



Measuring coordination of care for children with special health care needs: Alternative methods and findings in national and state level surveys

Christina Bethell, PhD, MBA, MPH

Co-Authors: Kathleen Newton, BS and Debra Read, MPH

Oregon Health and Science University
The Child and Adolescent Health Measurement Initiative

Research Objectives

- To compare care coordination (CC) measurement methods and findings for children with special health care needs (CSHCN) in national and state level surveys.
- To identify measurement issues and options for consideration in future measurement development.

Surveys Assessed

- The National Survey of Children with Special Health Care Needs (NS-CSHCN: 2001, 2005)
 - 2001: n = 372,174 children age 0-17;
 - 38,866 CSHCN
- The National Survey of Children's Health (NSCH: 2003, 2007 (proposed))
 - 2003: n = 102,353; age 0-17;
 - 18,578 CSHCN
- The Consumer Assessment of Health Plans Survey, Children with Chronic Conditions (CAHPS CCC)
 - 14 health plans in one state Medicaid Program:
 - n = 10,792; age 0-12

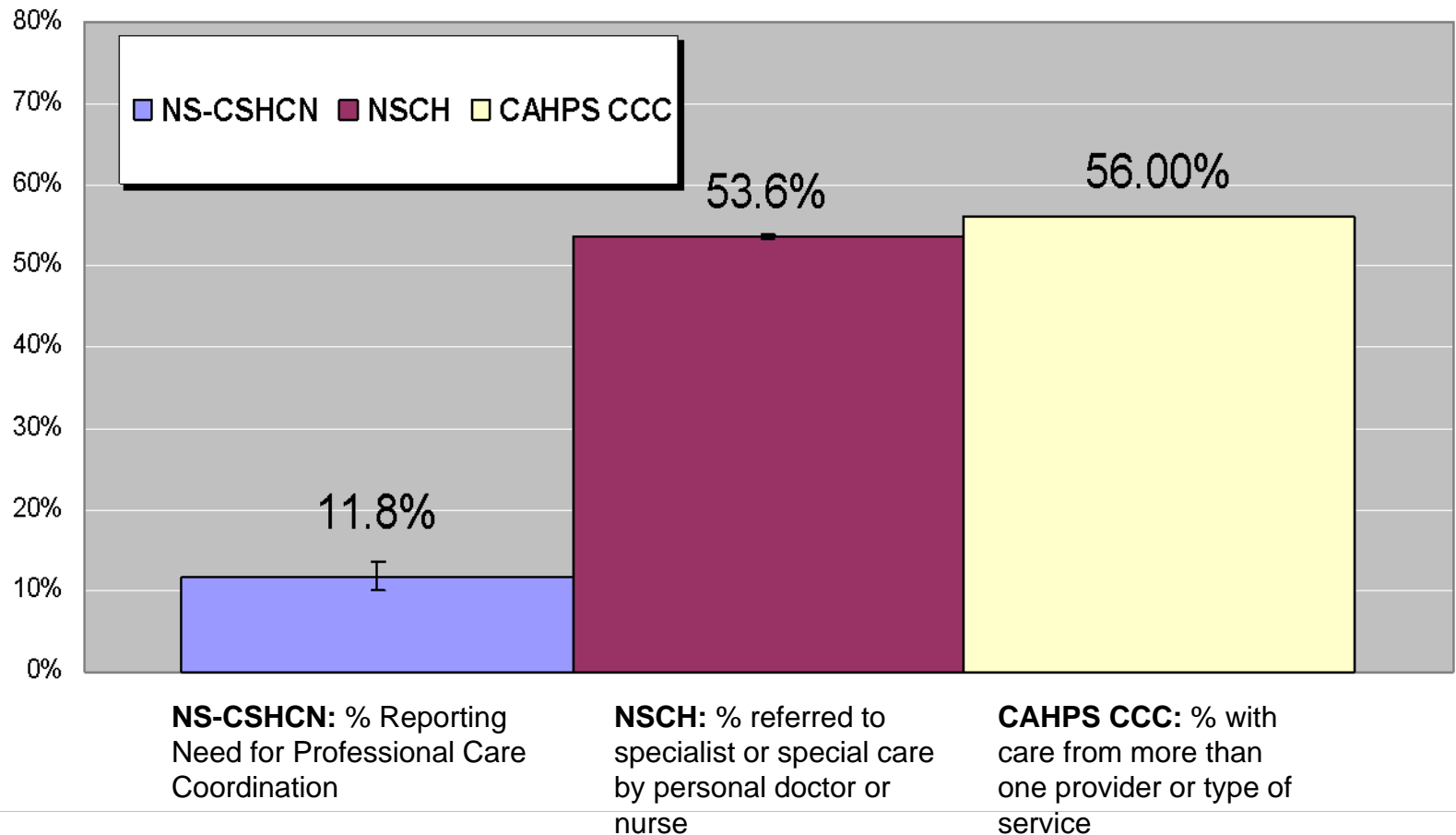
Methods

1. Identified and compared care coordination relevant survey items within and across surveys
2. Calculated measures produced by survey items and compared across demographic subgroups using bi-variate and multi-variate methods
3. Assessed convergent validity of existing measures with other measures of quality
4. Evaluated implications for advancing measurement of care coordination quality

Care Coordination (CC) Inclusion Criteria	CAHPS CCC	NS-CSHCN		NSCH	
		2001	2005	2003	2007
Parent perceived need for professional CC		√			
Parent reports child needs two or more types of services	√		√		√
Parent reports that child has a PDN and needed care from a specialist or other special care				√	

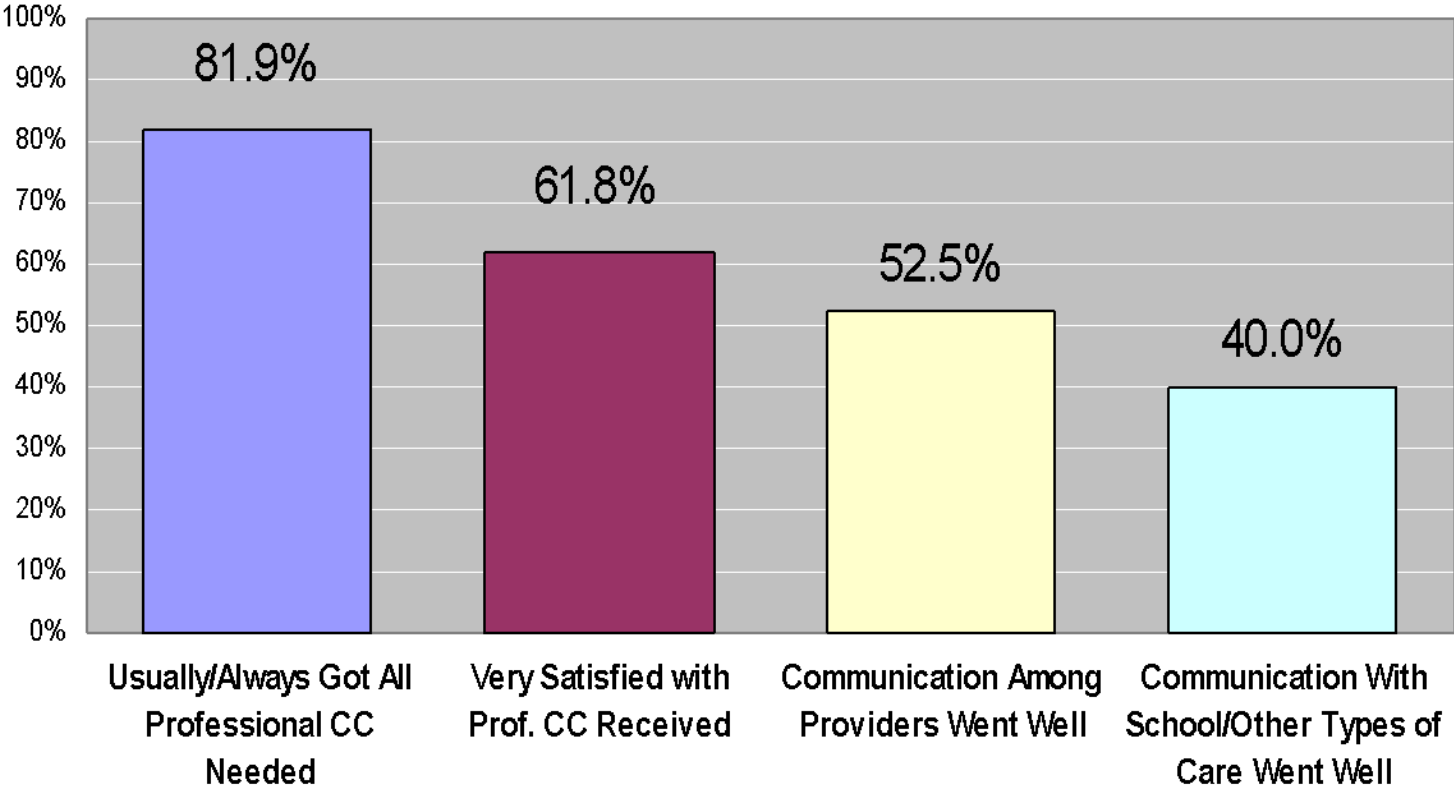
How many meet inclusion criteria?

Percentage of CSHCN Meeting Inclusion Criteria for Needing Care Coordination

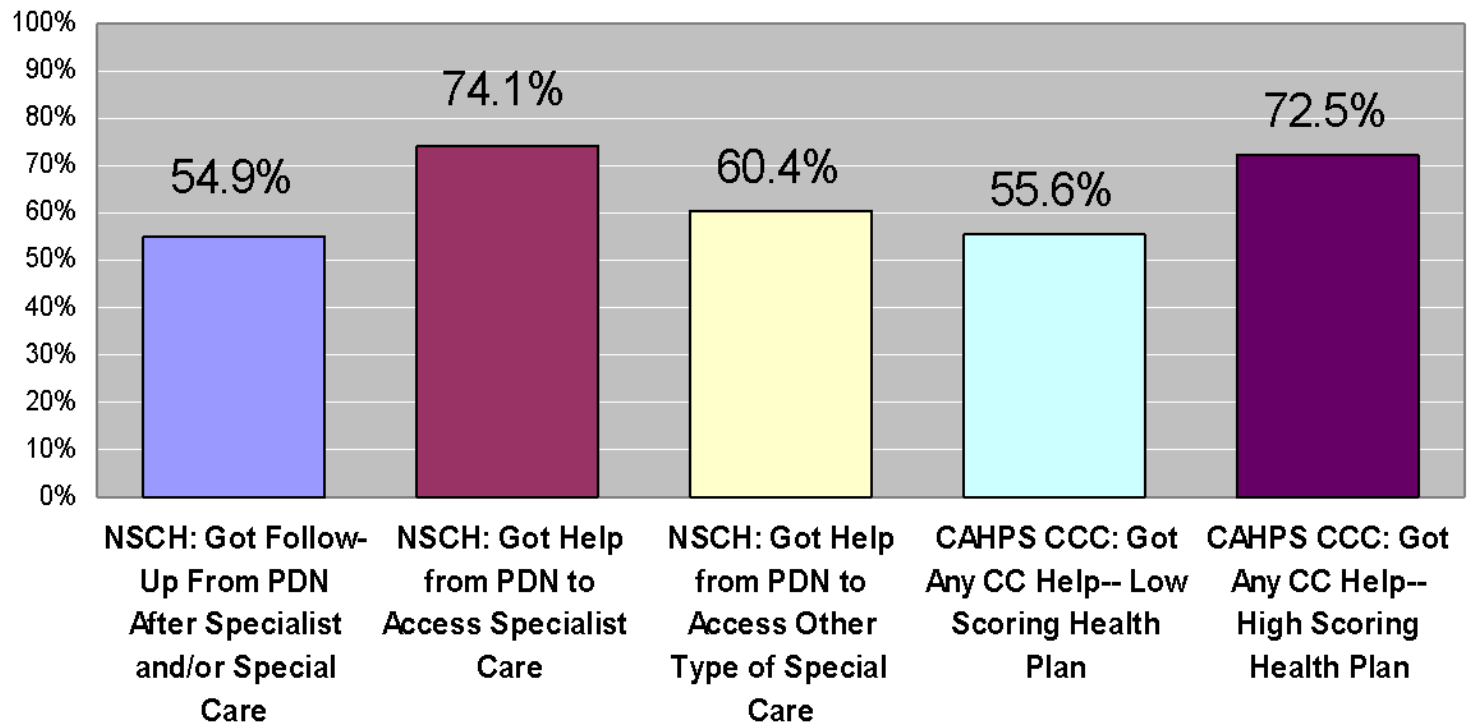


Care Coordination (CC) Measures	CAHPS CCC	NS- CSHCN		NSCH	
		2001	2005	2003	2007
Got follow up from PDN after specialist or special care?				√	
Got help accessing specialist or special care by PDN?				√	
Got all needed professional CC?		√			
Overall satisfaction with professional CC.		√			
Satisfaction with communication among providers and/or with school?	√	√	√		√
Does anyone help with CC?	√		√		√
Got all/could not have used more help with CC?			√		√

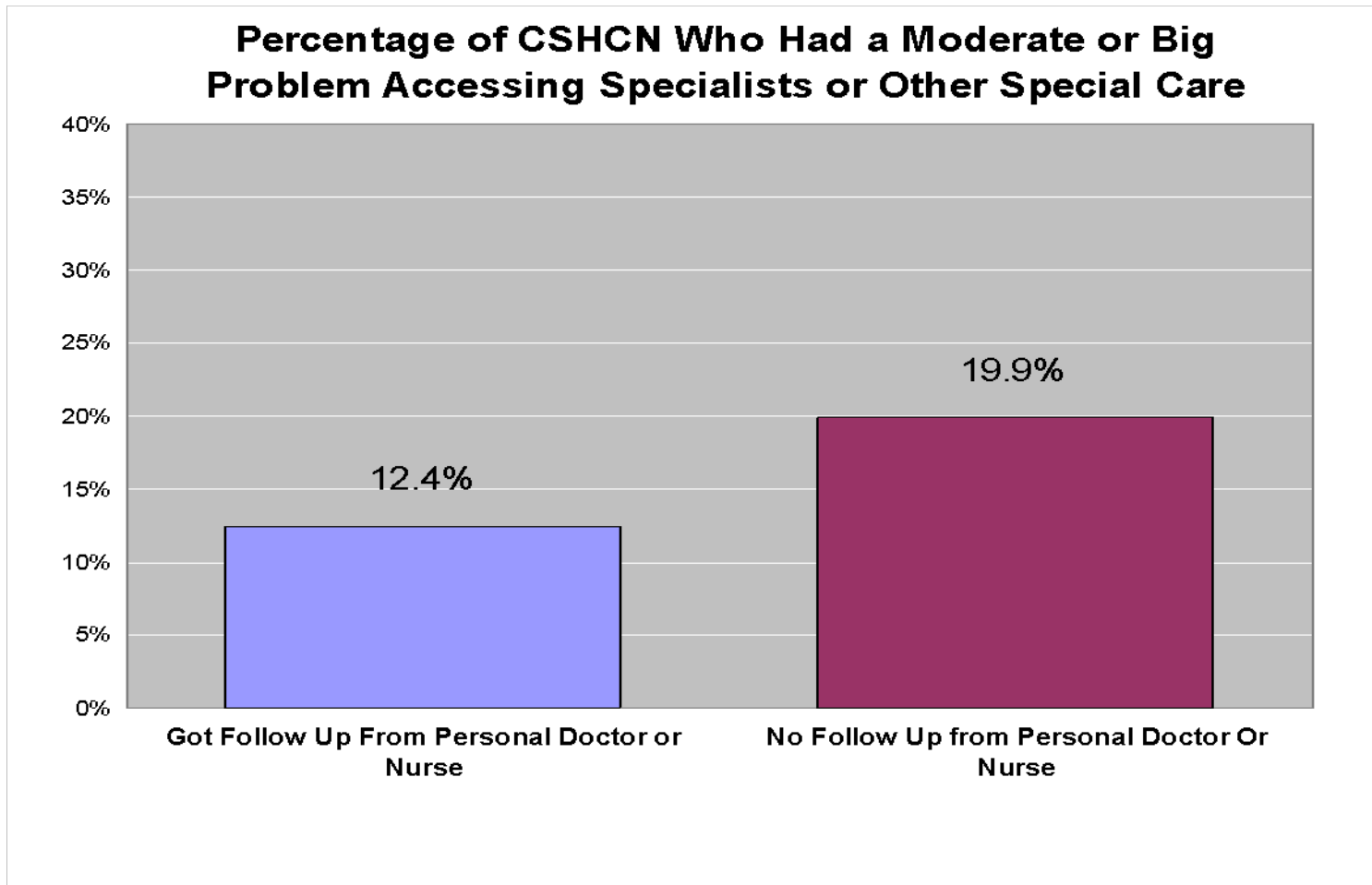
Percentage CSHCN Meeting 2001 NS-CSHCN Care Coordination Measure Criteria



Percentage CSHCN Meeting 2003 NSCH and Medicaid CAHPS CCC Care Coordination Measure Criteria

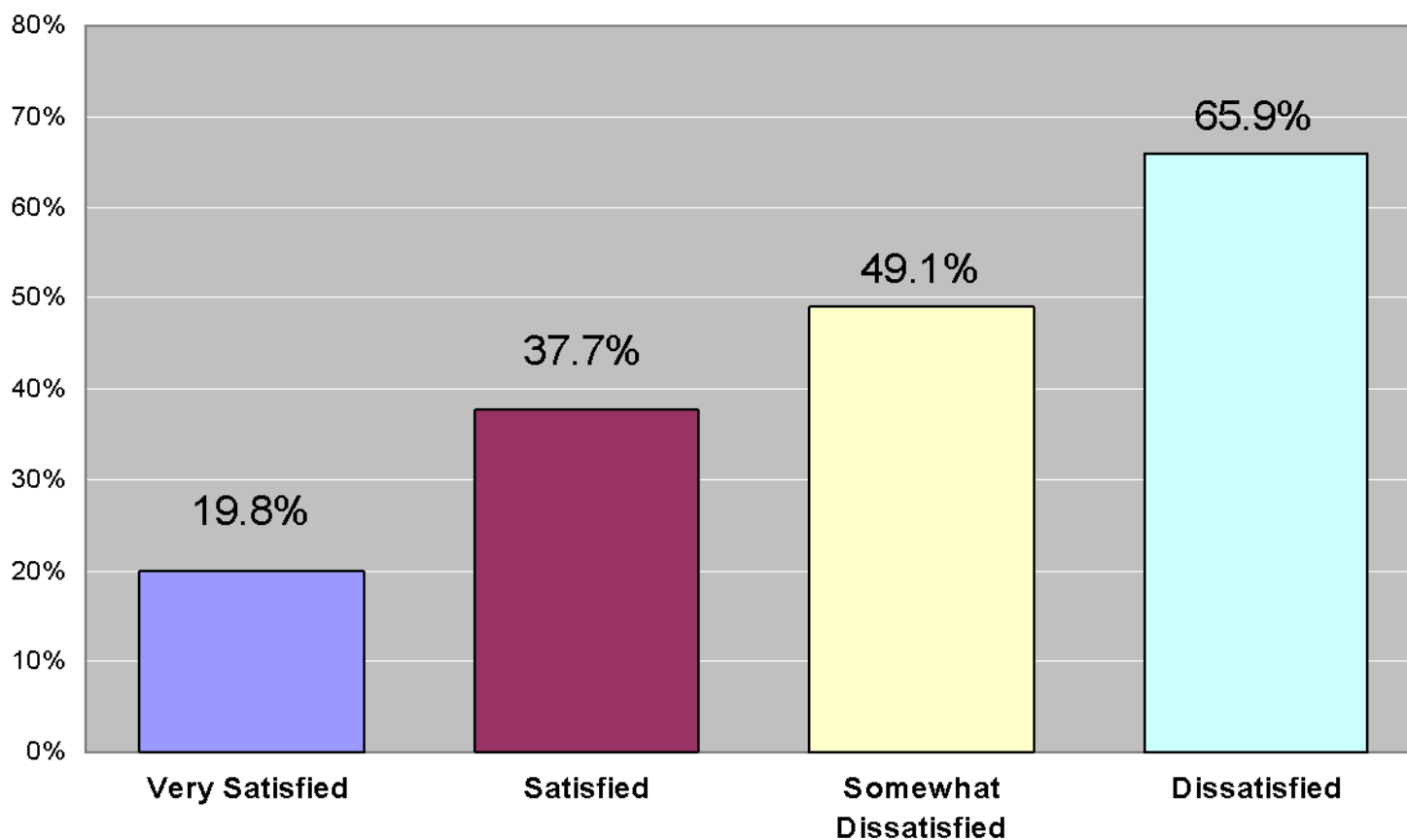


Association Between One NSCH Care Coordination Measure and Other Quality Indicators



Association Between One NS-CSHCN Care Coordination Measure and Other Quality Indicators

Percentage of CSHCN With One or More Unmet Needs for Specialized Services: By Level of Satisfaction with Professional Care Coordination Services



Key Differences in Approaches to Measuring Care Coordination

- **Inclusion criteria (objective vs. subjective)**
 - Perceived need for care coordination
 - Number/type of services needed/used
- **Anchor**
 - Professional care coordinator
 - Personal doctor or nurse
- **Evaluation of quality**
 - **Perceptions**
 - got all needed
 - satisfaction
 - **Reports of Experience**
 - Follow up after special care
 - Help with accessing care

Other Issues and Options

- Catch-22's
 - Need/Use Based Inclusion Criteria
 - Perceived Need Based Inclusion Criteria
- Scoring Issues
 - All or nothing vs. concept by concept
- Negative Indicators vs. Positive Indicators
- Linking and complimenting with other data sources
 - Repetition of tests?
 - Specialist and/or other special care no-show rates?

Some Conclusions

- About 40-82% of CSHCN Meeting Inclusion Criteria for Needing Care Coordination Meet Quality Criteria Depending Upon Measure
- Even though they are different, NS-CSHCN and NSCH care coordination measures for CSHCN exhibit reasonable concurrent validity with other measures of quality and access.

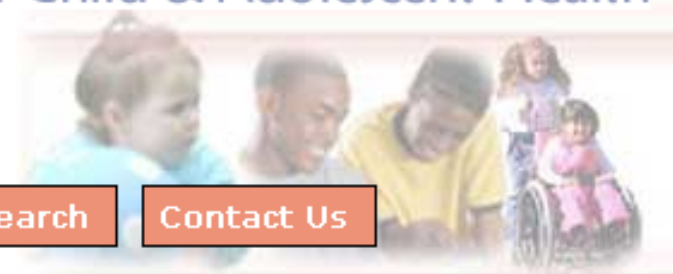
Some Conclusions

- Further assessment of the validity of existing measures is required.
- Future measurement development should seek to clarify and align concepts of care coordination.



Data Resource Center for Child & Adolescent Health

Your Data... Your story



- [DRC Home](#)
- [What's New](#)
- [Glossary](#)
- [Search](#)
- [Contact Us](#)

Get Connected!

- [Ask a Question](#)
- [Tell a Friend](#)
- [Sign Up for E-Updates](#)
- [Link To Us](#)
- [Answer Our Brief User Poll](#)

The Data Resource Center (DRC) on Child and Adolescent Health website puts national, state and regional survey findings right at your fingertips!

Start **HERE!** -click on a survey to begin

National Survey of Children's Health (NSCH), 2003



- Search and compare results on over 60 indicators of child health and well-being.
- View state and regional profiles on key measures.
- Explore survey content relevant to Healthy People 2010 objectives.
- Compare findings at every level for children from different age, race, income, or health status groups.

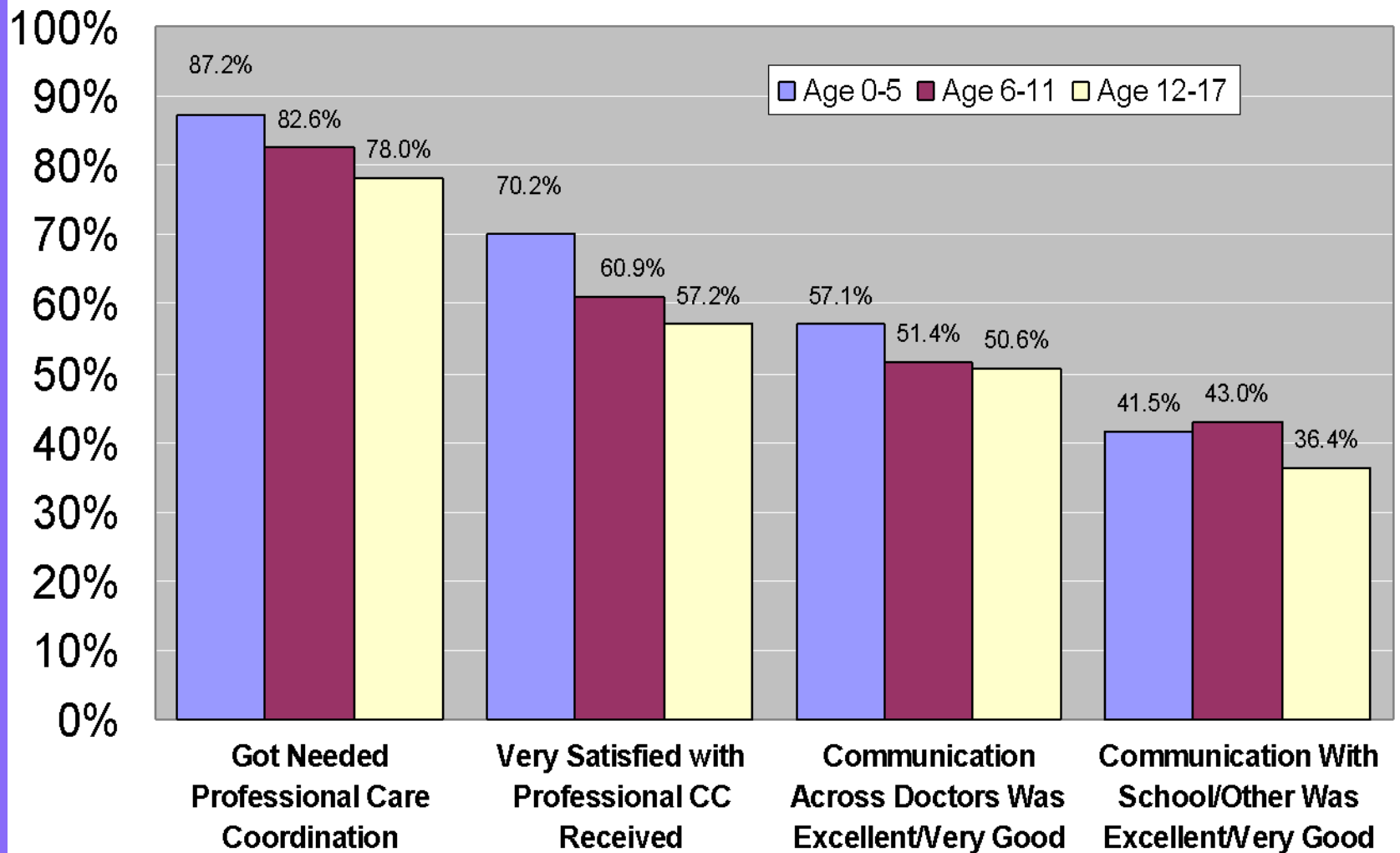
What you'll find:

- Interactive data search tools
- Personalized technical help by email or phone
- Information and examples to help you use data more

Inclusion Criteria Findings Variations by Child Characteristics

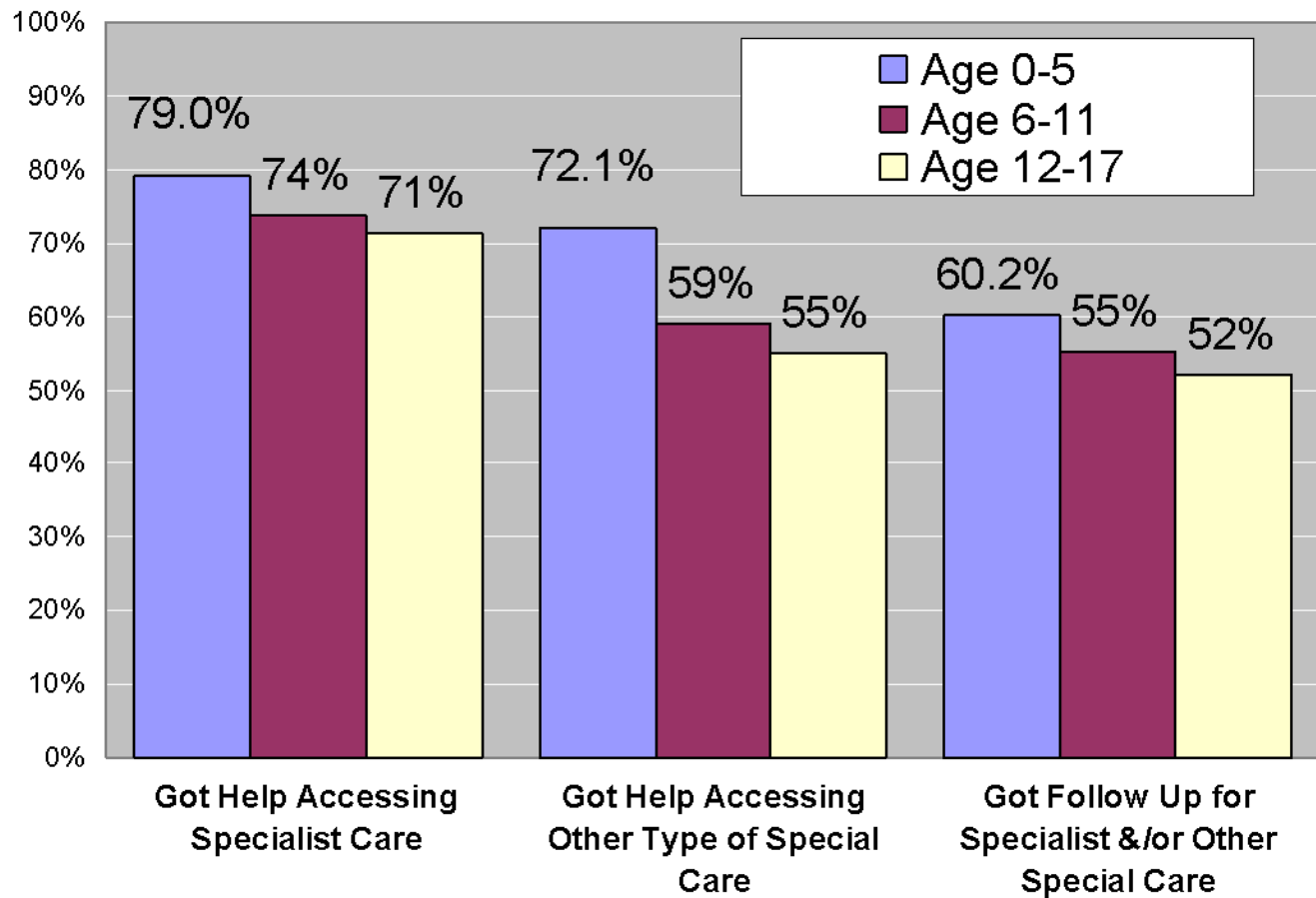
- Younger children are more likely to meet inclusion criteria for all surveys compared to older children
- Children from higher income households are less likely to meet NS-CSHCN criteria and more likely to meet NSCH criteria

Percentage of CSHCN Who Met NS-CSHCN Care Coordination Quality Criteria: By Child's Age



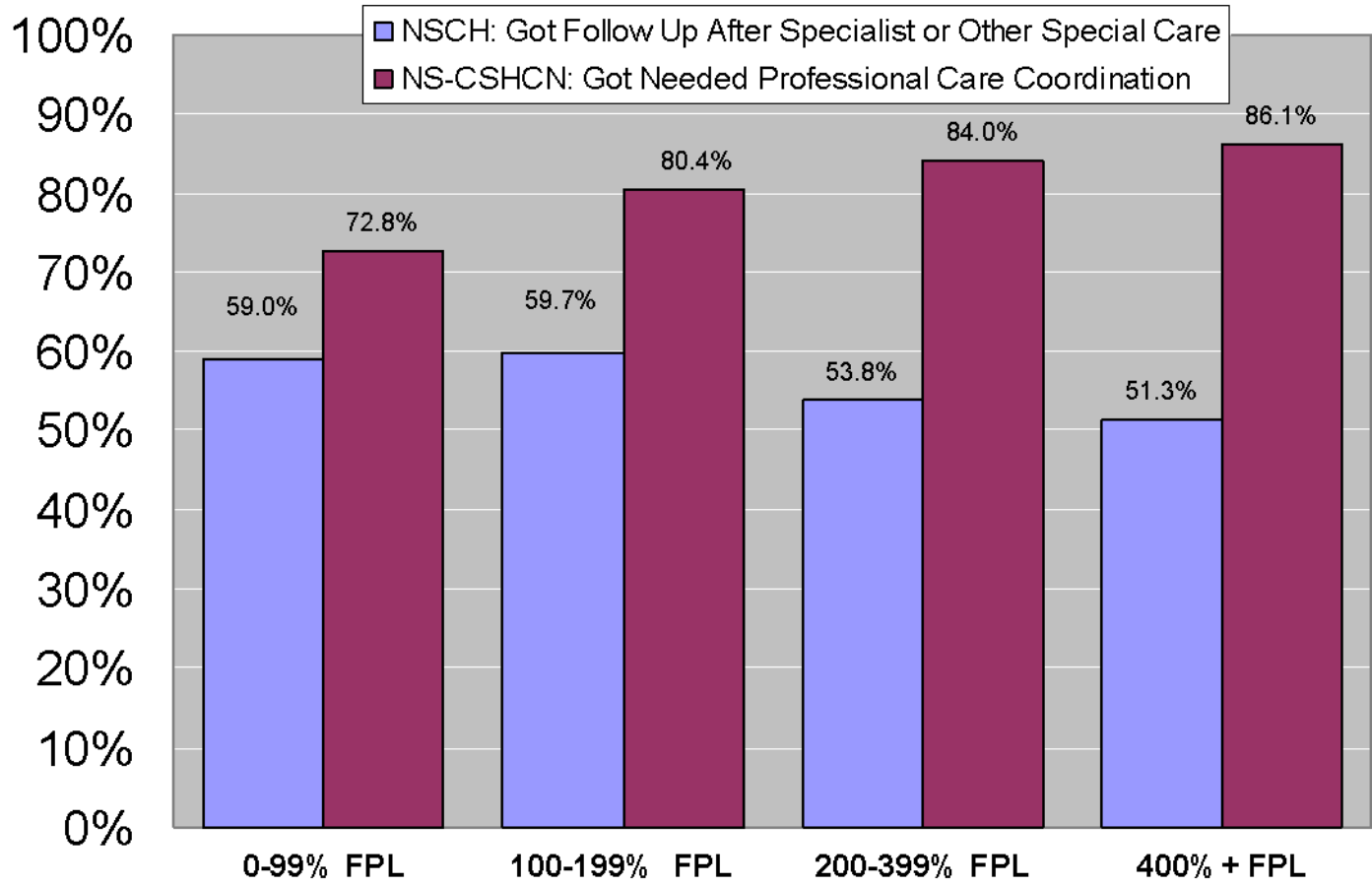
NSCH Quality Scores Variations by Child's Age

Percentage of CSHCN Who Met NSCH Care Coordination Quality Criteria: By Child's Age



Opposite Story

Percentage of CSHCN Who Met NSCH and NS-CSHCN Care Coordination Quality Criteria: By Child's Household Income



Background

American Academy of Pediatrics Statement on Care Coordination for Children with Special Health Care Needs

- “Care coordination occurs when a specified care plan is implemented by a variety of service providers and programs in an organized fashion”

Background

American Academy of Pediatrics Statement

Nine components of care coordination

1. **Planning** treatment strategies and care plan
2. **Monitoring** outcomes and resource use
3. **Coordinating** visits with sub-specialists
4. **Organizing** care to avoid duplication of diagnostic tests and services
5. **Sharing** information among health care professions, other program personnel and family
6. **Facilitating** access to services
7. **Planning** a hospital discharge
8. **Notification**, advanced planning, training of caregivers, education of local emergency medical services when a child with special health care needs lives in their community
9. **Ongoing reassessment** and refinement of the care plan

Inherent Challenges in Definition and Measurement Different Care Coordination Roles and Range of Players Suggested by AAP Statement

- Care Coordination Roles
 - Partner
 - Planner
 - Gatekeeper
 - Advocate
 - Arbitrator
 - Integrator
 - Accountant
- Care Coordination Players
 - Primary provider
 - Individuals in each service and setting in which child receives care
 - Family or Adolescent
 - Payers
 - Professional care coordination or case manager

Background

American Academy of Pediatrics Statement on Care Coordination for Children with Special Health Care Needs

- Provision of components of care coordination will vary depending upon:
 - The setting- health care system, educational system, social services, public health, home setting
 - Extent and multiplicity of child's needs, families strengths, services available, limitations of the payer and so on.
- Primary care coordinator responsible for:
 - ensuring child has a care plan
 - documenting completion of tasks and receipt and outcomes of services
 - Communicating with payers to obtain prior approval for services



National Survey of Children's Health

Data Resource Center - Your Data~Your story

- More Surveys
- What's New
- Glossary
- Search
- Contact Us

- NSCH Survey Home
- Start Data Query
- State Profiles
- Quick Guides
- Resources for Data Users
- Especially for Families

Begin by selecting a starting point below - and don't forget to check out the State Profiles option on the left.

Start HERE!



1. Learn about the survey



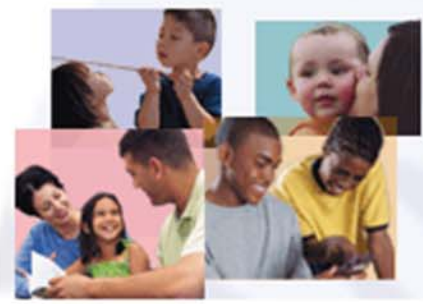
2. Search the data



3. Report your results

The Data Resource Center for the National Survey of Children's Health provides immediate access to the survey data - plus resources and assistance for interpreting and reporting your findings.

Use the interactive data query to search and





Data Resource Center Features

www.childhealthdata.org

- **Learn** about the surveys
- **Search and compare** national, state, and regional survey results and over 100 child indicators for subgroups of children (age, race, sex, income, insurance and health status, etc.)
- **Get resources** and ideas on how to report your findings in a valid and effective manner
- **Get expert help** – by e-mailing us your questions, plus get links to other data sets and resources



Common CSHCN Identification Method Used CSHCN Screener

- **Five item consequences-based**, parent reported screening tool that is not based on a condition check-list or ICD-9/10 diagnostic codes
- Identifies children and youth who **currently** experience one or more of five health or health need **consequences** due to an **ongoing** health condition.
 - Current use of **RX meds** for ongoing condition
 - **Above routine use** of medical, mental or other type of health services for ongoing condition
 - Need or use **specialized therapies** for ongoing condition
 - Need or use **treatment or counseling** for an ongoing emotional, developmental or behavioral health condition
 - **Functional difficulties**/problem doing things other children his/her age can do due to ongoing condition