

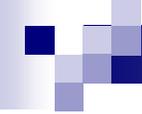
# Children with Special Health Care Needs

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# Overview

- CSHCS Program
  - Premature birth
  - Linkage with Birth Defects
  - Enrollment
- National CSHCN data
  - Title V indicators
  - Impact on Parents
- Epilepsy

# CSHCS Program Overview

## ■ Eligibility

- Based upon diagnosis (ICD-9) ~ 2,600 diagnoses
- Age 0-21, life for CF and Hemophilia
- Not limited by income

## ■ Benefits

- Final pay source for health care claims
- Care coordination
- Parent networks

## ■ Data Source: Michigan Data Warehouse – administrative data

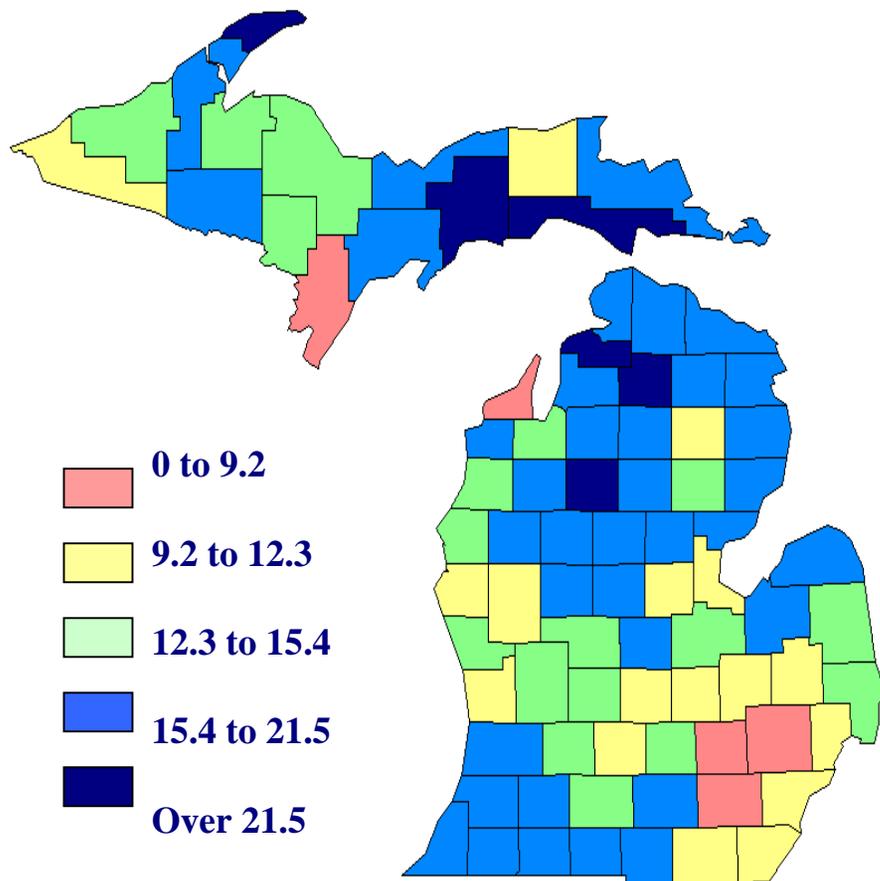
# CSHCS Population Profile

Age	N	%
0 to 4	8,689	23.8
5 to 9	9,016	24.7
10 to 14	8,517	23.4
15 to 19	7,640	21.0
20+	2,579	7.1

Gender	N	%
Female	16,372	44.9
Male	20,068	55.1

Race/Ethnicity	N	%
White	25,135	69.0
Black	8,280	22.7
Native American	169	0.5
Hispanic	1,418	3.9

Enrollment rate (per 1,000 children) in CSHCS, ages 0 to 17 years - 2006



# Gestational age among CSHCS enrollees born 1992-2003 (A) and 2001-2003 (B)

**[A]**

Enrollment Year	Very Preterm < 32 Weeks		Moderate Preterm 33-36 Weeks		Term 37+ Weeks	
	N	%	N	%	N	%
<b>2001</b>	1693	14.3%	1634	13.8%	8543	72.0%
<b>2002</b>	2604	14.2%	2561	14.0%	13160	71.8%
<b>2003</b>	2360	13.2%	2456	13.8%	13036	73.0%
<b>Total</b>	3329	14.5%	3203	13.9%	16496	71.6%

**[B]**

Enrollment Year	Very Preterm < 32 Weeks		Moderate Preterm 33-36 Weeks		Term 37+ Weeks	
	N	%	N	%	N	%
<b>2001</b>	298	27.6%	171	15.9%	609	56.5%
<b>2002</b>	768	25.5%	497	16.5%	1751	58.1%
<b>2003</b>	1073	22.3%	768	16.0%	2973	61.8%
<b>Total</b>	1268	23.9%	845	15.9%	3203	60.3%

# CSHCS and Birth Defects

## Eligible Children with Birth Defects Enrolled in CSHCS by race, 1998-2003

- CSHCS data linked with BDR data
  - Identify missing BDR cases
  - Identify BDR children eligible for CSHCS

Race / Ethnicity	MBDR Cases with a CSHCS Diagnosis	CSHCS Covered (%)
White	29,820	24.0
Black	10,109	24.9
Amer. Ind.	205	28.8
Asian/PI	1,248	13.3
Hispanic	1,928	25.1
Arab	1,387	16.7
<b>Total</b>	<b>45,224</b>	<b>23.7</b>

# CSHCS Enrollment

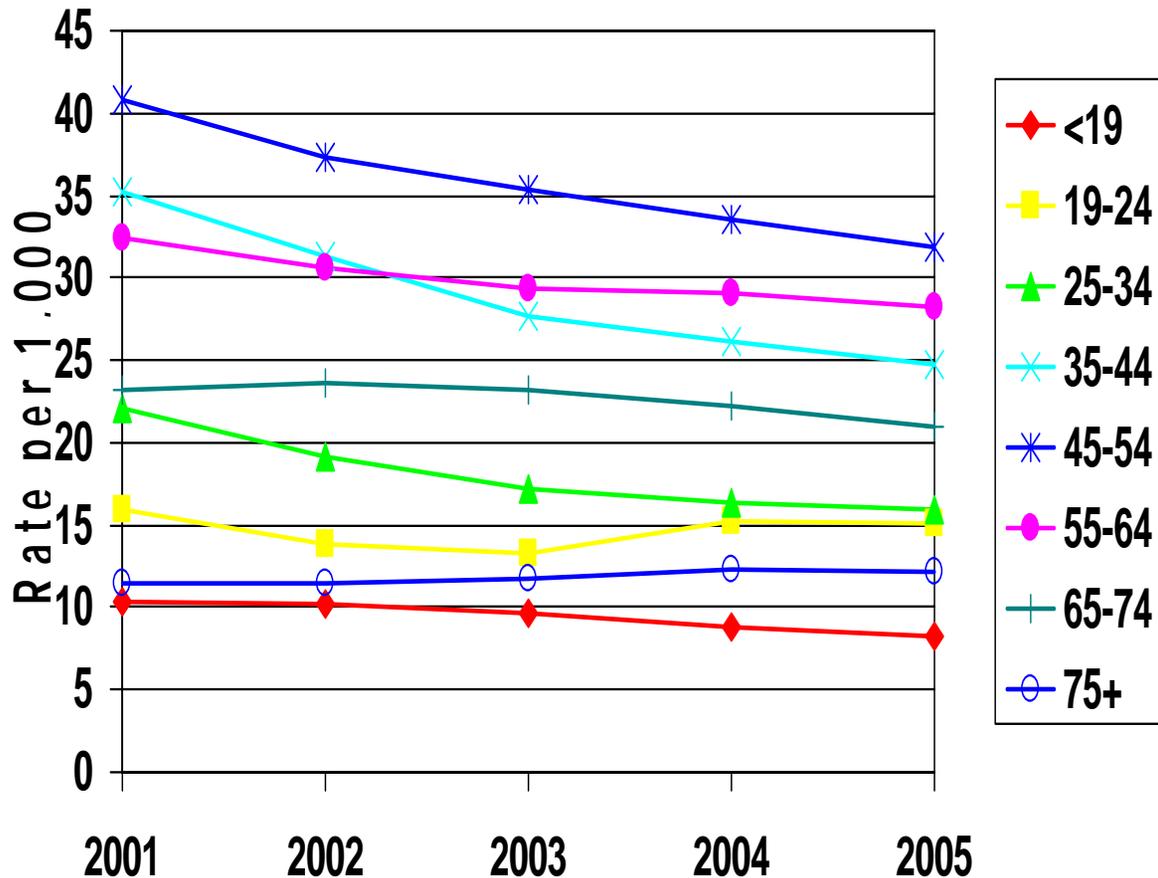
- Reduce time to enrollment, ages 0-2
  - Transfer to NICU
  - Medicaid at birth
  - Private insurance after birth
  - Health condition

**Average Number of Days Between Birth and CSHCS Enrollment, 2004 Michigan Birth Cohort, by Condition**

Condition	N	Avg Days
Respiratory Disorders	400	37
Heart Anomalies	170	47
Cleft lip/palate	88	51
Glandular/Metabolic	54	181
Anemias	44	186
Hearing loss	66	205
Cerebral palsy	127	238
Epilepsy	50	243
Asthma	87	266

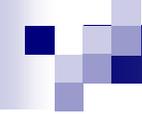
# Surveillance of Epilepsy

■ Epilepsy prevalence has decreased for every group except 19-24 year olds



■ Represents Medicaid and CSHCS populations

■ Dual enrollment of children with epilepsy rose from 38.6% to 46.4% between 2003 and 2005



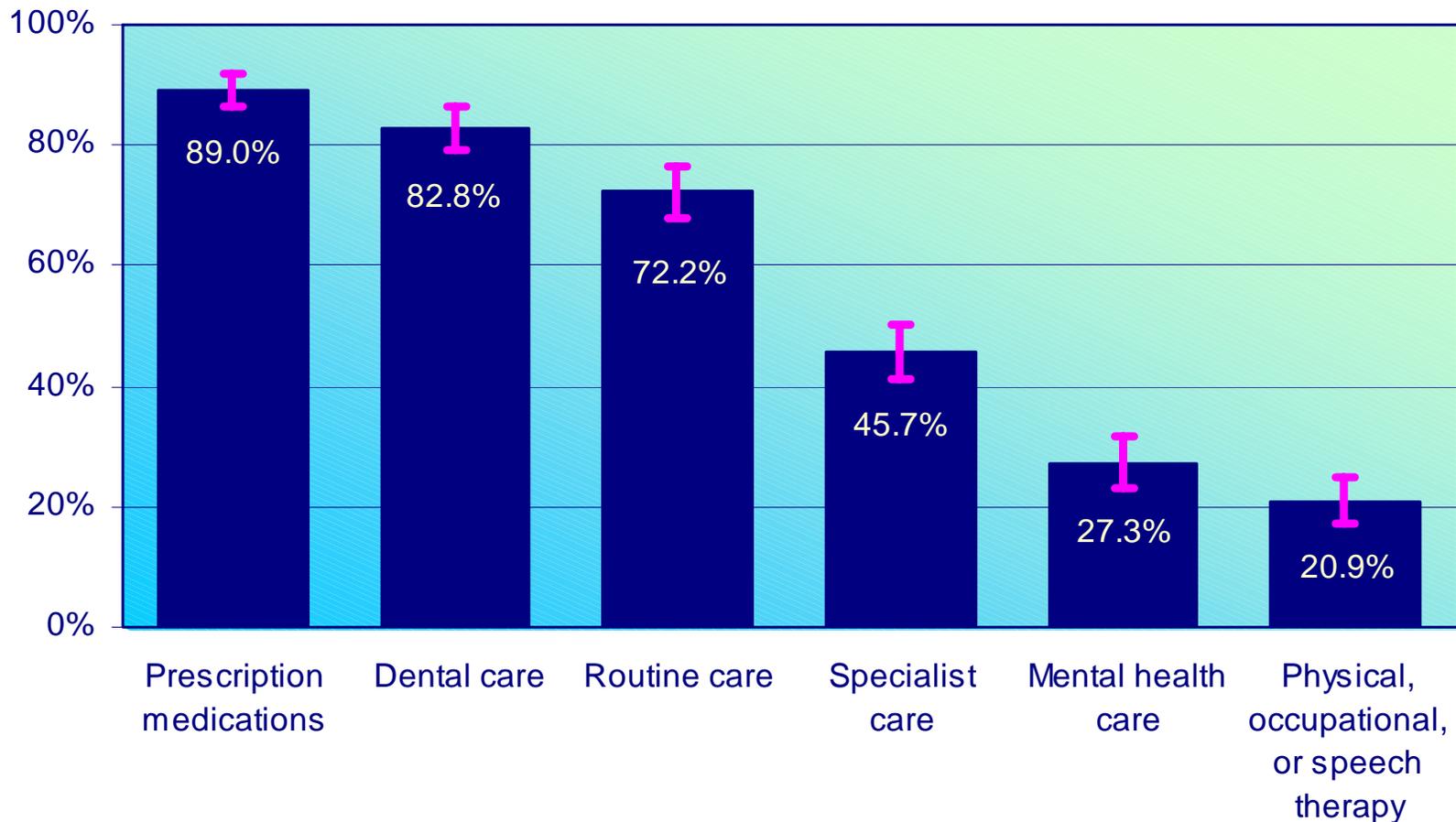
# National CSHCN data

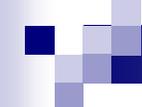
- 2001 National Survey of Children with Special Health Care Needs
  - Source for CSHCS Title V reporting
- 2003 National Survey of Children's Health
- Surveys to be repeated every four years

# Title V Reporting

- **#1:** The family participates in decision-making and is satisfied with care. **(61.3%)**
- **#2:** CSHCN receive coordinated ongoing comprehensive care within a medical home. **(55.8%)**
- **#3:** CSHCN are adequately insured for the services they need. **(66.5%)**
- **#4:** Children will be routinely screened for special health care needs. **(Unmeasured)**
- **#5:** CSHCN have services organized so their families can easily use them. **(75.7%)**
- **#6:** CSHCN receive the necessary services to make transitions to adult life including adult health care, work, and independence. **(5.3%)**

# Proportion of CYSHCN who reported a need for health care services by service category, NSCSHCN 2001



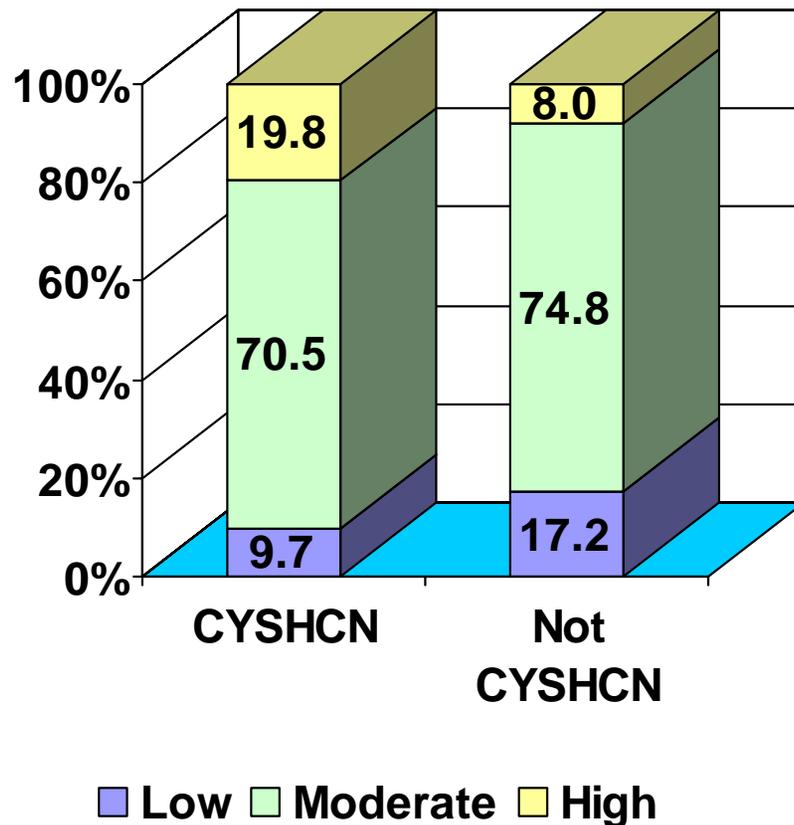


# Parent Aggravation Index (Parent Stress), NSCH 2003

- Four-question scale to classify parents with low, moderate, or high levels of parenting stress
  - Child is much harder to care for than most children?
  - Child does things that really bother you a lot?
  - Giving up more of your life to meet your child's needs than you ever expected?
  - Felt angry with your child?

# Parent Stress and Child Health

Parent Stress Level by Child's CYSHCN Status in Michigan, 2003 NSCH



- Increase parent stress:
  - CYSHCN
  - Non-private insurance
- Reduce parent stress:
  - Medical home
    - Personal doctor
    - Family-centered care
  - Support in parenting



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**Questions!!!!**