



CARE COORDINATION DATA MONOGRAPH

Care Coordination for Children and Youth with Special Health Care Needs in Washington State

Washington State Department of Health, Division of Community and Family Health
Office of Maternal and Child Health, April 2010

Family Story

A child was having seizures 2-3 times per week, often at school. During the seizures, the school staff called 911. Afterward the child was sent home. This was difficult for the family and child. The mother was losing work hours and the child was missing too much school.

A Care Coordinator made a home visit to talk with the family. She then facilitated a meeting at the school with the family and everyone involved in the child's care. The Care Coordinator helped the school incorporate the parents' recommendations and wishes into the child's care plan. The plan also included teachers, classmates and other school staff on how to assist the child before, during and after a seizure.

BACKGROUND

Children and Youth with Special Health Care Needs in Washington State

In Washington State, an estimated 14%-18% of children and youth age 17 and younger have a special health care need.¹ Children and youth with special health care needs (CYSHCN) have chronic physical, developmental, behavioral, or emotional conditions. They require types and amounts of health and related services beyond those generally required by their peers.^{2,a}

What is Care Coordination?

The American Academy of Pediatrics defines care coordination as a process that “links children and youth with special health care needs and their families with appropriate services and resources in a coordinated effort to achieve good health.”³ Ideally, care coordinators partner with families to assure smooth transitions between systems and services. The care coordinators assist in accessing resources and services, making referrals, coordinating with specialty providers, dental providers, schools, and other agencies.

Care coordination is provided in a variety of settings such as a primary care provider's office or a community setting. In addition to medical care, CYSHCN may receive educational, developmental, and other services through different organizations and agencies. Each organization can vary greatly in its mission, eligibility criteria, services provided, and funding sources. Multiple entry points for receiving needed services can be confusing for families, creating a barrier to care.

Care coordination has a critical role in ensuring a medical home,^b and can also improve patient satisfaction.⁵ Other benefits of care coordination include reduced:

- emergency department visits.⁴
- hospital admissions.^{5,6}
- length of hospital stays.⁷
- inpatient charges.^{7,8}
- parental days of lost work.⁵

Many articles have been written about the characteristics, personnel, and reimbursement needs of medical practices that provide care coordination.^{4,9,10,11} In this report, we use survey data to focus on the children and youth who do or do not receive care coordination services in Washington State. We also examine where care coordination is provided and who needs more of it.

METHODS: Measuring Care Coordination

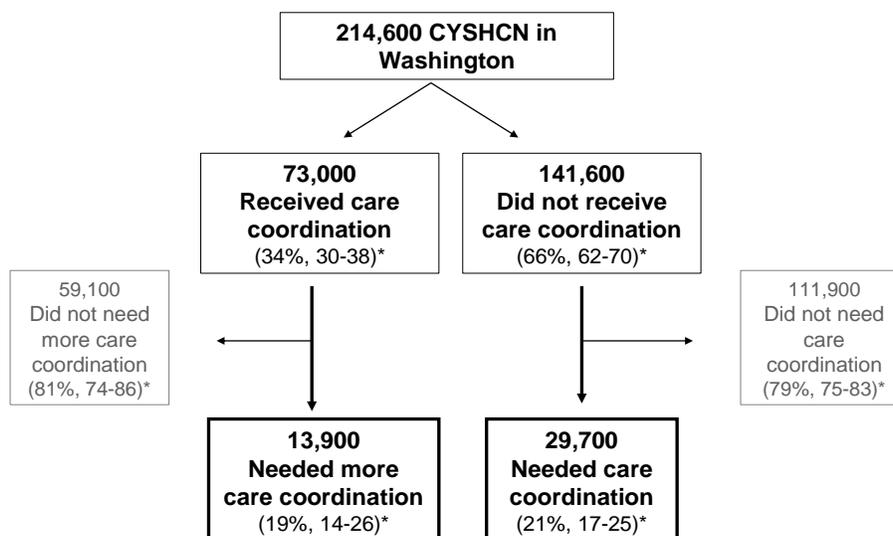
In 2005 and 2006 the Maternal and Child Health Bureau sponsored the National Survey of Children with Special Health Care Needs (NS-CSHCN). The Centers for Disease Control and Prevention (CDC) administered this telephone-based survey of parents or guardians. The survey only asked about care coordination provided by individuals other than the parent being surveyed. It collected state and national data on the prevalence of special health care needs among children and youth. The survey also collected information on demographics, health status, health care and care coordination.^c

This report presents survey data from Washington State and the U.S.^d We adjusted all results using demographic characteristics for potential confounding.^e Data are weighted for non-response and demographic characteristics.¹²

RESULTS:

Based on parental report, 34% of CYSHCN in Washington (95% Confidence Interval [CI]; 30-38)^f received care coordination. Of this group, 19% (95% CI; 14-26) needed additional care coordination. Approximately 66% (95% CI; 62-70) of CYSHCN did not receive care coordination. Among this group, 21% (95% CI; 17-25) needed care coordination (Figure 1).

Figure 1: Care Coordination among Children and Youth with Special Health Care Needs Washington State, 2005/06 NS-CSHCN



*95% Confidence Interval; for definition see Technical Notes.

Who is receiving care coordination?

Among CYSHCN in Washington, 34% (95% CI; 30-38) received care coordination; similar to the U.S. rate of 33% (95% CI; 32-34) (Table 1). CYSHCN in Washington who live in households **below 200% of the Federal Poverty Level (FPL)**^h were more likely to receive care coordination (43%), compared with those at or above 200% of the FPL (29%). There were no other significant differences by demographic or health condition status in Washington.

In the U.S., children ages 0-4 with special health care needs were more likely to receive care coordination than any other age group. In addition, children with a functional limitation^{13,i} or with public or public and private health insurance had a higher rate of care coordination (Table 1).

**Table 1: Percent of CYSHCN who Received Care Coordination
WA and U.S., NS-CSHCN 2005/06**

	WA (N = 794)		U.S. (N = 39,123)	
	%	95% CI	%	95% CI
Overall percentage	34	30 , 38	33	32 , 34
Ethnicity				
Hispanic	39	26 , 53	36	34 , 39
Non-Hispanic	34	30 , 38	33	32 , 34
Race				
White	32	28 , 36	32	29 , 34
Black	50	30 , 70	38	33 , 44
Asian	30	14 , 51	29	21 , 39
Multiple race/Other	39	28 , 50	35	30 , 41
Age of child*				
0-4	41	29 , 54	41	39 , 44
5-9	34	27 , 42	34	32 , 35
10-14	33	27 , 39	31	30 , 32
15-17	32	25 , 40	30	29 , 32
Poverty status*^				
< 200% FPL	43	36 , 51	40	38 , 41
≥ 200% FPL	29	25 , 34	29	28 , 30
Highest Education in Household				
≤ High School	40	31 , 50	40	38 , 42
> High School	32	28 , 36	31	30 , 32
Language spoken at home				
English	34	30 , 38	33	32 , 34
Non-English	37	21 , 57	39	34 , 44
Health insurance of child*				
Private	32	27 , 36	29	28 , 30
Public	38	29 , 47	42	41 , 44
Private and Public	36	23 , 52	41	38 , 44
Other	43	27 , 61	29	24 , 34
None	24	10 , 49	27	23 , 32
Functional limitation of child*				
No	33	29 , 38	31	30 , 32
Yes	36	29 , 44	40	39 , 42
Number of health conditions				
None	32	22 , 44	32	30 , 35
1-2	35	30 , 35	32	31 , 33
3+	32	24 , 41	37	36 , 39

*Significant difference for U.S., p < 0.05. Adjusted for poverty status.

^Significant difference for WA, p < 0.05. None of the demographics characteristics in this table were confounders.

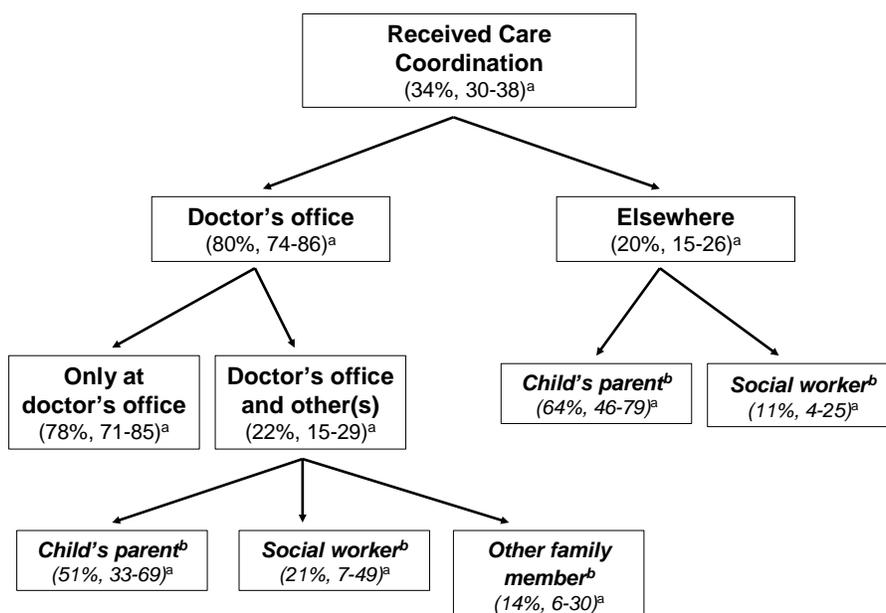
Who provides care coordination in Washington?

Based on parental report, the majority (80%, 95% CI; 74-86) of CYSHCN receiving care coordination received it at a doctor's office (Figure 2). This is significantly higher than the U.S. rate of 73% (95% CI; 72-75).

Around one-fifth (22%) of those receiving care coordination from a doctor's office in Washington also had one or more other person involved in care coordination. This other person was usually the child's parent (51%), followed by a social worker (21%) or other family member (14%). Twenty percent of those who had care coordination did not receive it from the doctor's office. In these cases, most of the care coordination was being provided by the child's parent (64%), followed by a social worker (11%).

Of those who received care coordination at the doctor's office, 18% (95% CI; 12-26) report needing additional care coordination (data not shown). Of those who received care coordination elsewhere, 25% (95% CI; 12-44) report needing additional care coordination (data not shown).

Figure 2: Where Care Coordination was Received Washington, 2005/06 NS-CSHCN



^a 95% Confidence Interval; for definition see Technical Notes.

^b From "check all that apply" questions. Boxes do not add to 100%.

Among those who receive care coordination, who needed additional care coordination?

Based on parental report, approximately 19% (95% CI; 14-26) of CYSHCN in Washington who received care coordination needed additional help arranging or coordinating care (Figure 1). This rate is similar to the U.S. rate of 17% (95% CI; 16-18).

Compared to those who received care coordination but did not need additional help, Washington children in households below 200% of FPL or children with functional limitations more often needed additional care coordination (Figure 3).

In the U.S., black children, children living in households where the highest education level was less than 12 years, or households that did not speak English more often needed extra care coordination.

Children with public health insurance or with three or more health conditions were also more likely to need additional care coordination.

Among those who did not receive care coordination, who needed it?

Among CYSHCN in Washington who did not receive care coordination, approximately 21% (95% CI; 17-25) needed care coordination (Figure 1). The rate for the U.S. was also 21% (95% CI; 20-22).

Compared with CYSHCN in Washington whose parents received care coordination and did not need additional help, those who needed it and didn't receive it were more likely to be **without health insurance** or **with a functional limitation** (Figure 3).

In addition to being without health insurance or having a functional limitation, U.S. CYSHCN who were Hispanic, age 10 and older, or with three or more health conditions were less likely receive care coordination when they needed it. In addition, those living in households below 200% of the FPL or in a household with only one adult were less likely to receive care coordination when they needed it.

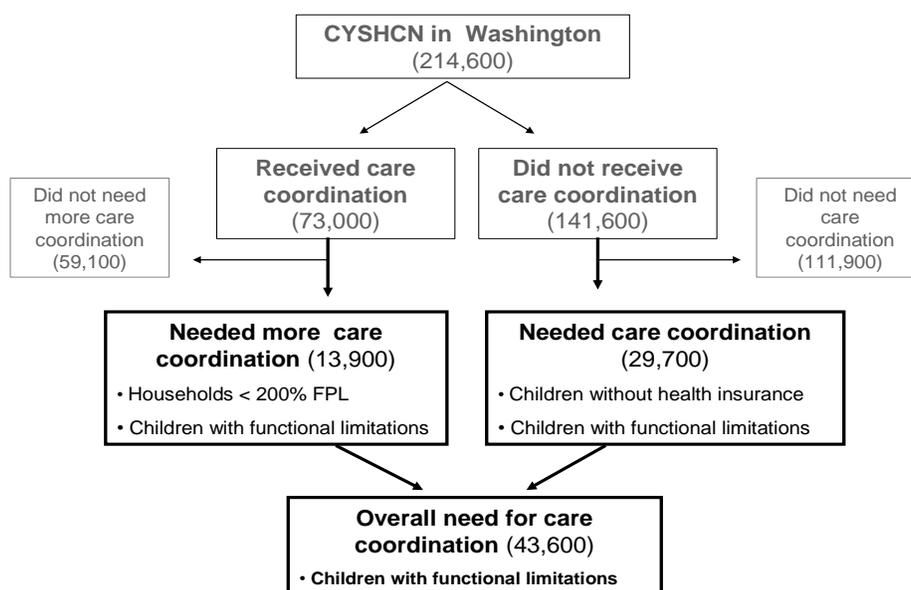
Overall need for care coordination

Overall, 43% (95% CI; 37-49) of CYSHCN in Washington who needed care coordination did not get any or all the care they needed.⁹ This represents approximately 43,600 CYSHCN in Washington (Figure 3). Washington's rate similar to the U.S. rate of 41% (95% CI; 40-43) (data not shown).

Compared with CYSHCN who received enough care coordination in Washington, those who did not receive any or enough care are more likely to have **with a functional limitation** (Figure 3).

In addition, CYSHCN in the U.S. who did not receive any or enough care coordination were more likely to speak a language other than English at home, live in households where adults had less than 12 years education, or live in households with only one adult. They were also more likely to be without health insurance or to have three or more health conditions.

Figure 3: CYSHCN at Increased Risk of Not Receiving Care Coordination Washington, 2005/06 NS-CSHCN



DISCUSSION

An estimated 34% of CYSHCN in Washington receive care coordination, the majority of which takes place in a doctor's office. Children and youth who live in families with household incomes below 200% of the FPL were more likely to receive coordination than those above 200% of the FPL. There are a number of possible explanations for this finding. For example, lower income families may be eligible for more public services that have program-specific case managers. In addition, managed care plans may offer services that families identify as care coordination. This may be a factor since Washington State's goal is to have the majority of Medicaid children in managed care plans. While lower-income households were more likely to report having care coordination, they were also more likely than higher income families to need additional care coordination.

When examining children in Washington who needed care coordination, an estimated 43% do not get any or all of the care coordination needed. Compared with those who receive enough care coordination, this group is more likely to have a child with a functional limitation. While concerning, this finding is not unexpected. Previous research has documented that children with complex health conditions need additional care coordination and CSHCN with clinically complex conditions required encounters with office staff four times as long as CSHCN without clinically complex conditions.¹⁷ In addition, families of children with more severe conditions report less satisfaction with the care coordination that they receive.¹⁴

There are many reasons why families are not getting the care coordination that they need. Although there are considerable long-term fiscal benefits for care coordination within a medical home, up-front costs are often borne by the medical providers and not currently reimbursable.³ Other barriers to care coordination cited by physicians include lack of time, medical staff and administrative support,¹⁵ and community resources.¹⁶ The use of office-based nurses or other nonphysician support instead of physicians in providing care coordination could decrease the cost.^{4,17} Additional barriers include limited or no access to health information technology by providers or technology that is not compatible across different medical sites. Washington State's increasingly diverse population also requires providers to become well versed in cross-cultural communication and care.

An additional barrier to providing care coordination by pediatricians may be an incomplete understanding of the care coordinator's role and activities.³ For example, a survey of pediatricians found that most (71%) report that they or someone else in their office provides care coordination services to CSHCN. However, only 23% regularly contacted the child's school about the child's health needs and 19% scheduled time with the family to discuss findings of a specialist.¹⁵ Another study examining parental experience of medical home reported that the most common dissatisfaction of parents was with the pediatrician's and staff's lack of knowledge about community resources.¹⁴

Parents also play a key role in coordinating care for their child. Among children who receive care coordination outside of the doctors' office, the majority is provided by the child's parents (64%, Figure 2). Even among those who receive care coordination at a doctor's office, parents often provide additional care coordination.

WASHINGTON STATE ACTIVITIES

Care Coordination in the Community

Each public health department has a public health nurse who coordinates care for families of children with complex physical and psychosocial needs, such as linking families to a medical home, insurance, and community resources and is knowledgeable about local supports and services.

Each county prioritizes the extent to which care coordination is provided and may limit services by age, severity of need, or telephone care coordination only. Children ages birth to three who have a developmental delay and meet eligibility requirements for the Individuals with Disabilities in Education Act (IDEA) Part C may receive care coordination from a Family Resources Coordinator (FRC) in their area.

Medical Home Collaborative

The American Academy of Pediatrics defines care coordination as a key component of medical home. Based on the 2005/06 NS-CSHCN, an estimated 48% of CSHCN in Washington receive care through a medical homes.¹ To improve and increase medical homes in Washington, the Department of Health and Washington Academy of Family Physicians are implementing the Washington Patient-Centered Medical Home Collaborative for primary care practices, including those who serve children with special health care needs.

Medical Home Outcome Measures

In 2007, the National Committee for Quality Assurance (NCQA) developed standards to assess whether physician practices are functioning as medical homes. They based their standards on joint standards of the American College of Physicians, American Academy of Family Physicians, American Academy of Pediatrics, American Osteopathic Association. NCQA's nine standards emphasizing the use of systematic, patient-centered, coordinated care management processes (Physician Practice Connections®-Patient-Centered Medical Home™ (PPC®-PCMH™)). The Washington Collaborative has aligned its outcome measures to assure practices can achieve NCQA status. NCQA Standard 3 is assuring that practices implement care management.

CSHCN Care Plans

The Department of Health's CSHCN Program is identifying existing care plans. It is also developing new plans, based on gaps identified by primary care providers and families. The care plans will assist both families and providers work toward achieving desired outcomes for children. While the care plan is a tool for use within the medical home, it also documents coordination with community and educational agencies, specialists, and other health professionals.

Medical Home Enhanced Reimbursement

Washington State has passed legislation in recent years with the intent of improving care within medical homes as well as implementing medical home reimbursement pilots. For example, the Department of Health has worked with the Department of Social and Health Services Medicaid program to develop criteria determine whether a medical practice is a medical home, through the 2008 legislation, HB 5093. A tiered-system has been recommended that includes immunizations, well-child checks, developmental screening, and the use of a care plan as an indicator of care coordination.

Care Coordination Improvement Strategies

The Commonwealth Fund released a report in April 2009 by Johnson and Rosenthal¹⁸ describing actions states can take to improve care coordination. A number of these activities are underway in Washington, such as piloting medical home reimbursement models, facilitating strategies to improve co-management between providers, and providing grants to improve Health Information Technology in practices.

LIMITATIONS

All data presented in this report are from the 2005/06 NS-CSHCN, and were self-reported by a parent or guardian. Washington State-level analytic power to examine statistical differences

between groups was limited due to the small sample size at the state level. The survey did not directly ask about or measure the care coordination provided by the parent completing the survey.

FOR MORE INFORMATION

Washington State Department of Health, Children with Special Health Care Needs Program, (360) 236-3571
<http://www.doh.wa.gov/cfh/mch/CSHCNhome2.htm>

The Center for Children with Special Needs, Seattle Children's:
<http://www.cshcn.org/resources/resources.cfm>.

TECHNICAL NOTES

^a **Definition of children with special health care needs**

The U.S. Maternal and Child Health Bureau (MCHB) defines children with special health care needs as those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. However, the screener used in the National Survey of Children with Special Health Care Needs and the data presented in this report only includes children who have a chronic physical, development, behavioral, or emotional condition. It does not include children who are at increased risk for these health conditions.

^b **Definition of a medical home**

A medical home is an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. (American Academy of Pediatrics)

^c **Care Coordination question in the 2005/06 National Survey of Children with Special Health Care Needs (NS-CSHCN)**

The main care coordination question in the NS-CSHCN is as follows:

“Does anyone help you arrange or coordinate [your child’s] care among the different services that he/she uses? By “arrange or coordinate, “ I mean: Is there anyone who helps you make sure that [your child] gets all the health care and services he/she needs, that health care providers share information, and that these services fit together and are paid for in a way that works for you?”

The complete survey, including additional care coordination questions, is available at http://www.cdc.gov/nchs/about/major/slats/nscshcn_05_06.htm

^d **Analyzing Washington and National Data**

The survey sample size for Washington in 2005 and 2006 was 823, compared to a 40,465 sample size for the U.S. Due to the small survey sample size for Washington, care must be taken when interpreting demographic or health status data, especially when the 95% confidence intervals are wide. The U.S. data analyses included in this report provide additional information to the state analysis. There are more statistically significant findings in the U.S. analysis due to the larger sample size and increased statistical power. Most of the state-level analytical findings are similar to U.S. analytic findings. However, we do not know the extent that U.S. findings reflect what is happening in Washington.

^e **Crude and Adjusted Analysis**

People of different ages, income, education, health status, language, health insurance, race or ethnicity may be more or less likely to receive health care services such as care coordination. Adjusting for differences in demographic characteristics helps us to understand whether an association truly exists, or whether an association is due to related characteristics (confounding). Data analysis in this report adjusted for child’s age, race, ethnicity, functional limitations, number of health conditions, or health insurance status. Other variables may include household characteristics such as income, highest education in household, or language spoken at home. Statistical methods used in this report were primarily logistic regression with backwards elimination of potential confounders.

^f **95% Confidence Intervals**

Confidence intervals are used with survey data to account for the difference between a sample from a population and the population itself. Confidence intervals provide a measure of how much a rate, percent, or other point estimate might vary due to random factors or chance. A 95% confidence interval captures the true value of the point estimate in 95 out of 100 cases. They do not account for several other sources of uncertainty, including missing or incomplete data, bias resulting from non-response to a survey, or inaccurate data collection. Confidence intervals are used with survey data to account for the difference between a sample from a population and the population itself.

^g **Care Coordination**

For this report, parents needing care coordination were 1) those who received care coordination and did not need additional help, 2) those who received care coordination and needed additional help, and 3) those that did not receive care coordination and report needing help with care coordination.

^h **Poverty Levels**

Households below 200% of the Federal Poverty level had incomes of \$40,000 or less for a family of 4 in 2006. US Department of Health and Human Services, 2006 HHS Poverty Guidelines.

ⁱ **Functional Limitation**

A child with a functional limitation is limited in their ability to do things due to a medical, behavioral, or other health condition which has lasted or is expected to last 12 or more months.

^j **Medical Home Measurement**

The measurement does not include every quality typically used to define a medical home. See the American Academy of Pediatrics Medical Home Policy Statement (<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/1/184>) for more detail.

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