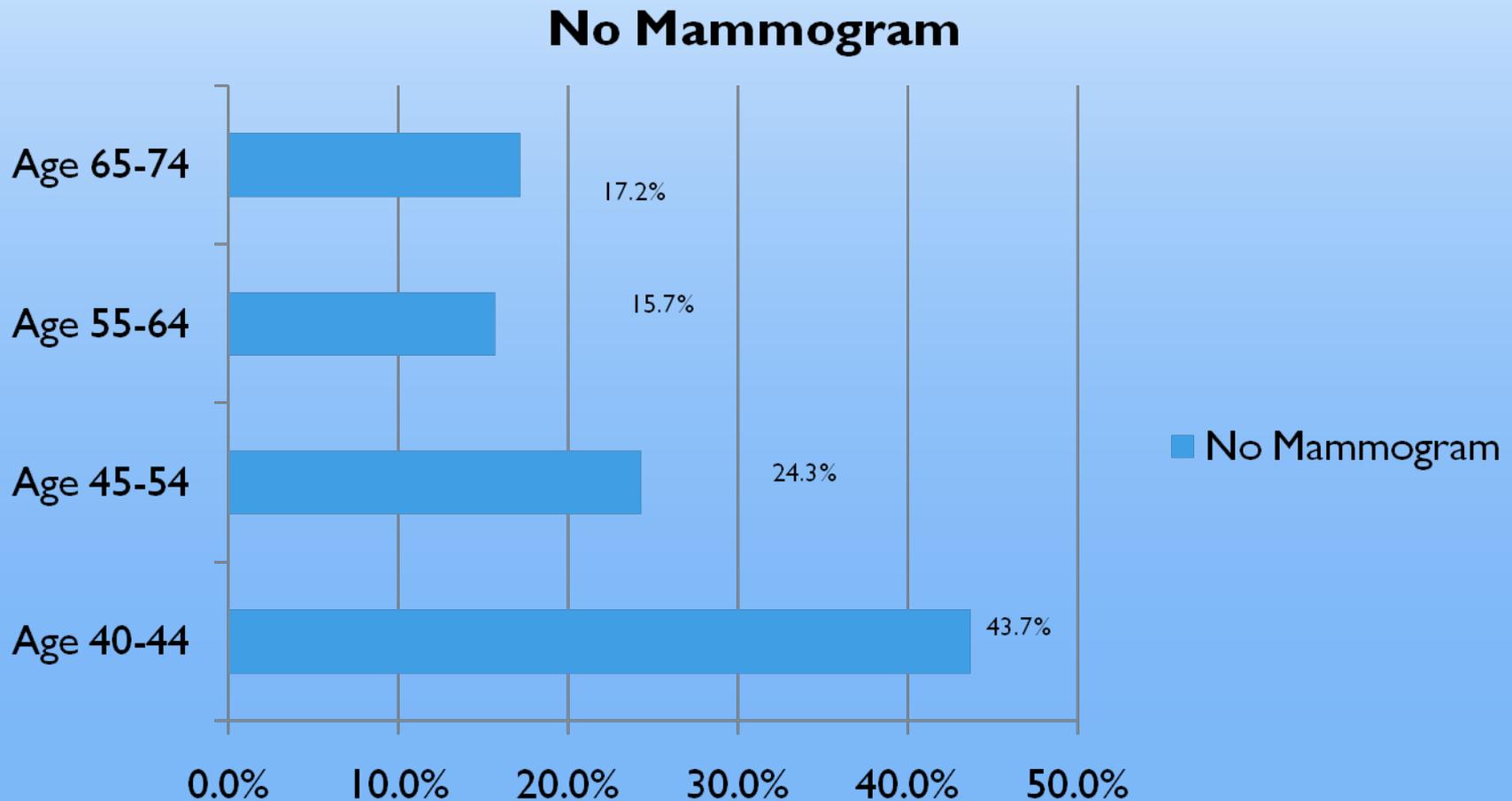
2008 Women Without Health Insurance



No Preventive Medical Care Visits in Past Year



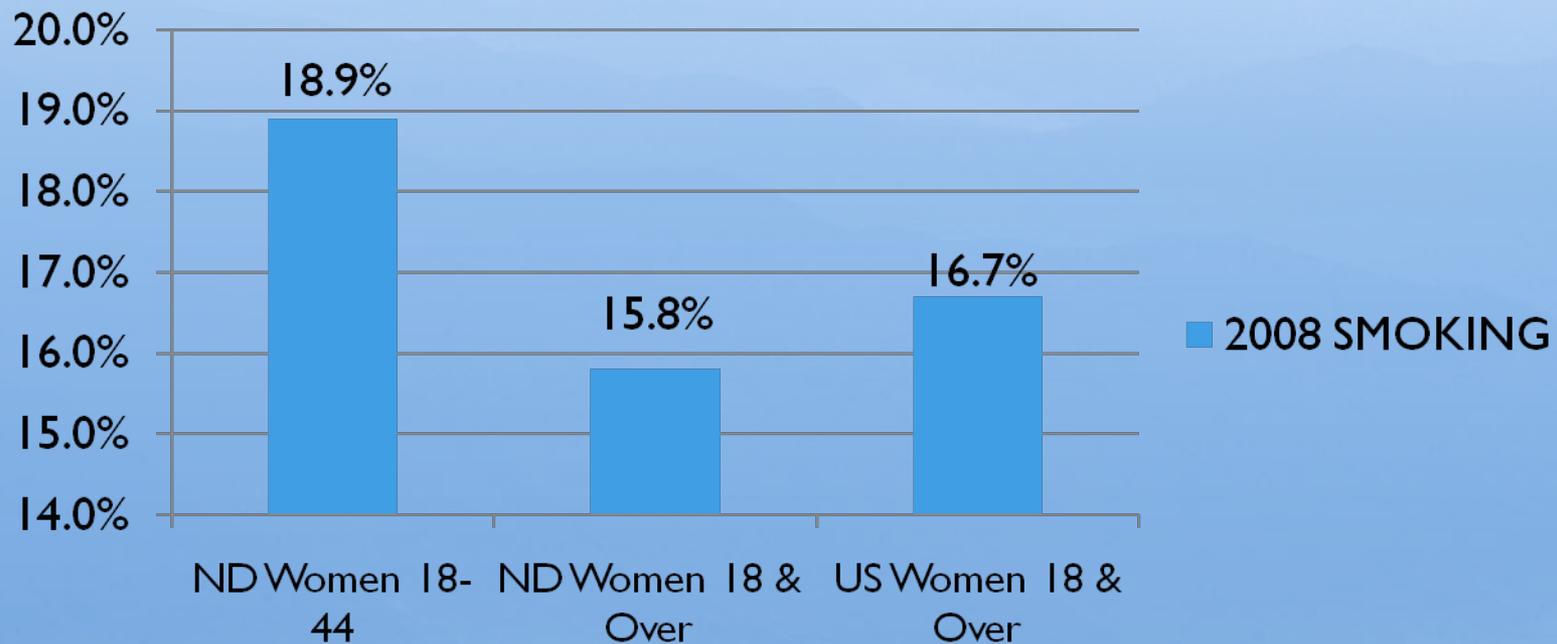
No Mammogram in Past 2 Years



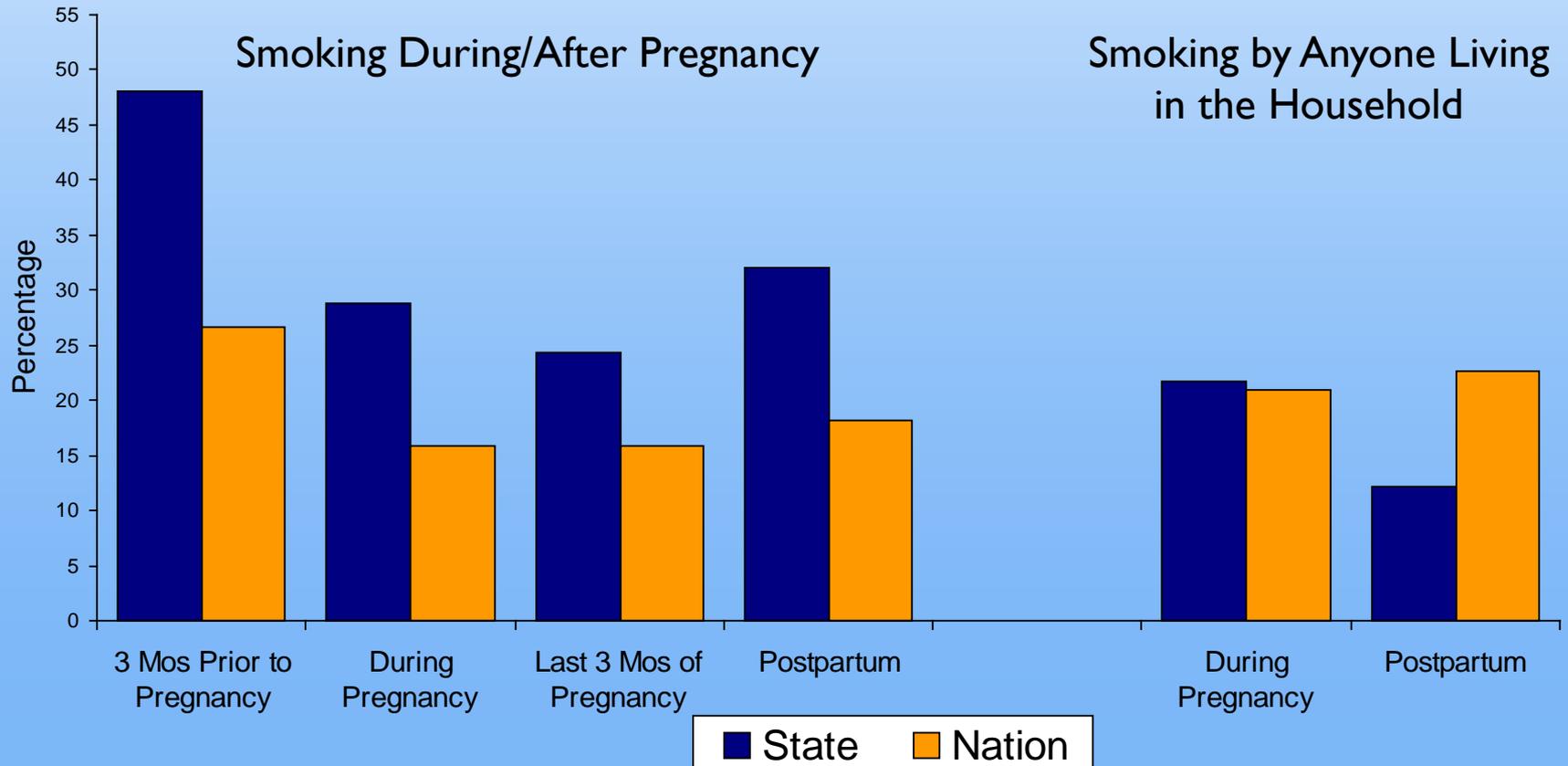


WOMEN CURRENTLY SMOKING

Smoking is defined as having ever smoked 100 cigarettes in a lifetime and currently smoking everyday or some days.



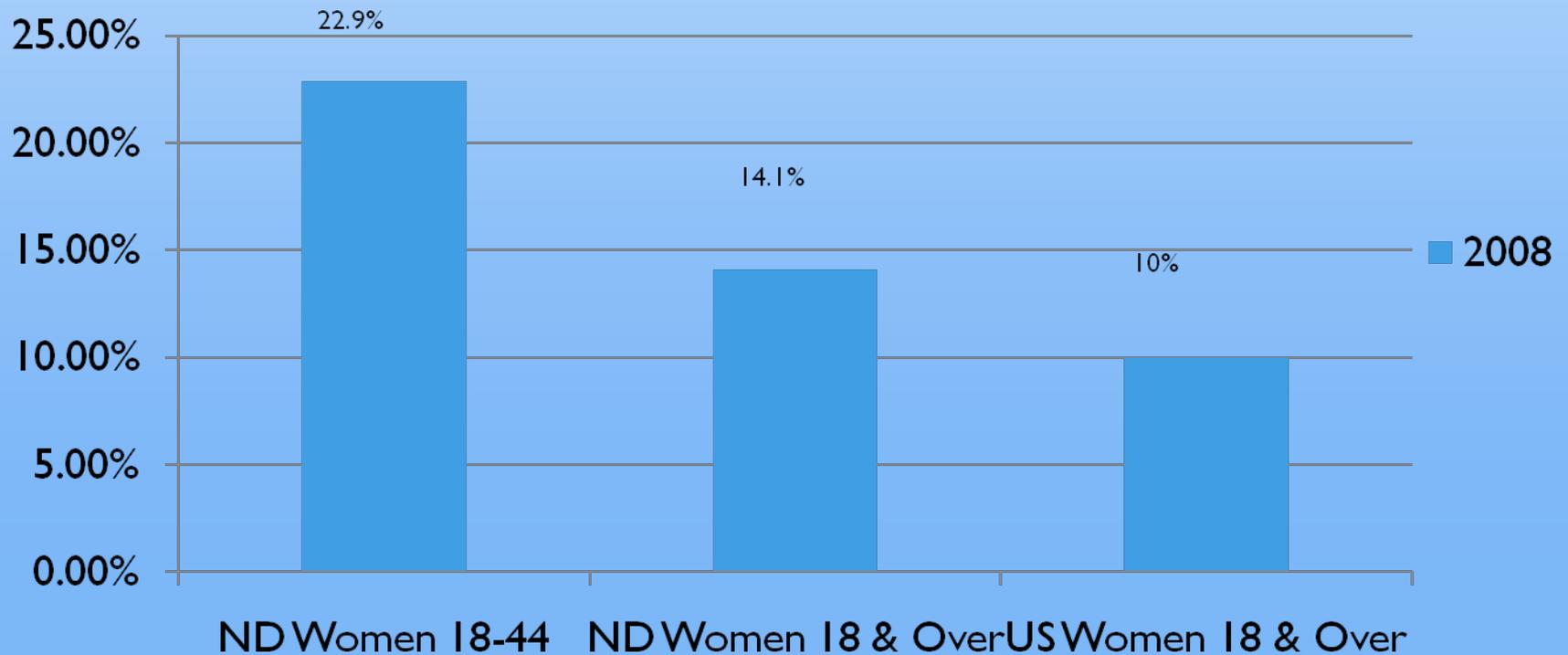
Prevalence of Smoking and Smoking in the Household by Pregnancy Status



Binge Drinking

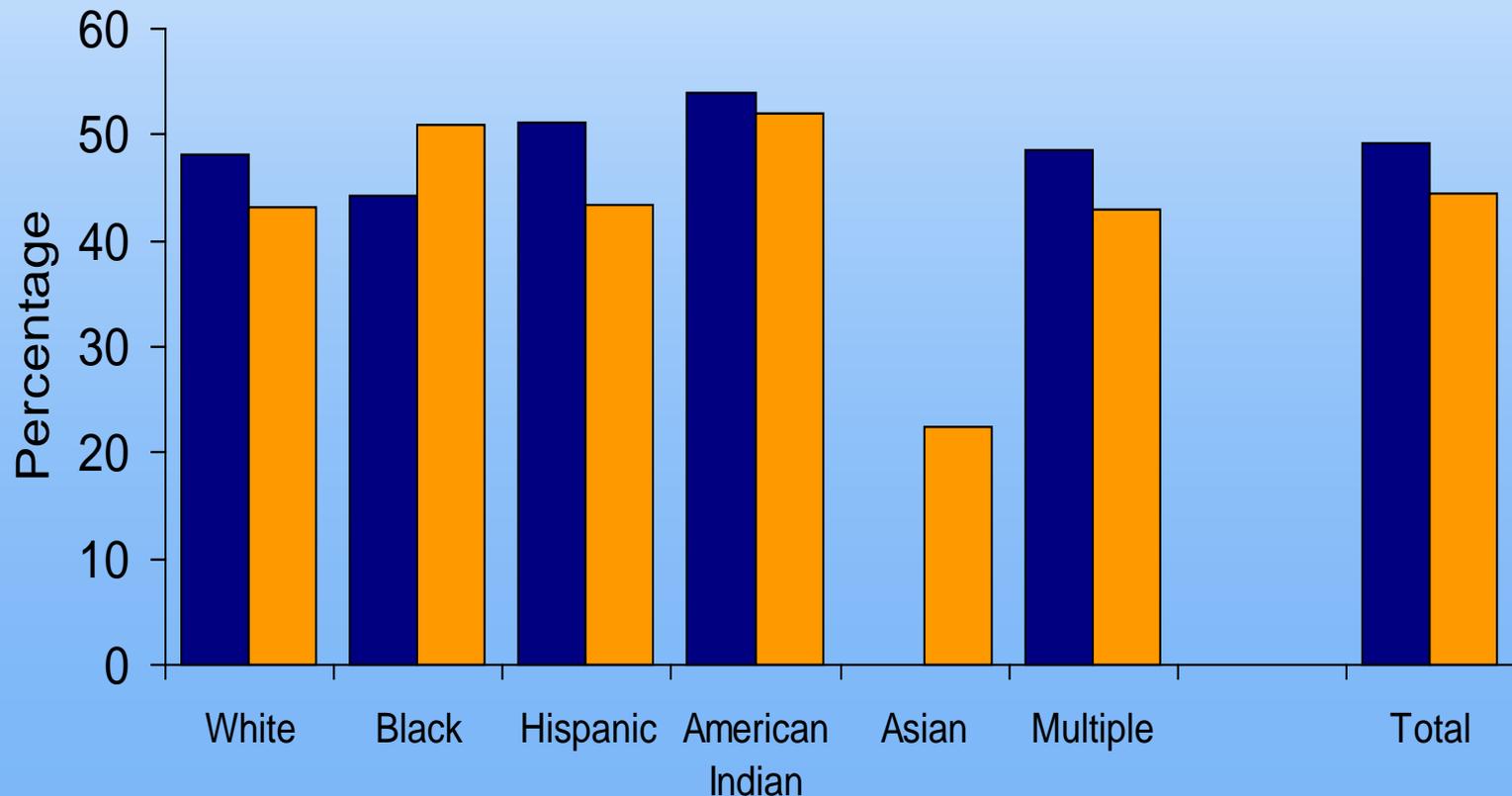
(Defined as 4 or more drinks on one occasion)

2008





2008 Prevalence of Pre-pregnancy Overweight & Obesity



Body Mass Index (BMI) \geq 26

■ State ■ Nation

Reasons For No Prenatal Care

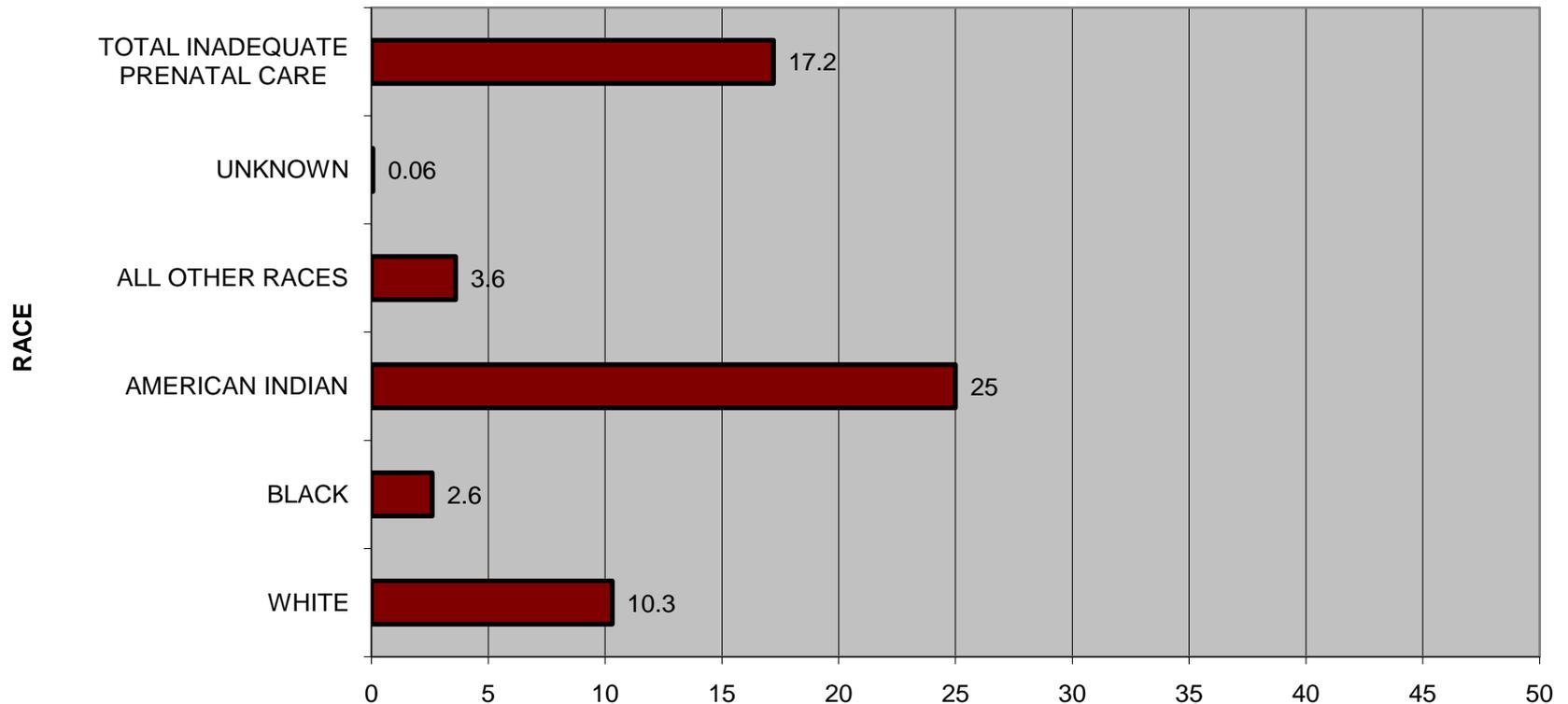
- Did not know they were pregnant (38%)
- Couldn't get an appointment earlier in the pregnancy (27%)
- Doctor or health plan would not start prenatal care earlier (22%)
- Did not have enough money or insurance to pay for prenatal care (12%)

The prevalence of North Dakota mothers who did not start prenatal care in the first trimester was higher in the following groups:

- Women ages 15 to 19
- Women with less than a high school degree
- Unmarried women
- American Indian women
- Women receiving Medicaid before or during pregnancy

Inadequate Prenatal Care by Race

PERCENT INADEQUATE PRENATAL CARE BY KOTELCHUCK INDEX
IN 2008 ND RESIDENT BIRTHS BY RACE



Postpartum Depression

North Dakota Mothers on Postpartum Depression:

“I think doctors or nurses should help other pregnant women understand and deal with postpartum blues, because I’m still struggling with it. No doctors [said] what to do if I got them. I still have episodes when all I want to do is scream and cry and there is no good reason I can think of.” “Postpartum depression - [there is] not enough information about that. I think that happens more often than we think.”

In 2000, more than half of the mothers reported low to moderate depression after delivery (52%). Overall, 7 percent reported severe depression after delivery.

Domestic Violence 2008

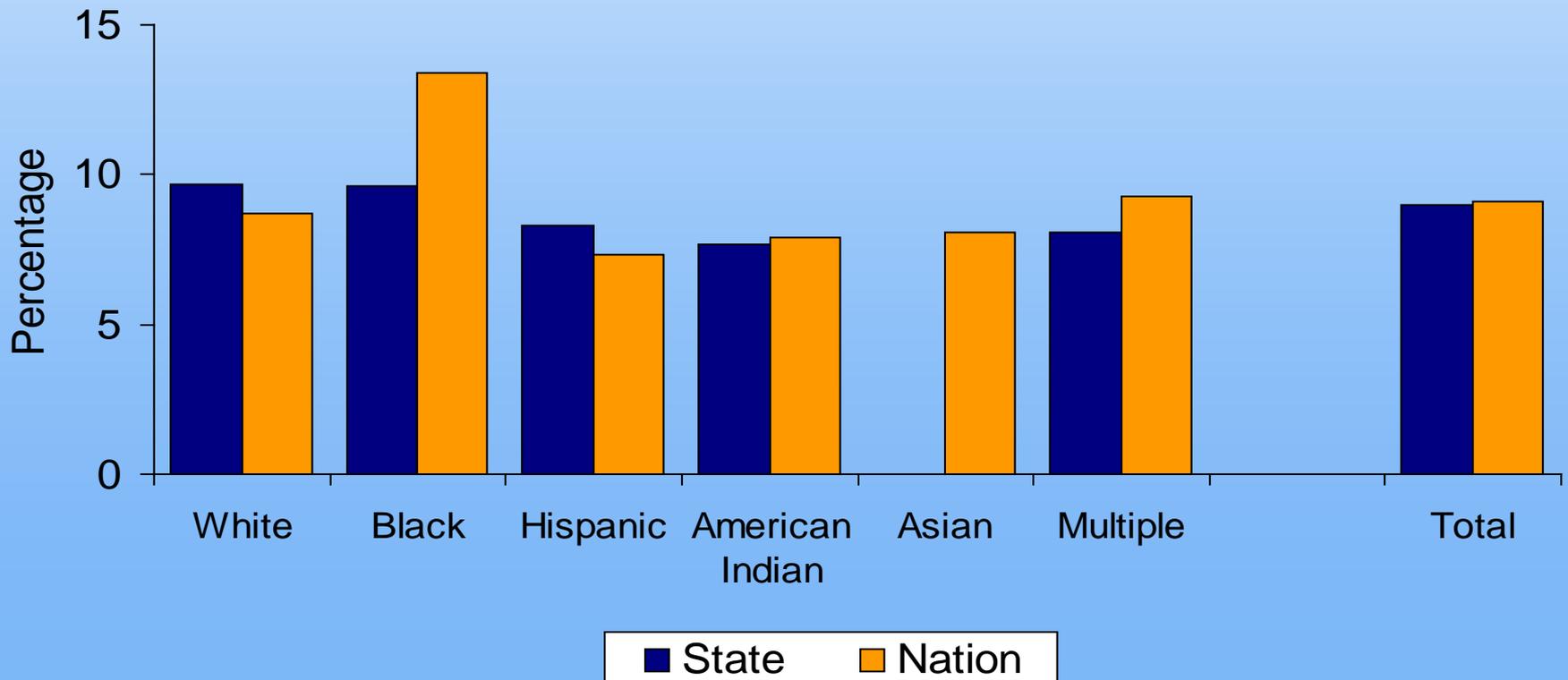
- 4,563 incidents of domestic violence were reported to crisis intervention centers in North Dakota.
- 153 women (3.5% of total new victims) were pregnant at the time they were assaulted.



Preterm and Low Birthweight Births in North Dakota

- In 2006, there were 1,047 preterm births in North Dakota, representing 12.1% of live births.
- Between 1996 and 2006, the rate of infants born preterm in North Dakota increased more than 30%.

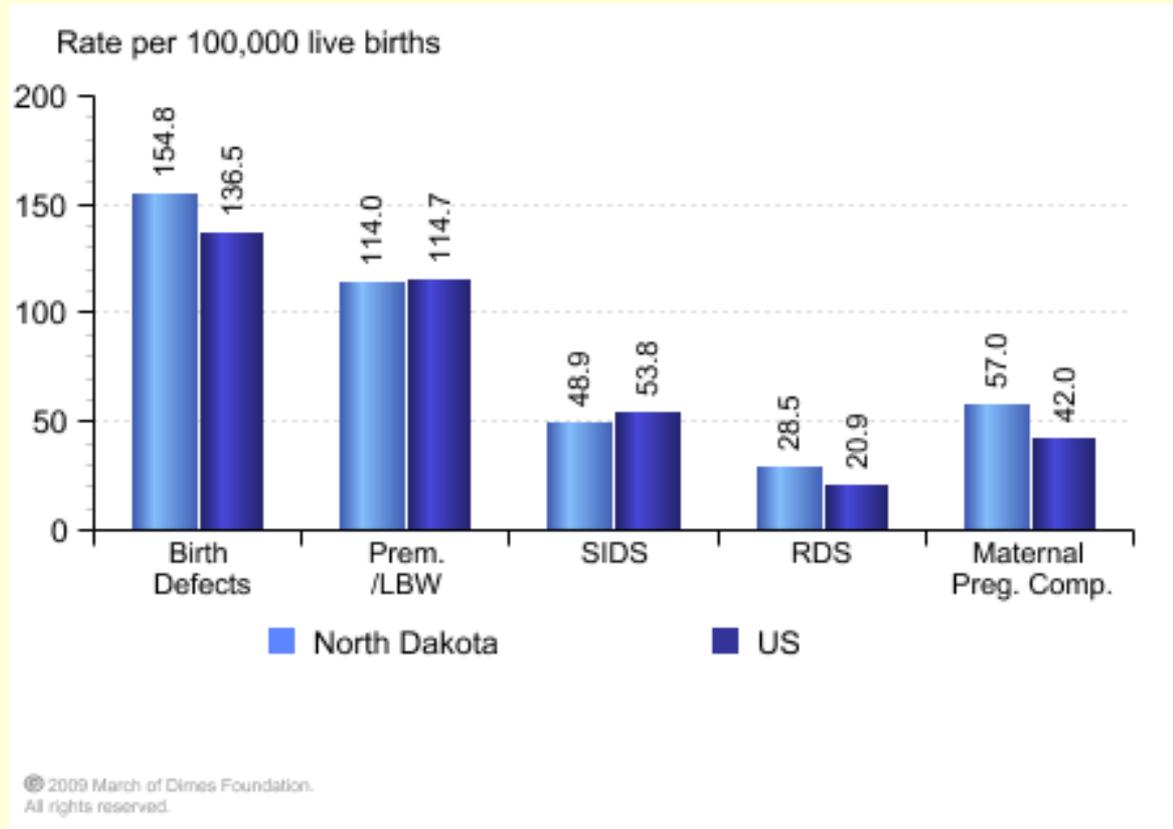
2008 Prevalence of Low Birth Weight by Race and Ethnicity





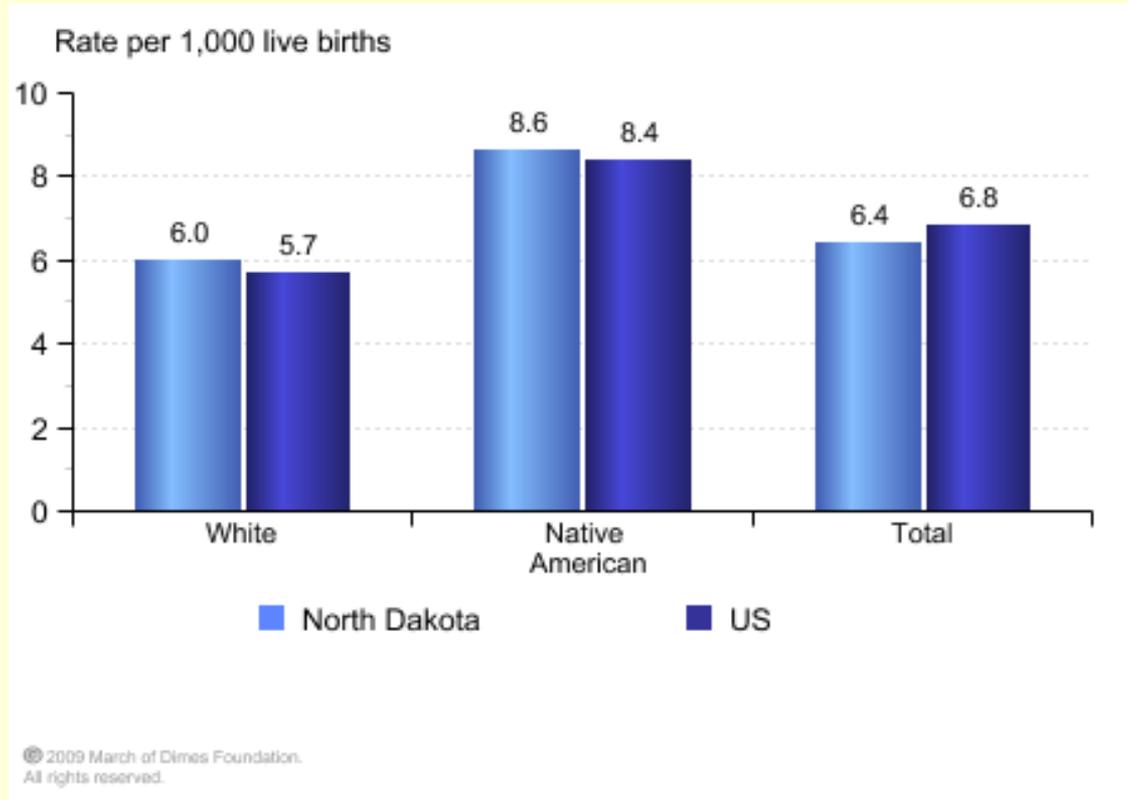
Infant Deaths by Cause of Death

North Dakota and US, 2003-2005 Average

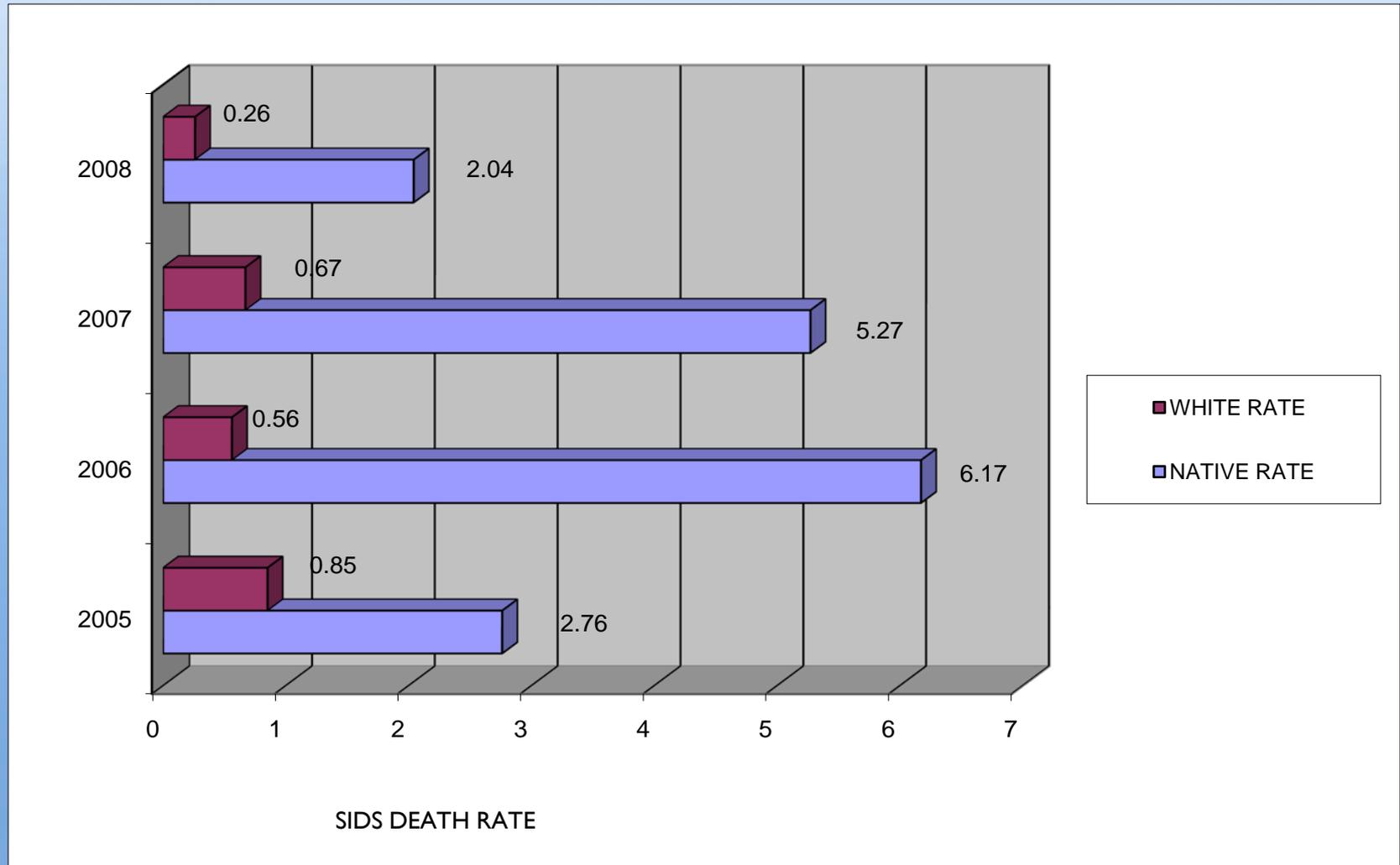


Infant Mortality Rates by Race

North Dakota and US, 2003-2005 Average



ND Sudden Infant Death Syndrome Death Rate per 1,000 Births

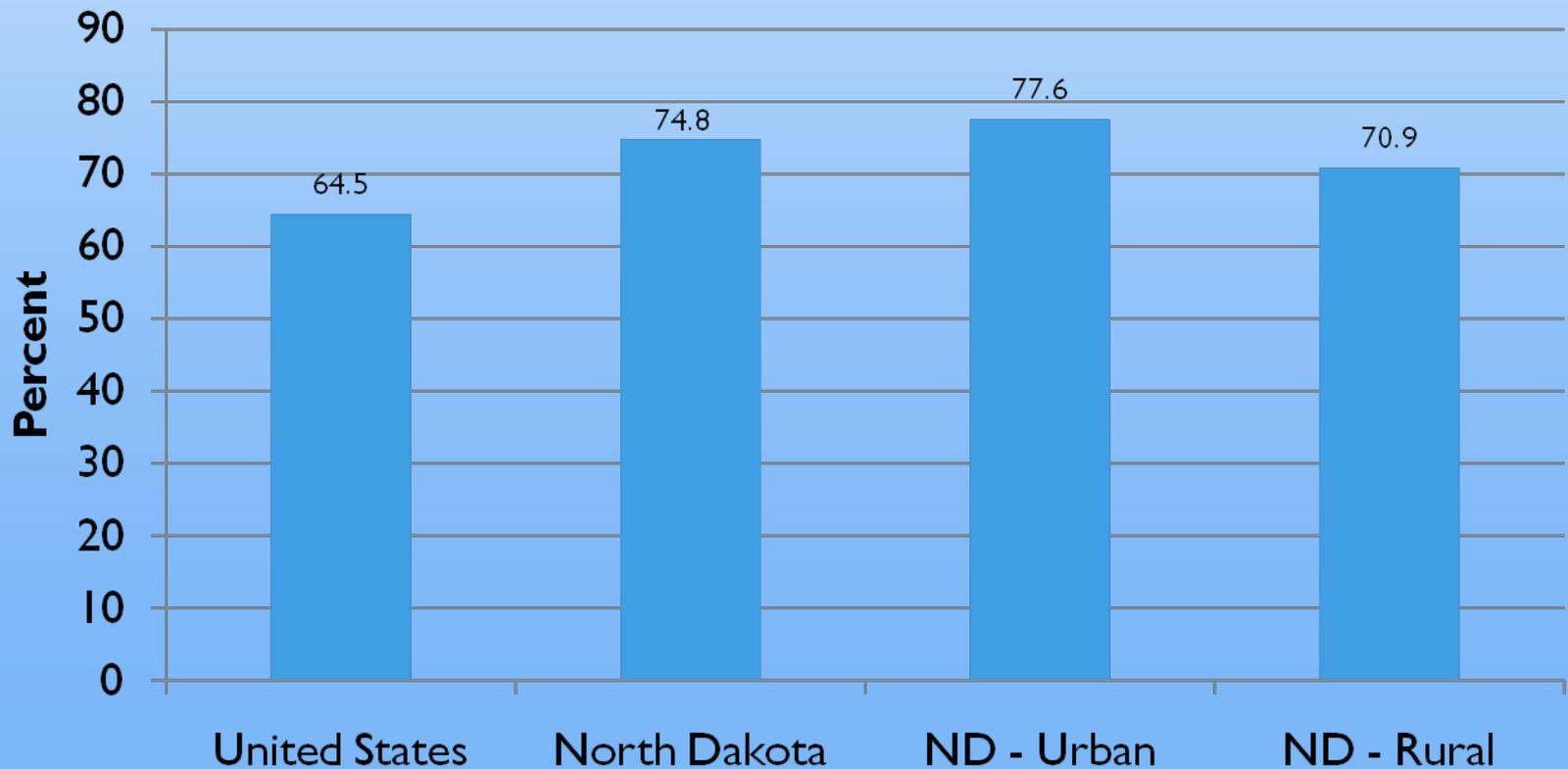


we need child care
to work

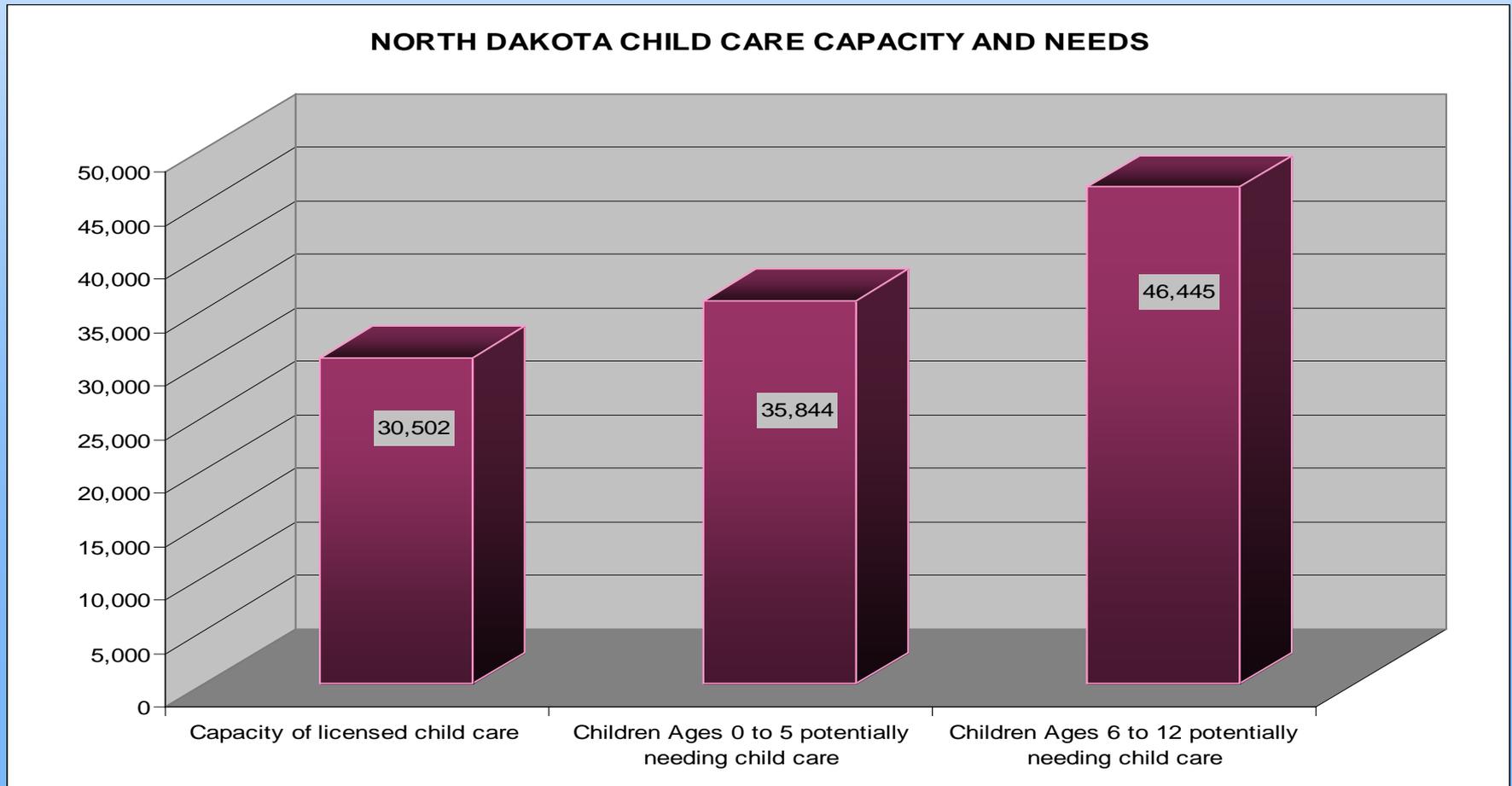


Working Parents

Children ages 0 to 5 With All Available Parents in the Labor Force

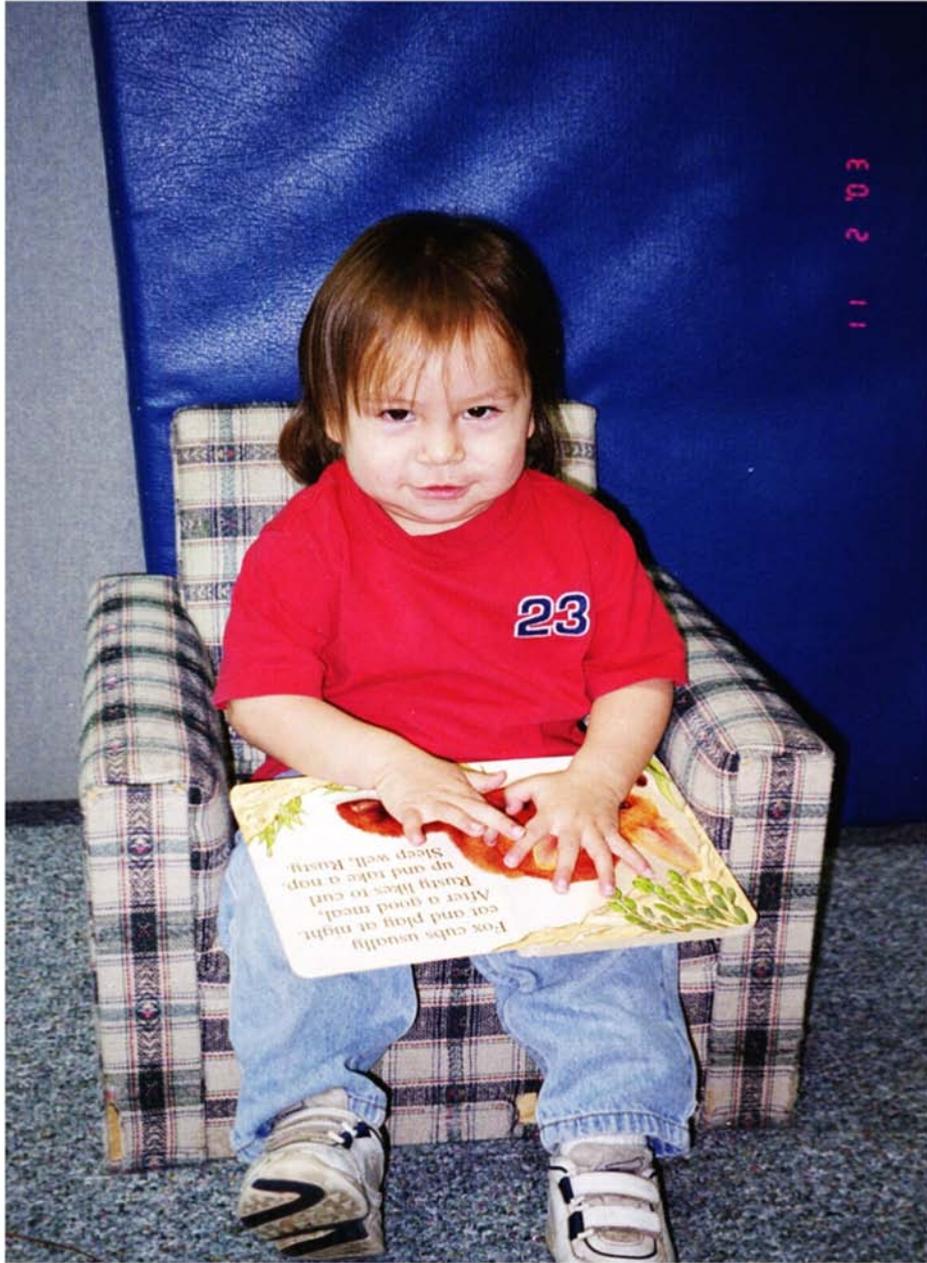


2006 North Dakota Child Care Capacity and Need



Child Care

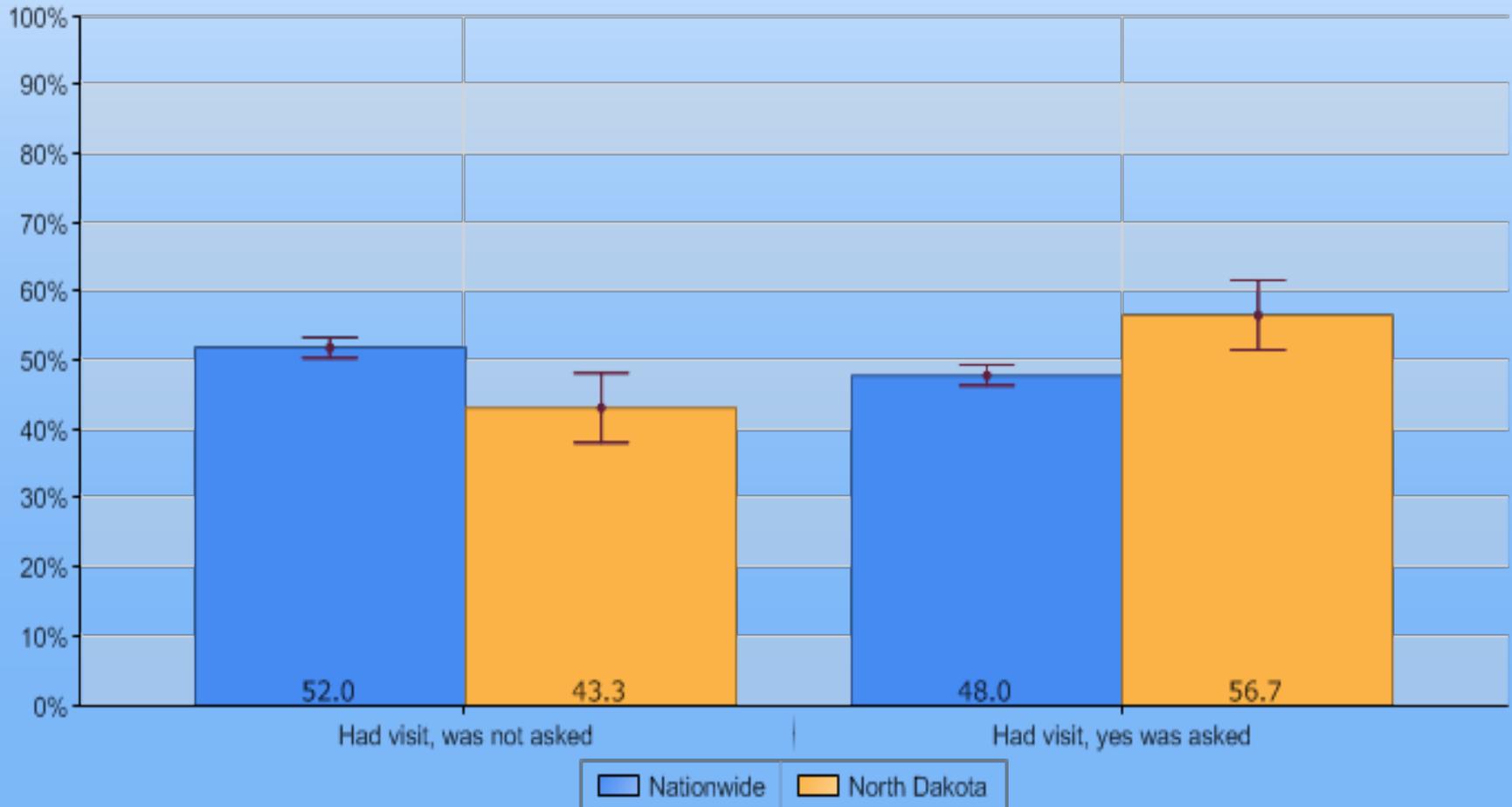
- In 2006, the percent of children age 0-5 whose parents made emergency child care arrangements and/or a job change for child care reasons was 33% in ND. National rate was 31%.
- In 2006, the average cost of child care at a center for a child 0 to 11 months of age was \$132.00 per week.



11 2 03

Fox cubs usually
eat and play at night.
After a good meal,
Koshy likes to curl
up and take a nap.
Sleep well, Koshy!

Doctor Asked about Parental Concerns During Past 12 Months Children Age 0-5 Years Only Nationwide vs. North Dakota

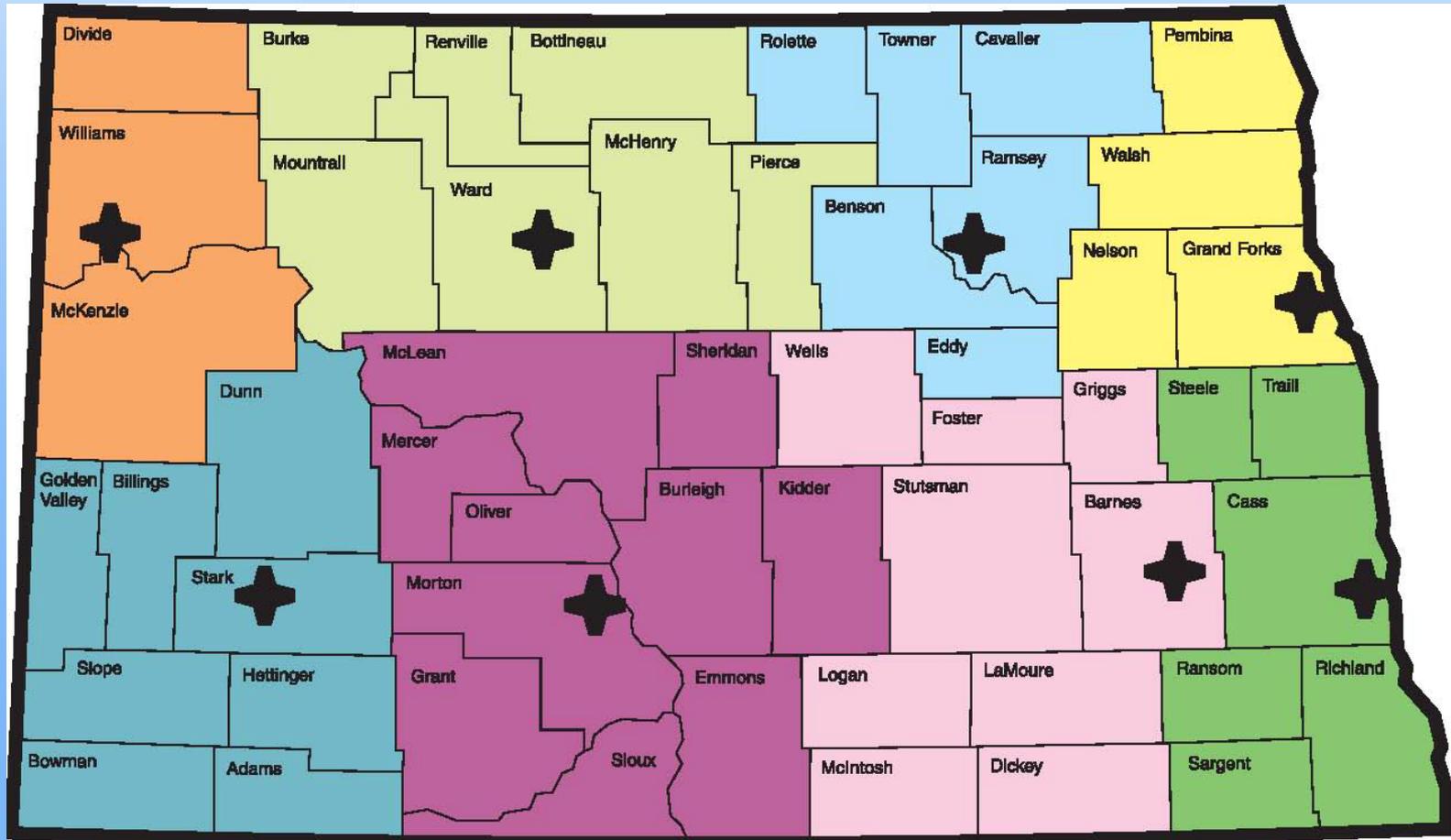


Source: 2007 National Survey of Children's Health

Community Resources/Partners Looked to for Parent Education

- NDSU Extension Service
- County Social Services
- Department of Human Services
- Department of Health
- Head Start
- Public Schools
- Mental Health
- Domestic Violence or Prevention Programs
- Regional Human Services
- Parent Resource Centers
- Child Care Resource and Referral
- Non-profit Agencies

North Dakota Parent Education Network



Barriers to Participation in Parent Education Programs

1. Lack of parent effort to participate
2. Lack of time and busy schedule of parents
3. Life challenges that interfere with participation
4. Lack of transportation
5. Child care not provided
6. Stigma associated with participation



Presentations: Population Specific Data



Children and Adolescents Ages 1 to 24:

- Cheryle Masset
- Diana Read

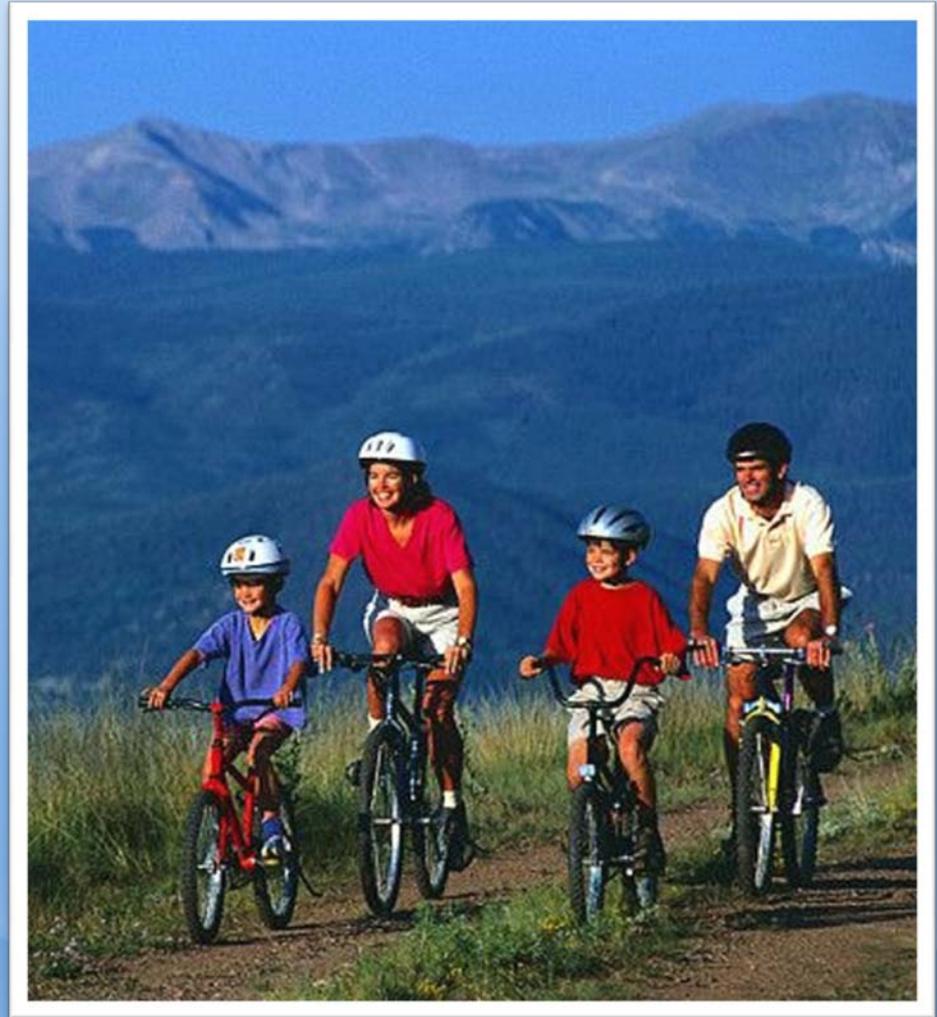
Children and Adolescents Ages 1 to 24

Survey Responses - Perceived Need

1. Nutrition and Physical Activity
2. Alcohol Use
3. Child Abuse and Neglect
4. Access to Care
5. Mental Health screening, assessment and treatment
6. Drug Use
7. Childcare/Daycare
8. Screening assessment, treatment (vision, hearing, social, emotional, dental, developmental)
9. Healthy Youth Development
10. Violence (sexual assault, bullying, cyber bullying)

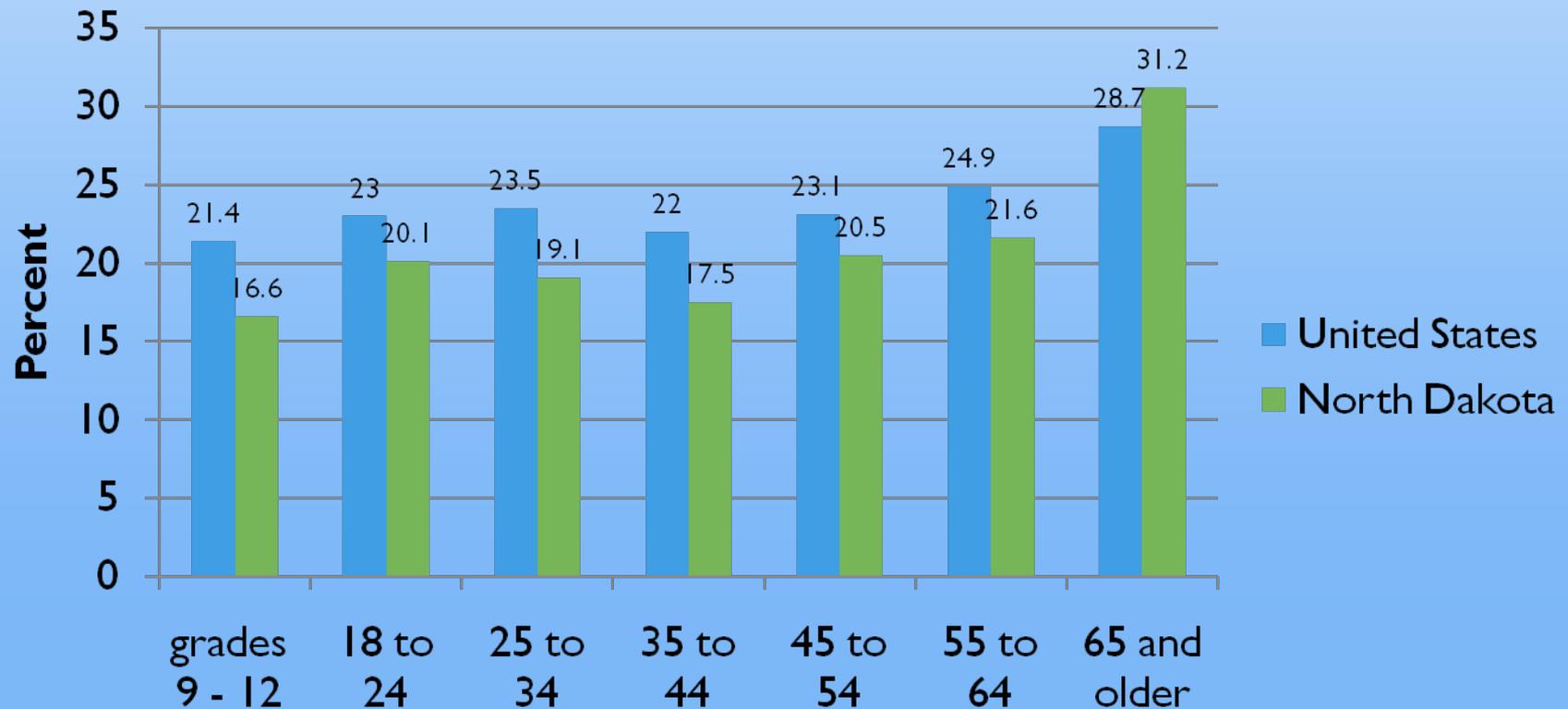


As of July 1, 2008, there were 216,679 persons ages 1 to 24 in North Dakota.

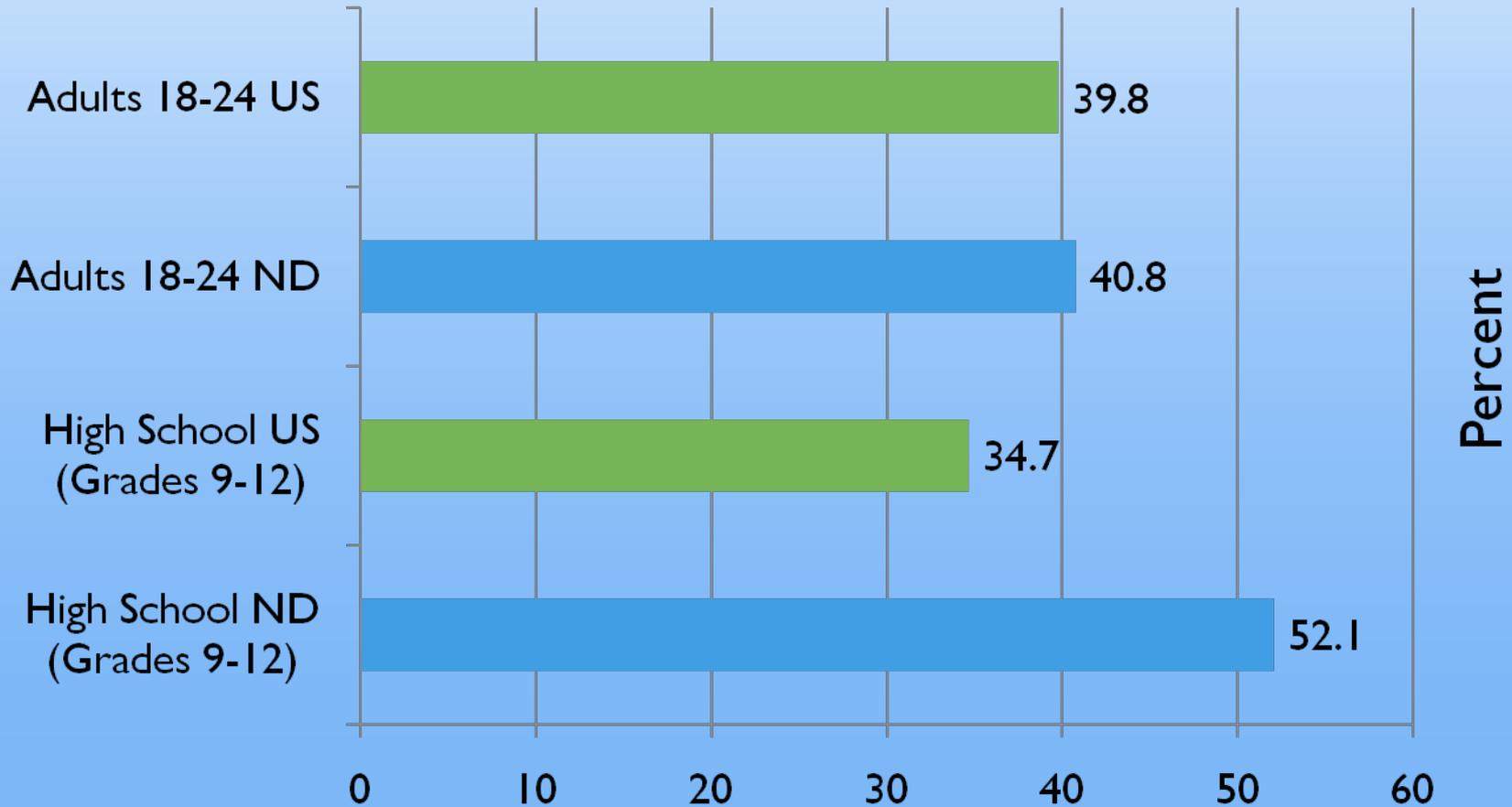


Nutrition

Consumed at Least Five Servings of Fruits and Vegetables Per Day by Age, 2007



Insufficient Physical Activity

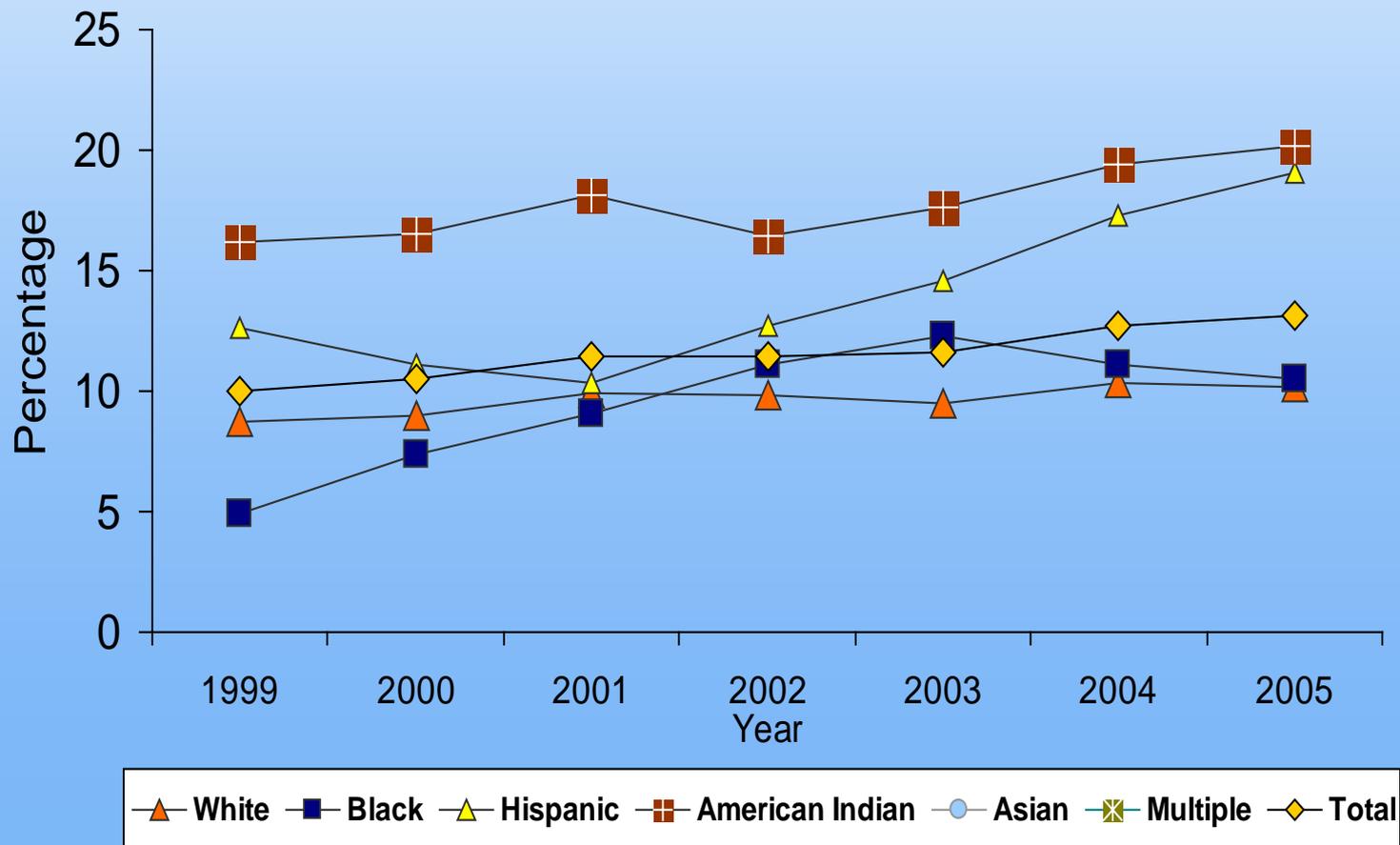


Source: YRBS, BRFSS

Obesity

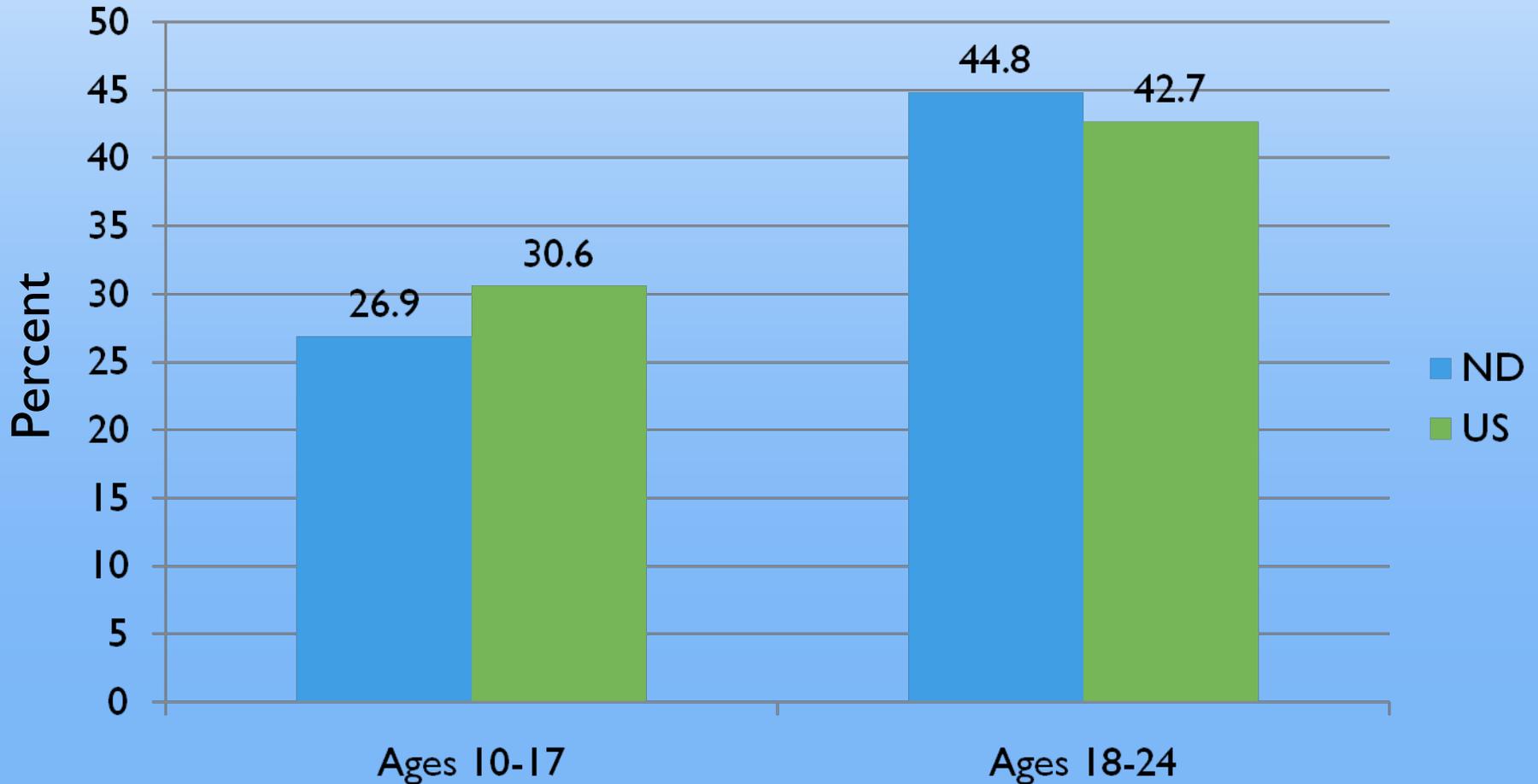


Trends in Prevalence of Overweight Among Children Aged 2 to <5 Years Enrolled in WIC, By Race and Ethnicity



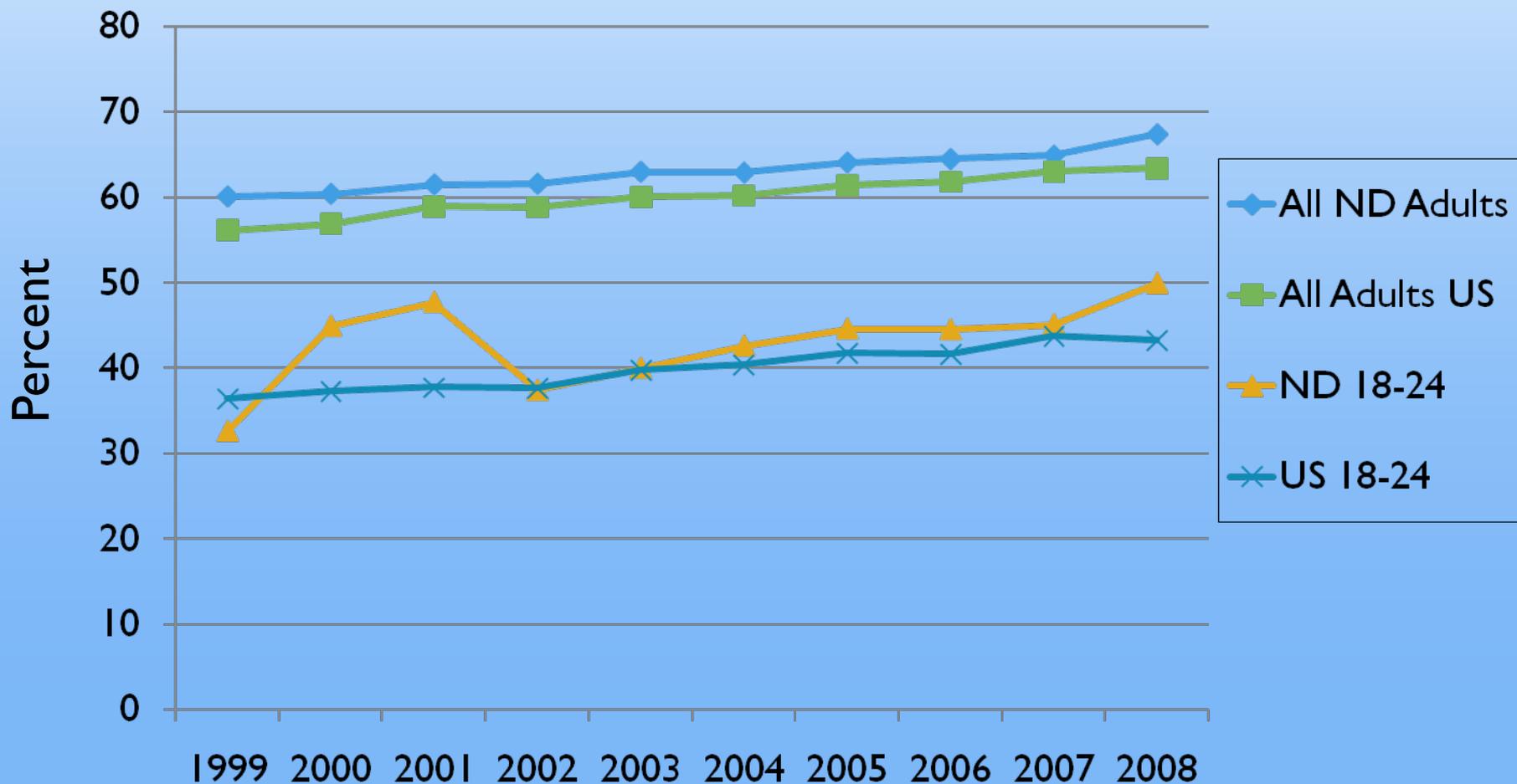
* ≥ 95 th percentile BMI-for-age, CDC Growth Charts, 2000. 5% of children are expected to fall above the 95th percentile.

Overweight or Obese



Source: NCHS (2007), BRFSS (2005 & 2007)

Prevalence of Overweight and/or Obese Among Adults 18 and Older in ND

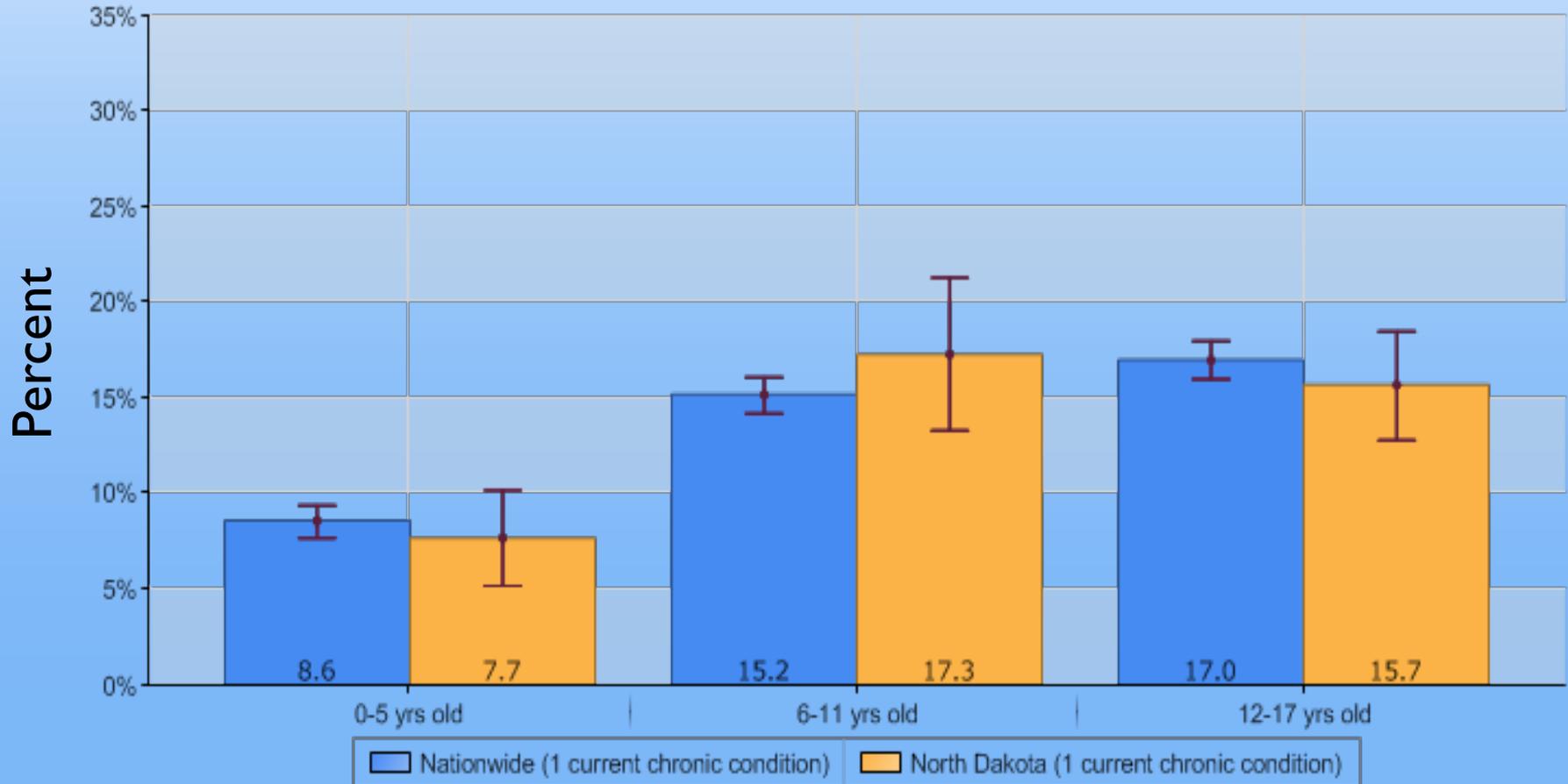


Chronic Disease



Chronic Health Conditions

Children with 1 or More Current Chronic Health Conditions

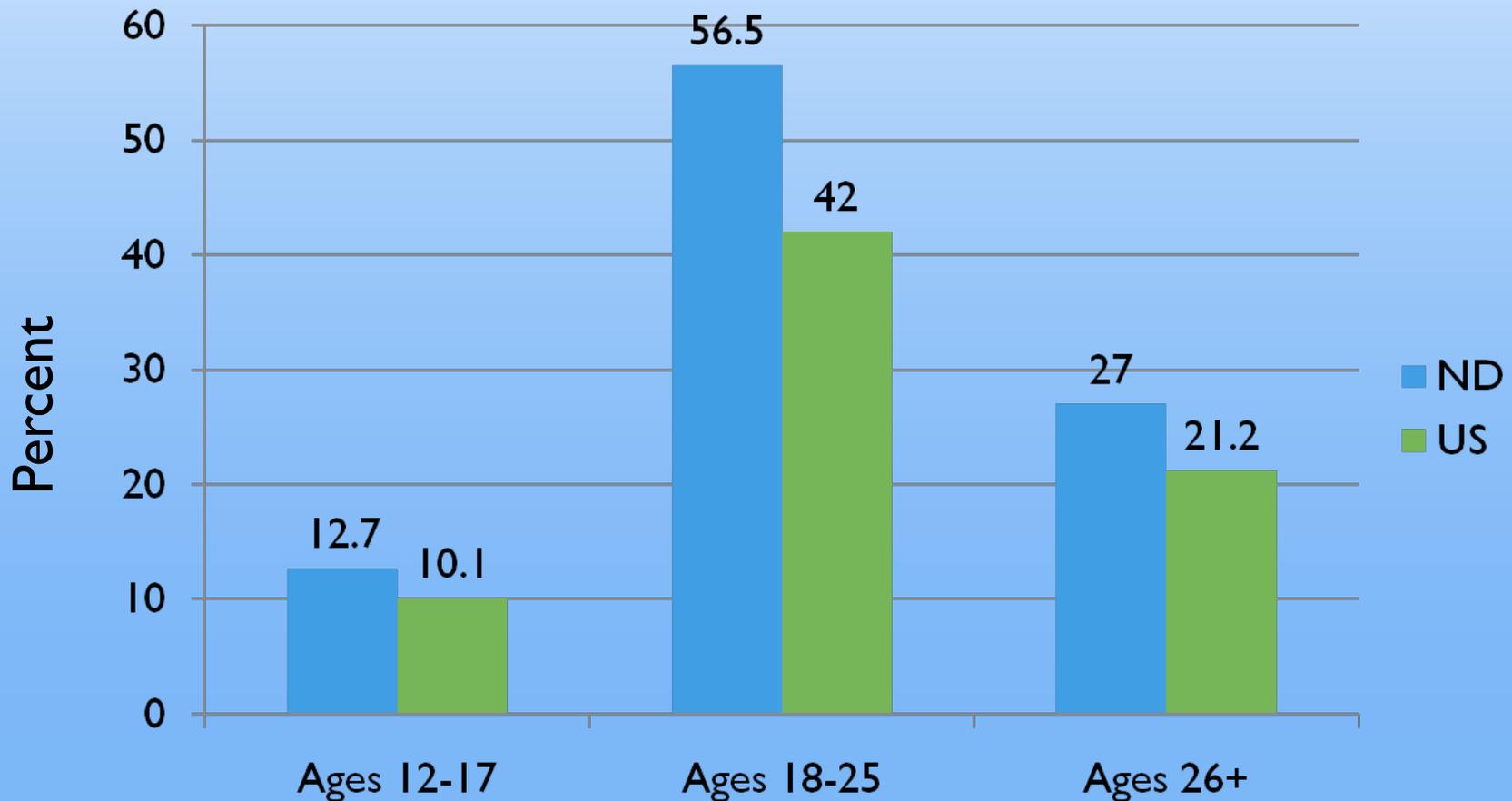


Chronic Disease

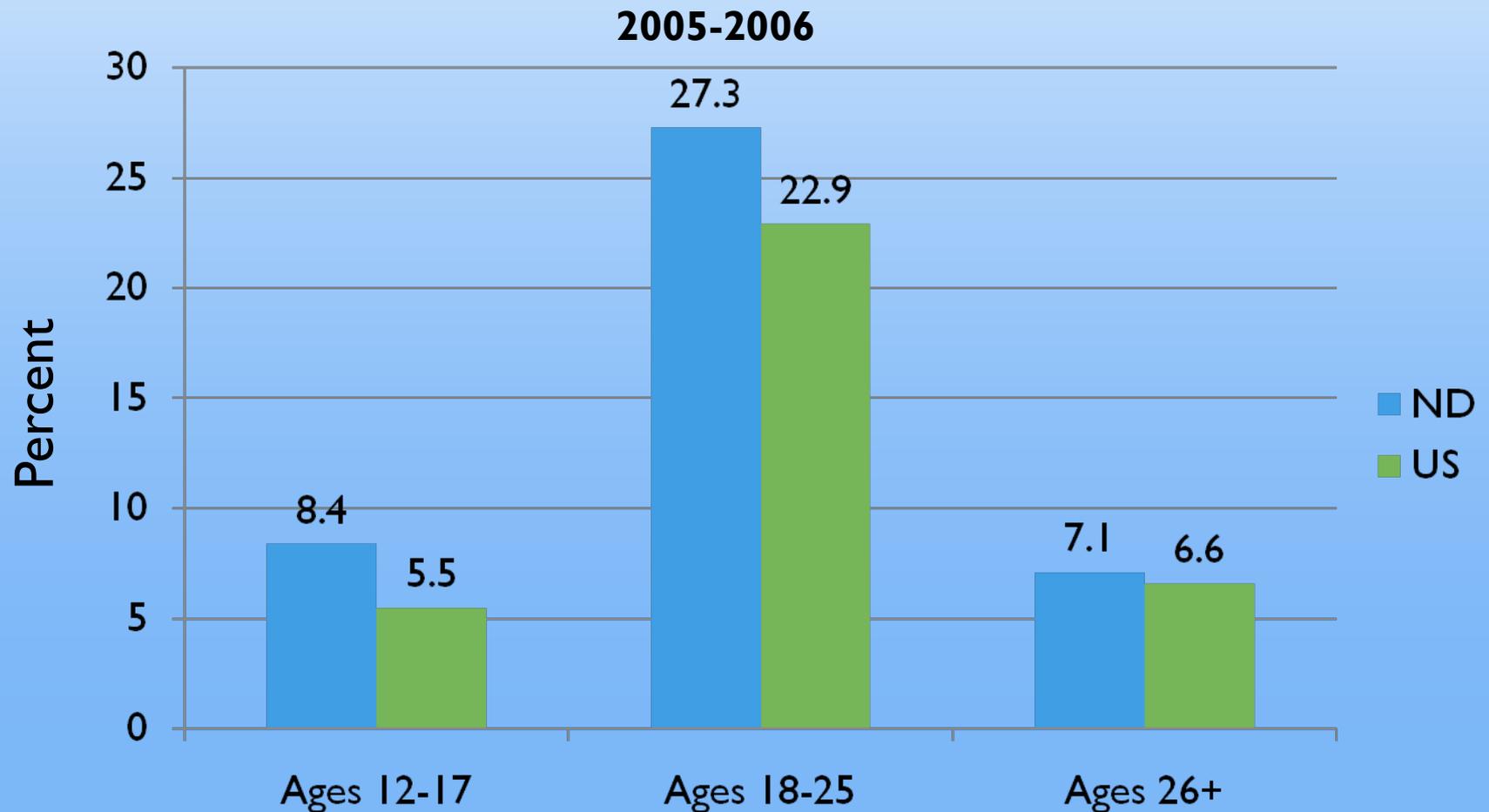
- Cancer
 - Between 2003-07, 17.3 per 100,000 children ages 19 and younger were diagnosed with cancer (all sites)
- Diabetes
 - In 2007, 4.5 per 1,000 children 18 and younger had diabetes
 - 31% of children with diabetes have type 2 diabetes, historically rare among children and adolescents
- Asthma
 - In 2007-08, 6.1% of children under age 18 had asthma (equates to ~10,000 children)



Binge Alcohol Use in Past Month

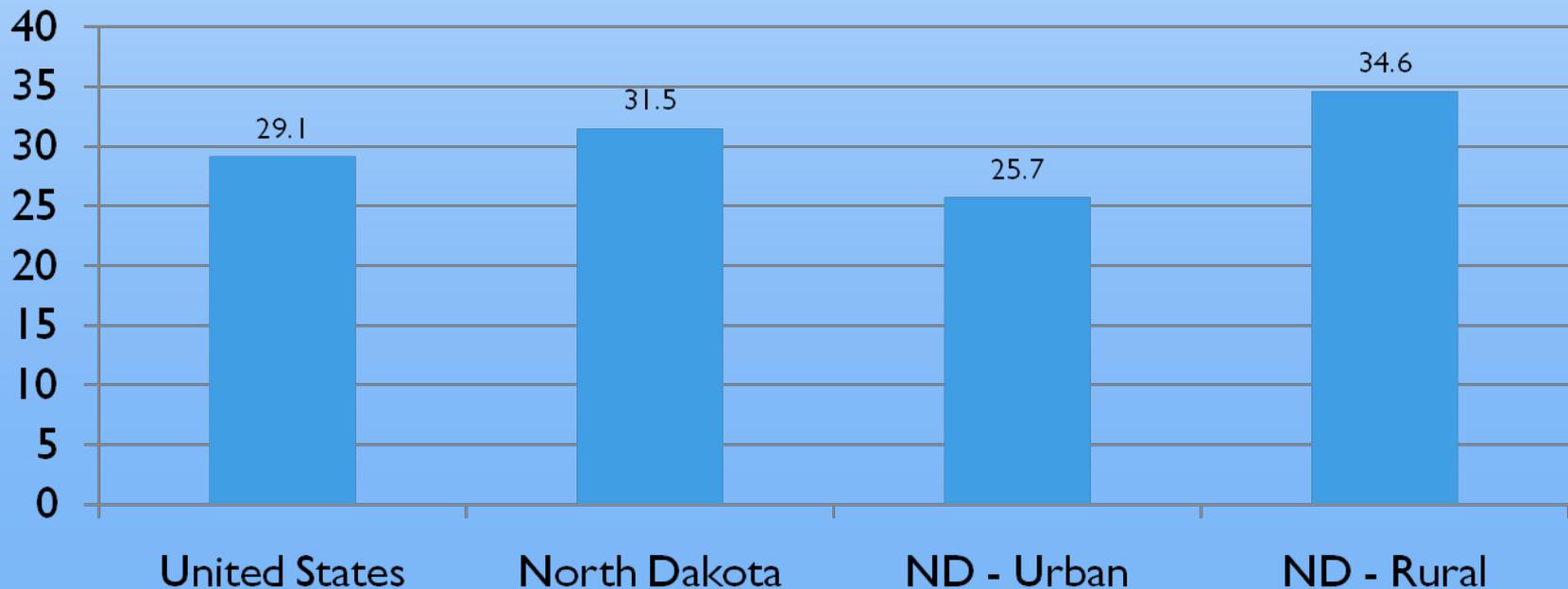


Alcohol Dependence or Abuse

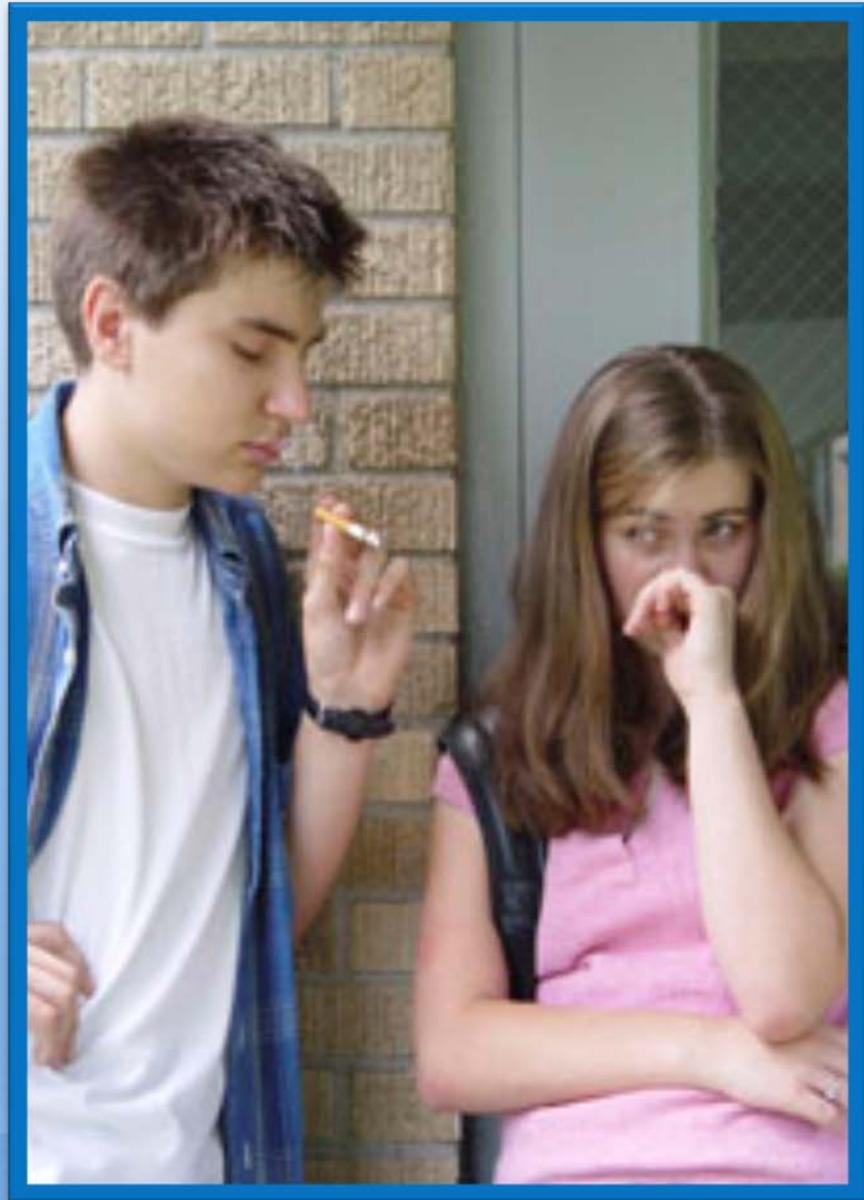


Riding With Someone Who Has Been Drinking

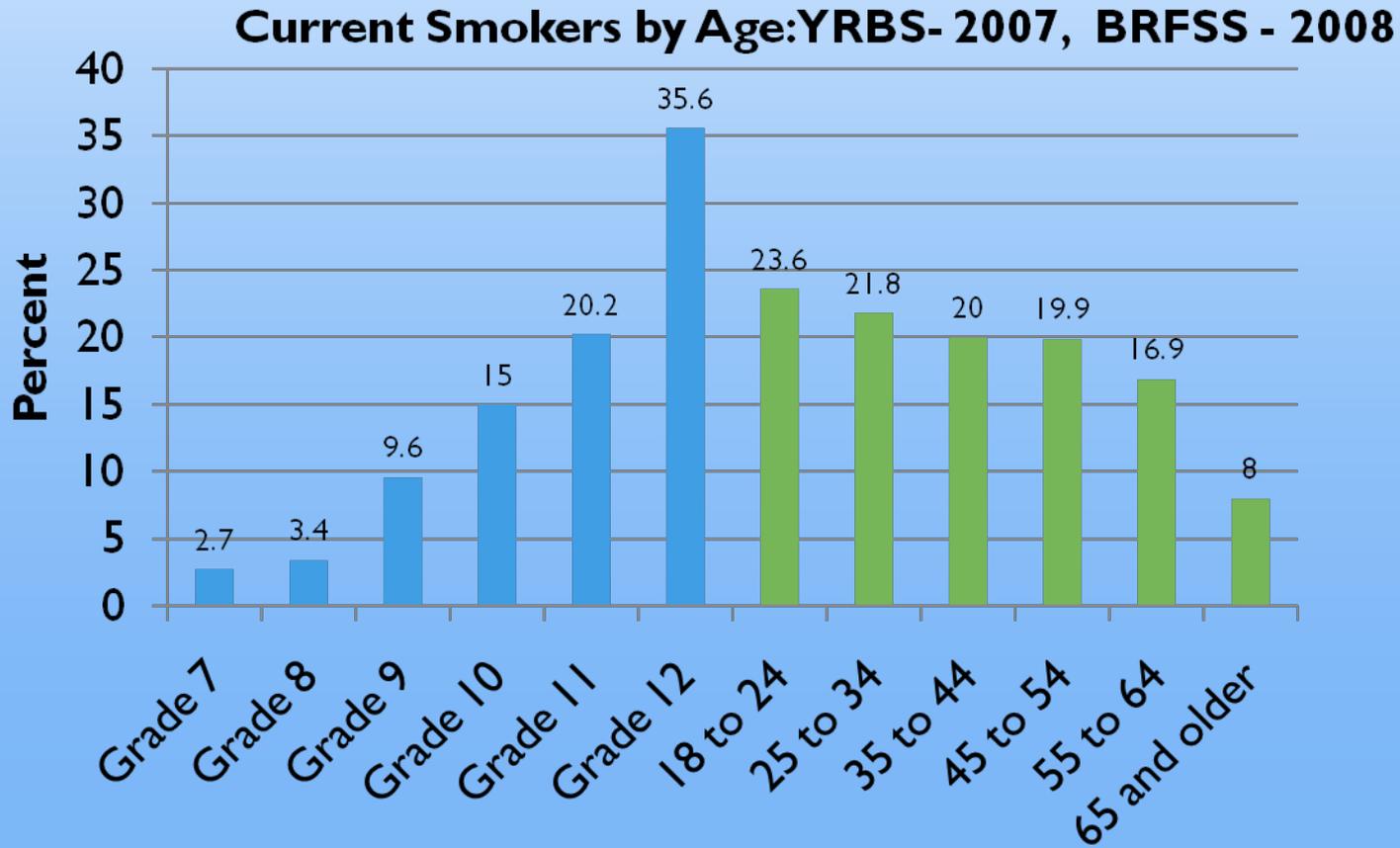
Students in Grades 9-12 Who Rode One or More Times in the Past Month in a Vehicle Driven by Someone Who Had Been Drinking Alcohol, 2007



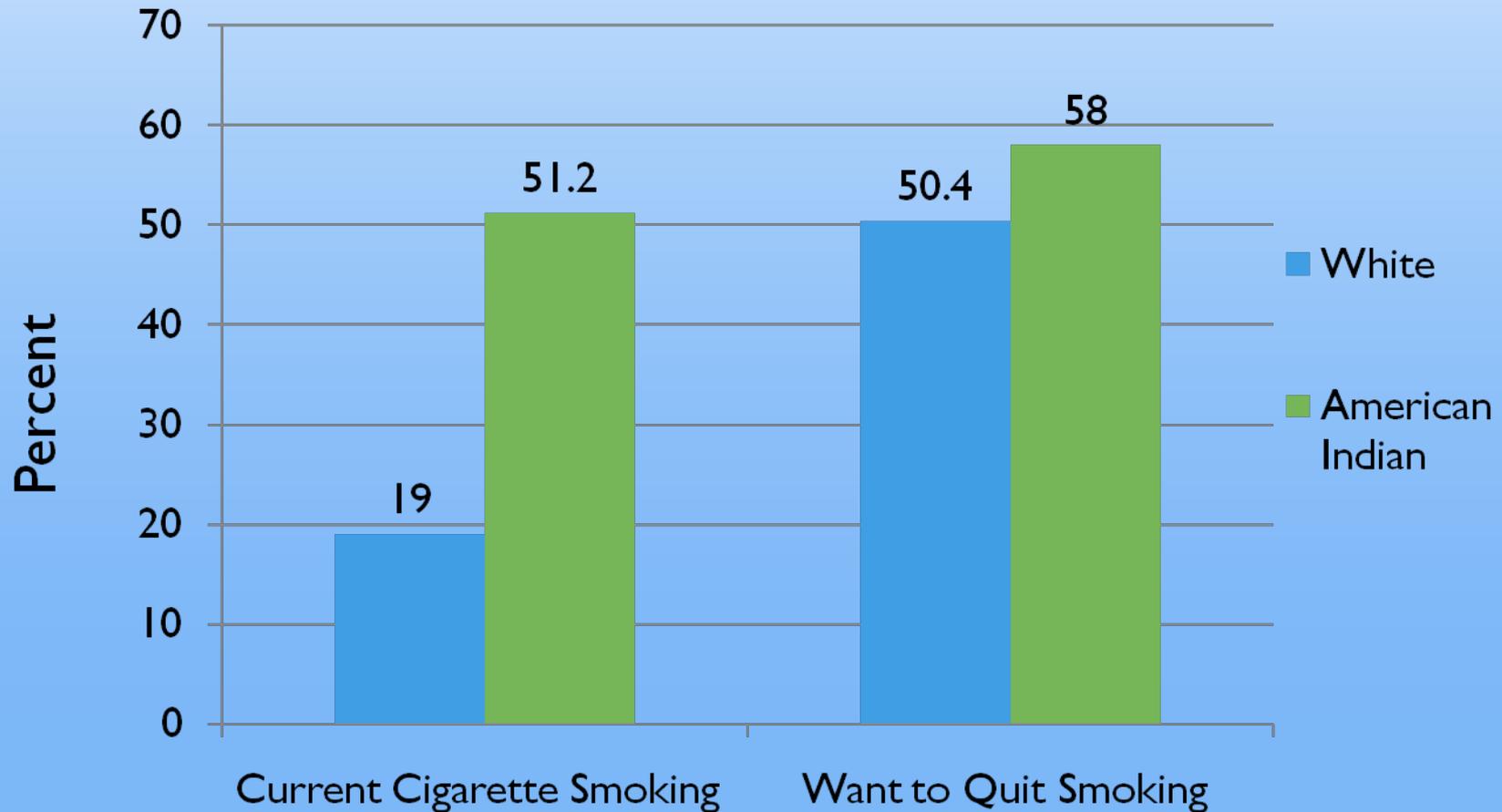
Drug Use



Cigarette Use

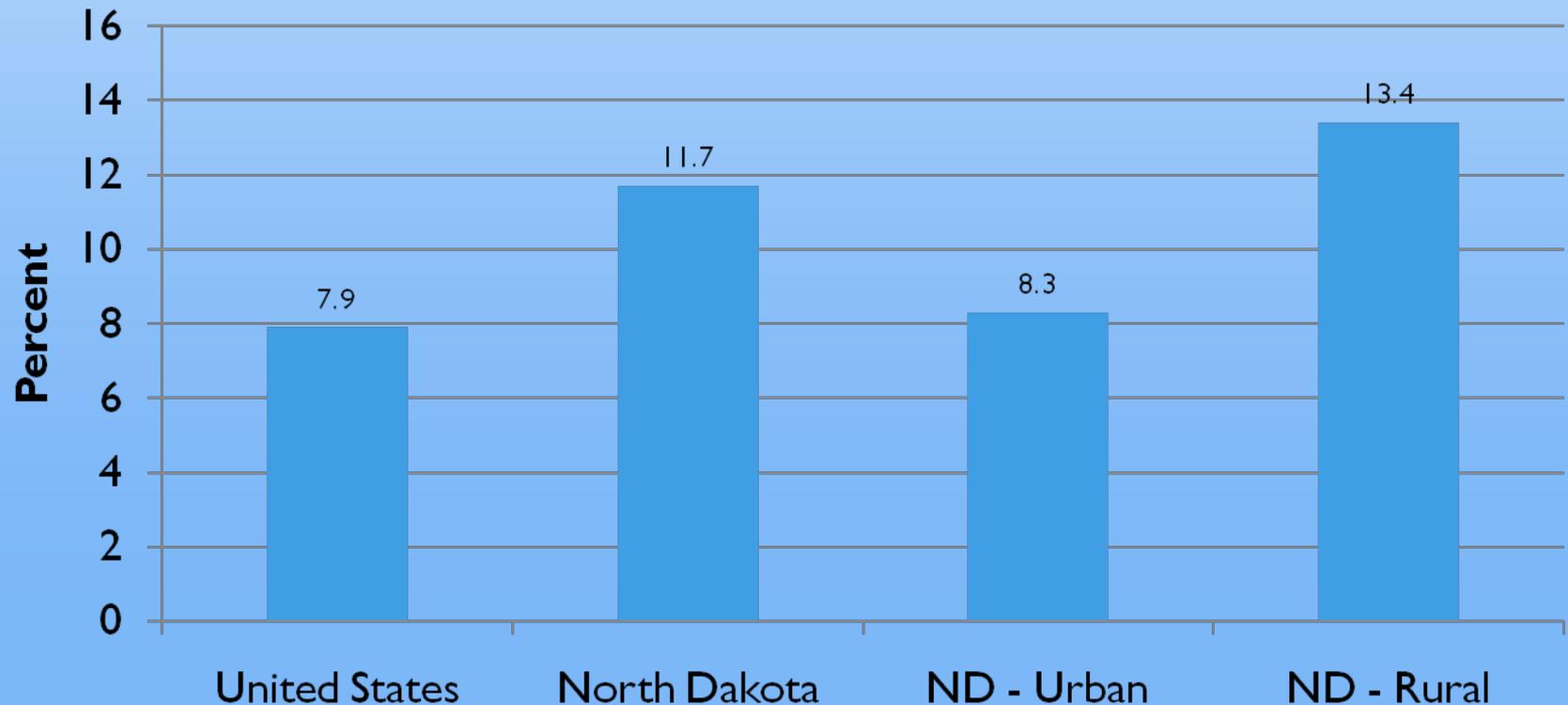


Smoking Among All Adults in ND

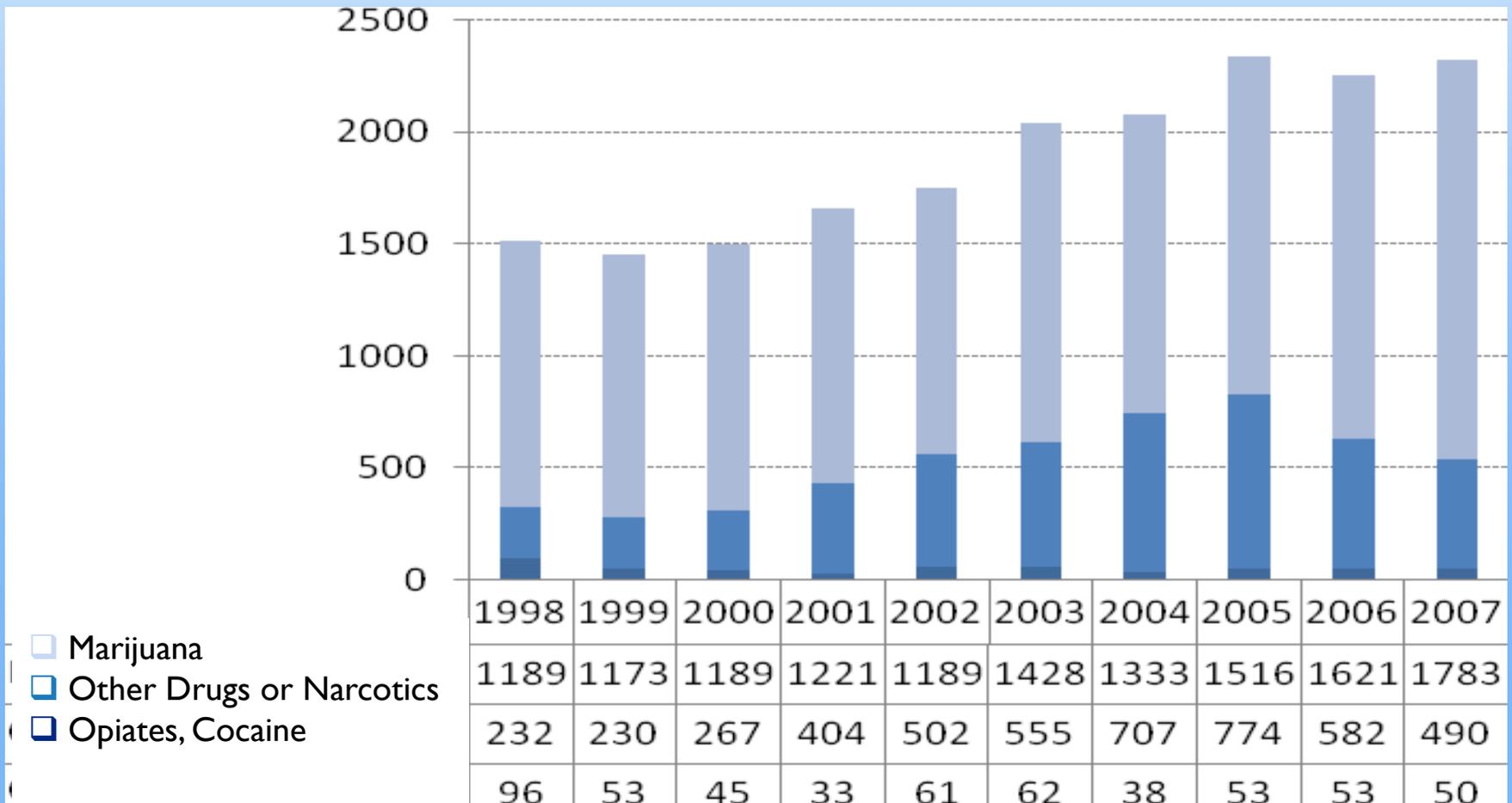


Smokeless Tobacco

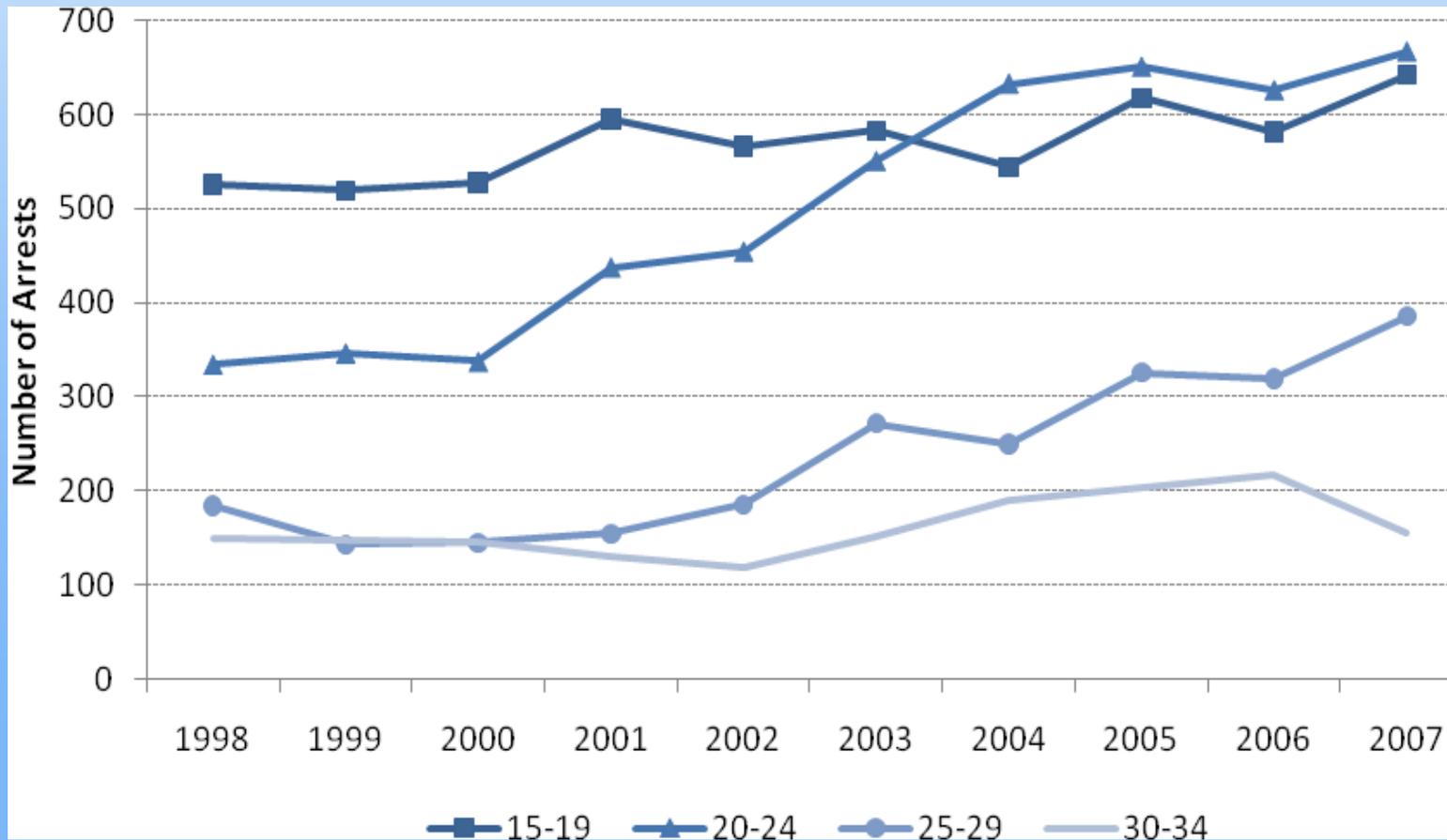
Students in Grades 9-12 Who Used Chewing Tobacco, Snuff, or Dip on at Least One Day During the Past Month, 2007



All Drug Arrests by Type



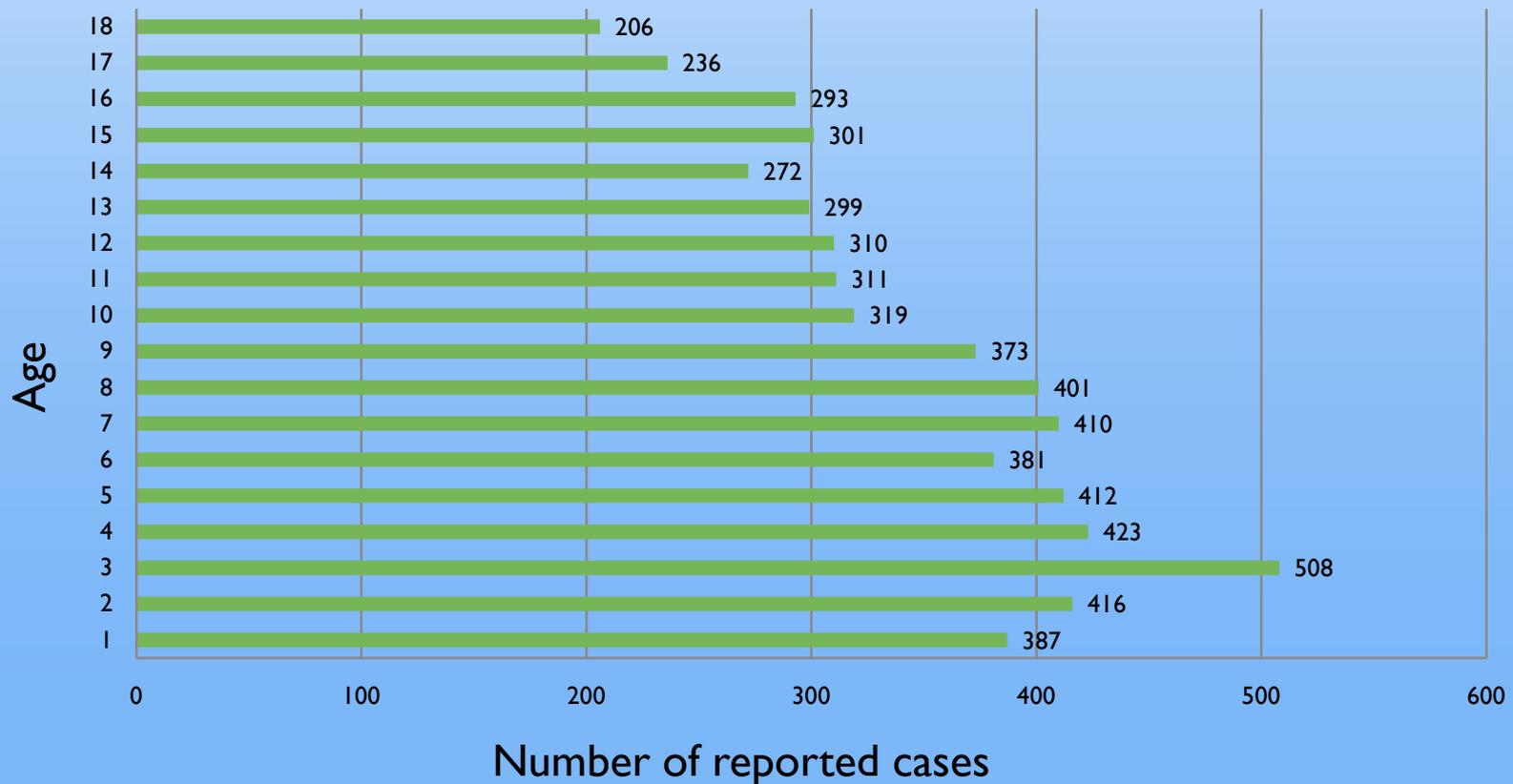
Drug Arrests by High-Risk Age Groups





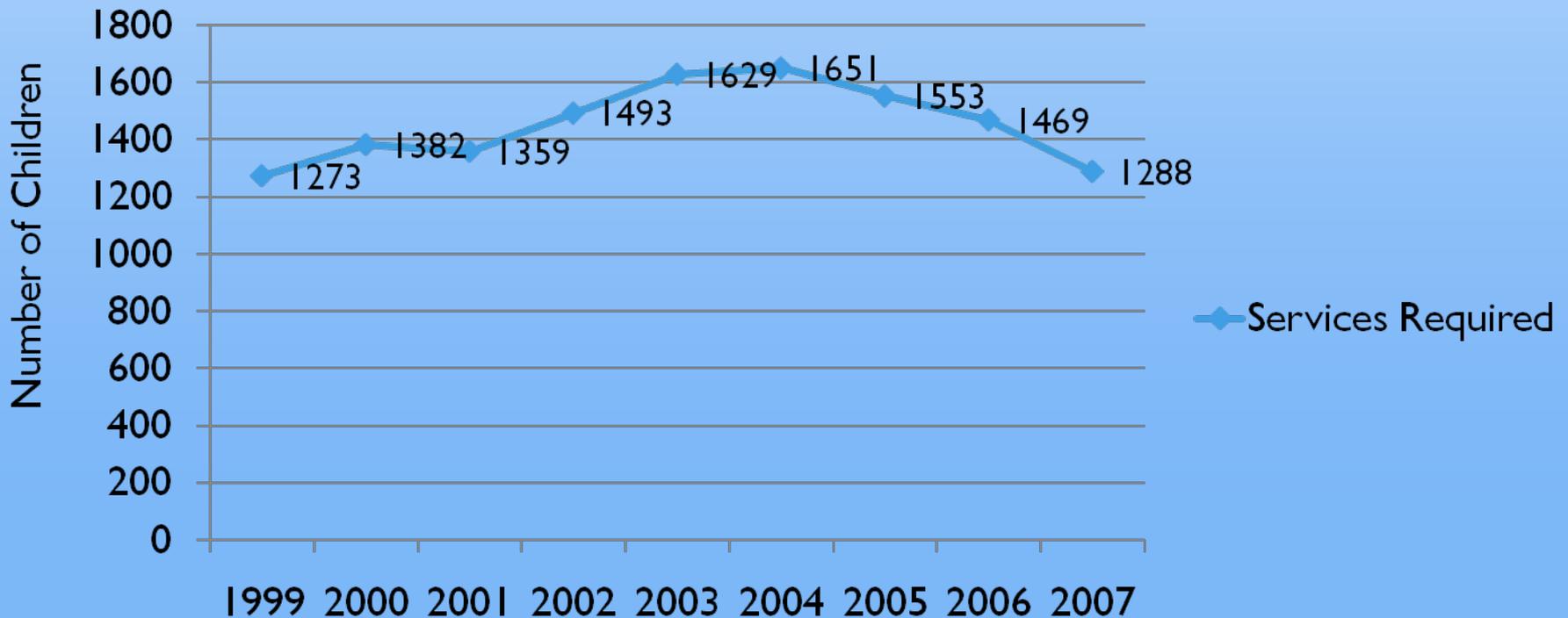
Child Abuse and Neglect

Reported in North Dakota - 2007



Child Abuse and Neglect

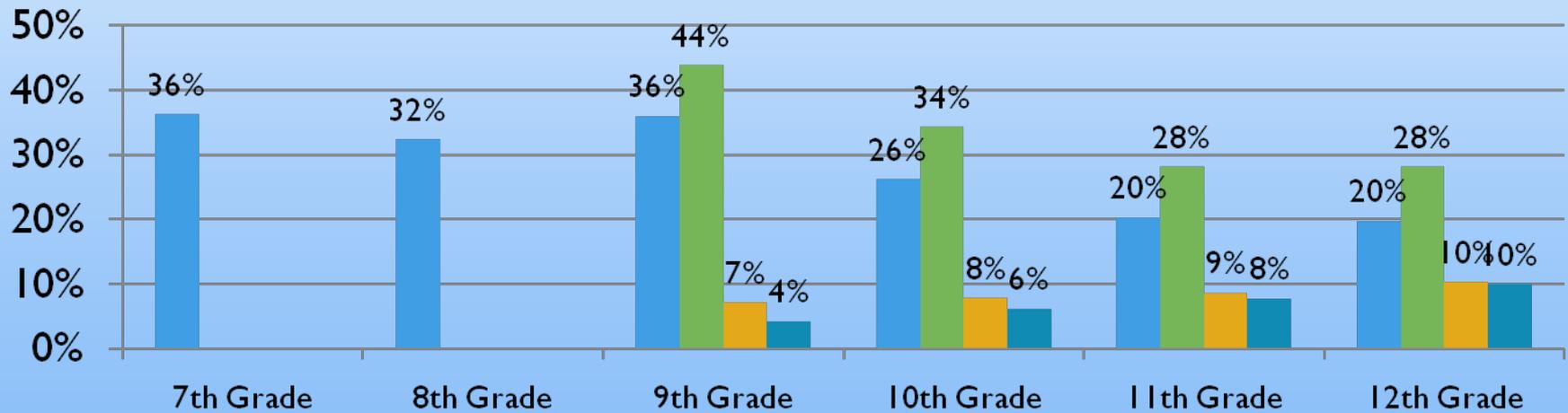
Victims of Child Abuse and Neglect Where Services Were Required – Children Ages 0 to 17 in North Dakota: 1999 to 2007



Violence



Violence



■ Students who were harassed or bullied on school property by other students during the last 12 months

■ Students who have been harassed or bullied one or more times during past 12 months.

■ Students who were ever hit slapped or physically hurt on purpose by their boyfriend or girlfriend during the past 12 mo.

■ Students who had ever been physically forced to have sexual intercourse when they did not want to .

Domestic Violence

	2006	2007	2008
New Victims	4,319	4,179	4,258
Children impacted by DV	4,300	4,673	4,769

- 94-95% of the victims were women
- 41% of the victims were under the age of 30
- 12%-13% of the victims were disabled, 16% were developmentally delayed and 32% were physically delayed
- Data is collected from 19 from the 21 DV/SA programs

Sexual Assault

	2006	2007	2008
Primary Victims	966	850	854
Secondary Victims	450	694	409

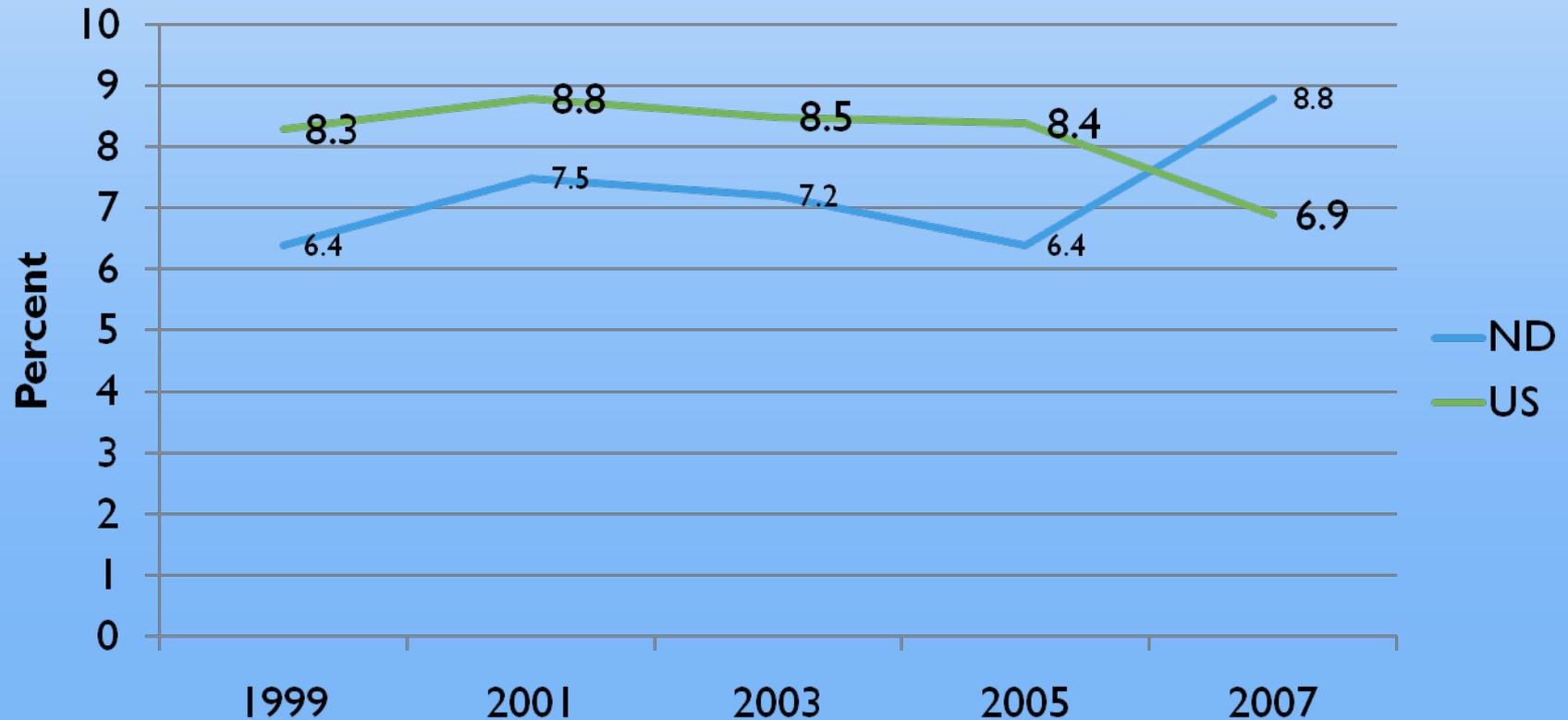
- 41%-42% of the primary victims were under the age of 18
- Child cases – 2%-3% were strangers
- 17 out of the 21 DV/SA programs reported data

Suicide



Attempted Suicide

North Dakota Students in Grades 9-12 Who Attempted Suicide One or More Times in the Past Year, 1999-2007



Suicide

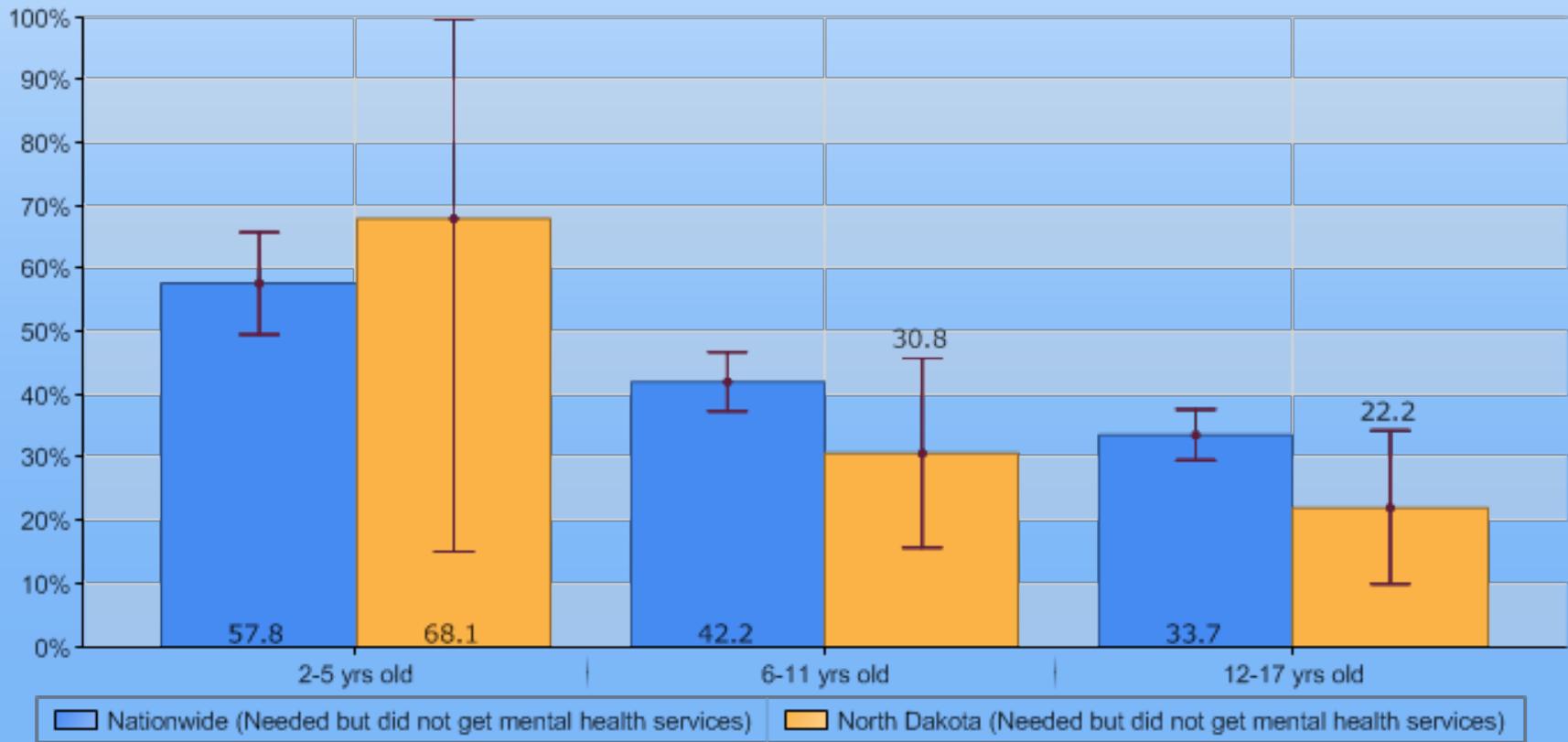
- The rate of suicide for American Indians is 67 per 100,000 compare to 14.4 per 100,000 overall in ND.
- 85% of the suicides age 10-24 from 2004-2008 were male.
- The method for 61% of suicides during this time frame was firearms.
- Men in ND and nationally are 4 times more likely than women to die from suicide.

Mental Health



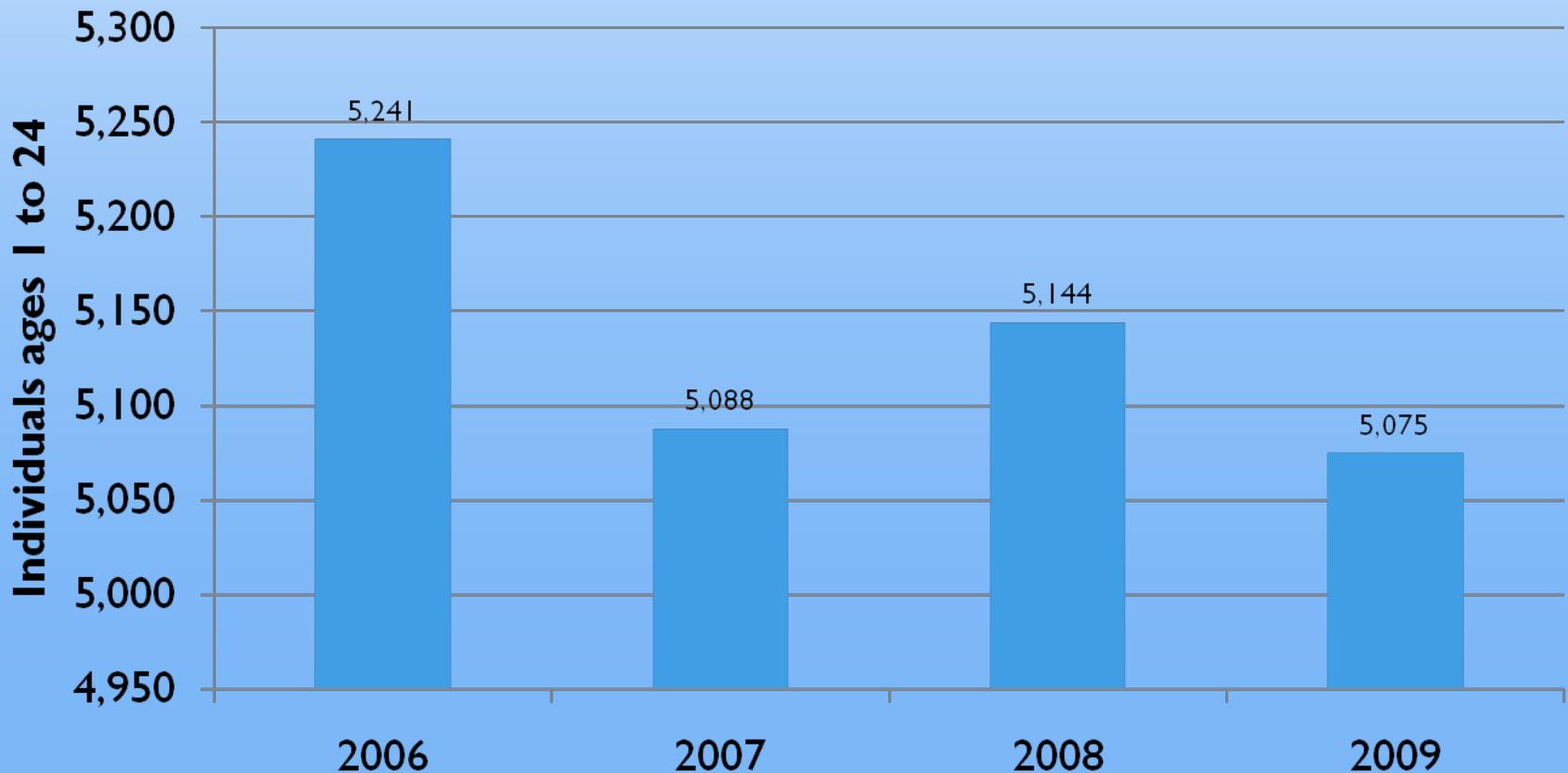
Mental Health – Ages 2 to 17

Needed But Did Not Get Mental Health Services



ND Regional Human Service Centers

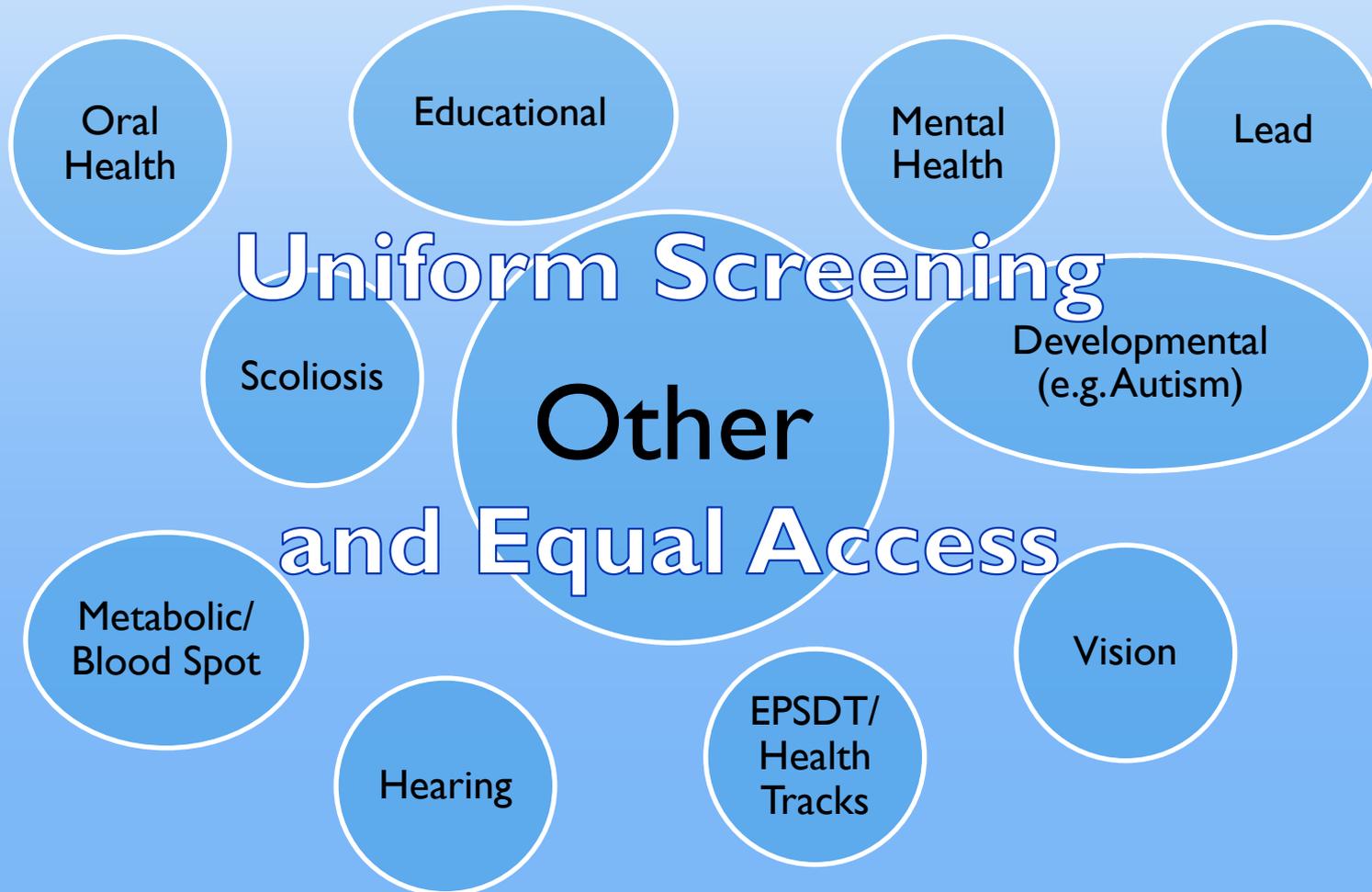
Individuals Ages 1 to 24
Who Received Mental Health Treatment Services



Screening, Assessment and Treatment



Screening, Assessment and Treatment



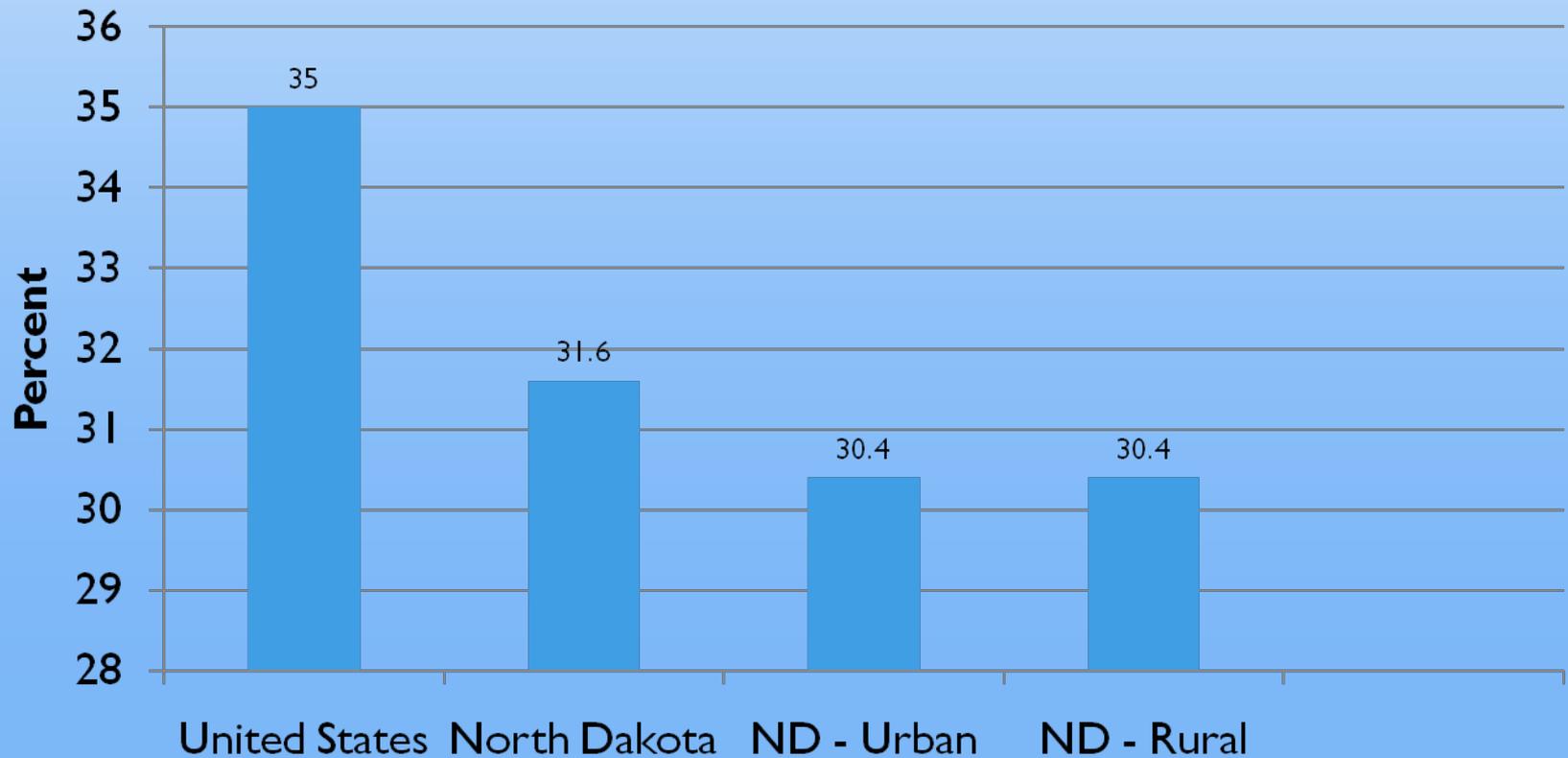
Screening, Assessment and Treatment

- No specialists available in the area, or they lack training, or may not be familiar with available services around the state.
- Primary doctors do not work together.
- No coordination of services.
- There is a need for medical home.
- The medical home doctor is not taking any new patients.
- Problems with health care.
- Case workers not properly trained.
- Parents must be the specialists.



Sexual Activity

Students in Grades 9-12 Who Had Sexual Intercourse
With at Least One Person During the Past Three Months, 2007



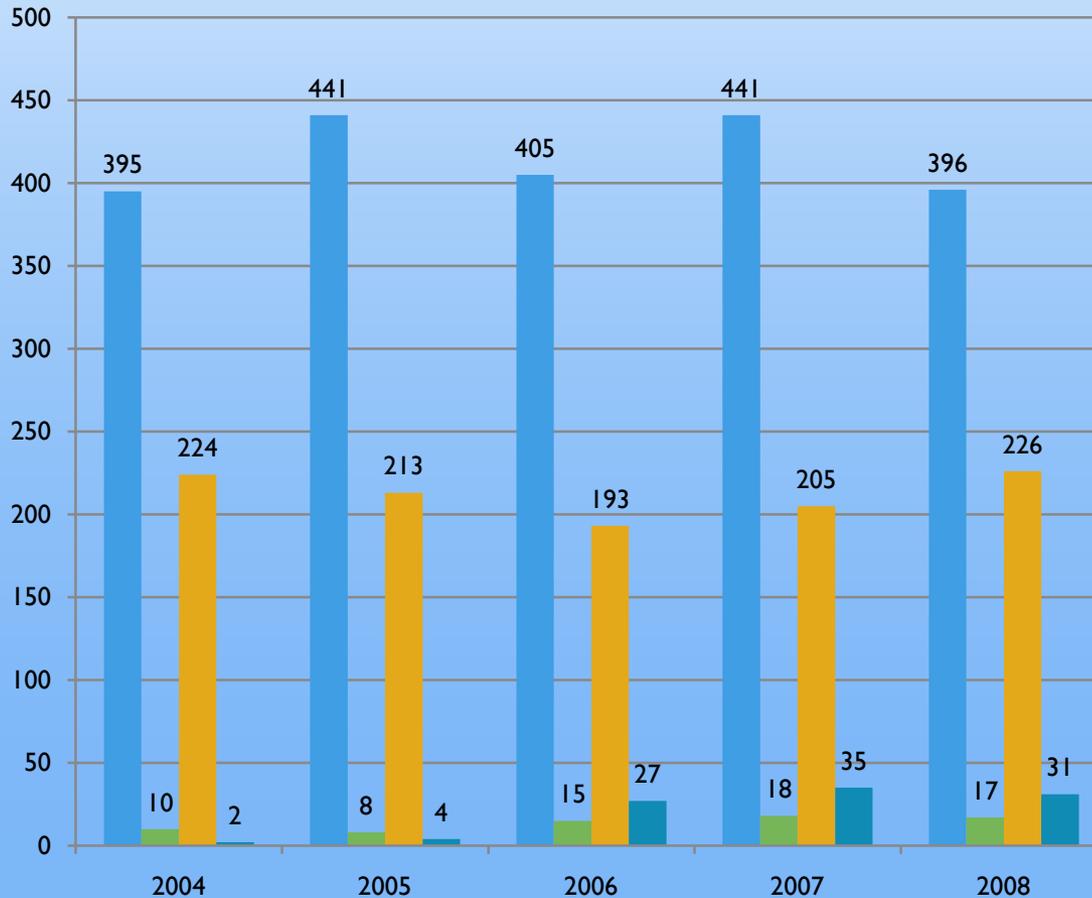
ND Family Planning Program

- Administered by ND Department of Health
 - 9 clinics and 10 satellite clinics
- 2008 records show 3,698 (24%) of clients were adolescents (ages 15 to 19 years old).
- 3,154 chose hormonal methods:
 - Oral contraceptives
 - Hormonal implant
 - Hormonal injection
 - Vaginal ring
 - Emergency contraceptive pill

**Did Not Use a Condom During
the Last Sexual Intercourse,
2007**

United States – 38.5%
North Dakota – 36.4%
ND Urban – 43.2%
ND Rural – 35.5%

Teen Pregnancy – Under Age 20

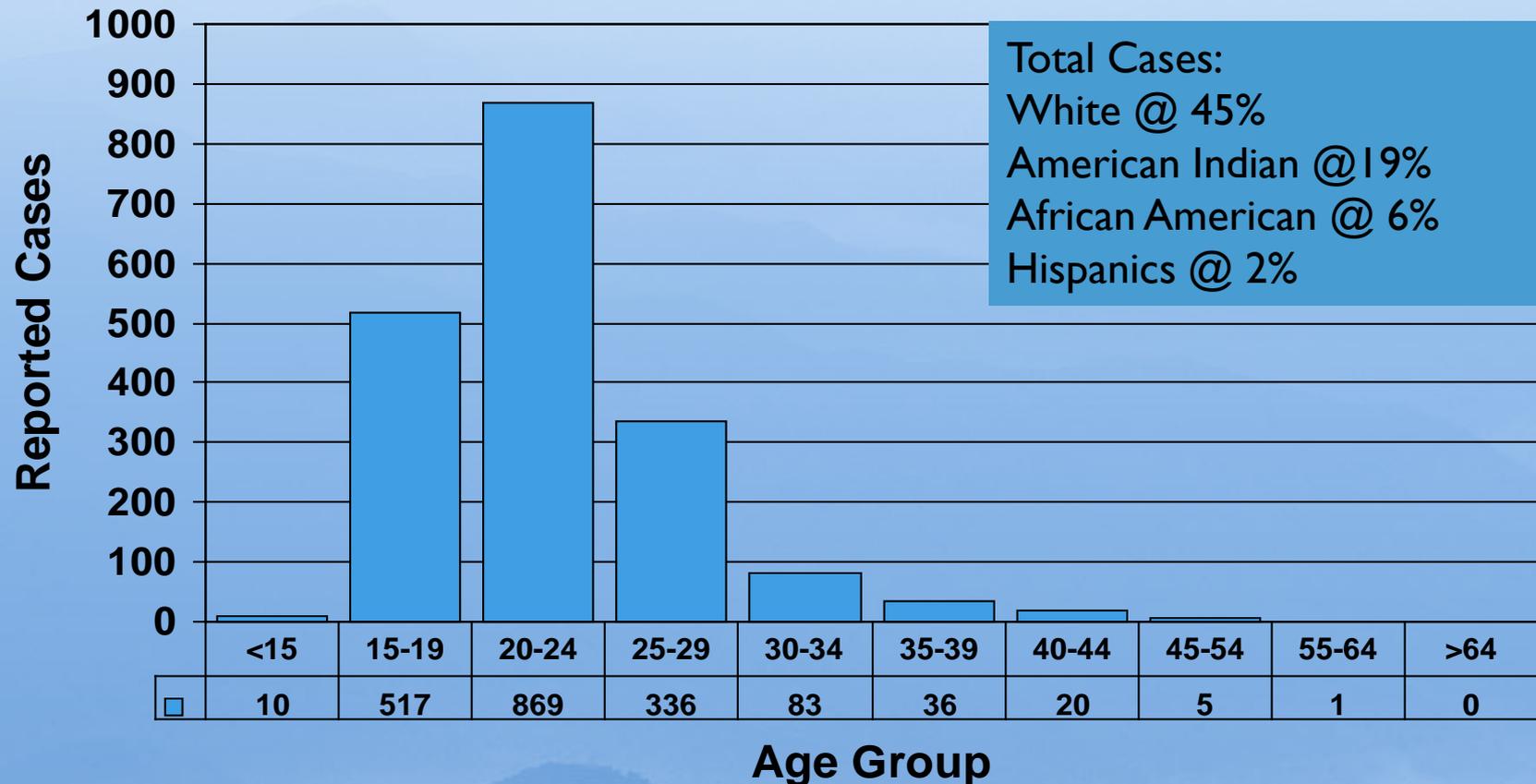


2008 Teen Birth Rate Per 1,000:

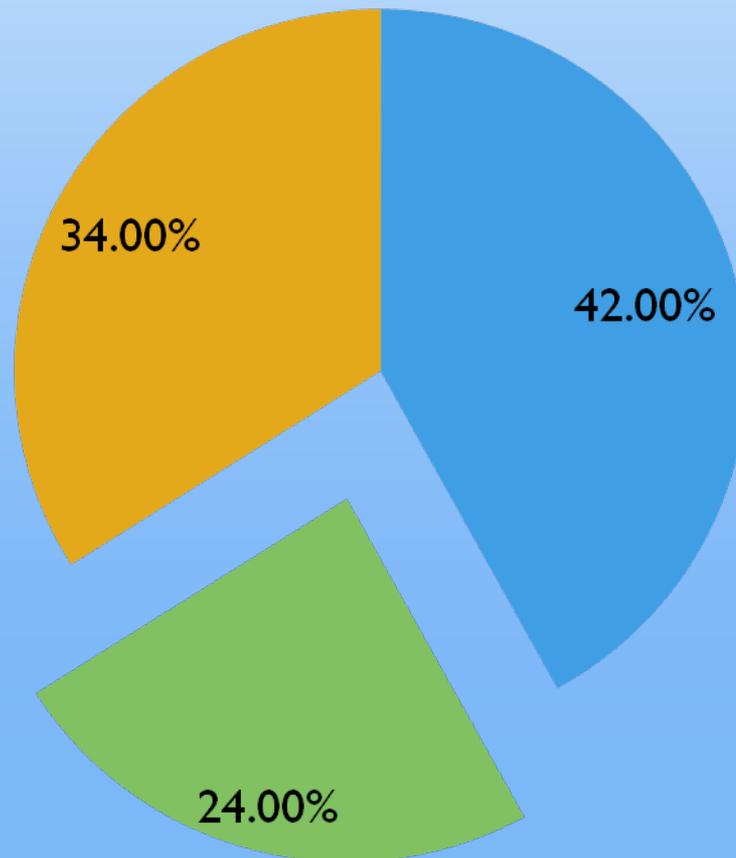
- White: 16.94
- Native American: 135.74
- Overall state teen birth rate: 25.1

■ WHITE
■ BLACK
■ AMERICAN INDIAN
■ ALL OTHERS

Reported Cases of Chlamydia by Age Group



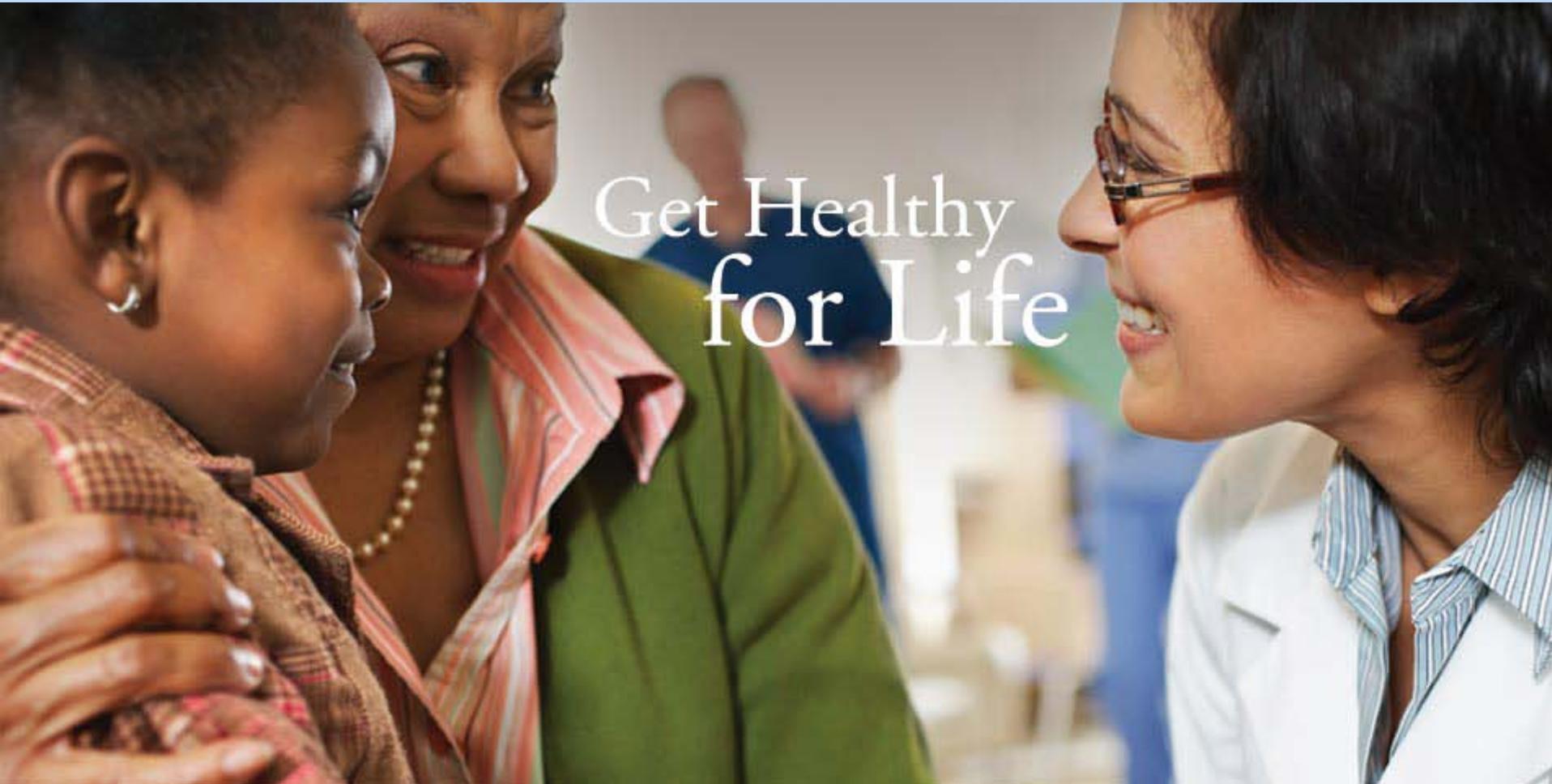
HIV / AIDS – Among Ages 13 to 29 Years



Note: Those between 30 and 39 who had AIDS at first diagnosis were actually infected with HIV between the ages of 13 - 29

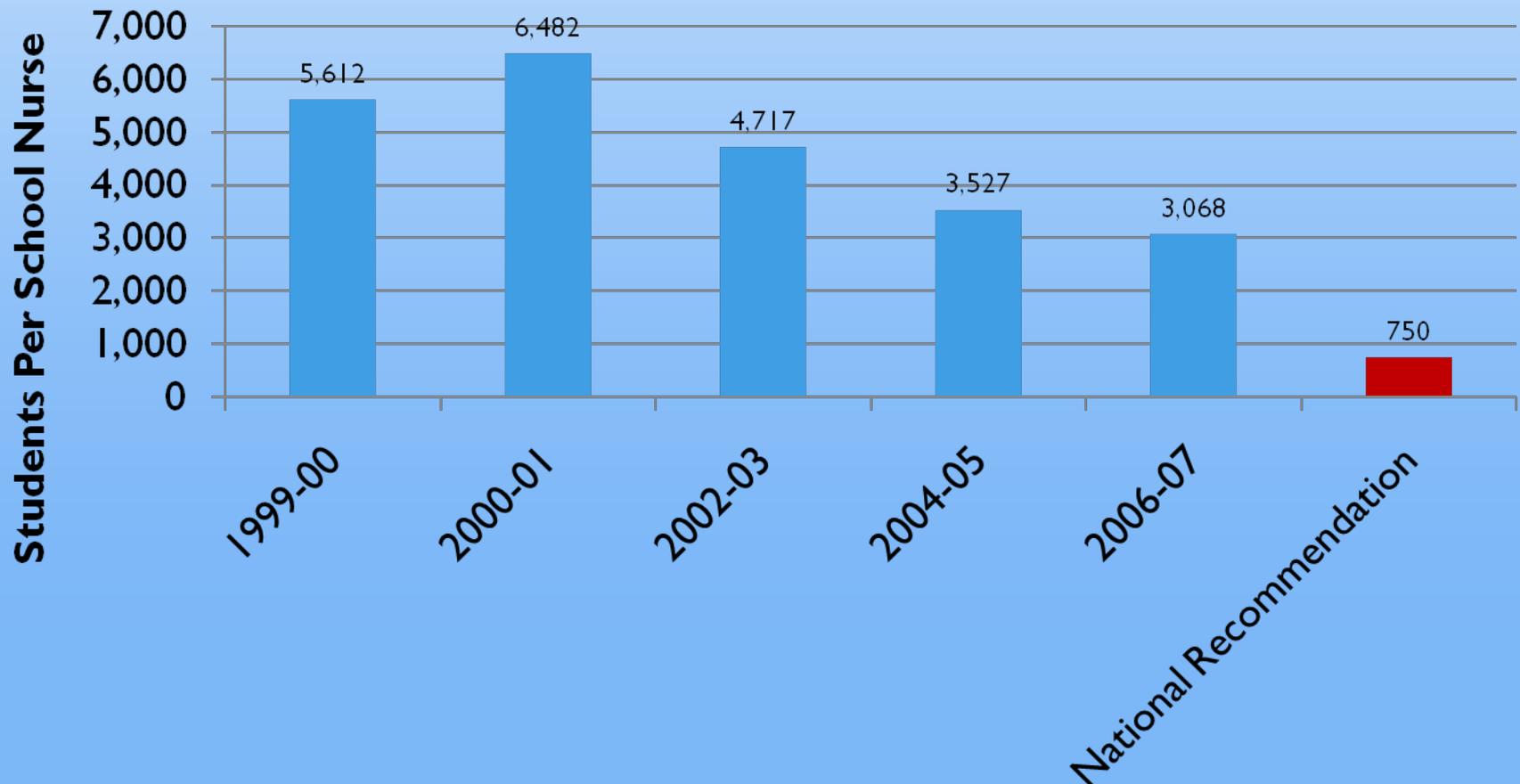
- Ages 30 to 39
- Ages 20 to 29
- Other ages

School Nursing and Health Education



School Nursing

**Number of Students for Every One School Nurse
in North Dakota Public Schools: 1999-00 to 2006-07**



School Health Education

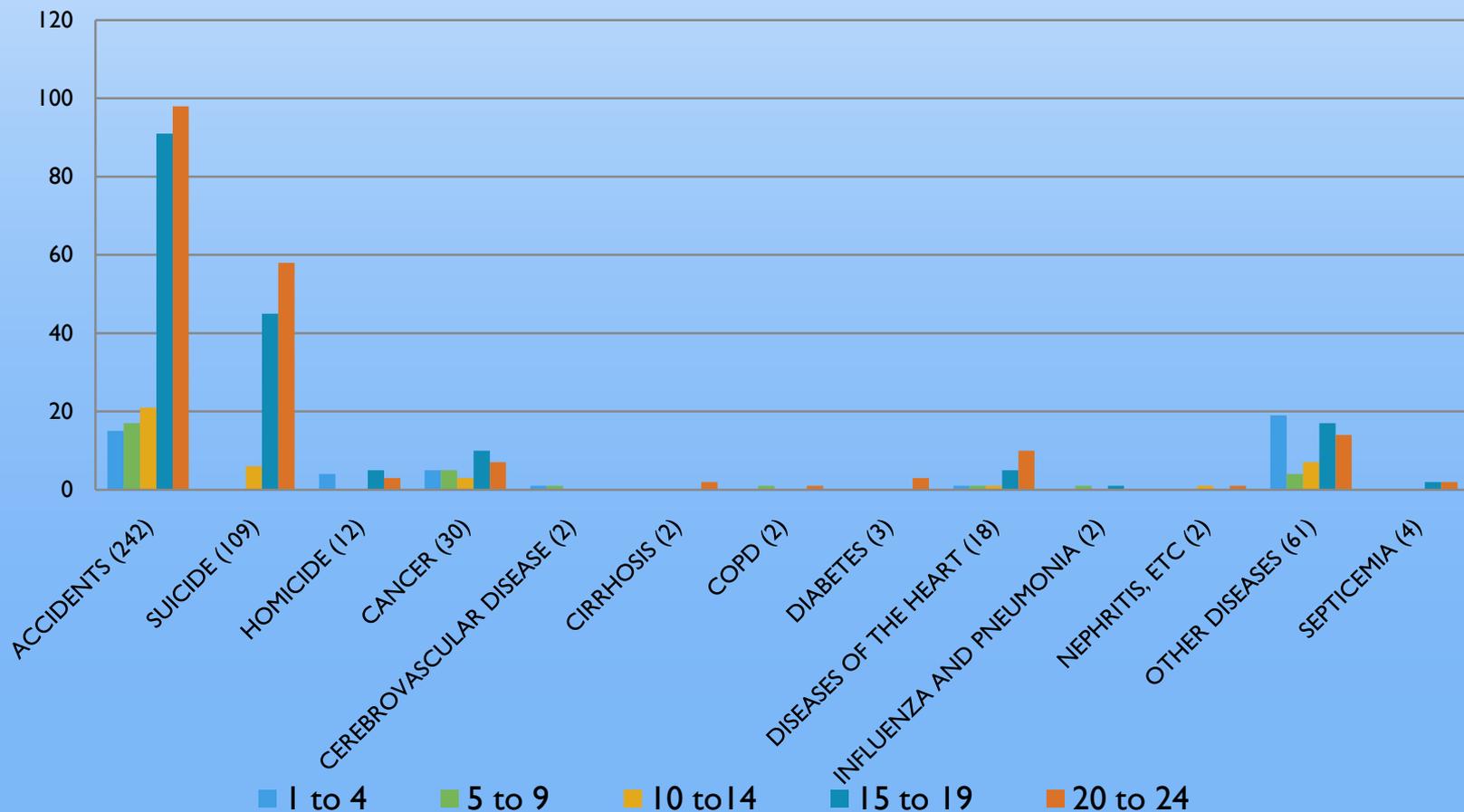
Schools in 2008

	ND	US
That required students to take two or more health education courses	 67.2%	50.6%
With a health education curriculum that addresses all 8 national standards for health education	 62.8%	66.1%



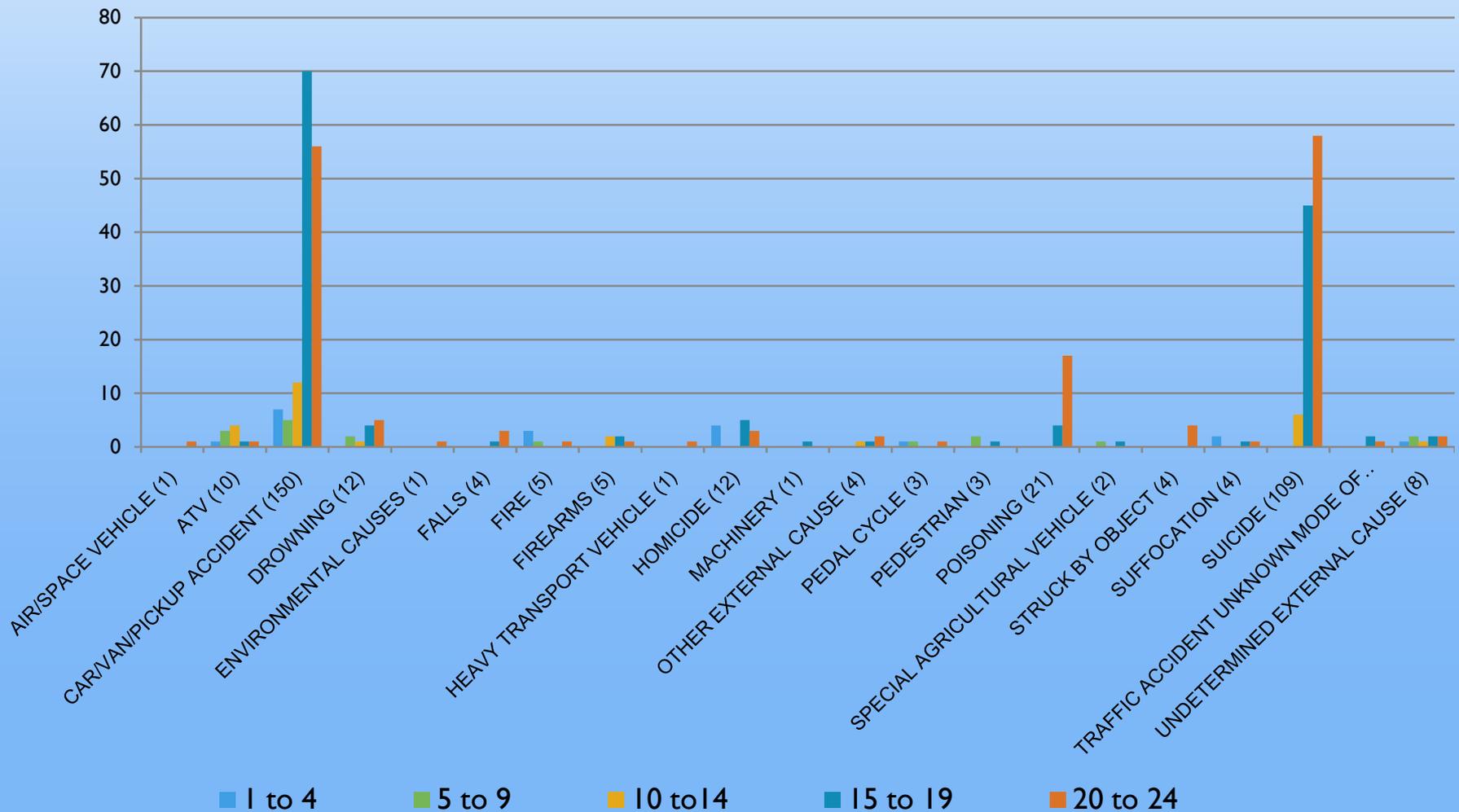
ND Leading Causes of Death Ages 1 to 24 for 2004-2008

ND Leading Causes of Death Ages 1-24



Source: NDDoH Vital Records

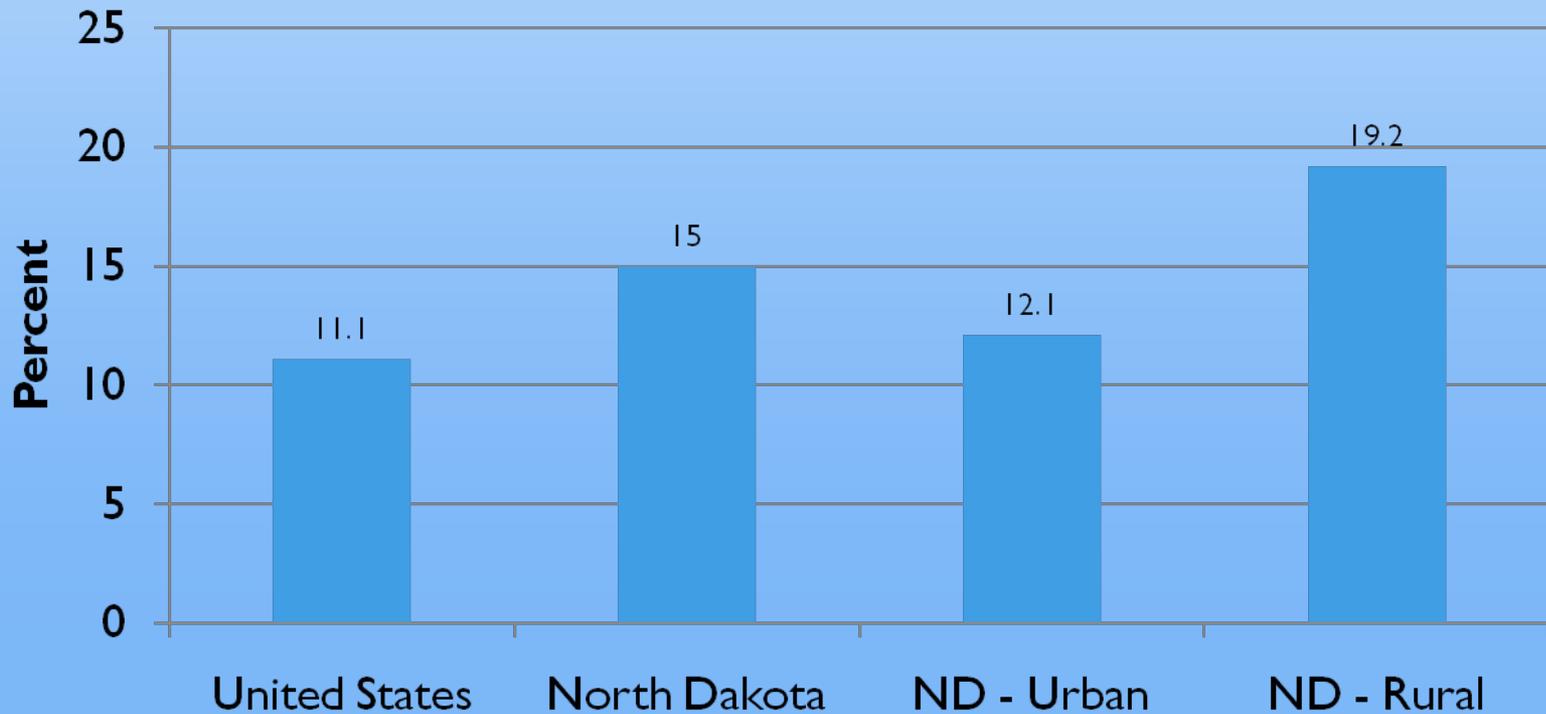
Injury Related Deaths Ages 1-24 for 2004-2008



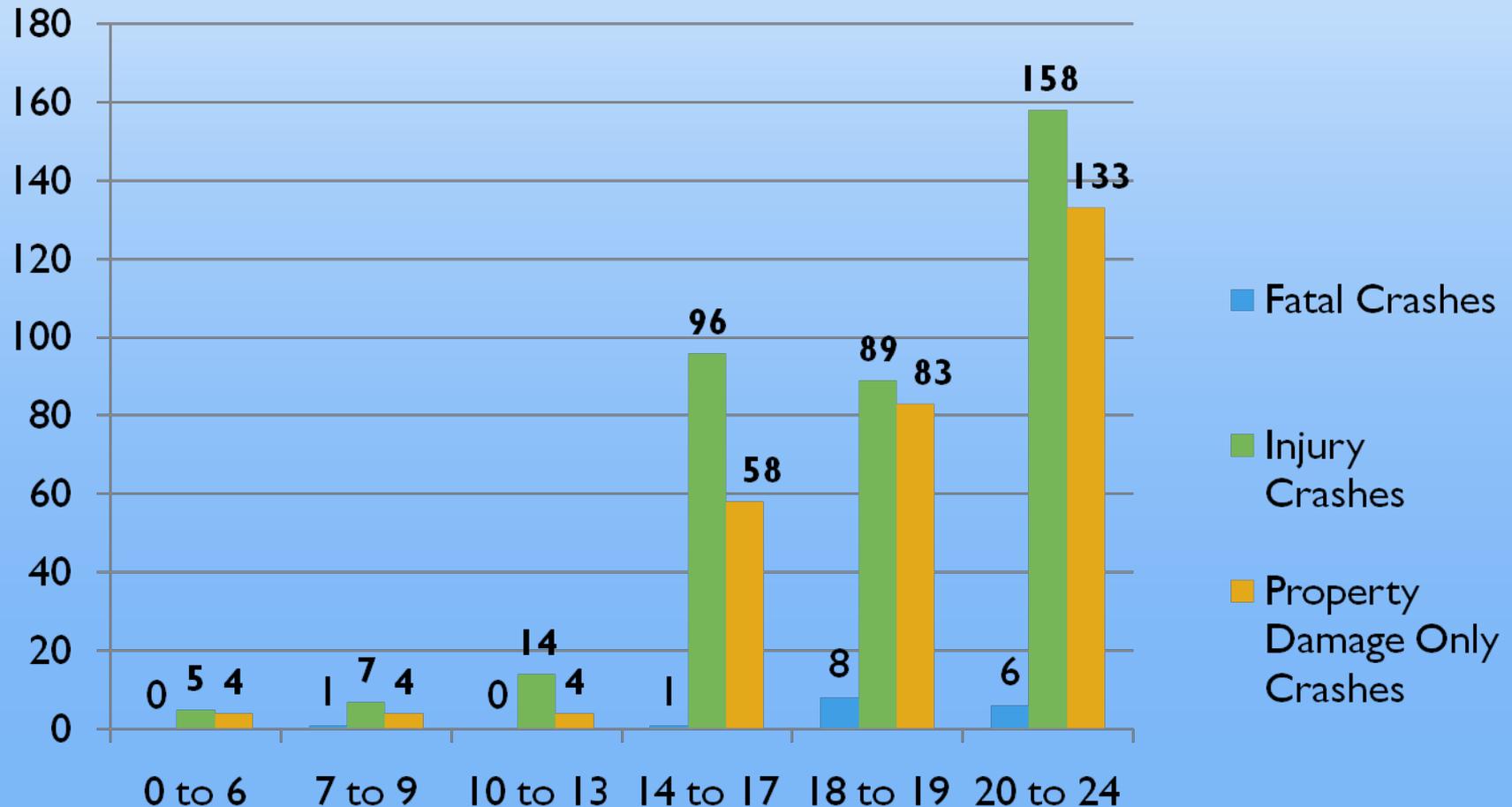
Source: NDDoH Vital Records

Seat Belt Usage

Students in Grades 9-12 Who Rarely or Never Wore a Seat Belt When Riding in a Car Driven by Someone Else, 2007



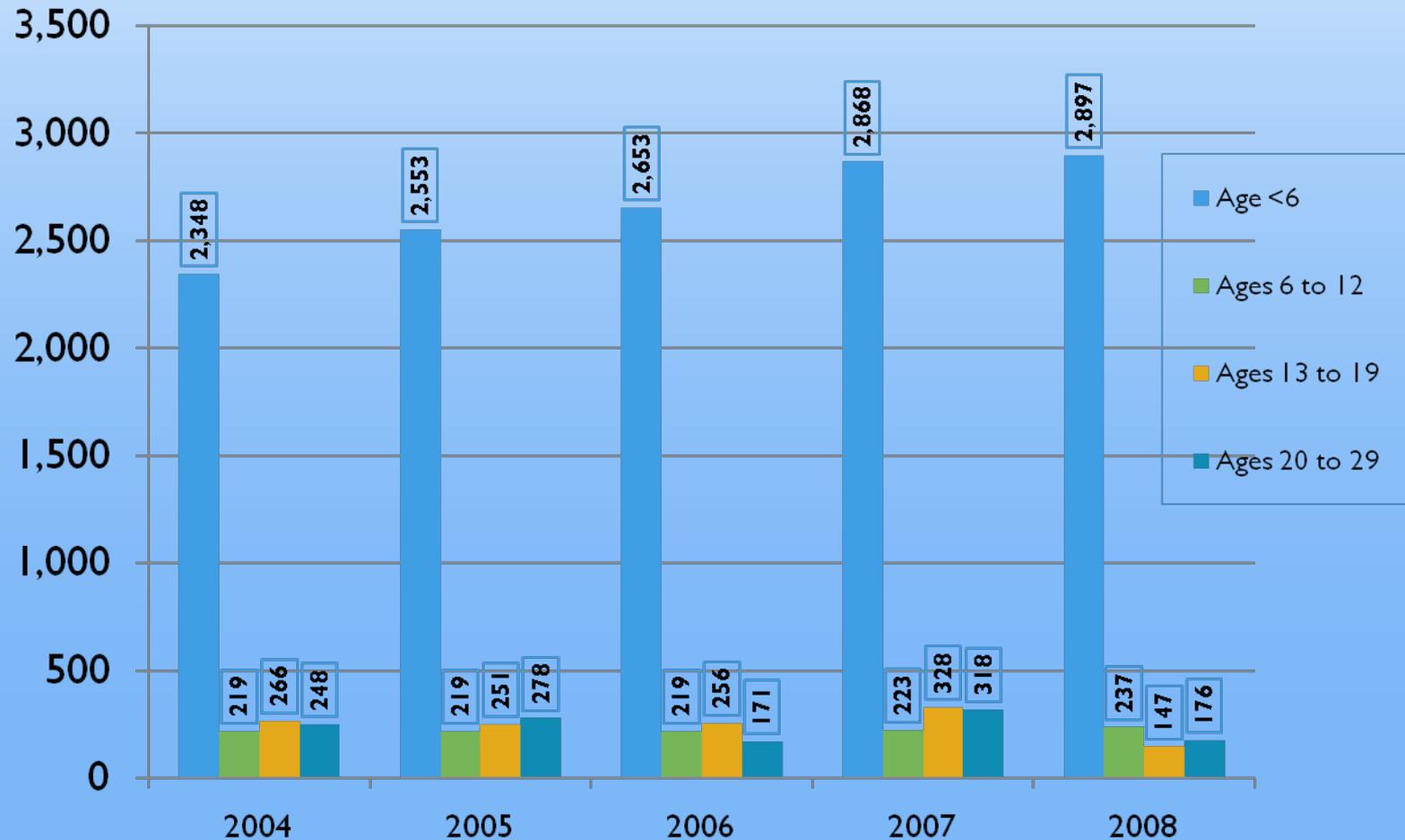
2008 Unbelted Crash Occupants



Poison



Poison – Exposure Calls



Oral Health



Oral Health Survey – 3rd Graders

Of the Total 3rd Graders Surveyed (all races combined):

- 56% have cavities or fillings
- 17% have untreated dental decay
- 53% have dental sealants
- 1% need urgent care

Of the Total Surveyed:

- ➔ 82% American Indian
54% White
- ➔ 33% American Indian
16% White
- ➔ 54% White
43% American Indian
- ➔ 7.5% American Indian
.05% White

Presentations: Population Specific Data

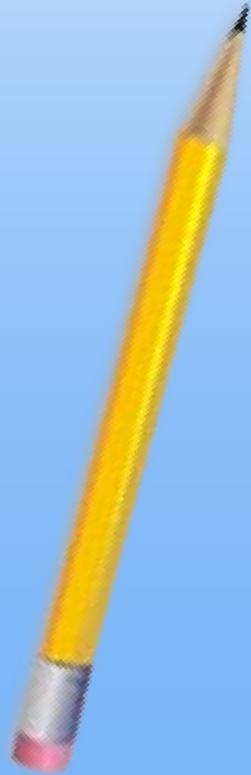
Children and Youth
with Special Health
Care Needs Ages
Birth to 21:

- Sue Burns
- Tammy Gallup-Millner



Children and Youth with Special Health Care Needs Ages Birth to 21

Children with Special Health Care Needs (CSHCN or CYSHCN)



2010 Title V MCH Block Grant Needs Assessment Survey Results

Top Ten Priority Needs for CSHCN	Percent
Access to Specialty Care and Services	60.5%
Early Identification of Special Health Care Needs	44.1%
Families Receive Needed Services	41.8%
Care Coordination/Case Management	34.4%
Early Intervention/Infant Development	33.4%
Childcare/Day Care	27.9%
Availability of Health Care Providers	26.4%
Uninsured or Underinsured	18.2%
Transition to Adulthood	16.0%
Safe and Stable Environments	16.0%

Access to Specialty Care and Services

Financial Eligibility

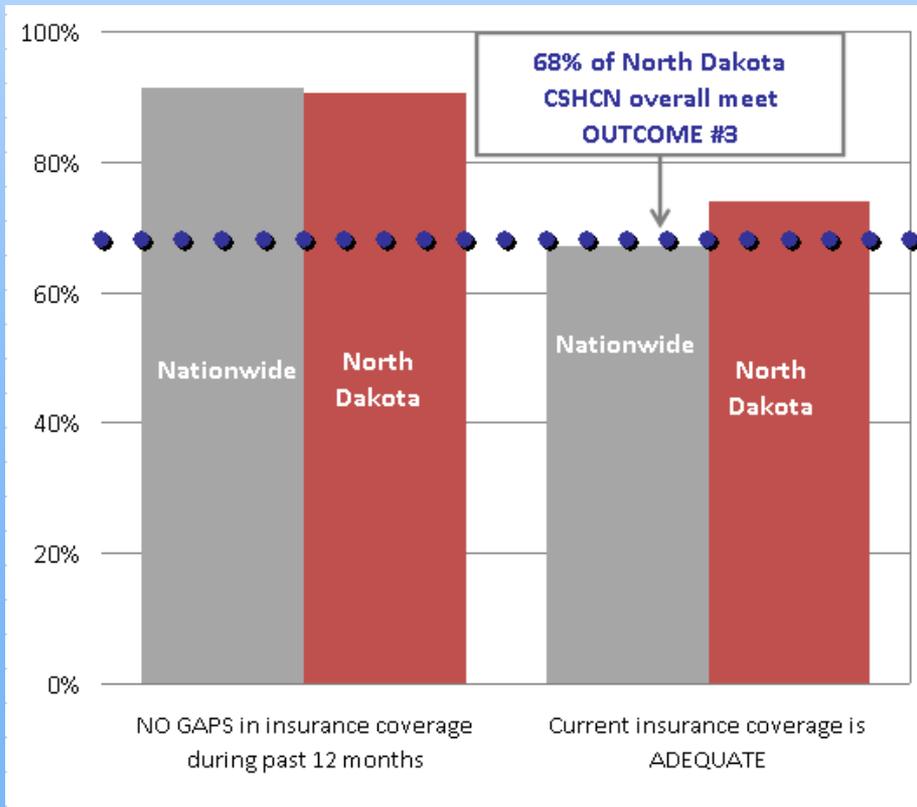
Medicaid	133% FPL to age 6 100% FPL to age 19
Healthy Steps	160% FPL to age 19
Caring for Children	200% FPL to age 19
Children's Special Health Services	185% FPL to age 21



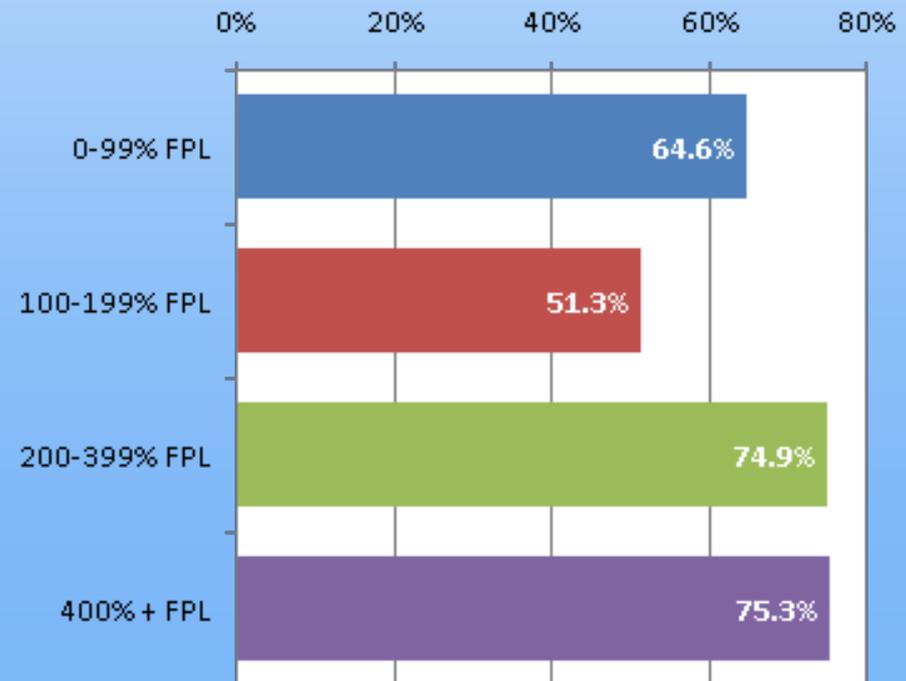
Data Source: Medical Services and CSHS

Access to Specialty Care and Services

Gaps and Adequacy in Insurance Coverage

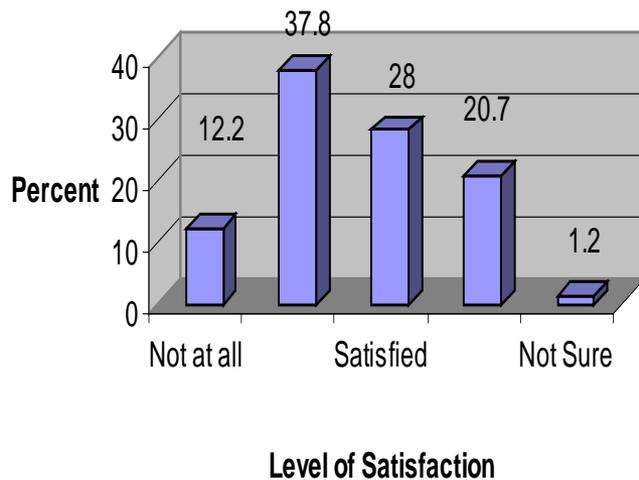


Percent of ND Families with CSHCN Reporting Adequate Insurance by FPL

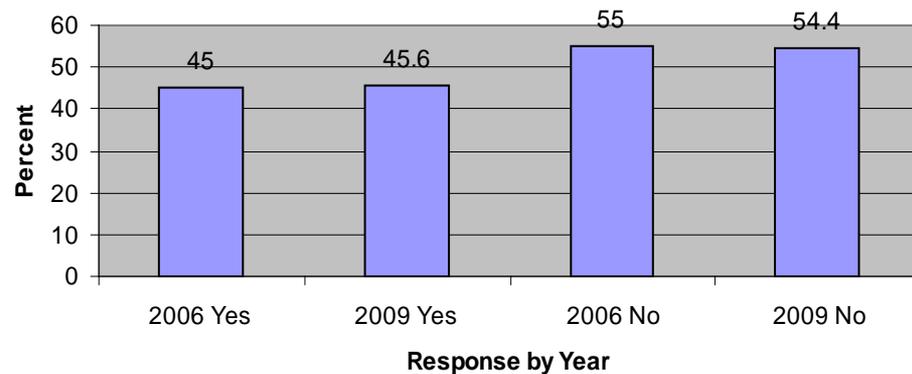


Access to Specialty Care and Services

Satisfaction with Covered Costs of Needed Services



Financial Stress Due to Child's Health Care Needs



Children with Special Health Care Needs (CSHCN or CYSHCN)

Transportation



Access to Specialty Care and Services

2009 Department of Human Services Public Stakeholder Meetings Draft Comments

Transportation remains an issue for many stakeholders

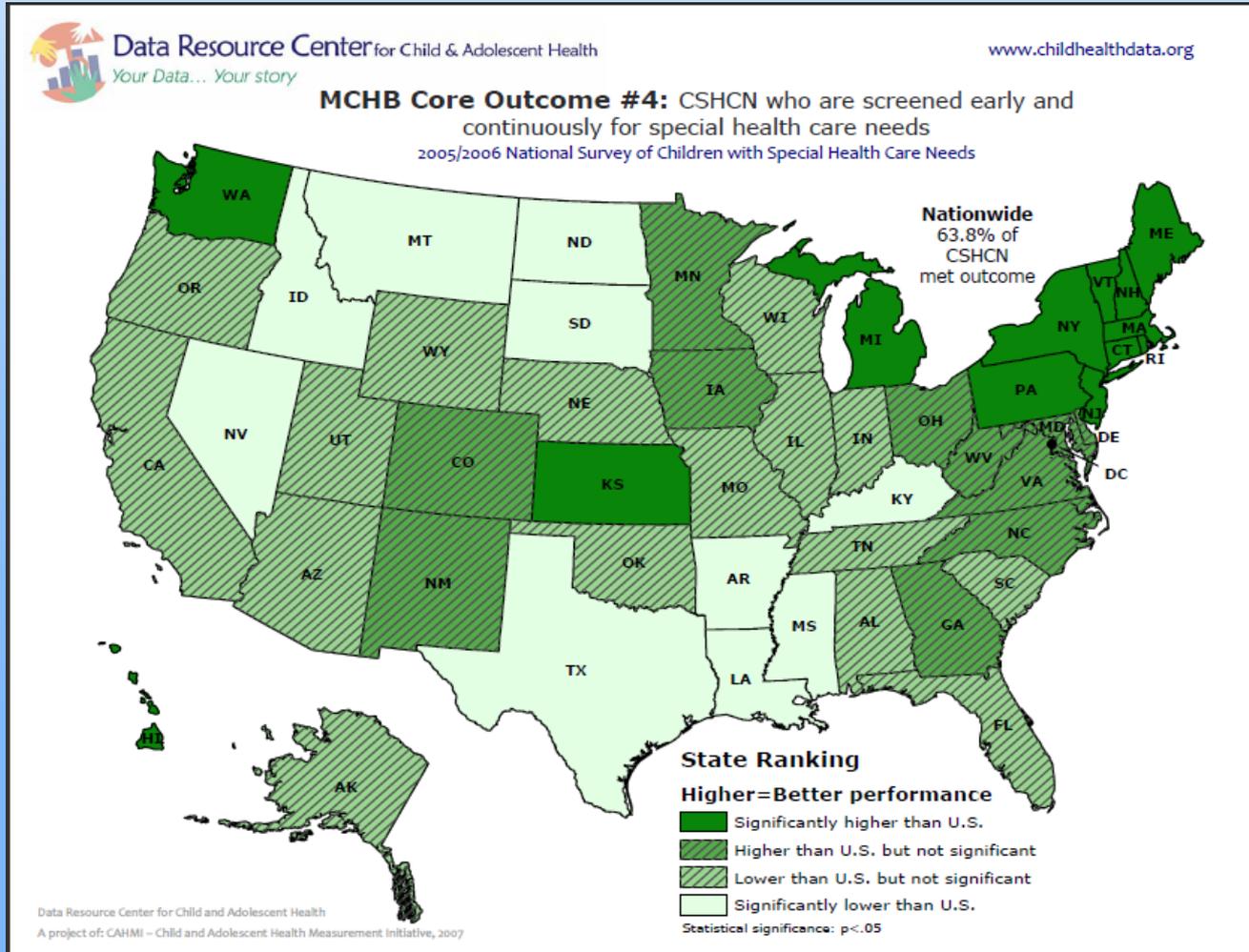
- There is lack of transportation providers, especially those that are wheelchair accessible.
- Getting transportation reimbursed is difficult . . . it is time consuming and many requests are denied.

Stakeholders also request expanding the use of telemedicine. They stated, in addition to its use with mental health, telemedicine could help rural areas access medical consultation with specialists.

Top Priorities from the 2009 North Dakota Developmental Disability Network Summit on Transportation

- Offer usable alternatives in all areas of state.
- Get providers to work together.
- Get a champion to help create a sustainable funding source.

Early Identification of Special Health Care Needs



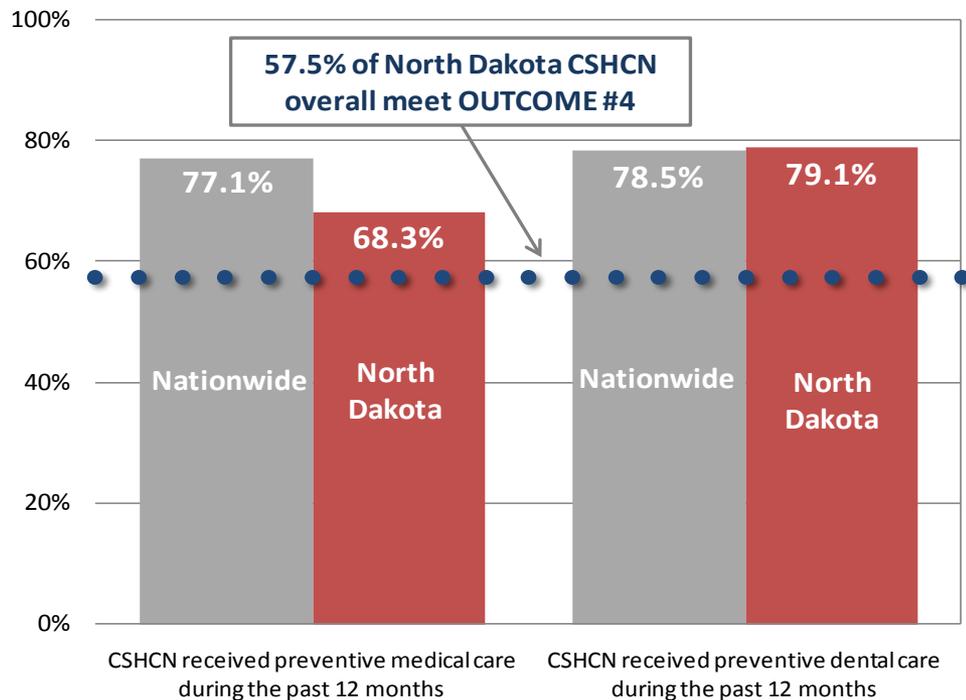
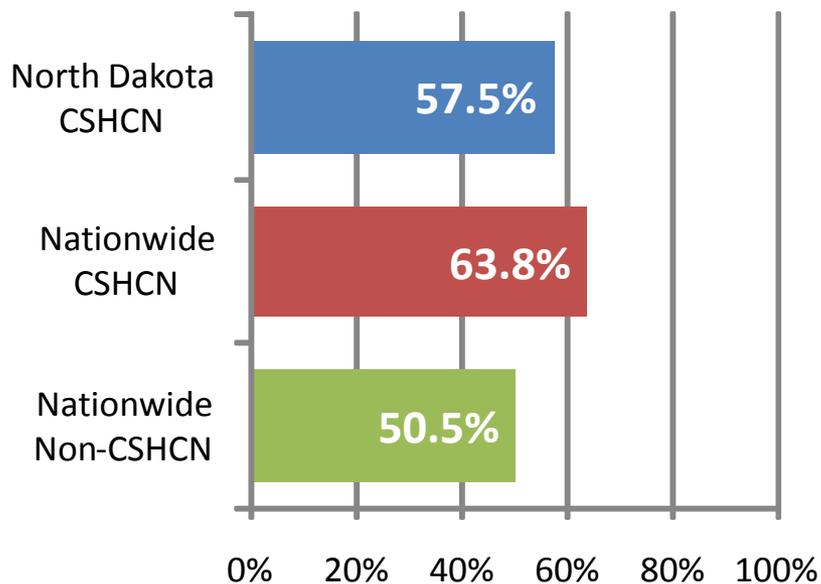
MCH Core Outcome #4

ND: 57.5%

US: 63.8%

Early Identification of Special Health Care Needs

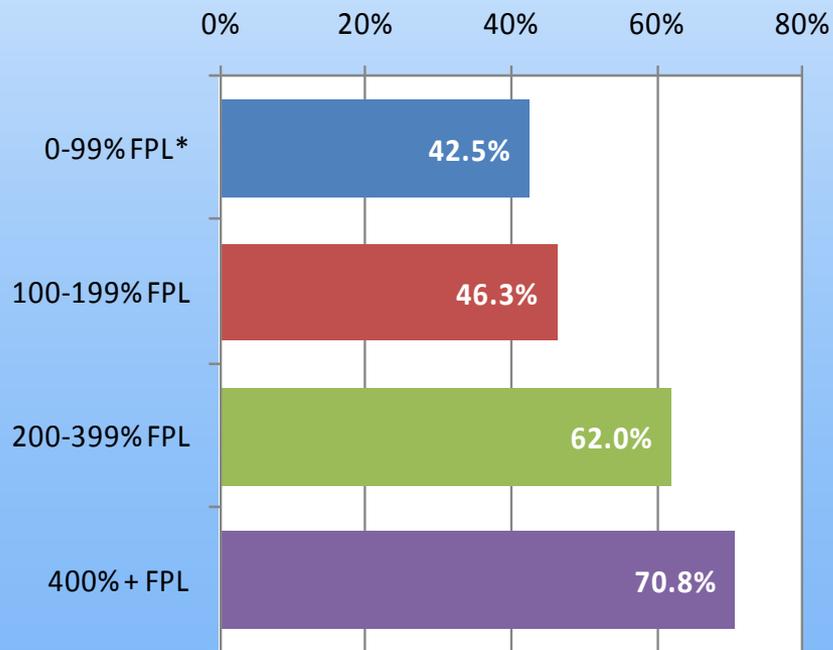
Percentage of children screened early and continuously for Special Health Care Needs



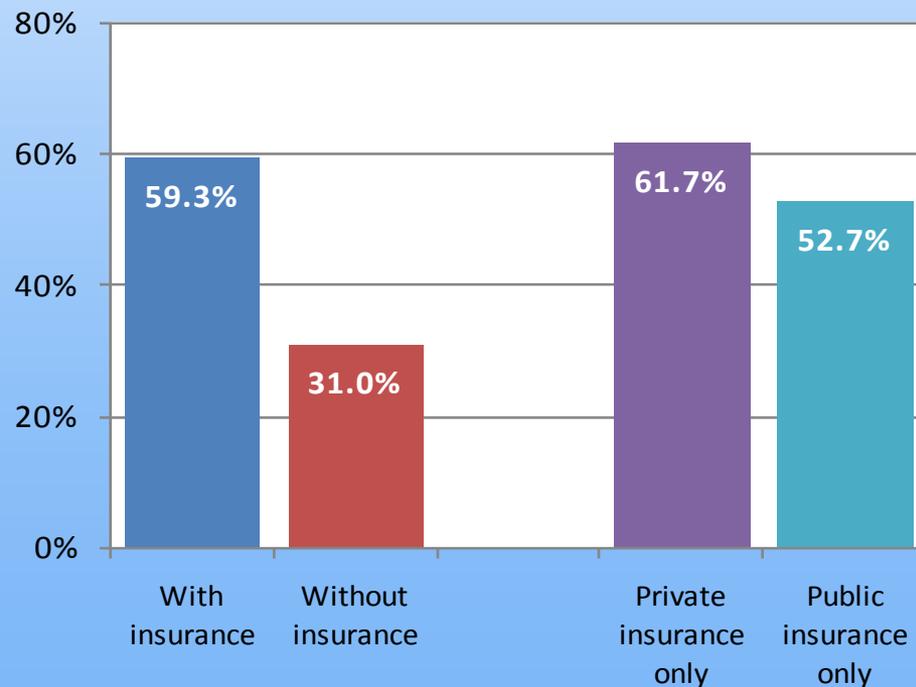
Outcome #4:

Percentage of children screened early and continuously for Special Health Care Needs

Early Identification of Special Health Care Needs



*FPL=Federal Poverty Level

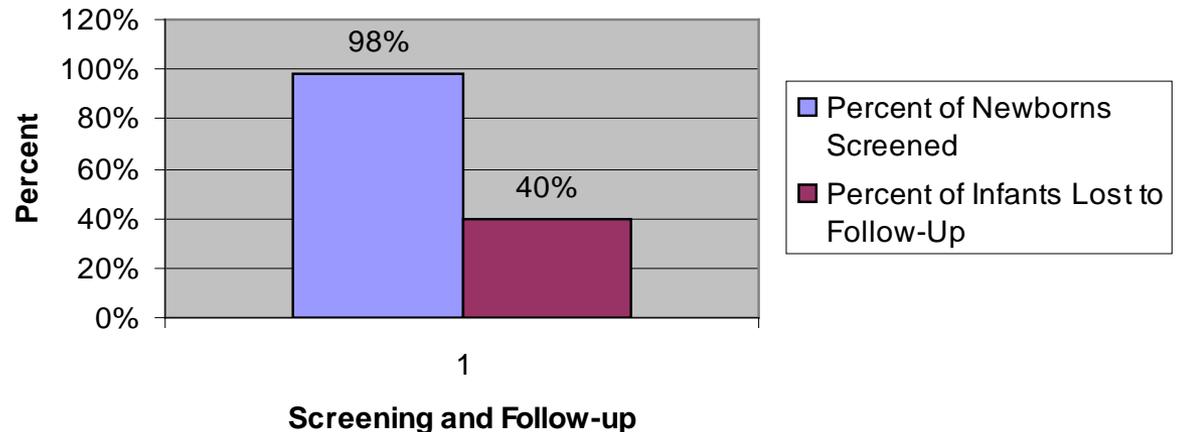


Early Identification of Special Health Care Needs

2008 Occurrent Births and Confirmed Diagnoses from Blood Spot (Metabolic) Screening

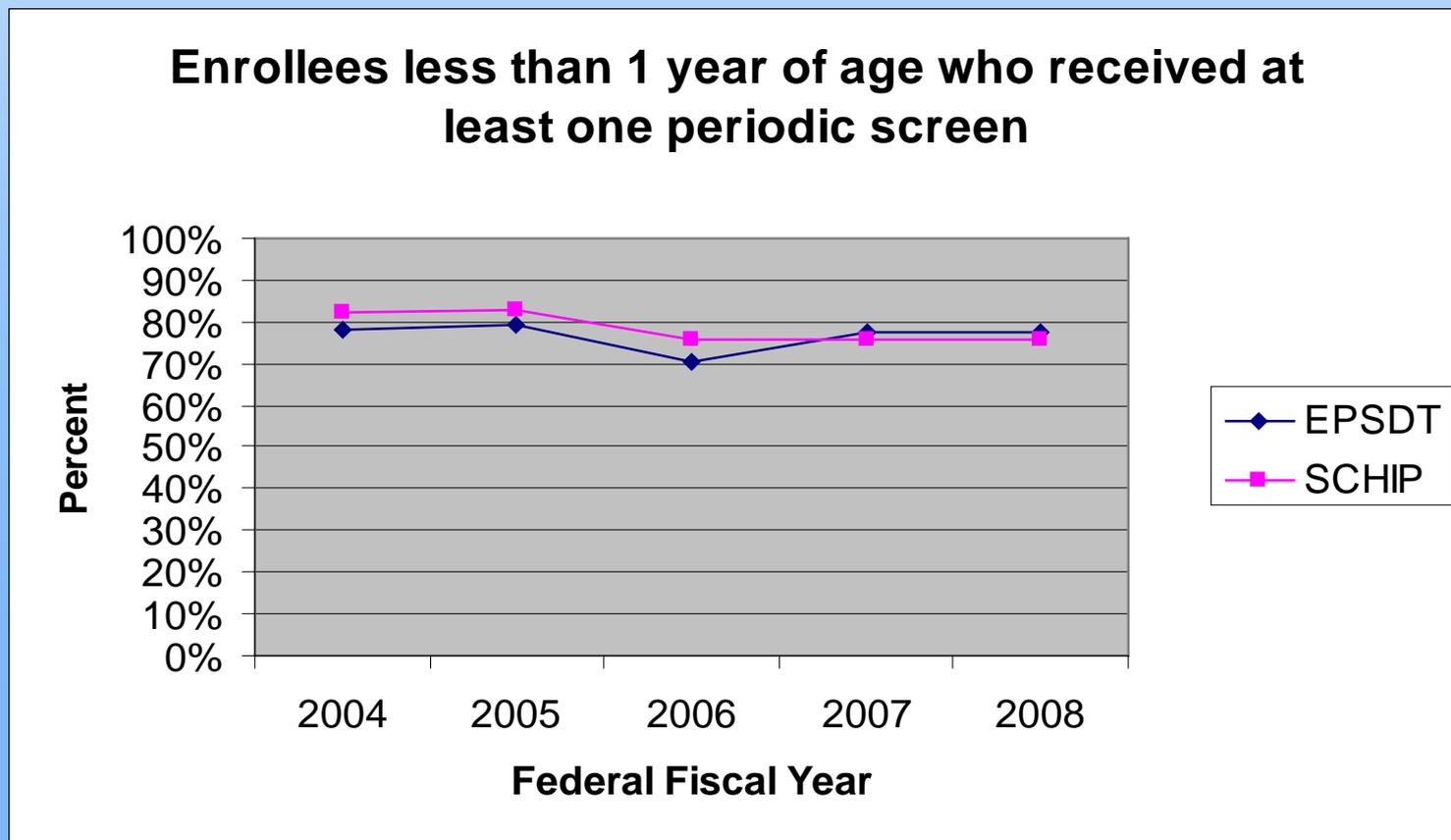
Occurrent Births	10,313
Confirmed Diagnoses	24

2008 Newborn Hearing Screening and Follow-up



Early Identification of Special Health Care Needs

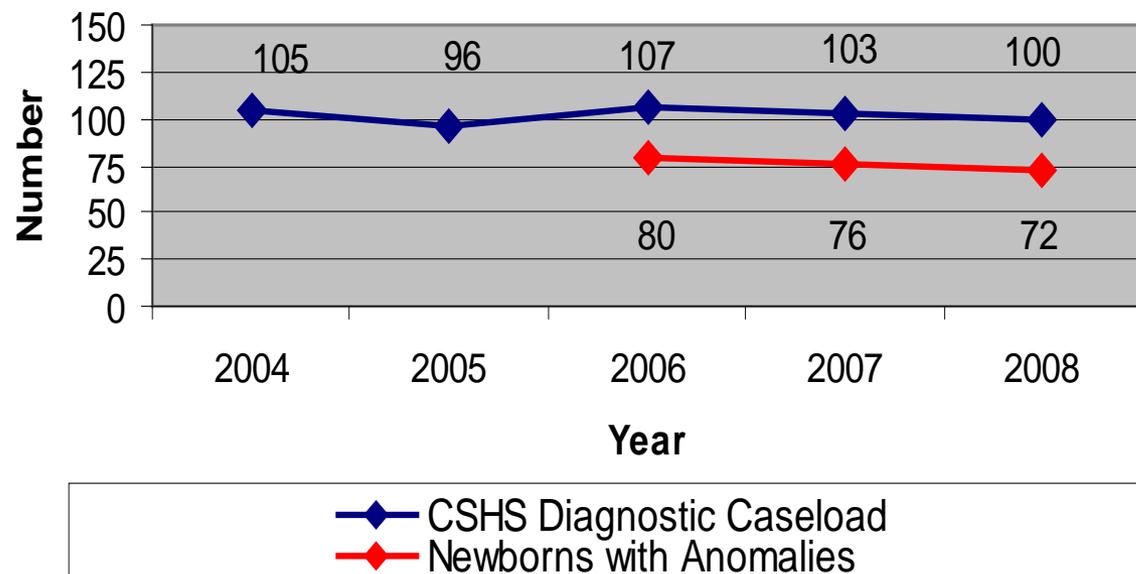
Health Tracks (EPSDT) and State Child Health Insurance Program (SCHIP)



Early Identification of Special Health Care Needs

Number of CSHS Diagnostic Cases and Major Birth Defects in ND

Approaches to Early Identification

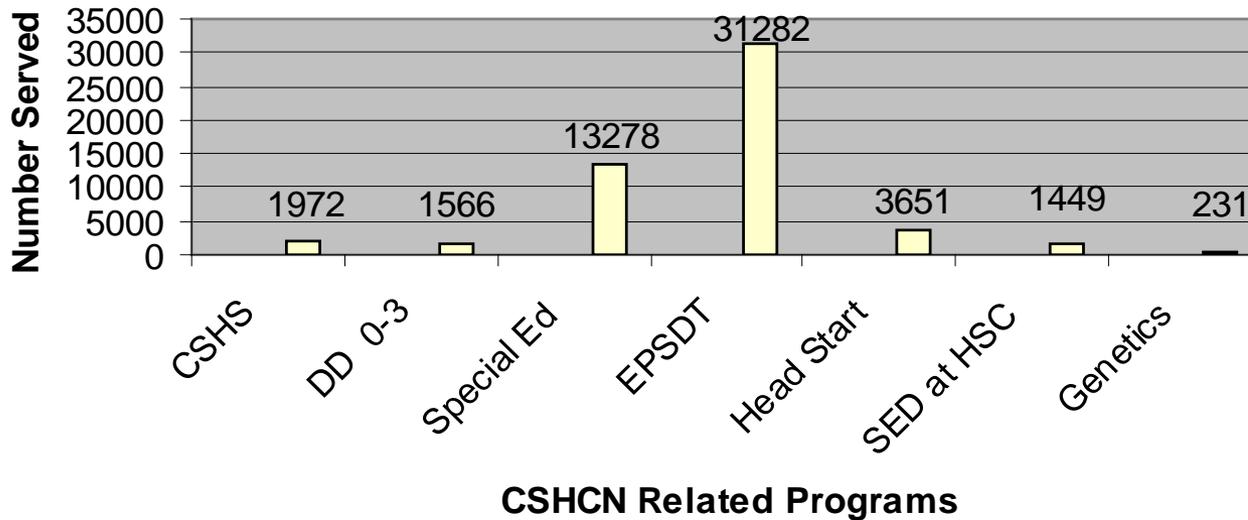


Birth Defects in North Dakota

5 Year Period	Number of Live Resident Births	Number of Major Congenital Anomalies
2000 thru 2004	39,250	1,277
2001 thru 2005	39,955	1,240
2002 thru 2006	40,887	1,216

Early Identification of Special Health Care Needs

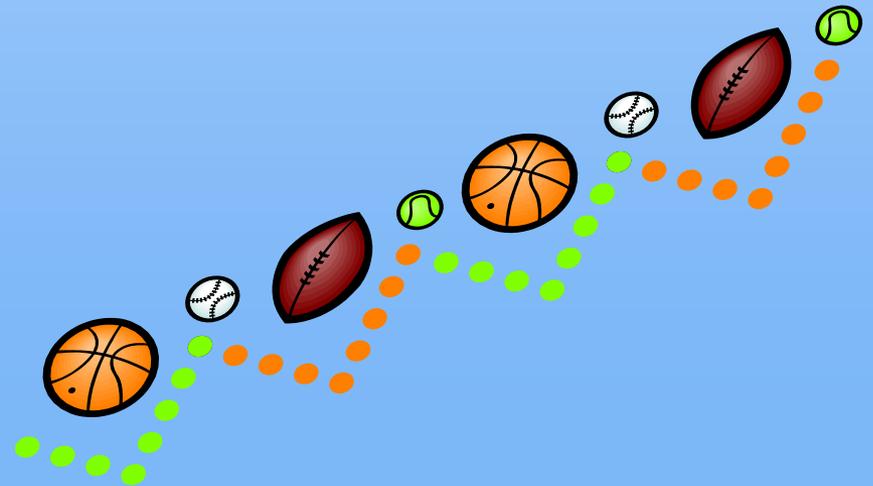
Program Participaton



2008 Program Participation

CSHS	1,972
DD 0-3	1,566
Special Ed	13,278
EPSDT	31,282
Head Start	3,651
SED at HSC	1,449
Genetics	231

Children with Special Health Care Needs (CSHCN or CYSHCN)



Families Receive Needed Services

	US	ND
Percent of all families with support service need(s)	17.5%	18.4%

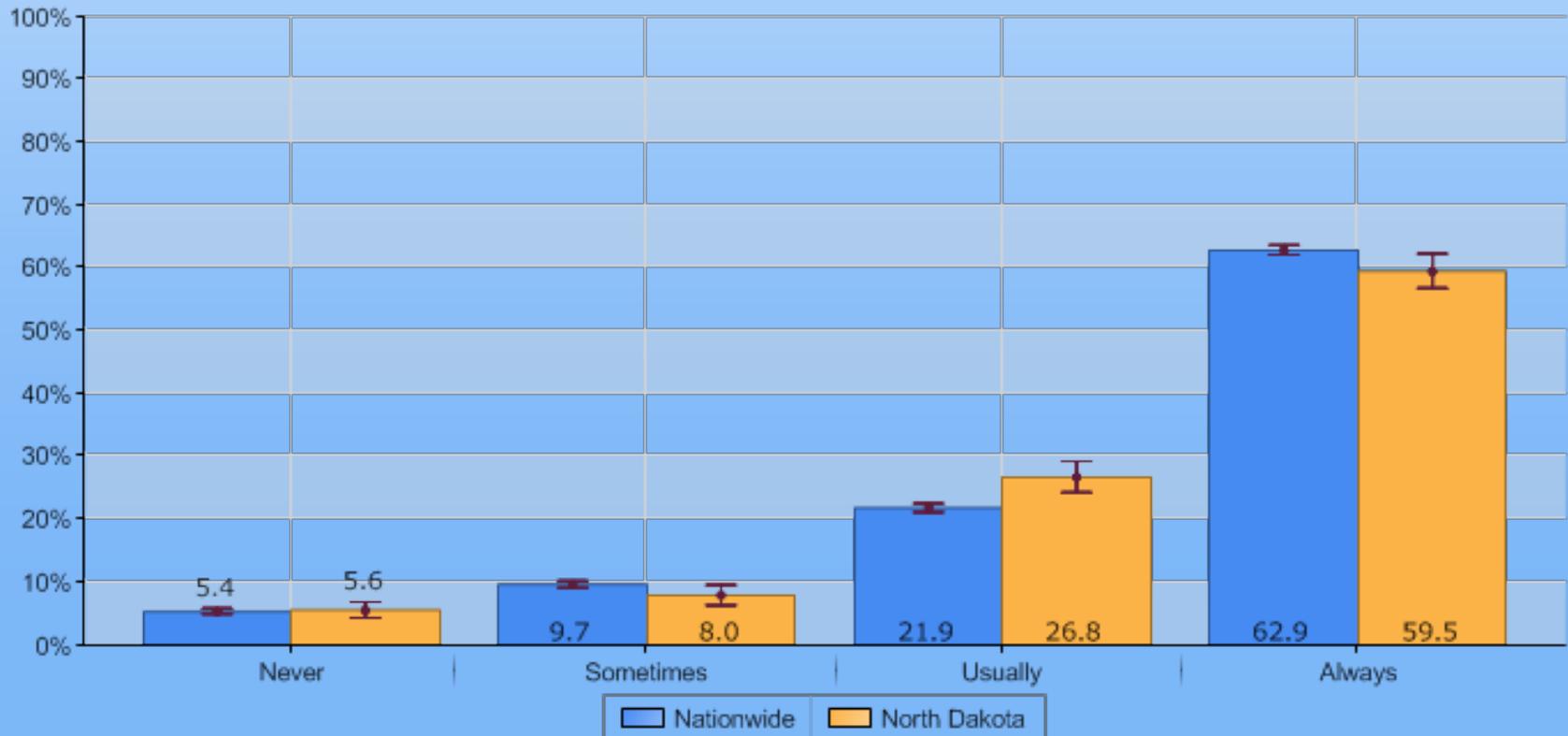
Family Support Service	Percent of Families Who Needed the Service and the Need was Unmet	
	US	ND
Respite Care	48.1%	23.9%
Genetic Counseling	23.8%	11.5%
Family Mental Health Care or Counseling	19.4%	13.1%

Families Receive Needed Services

Doctors Provided Information Specific to Child's Health

Children Age 0-17

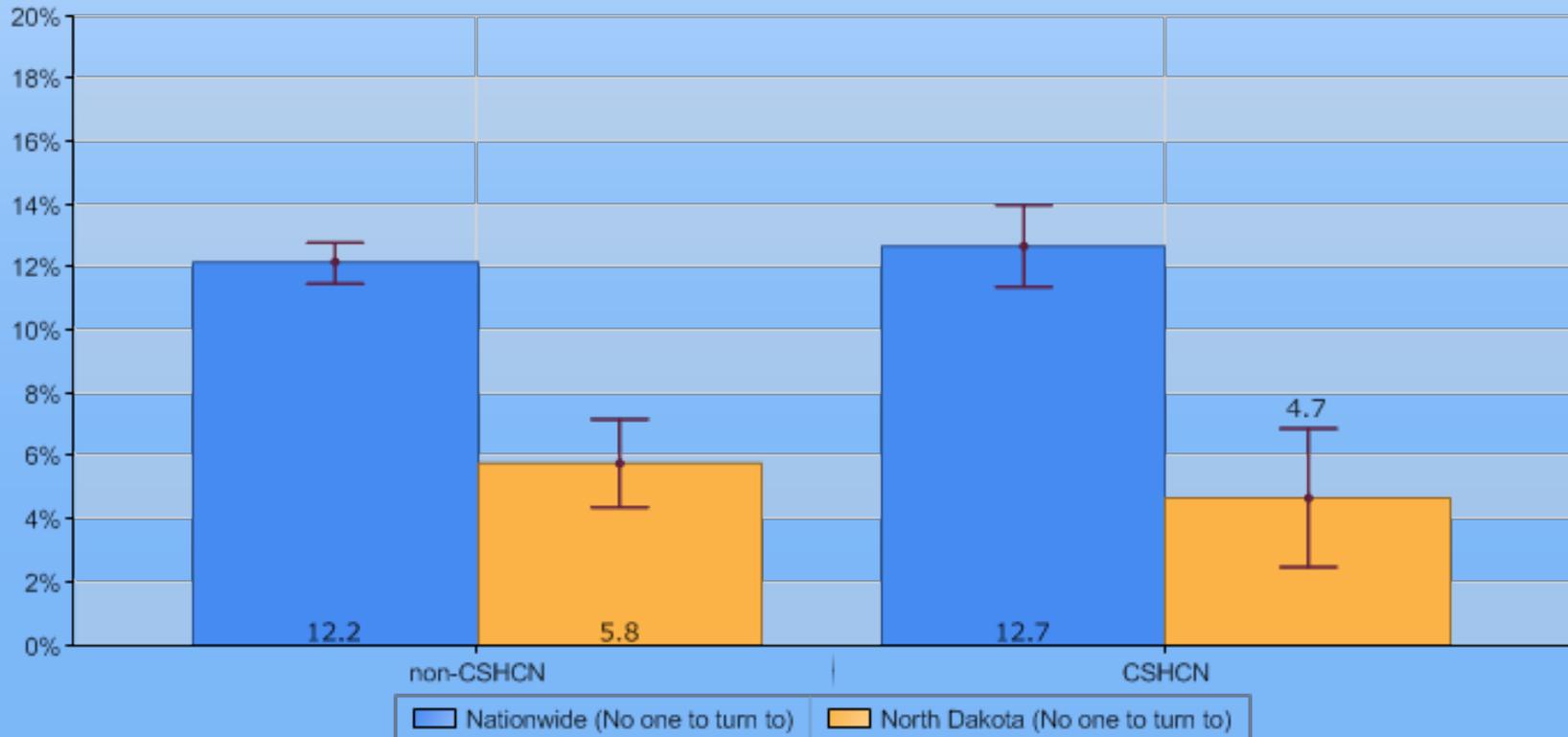
North Dakota vs. Nationwide



Source: 2007 NSCH

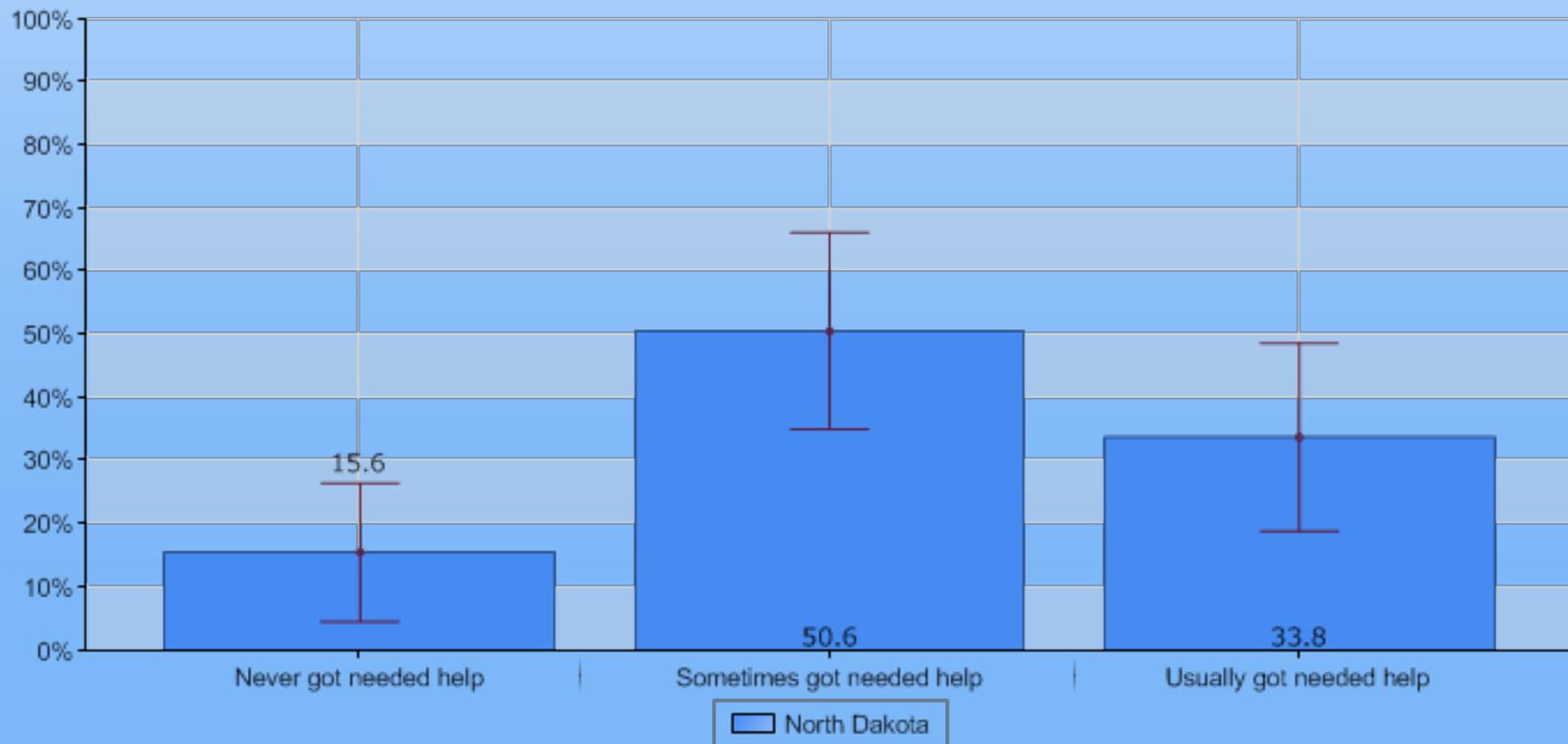
Families Receive Needed Services

Children Living With Parents Who Have Emotional Help With Parenthood Children Age 0-17 Years North Dakota vs. Nationwide



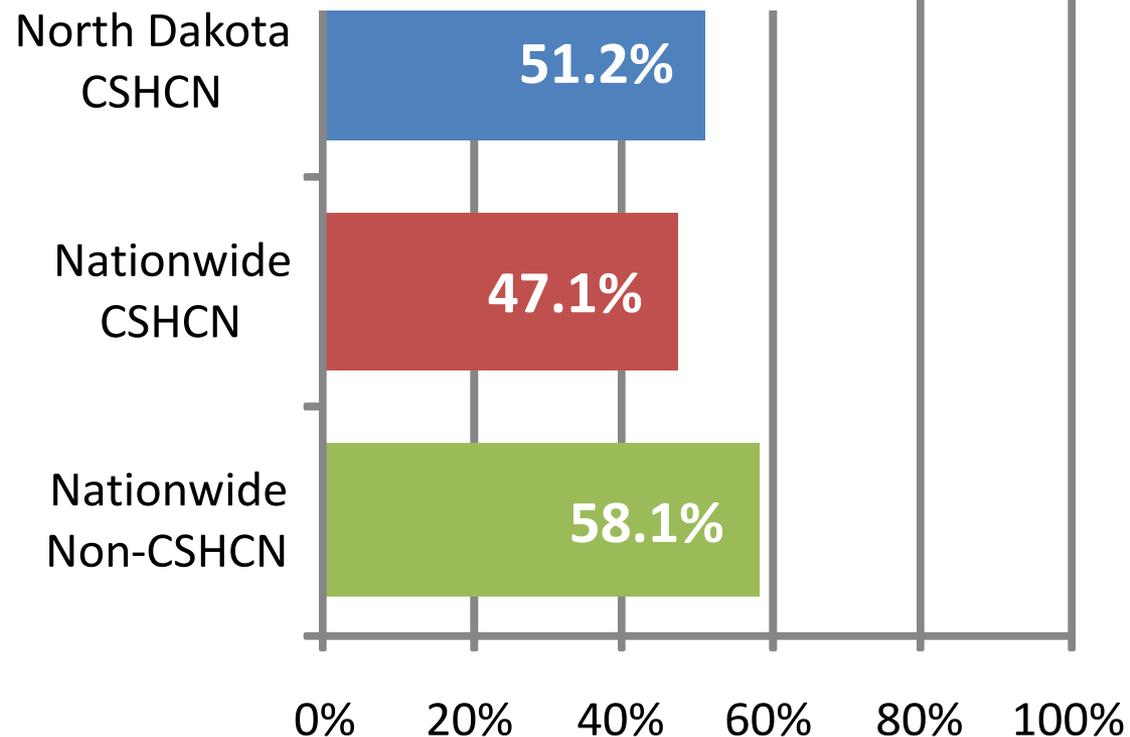
Care Coordination / Case Management

Got Extra Help With Care Coordination When Needed During the Past 12 Months
Children Age 0-17 Years Who Needed Extra Help With Care Coordination
North Dakota

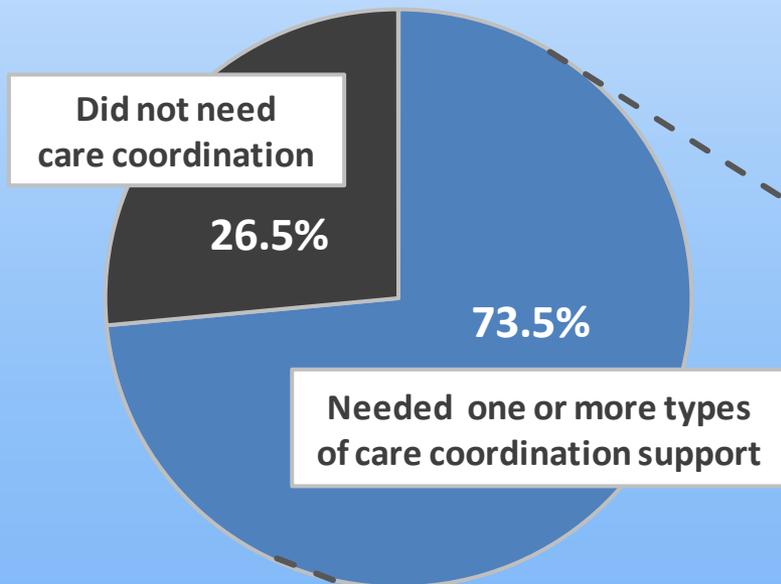


Care Coordination / Case Management

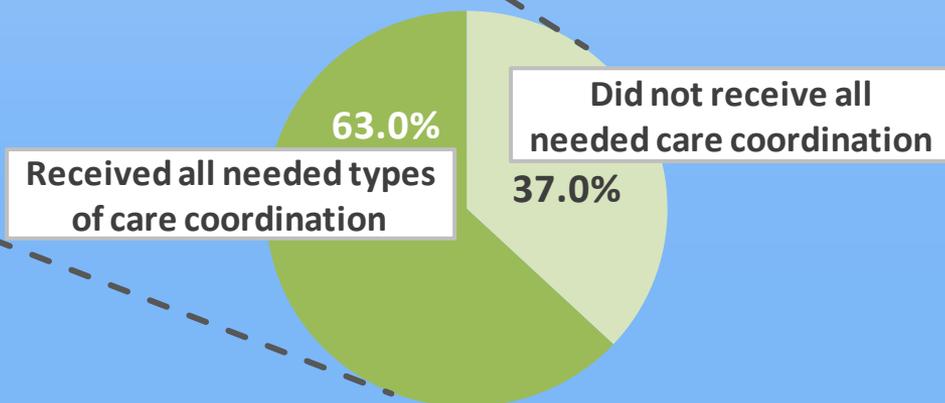
Children Receiving Coordinated, On-going, Comprehensive Care Within a Medical Home



Care Coordination / Case Management



Of CSHCN in ND who needed care coordination, percentage receiving all needed types



Care Coordination / Case Management

It would have been nice to have someone coordinate services outside of the typical medical model. Health is obviously important but making sure your child is safe and happy is just as important!

There is no coordination of services. We end up being the specialists and coordinators.

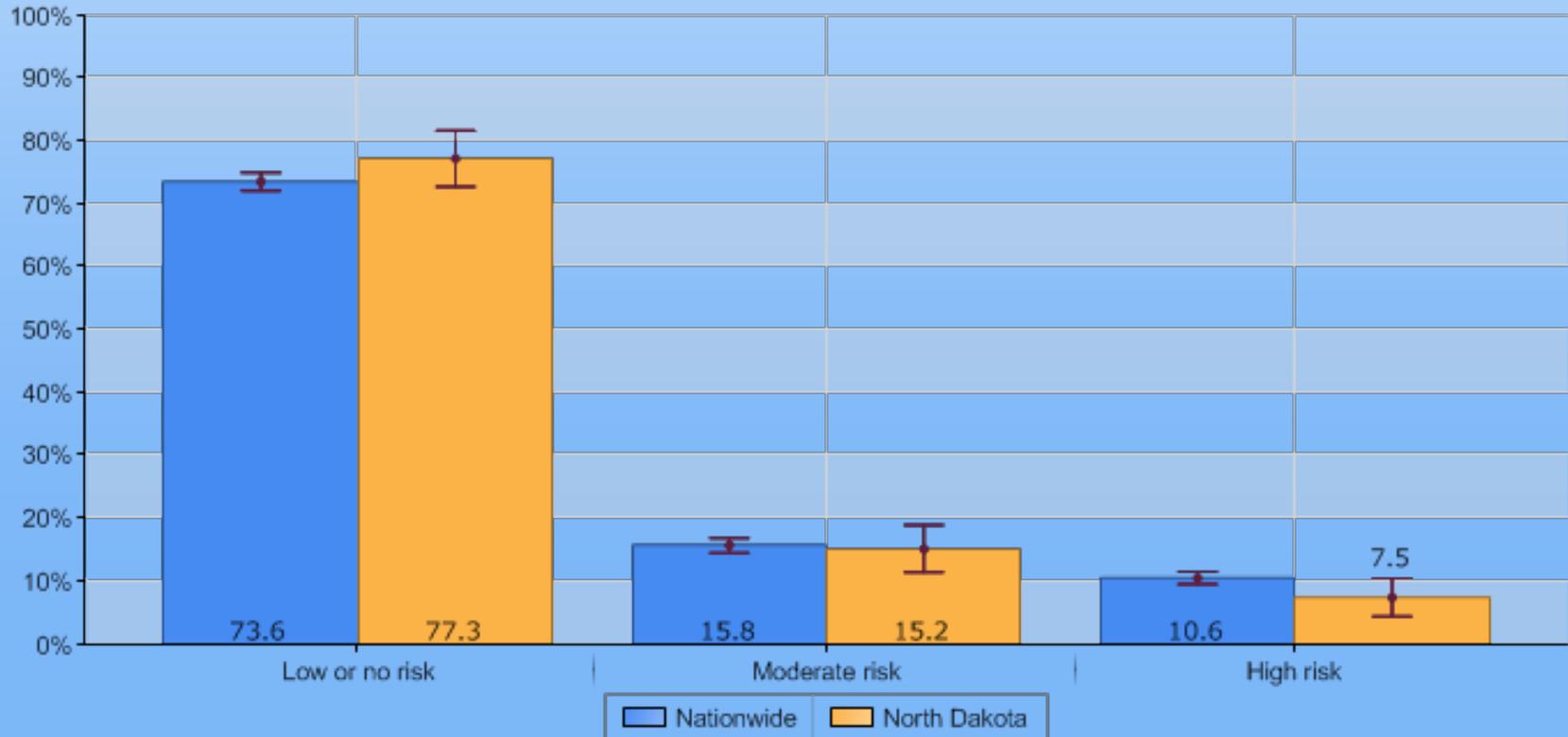
We wish there was a coordinator that would manage the system, who could answer questions and lead us in the correct way to receive services.

Children with Special Health Care Needs (CSHCN or CYSHCN)



Early Intervention / Infant Development

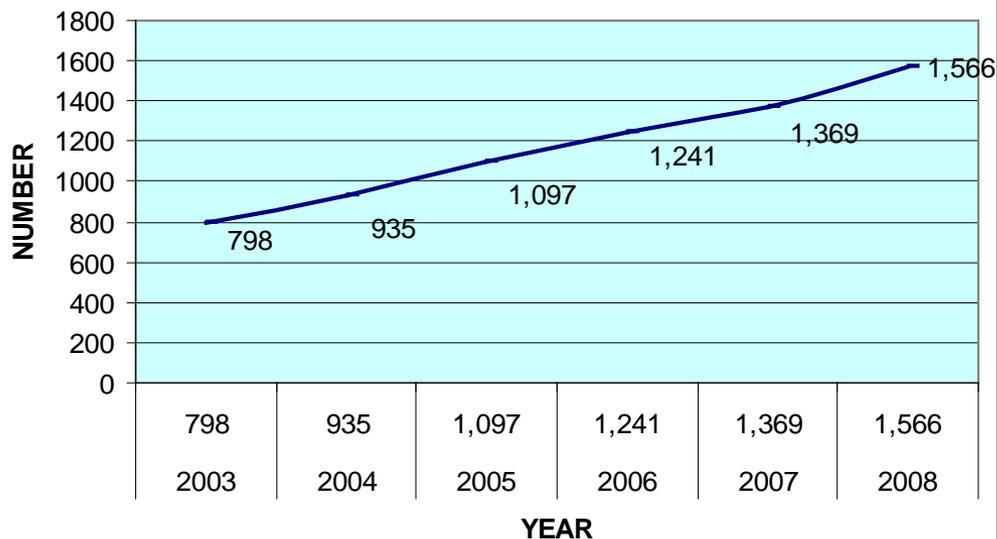
At Risk for Developmental, Behavioral, or Social Delays
Children Age 4 Months-5 Years Only
Nationwide vs. North Dakota



Source: 2007 NSCH

Early Intervention / Infant Development

**NUMBER OF DD CASES IN ND
AMONG 0-3 YEAR OLD CHILDREN**



Right Track Screenings: 7,819

Special Education 3 to 5: 1,576 (11.9%)

Top 10 Diagnoses for Children 0 to 3 years old in 2008

Communication

Disorder of Infancy, Childhood or
Adolescence NOS

Motor Skills

Mental Retardation, Severity
Unspecified

Feeding Disorder of Infancy or Early
Childhood

Adjustment Disorders

Autistic

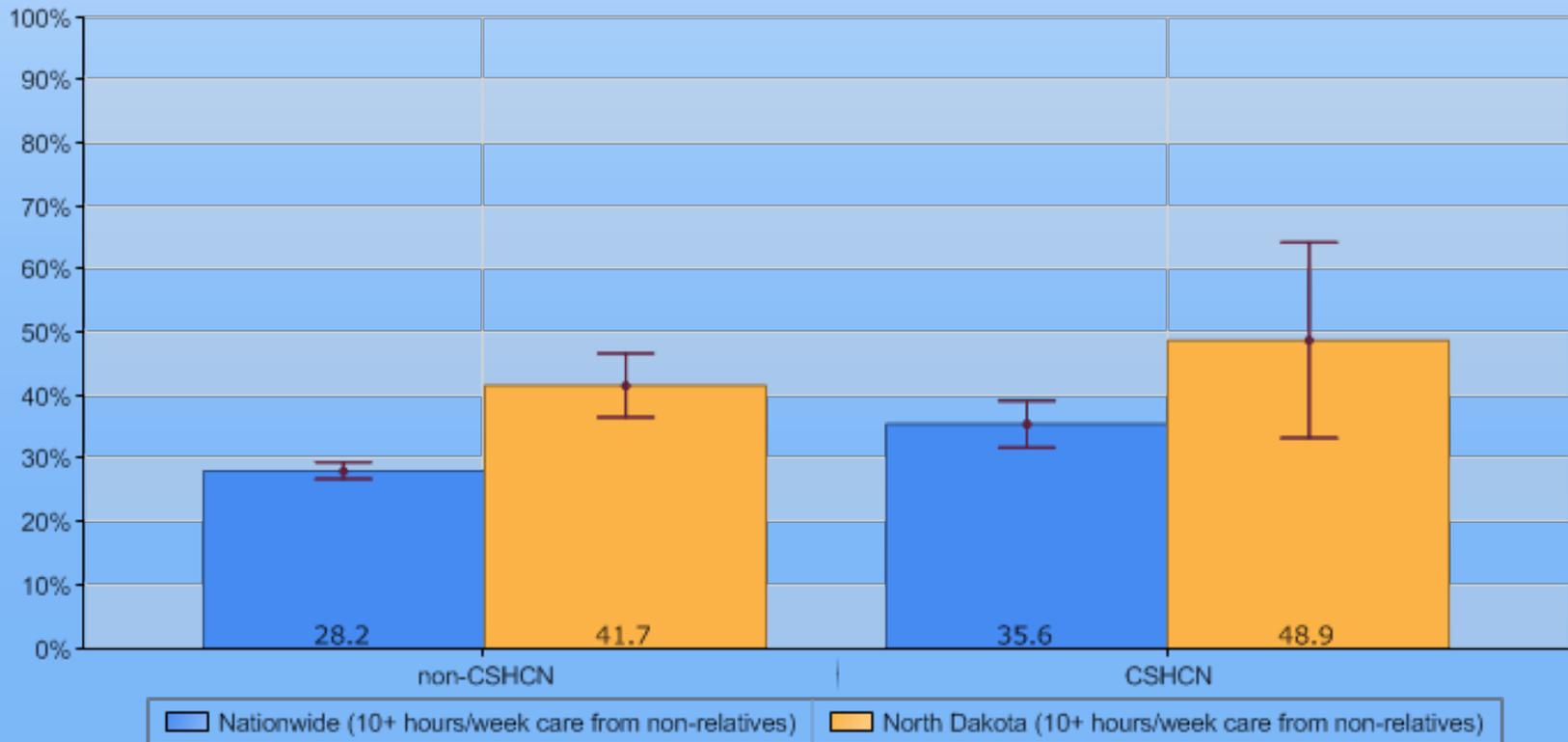
ADHD

ADHD NOS

Conduct

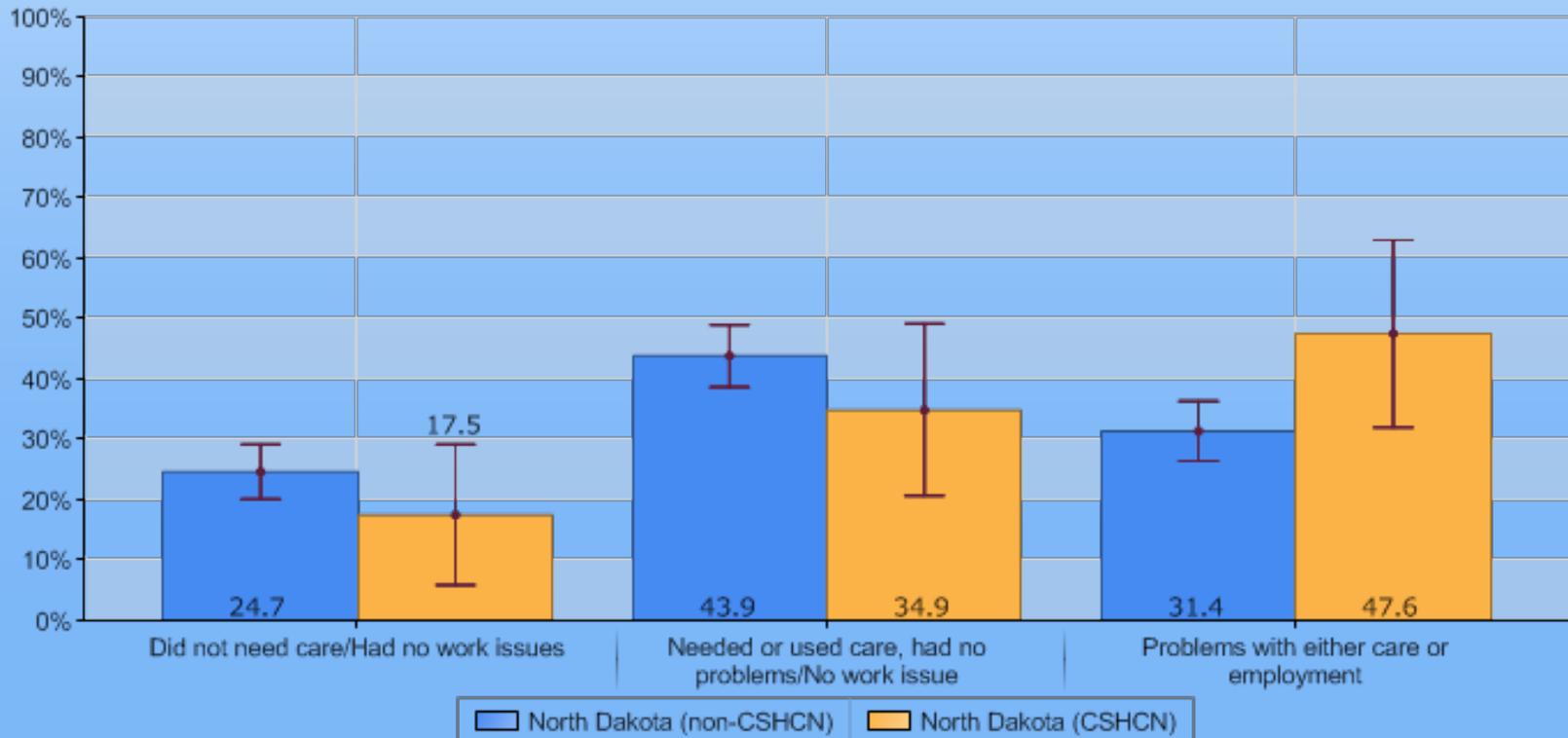
Child Care / Day Care

10+ Hours of Child Care Per Week from a Non-Relative
Children Age 0-5 Years Only
North Dakota vs. Nationwide



Child Care / Day Care

Children Whose Parents Report Child Care Issues
During the Past Month and/or Past Year
Children Age 0-5 Years Only
North Dakota



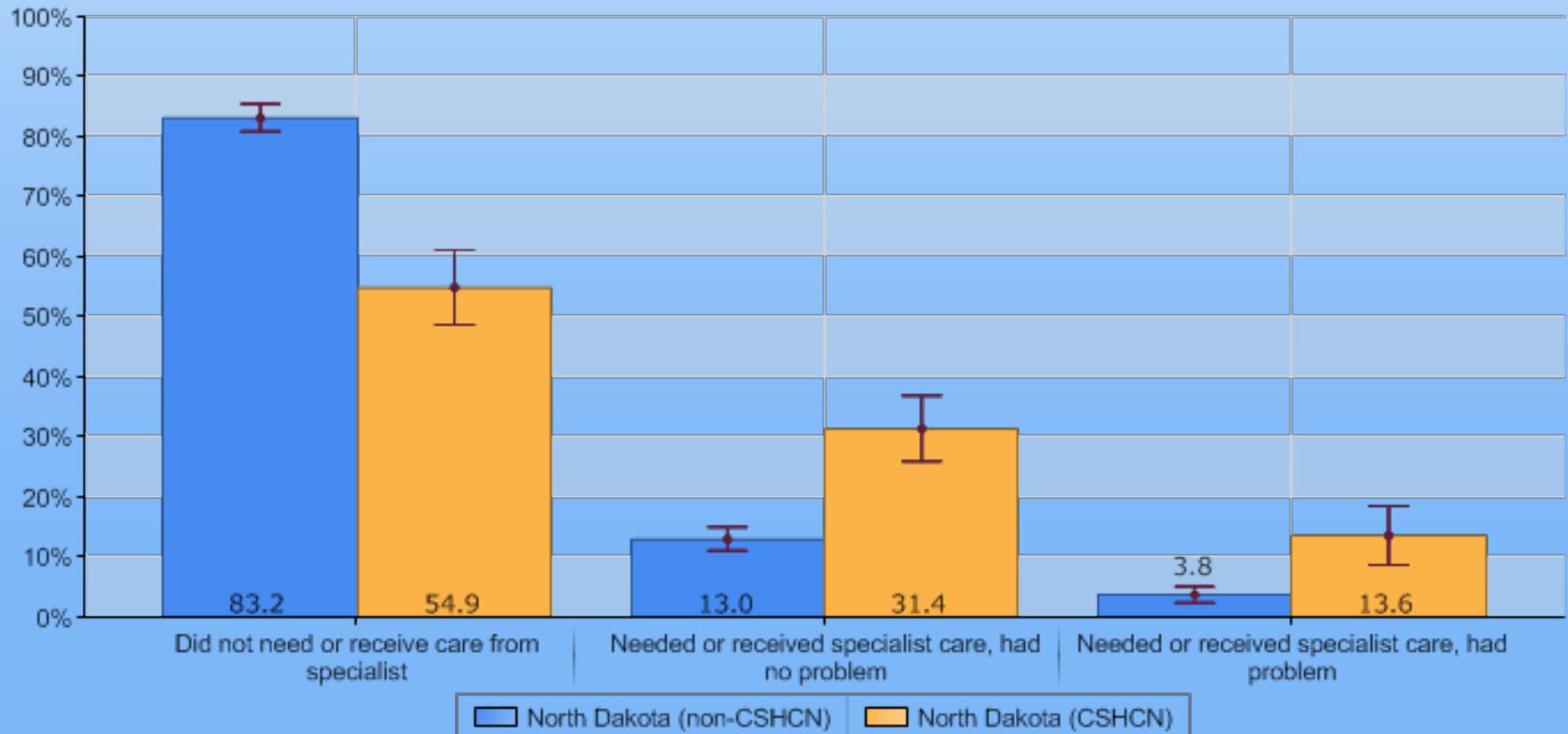
Children with Special Health Care Needs (CSHCN or CYSHCN)



Therapy

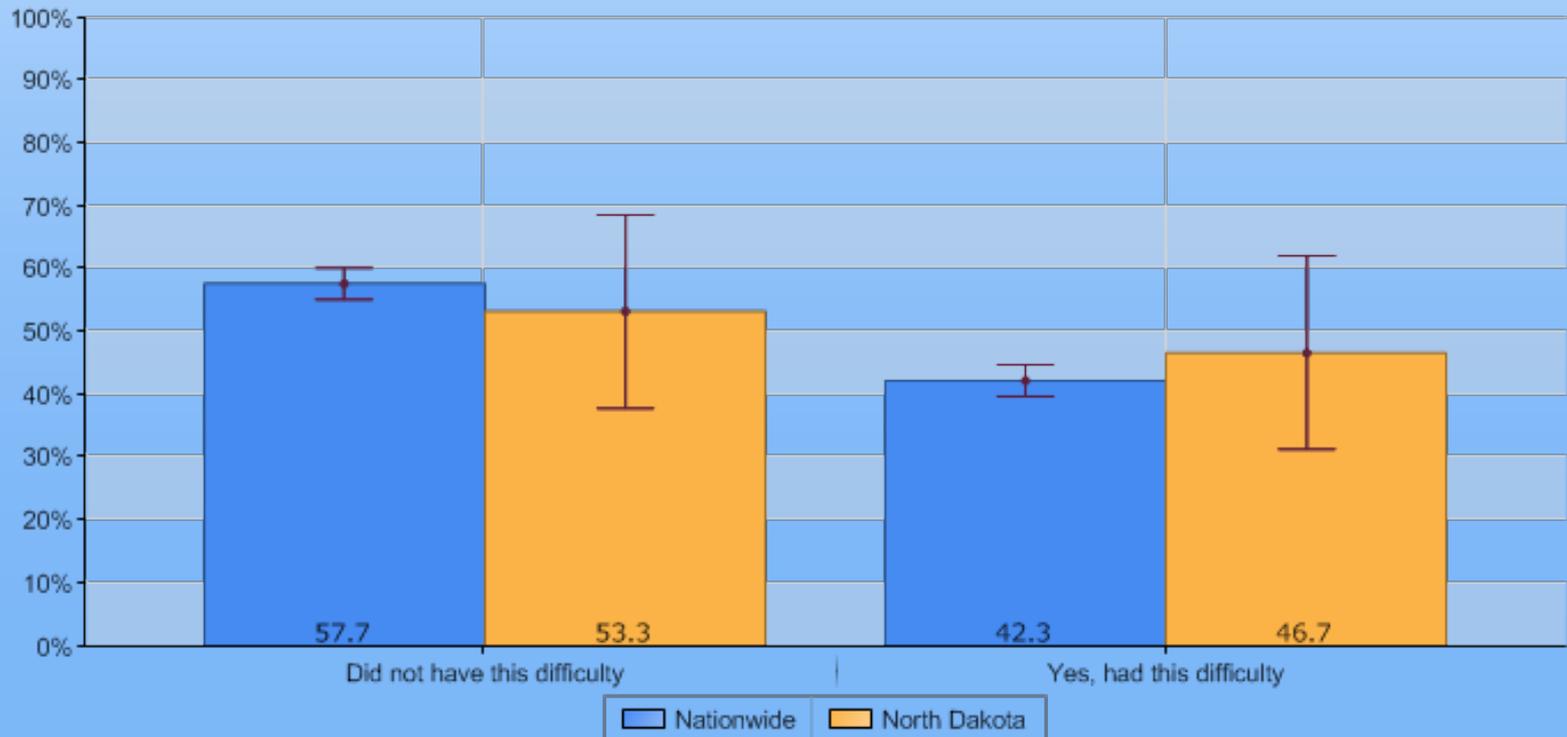
Availability of Health Care Providers

Problems Accessing Needed Specialist Care Children Age 0-17 Years North Dakota



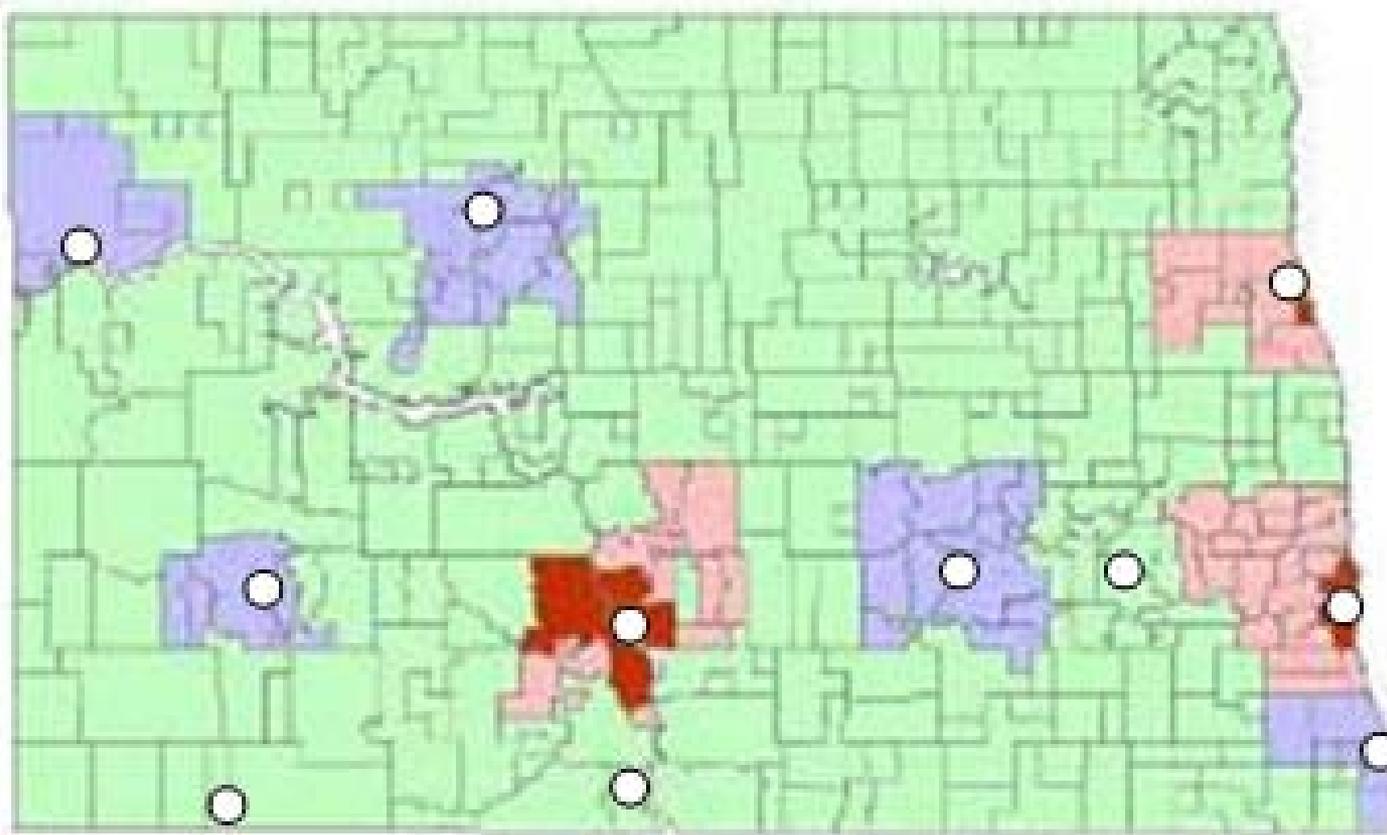
Availability of Health Care Providers

**CSHCN Whose Families Experienced Difficulties Using Services for Child Because They Could Not Find Providers with Necessary Skills --
for CSHCN With One or More Difficulties Only**



Availability of Health Care Providers

Population Distribution of CSHCN and location of Pediatricians/ Pediatric Specialists in ND



- Urban Core
39.1%
- Suburban
4.3%
- Large Town
21.7%
- Small Town/Rural
34.9%
- Pediatricians/
Pediatric Specialist
Location

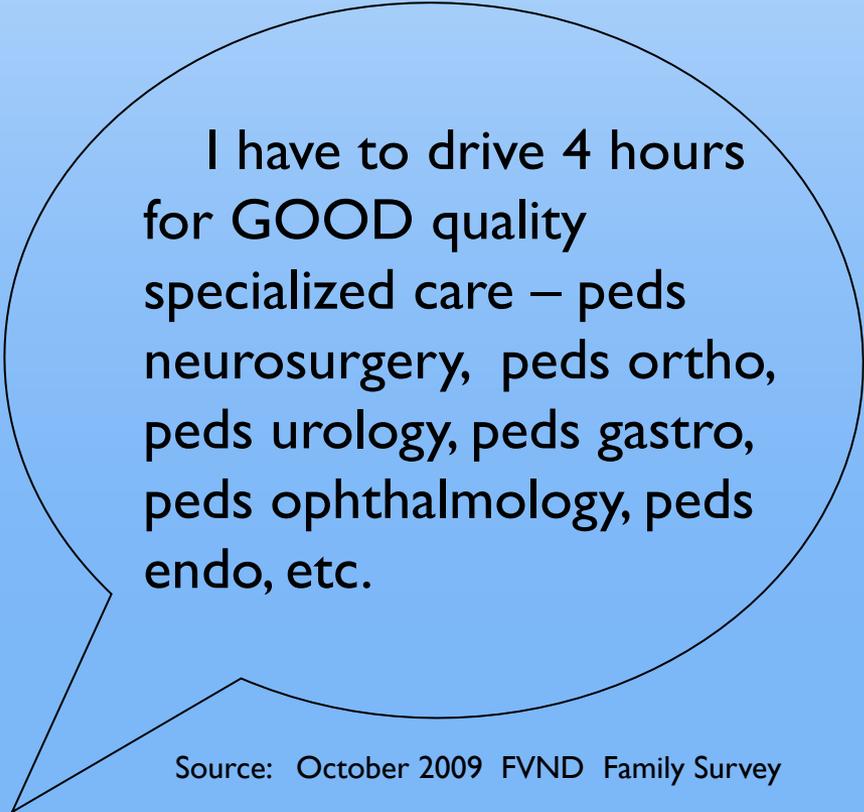
Availability of Health Care Providers

Health Professions Shortage Areas

- Primary Care 81%
- Mental Health 90%
- Oral Health 28%

Source: Center for Rural Health Report, Brief:
An Environmental Scan of Health and
Health Care in North Dakota, June 2009

Family Perspective on Availability of Pediatric Specialists

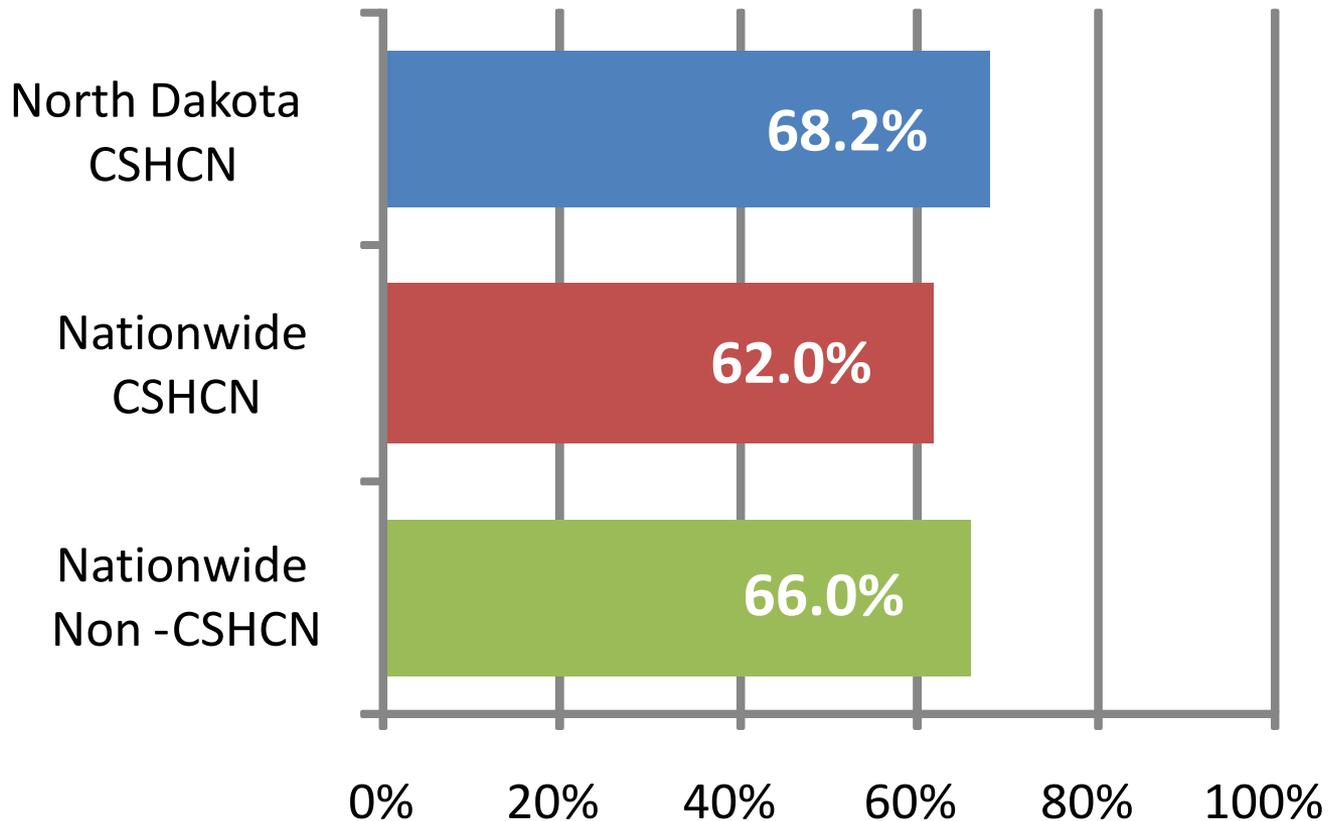


I have to drive 4 hours for GOOD quality specialized care – peds neurosurgery, peds ortho, peds urology, peds gastro, peds ophthalmology, peds endo, etc.

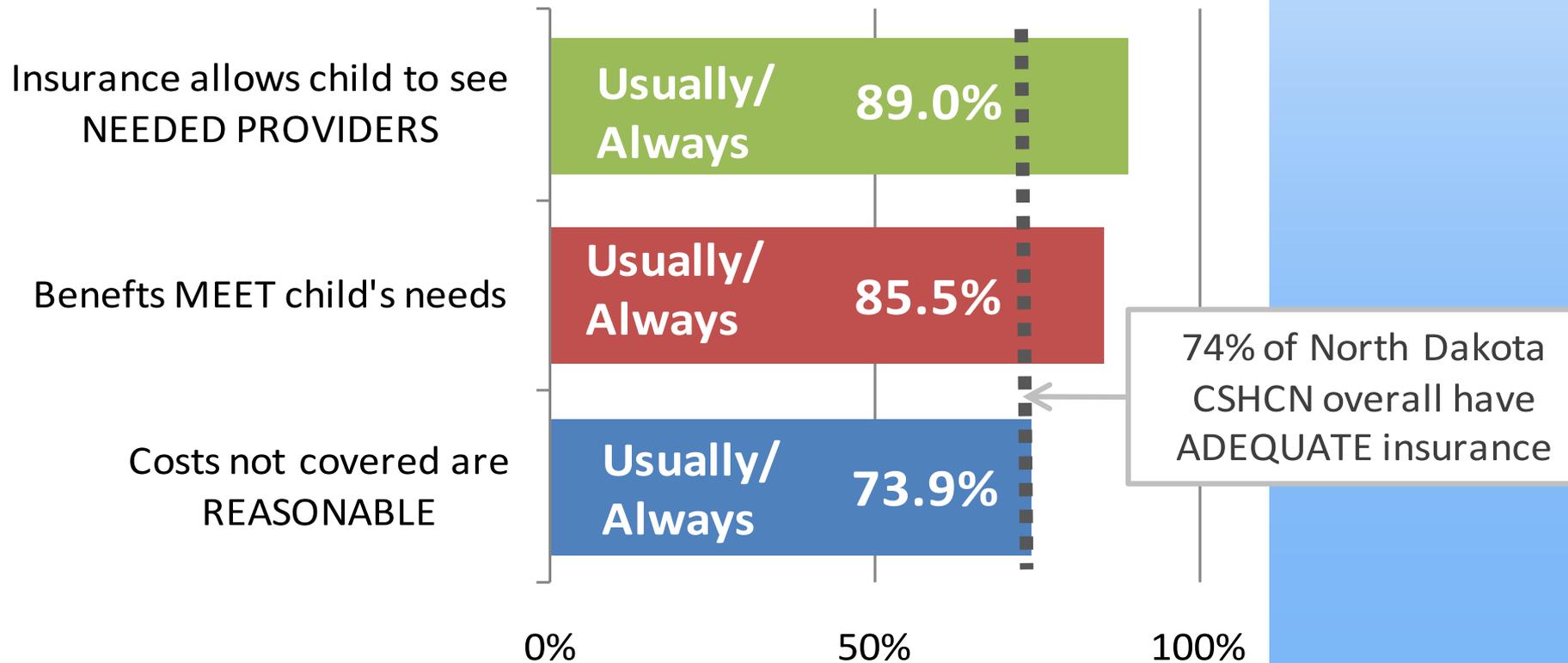
Source: October 2009 FVND Family Survey

Uninsured or Underinsured

All Families of CSHCN Will Have Adequate Private and/or Public Insurance to Pay for the Services They Need



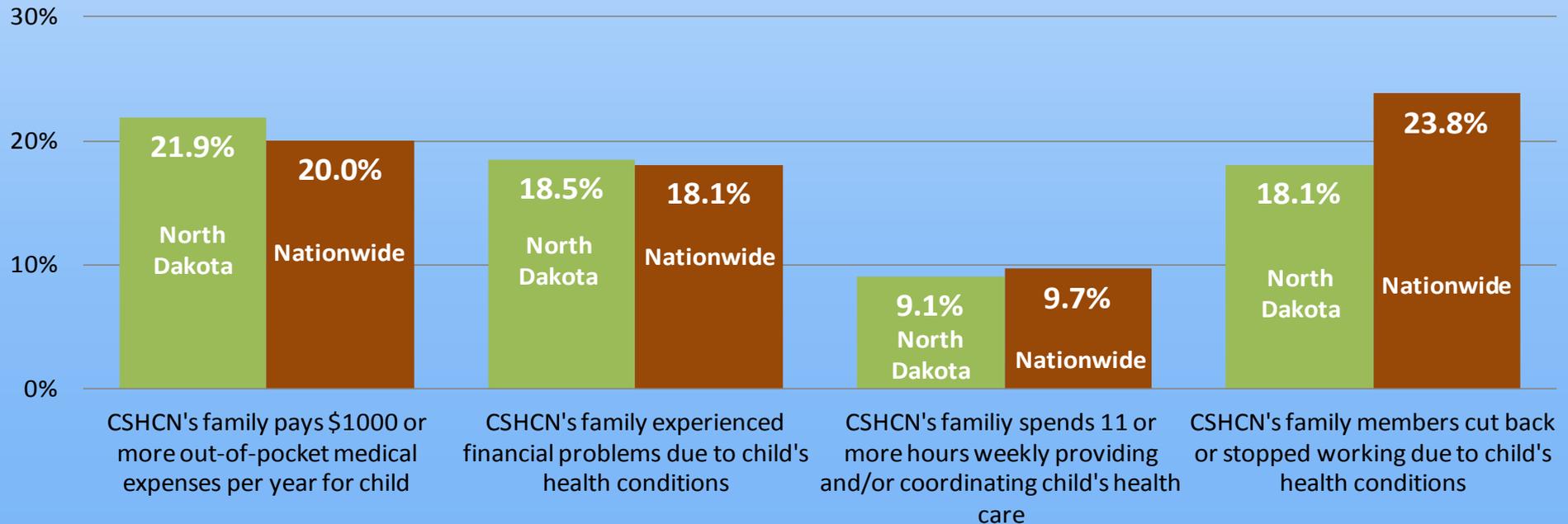
Uninsured or Underinsured



Uninsured or Underinsured

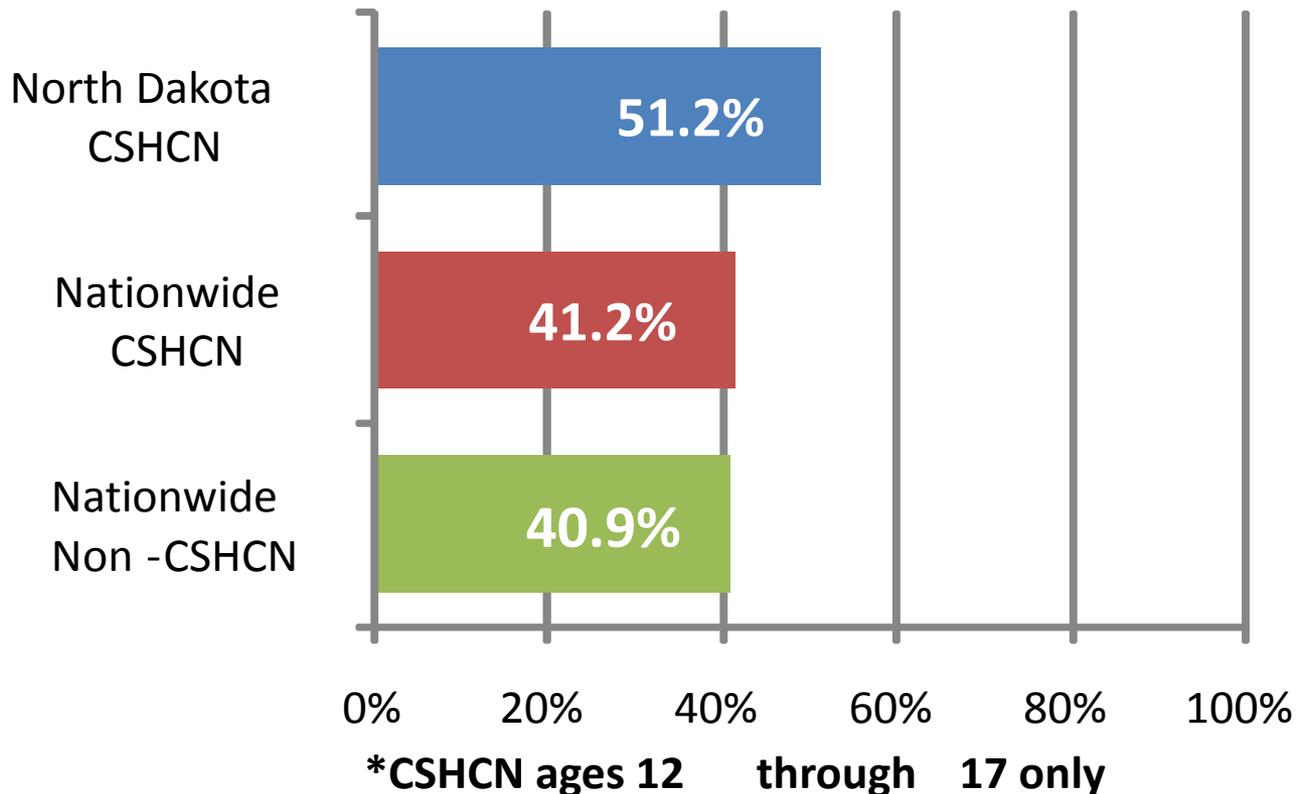
North Dakota vs. Nation

Percentage of CSHCN Who Met Each of Four Measures of Family Impact



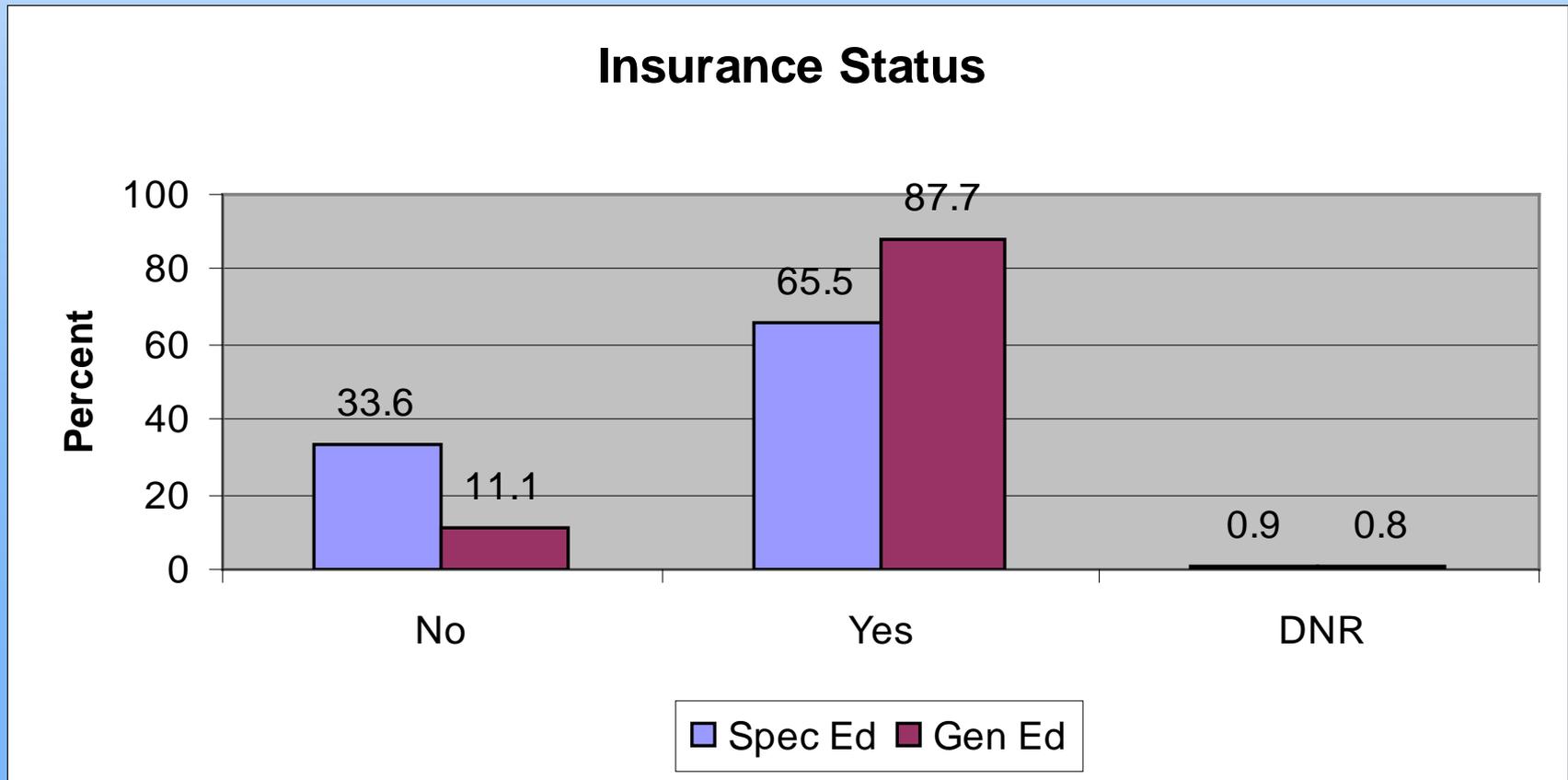
Transition to Adulthood

All Youth with CSHCN Will Receive the Services Necessary to Make Appropriate Transitions to Adult Health Care, Work and Independence



Transition to Adulthood

Pediatric to Adult Health Care



Transition to Adulthood

School to Work/ Secondary Education and Home to Independent Living

Currently Employed	Special Education	General Education
No	26.1%	33.0%
Yes	73.6%	66.7%
DNR	0.3%	0.4%
Secondary Education	Special Education	General Education
No	52.4%	14.6%
Yes	46.1%	84.3%
DNR	1.5%	1.1%

Program Participation

- 2007 Vocational Rehabilitation: 6,775
- 2007 Independent Living Services: 5,519

Source: ND Transition Follow-Up Annual Report Spring 2008
and ND State Rehabilitation Council Annual Report to the Governor FFY 2007

Children with Special Health Care Needs (CSHCN or CYSHCN)



Safe and Stable Environments

Abuse and Neglect

6,982 – 4.9% of children 0 to 17 suspected of being abused or neglected in 2008

Foster Care

2,134 - 1.4% of children 0 to 18 living in foster care in 2008

Juvenile Justice

5,555 children 10 to 17 referred to Juvenile Court in 2008

Other Priority Needs – Condition/Disease Management

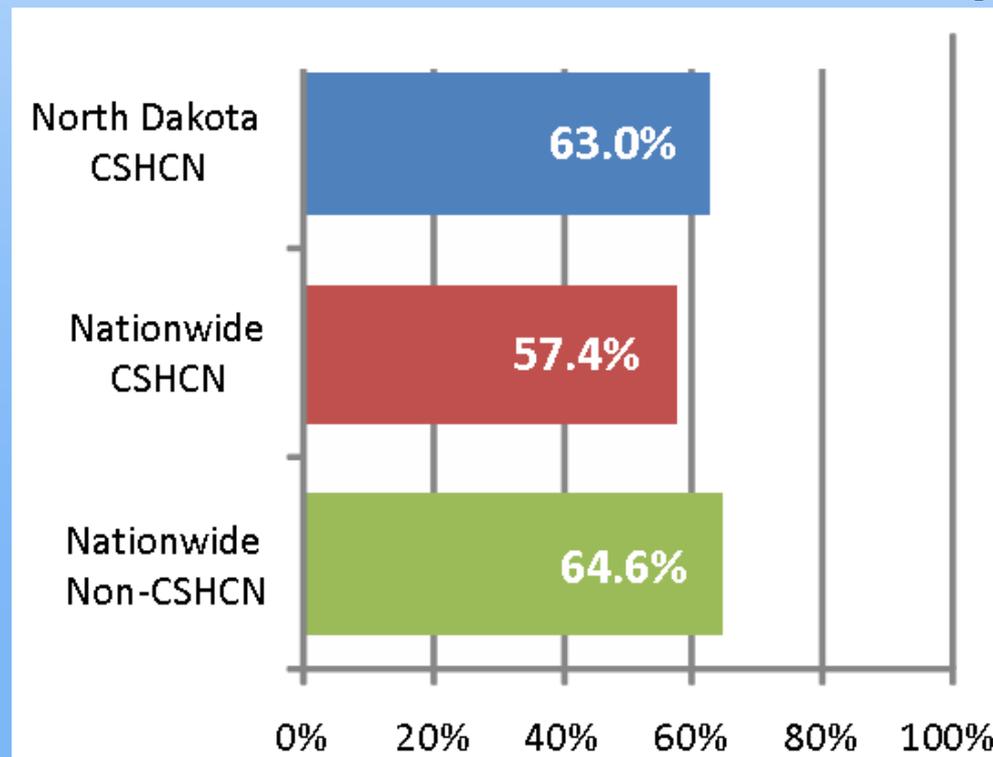
Prevalence* of Health Conditions Among CSHCN North Dakota and United States, 2005-2006

Condition	ND %	US %	Condition	ND %	US %
Allergies	42	53	Autism or autism spectrum disorder	NA	5
Asthma	31	38	Joint problems	NA	4
ADD/ADHD**	34	30	Seizure disorder	NA	4
Depression, anxiety or emotional disorder	21	21	Heart problems	NA	4
Migraine / frequent headaches	13	15	Blood problems	NA	2
Mental Retardation	11	11	Diabetes	NA	2
			Cerebral palsy	NA	2

* Some children have more than one condition **Attention deficit disorder or attention deficit hyperactivity disorder

Other Priority Needs – Parents and Youth as Decision Making Partners

Families of Children with Special Health Care Needs Will Partner in Decision-making at All Levels and Will Be Satisfied with the Services They Receive



Children with Special Health Care Needs (CSHCN or CYSHCN)



Credits

Our appreciation and thanks to the “many” people that made contributions to this process!

Next Steps



Consensus and Prioritization:

- Deb Nelson
- Lydia Camp



Thank You!

*For contributing to
this very important process.
Your involvement will benefit
North Dakota's Title V population.*