2013 Community Report

From the Autism and Developmental Disabilities Monitoring (ADDM) Cerebral Palsy Network

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

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Autism and Developmental Disabilities Monitoring (ADDM) Cerebral Palsy Network

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This Community Report summarizes the main findings from the following publication:

Christensen D, Van Naarden Braun K, Doernberg N, Maenner M, Arneson C, Durkin M, Benedict R, Kirby RS, Wingate M, Fitzgerald R, Yeargin-Allsopp M. Prevalence of cerebral palsy, co-occurring autism spectrum disorders, and motor functioning, Autism and Developmental Disabilities Monitoring Network, US, 2008. Developmental Medicine and Child Neurology. 2013.

To read more about cerebral palsy, go to CDC's cerebral palsy website at www.cdc.gov/cp

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC.

Table of Contents

Executive Summary iv

What Is Cerebral Palsy? 1

What Is The ADDM Network? 5

Overall Results 9

How Can The Data Be Used? 10

State Results And Resources 11

- Alabama 13
- Georgia 15
- Missouri 17
- Wisconsin 19

A Community Perspective: Stories From The ADDM CP Network States 21

Questions And Answers 28

Where Can I Get More Information? 30

References 33

Executive Summary

Introduction

The Centers for Disease Control and Prevention (CDC) estimates that about 1 in every 323 children in the United States (US) has been identified with cerebral palsy (CP). CDC's estimate comes from the Autism and Developmental Disabilities Monitoring (ADDM) Network, which tracks the number and characteristics of 8-year-old children with autism spectrum disorder (ASD) and other developmental disabilities in diverse communities throughout the US. In 2008, there were 14 ADDM Network sites tracking ASD, and four of those sites also tracked CP. These four sites, which include areas in Alabama, Georgia, Missouri, and Wisconsin, are referred to as the ADDM CP Network.

What is the purpose of this report?

This is the first Community Report from the ADDM CP Network. The purpose of this Community Report is to highlight the ADDM CP Network's most recent findings in a way that is useful for parents, providers, and policymakers and to provide health information for awareness and action.

What are the key findings?

Here are the key findings from this report (based on children who were 8 years old and living in these four communities in 2008):

- CP was more common among boys than among girls.
- CP was more common among Black children than White children. Hispanic and White children were about equally likely to have CP.
- Most (77%) of the children identified with CP had spastic CP.
- Over half (58%) of the children identified with CP could walk independently.
- Many of the children with CP also had at least one co-occurring condition - 41% had co-occurring epilepsy and almost 7% had co-occurring ASD.

Why is this information important and how can it be used?

CP remains the most common motor disability in childhood, and children with CP and their families continue to need support. The emotional toll on families and communities is staggering, and services and supports can cost thousands of dollars. Communities can use CDC's information on the number and characteristics of children with CP, such as subtype, walking ability, and co-occurring conditions, to plan for services, guide policy, and promote full participation in community and family life. Information about the co-occurrence of CP and other conditions, such as ASD, can also help direct research into shared risk factors and causes. We at CDC are committed to continuing to provide essential data on CP and to improve early identification in hopes that all children have the opportunity to thrive.

What Is Cerebral Palsy?

Cerebral palsy (CP) is a group of disorders that affects a person's ability to move and keep balance and posture. CP is the most common motor disability in childhood. *Cerebral* means having to do with the brain. *Palsy* means weakness or problems with using the muscles. CP is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles.

The symptoms and functioning of each person with CP varies. CP does not get worse over time, but the exact symptoms can change over a person's lifetime.

Types of CP

Doctors classify CP according to the main type of movement disorder involved. Depending on which areas of the brain are affected, one or more movement disorders can occur, including:

- Stiff muscles (spasticity)
- Uncontrollable movements (dyskinesia)
- Poor balance and coordination (ataxia)

There are four main types of CP:

1. **Spastic**- People with spastic CP have increased muscle tone. This means their muscles are stiff and, as a result, their movements can appear awkward.
2. **Dyskinetic**- People with dyskinetic CP cannot control the movement of their hands, arms, feet, and legs, making it difficult to sit and walk. Their movements can be slow and writhing or rapid and jerky.
3. **Ataxic**- People with ataxic CP have problems with balance and coordination. They might be unsteady when they walk.
4. **Mixed**- Some people have symptoms of more than one type of CP. The most common type of mixed CP is spastic-dyskinetic CP.

Early signs of CP

From birth to 5 years of age, a child should reach movement goals—also known as milestones—such as rolling over, sitting up, standing, and walking. A delay in reaching these movement milestones could be a sign of CP. The following are some other signs of possible CP. It is important to note that some children without CP also might have some of these signs.

In a baby younger than 6 months of age:

- ☐ When you pick him up while he's lying on his back, his head lags
- ☐ He feels stiff
- ☐ He feels floppy
- ☐ When held cradled in your arms, he seems to overextend his back and neck, constantly acting as if he is pushing away from you
- ☐ When you pick him up, his legs get stiff and they cross or scissor

In a baby older than 6 months of age:

- ☐ She doesn't roll over in either direction
- ☐ She cannot bring her hands together
- ☐ She has difficulty bringing her hands to her mouth
- ☐ She reaches out with only one hand while keeping the other fisted

In a baby older than 10 months of age:

- ☐ He crawls in a lopsided manner, pushing off with one hand and leg while dragging the opposite hand and leg
- ☐ He scoots around on his buttocks or hops on his knees, but does not crawl on all fours

Learn more about the early signs of CP on CDC's website, www.cdc.gov/ncbddd/cp/facts.html#early

> Talk with your child's doctor if you notice any of these signs.

Screening and diagnosis of CP

Diagnosing CP at an early age is important for children and their families. The earlier a child is diagnosed and connected to services, the more the child will benefit from intervention. CP generally is diagnosed during the first or second year after birth. If a child's symptoms are mild, it is sometimes difficult to make a diagnosis until the child is a few years older.

CP can be identified by:

- **Developmental Monitoring**- tracking a child's growth and development over time.
  - At each well-child office visit, the doctor monitors the child's development.
- **Developmental Screening**- performing a short test to see if the child has specific developmental delays, such as motor or movement delays.
  - Some developmental screening tests are in the form of interviews or questionnaires completed by parents; others are tests that the doctor gives to the child.
- **Developmental and Medical Evaluations**- diagnosing the specific type of disorder that affects a child.
  - To evaluate movement or motor delays, the doctor looks closely at the child's motor skills, muscle tone, reflexes, and posture, and takes a careful medical history from the parents. The doctor tries to rule out other disorders that could cause similar symptoms.

> A developmental evaluation can be performed by a primary care doctor or by a specialist, such as a:
>
> - Developmental pediatrician
> - Child neurologist
> - Pediatric physiatrist (or pediatric rehabilitation doctor)

A Parent's Perspective

"Like all parents, I hope and dream about my daughter going to college and having a fulfilling life. I also hope that one day we know what causes CP so that we can help others."

-Cynthia Frisina Gray, parent of a child with CP and Executive Director and Co-Founder of *Reaching for the Stars*

To hear more about the story of Cynthia and her daughter Cathryn, visit http://www.cdc.gov/ncbddd/cp/stories.html

Causes and risk factors for CP

CP is caused by abnormal development of the brain or damage to the developing brain that affects a child's ability to control his or her muscles. The brain damage that leads to CP can happen before birth, during birth, or during the first years of a child's life while the brain is still developing. The specific cause of most cases of CP is unknown.

Some things increase the chance that a child will have CP. These are called risk factors. It is important to remember that having a risk factor does not mean that a child will have CP.

CP related to brain damage that happened before or during birth is called congenital CP. Most (85%-90%) of CP is congenital.

Some of the risk factors for congenital CP are:

- Being born too small
- Being born too early

- Being born a twin or other multiple birth
- Being conceived by in vitro fertilization or other assisted reproductive technology
- Having a mother who had an infection during pregnancy
- Having kernicterus (a type of brain damage that can happen when severe newborn jaundice goes untreated)
- Having complications during birth

A small percentage of CP is caused by brain damage that happens more than 28 days after birth. This is called acquired CP.

Some risk factors for acquired CP are:

- Having a brain infection, such as meningitis
- Suffering a serious head injury

Gross motor function

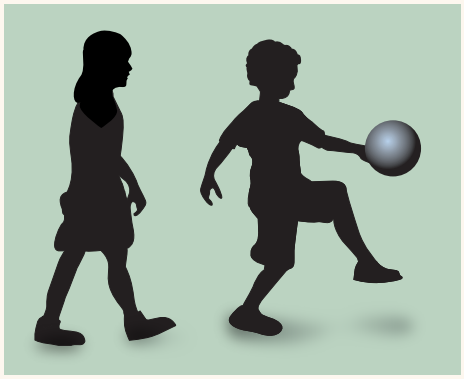
Information on gross motor functioning is necessary to fully understand the impact of CP on children and families. Gross motor functioning is how well a child can use his or her large muscles. It can affect activities like throwing a ball, sitting in a school desk, or walking up stairs.

The Gross Motor Function Classification System (GMFCS) is one method for classifying functional skills among children with CP[1]. The GMFCS is a five-level scale based on a child's ability to walk, move, and stand and his or her need for mobility devices.

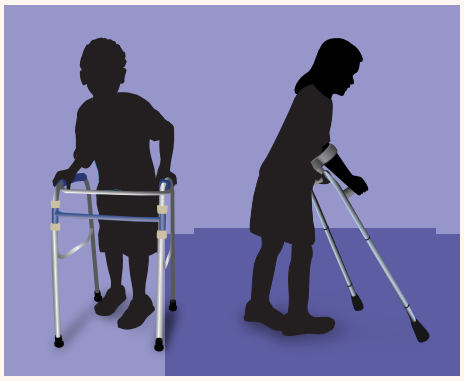
Another way to describe gross motor functioning among children with CP is by looking at walking ability. In the ADDM CP Network, we classify children with CP into three categories of walking ability: "walks independently", "walks with handheld mobility device", or "limited or no walking ability."

Identifying gross motor functioning among children with CP can be important for:

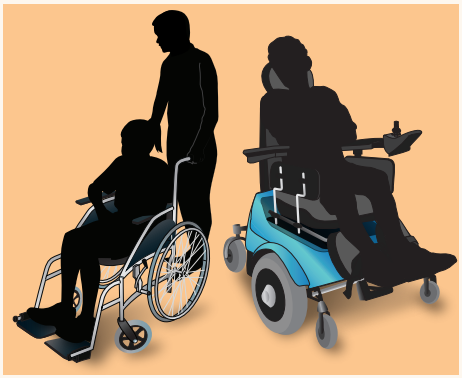
- Having a better understanding of the abilities of children with CP - for example, the ADDM CP Network found that over half of children with CP could walk independently.
- Predicting service needs - a child with no walking ability, for example, may have different needs than a child who walks independently.
- Planning and policy development - knowing how many children with CP walk with a handheld mobility device, for example, can help communities develop policies around assistive equipment like walkers.



Walks Independently



Walks with Handheld Mobility Device



Limited or No Walking Ability

Co-occurring developmental disabilities and neurological conditions

Children with CP often have other health conditions. Having CP and co-occurring conditions can make it more difficult for a child to carry out daily activities and participate at home, in school, and in the community.

- Almost half (41%) of the children identified with CP by the ADDM CP Network had co-occurring epilepsy.
- Some (about 7%) of the children identified with CP also had autism spectrum disorder (ASD). Co-occurring ASD is most common among children with non-spastic CP. It is important to note that the overall identified prevalence of ASD among children in the US is about 1%[2]. That means that the identified prevalence of ASD among children with CP is much higher than among their peers without CP.
- Children with CP can also have intellectual disability, seizures, and problems with vision, hearing, or speech.

> More needs to be done to ensure that *all* children with CP are screened for ASD so that they can be identified early and get access to the services and supports they need.

Economic costs of CP

The financial toll of CP on families and communities is staggering. CP-related medical costs for Medicaid-enrolled children with CP were found to be 10 times higher than for children without CP[3].

Having a co-occurring condition increases the financial burden. For example, the CP-related medical costs for Medicaid-enrolled children with CP and co-occurring intellectual disability were estimated to be 26 times higher than for children without CP and intellectual disability[3]. Costs related to CP can go beyond medical costs. For example, as they transition into adulthood, individuals with CP may have indirect costs, such as being unable to work or only being able to work at certain jobs[4]. CDC estimated that the combined lifetime costs for all people with CP who were born in 2000 will total $11.5 billion in direct and indirect costs[4].

Staying healthy with CP

Children and adults with CP need health care and health programs for the same reasons anyone else does—to stay well, active, and a part of the community. Some health conditions, such as chronic pain, have been found to be more common among children with CP[5]. Children with CP who get the flu may have more serious complications, including death, than their peers without CP[6]. Thus, it is especially important for children with CP to see a health care provider regularly. Regular medical and dental examinations should be part of a child's intervention plan, as should preventive measures such as routine childhood immunizations and flu shots.

Conditions	Average medical costs (2005 dollars), per Medicaid-enrolled child, per year
Neither CP or Intellectual Disability	**$1,674**
CP Alone	**$15,047**
Both CP and Intellectual Disability	**$41,664**

What Is The ADDM Network?

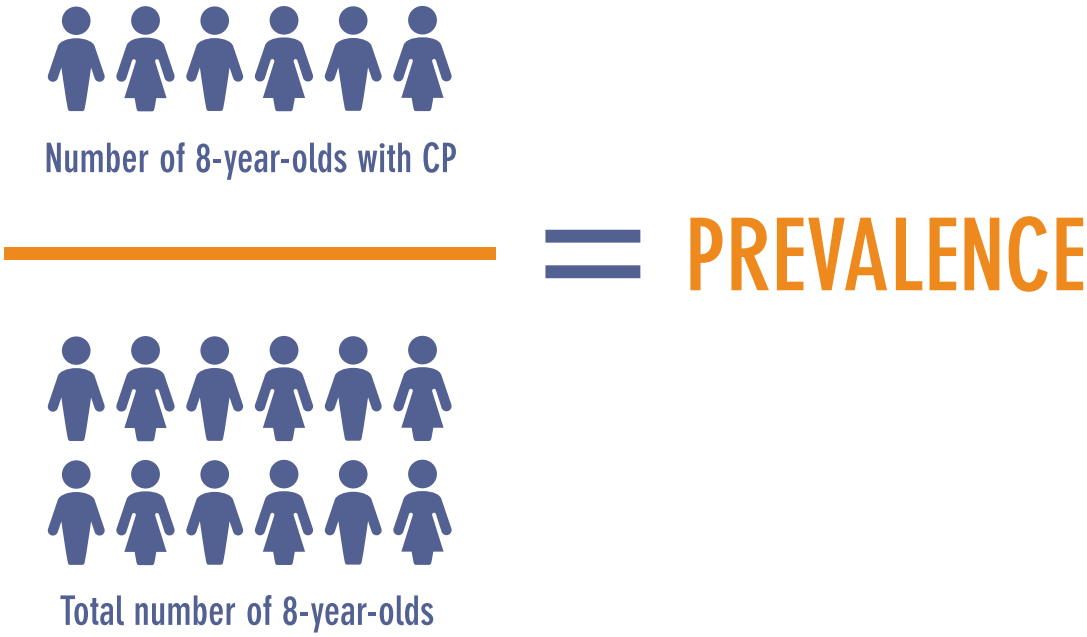
The Autism and Developmental Disabilities Monitoring (ADDM) Network is a group of programs funded by CDC to estimate the number of children with ASD and other developmental disabilities living in different areas of the US. Authorized by the Children's Health Act of 2000, the ADDM Network has been funded by CDC at 14 sites since 2000. Sites are selected through a competitive award process and are not intended to form a nationally representative sample. The ADDM Network sites all collect data using the same method, which is modeled after CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP).

The ADDM CP Network:

- In 2002, the ADDM Network began collecting and reporting information on CP at three sites. The sites that collect information on CP are known as the ADDM CP Network.
- In 2008, the ADDM CP Network tracked CP at four sites, which included areas in Alabama, Georgia, Missouri, and Wisconsin. The information highlighted in this Community Report covers children who were 8-years-old in 2008 in these four sites.
- For the 2010 and 2012 surveillance years, the ADDM CP Network is tracking CP at these same four sites.

The ADDM CP Network's goals are to:

- Obtain as complete a count as possible of the number of children with CP in each ADDM Network site.
- Study whether CP is more common in some groups of children than among others and whether rates are changing over time.
- Improve the consistency of identification of people with CP.
- Provide information on the characteristics of children with CP, including functional abilities and co-occurring conditions, such as epilepsy.



What is prevalence?

The ADDM CP Network tracks the prevalence of CP among children. Prevalence is a scientific term for the number of individuals with a disease or condition among a defined group of people at a specific period in time. For example, we estimated the prevalence of CP among 8-year-olds in 2008 in Atlanta, Georgia by counting all 8-year-olds in Atlanta who are identified with CP, and then dividing that number by the total number of 8-year-olds living in Atlanta during 2008.

What is the ADDM Network method?

The ADDM Network estimates the number of children with CP and other developmental disabilities using a two-stage process:

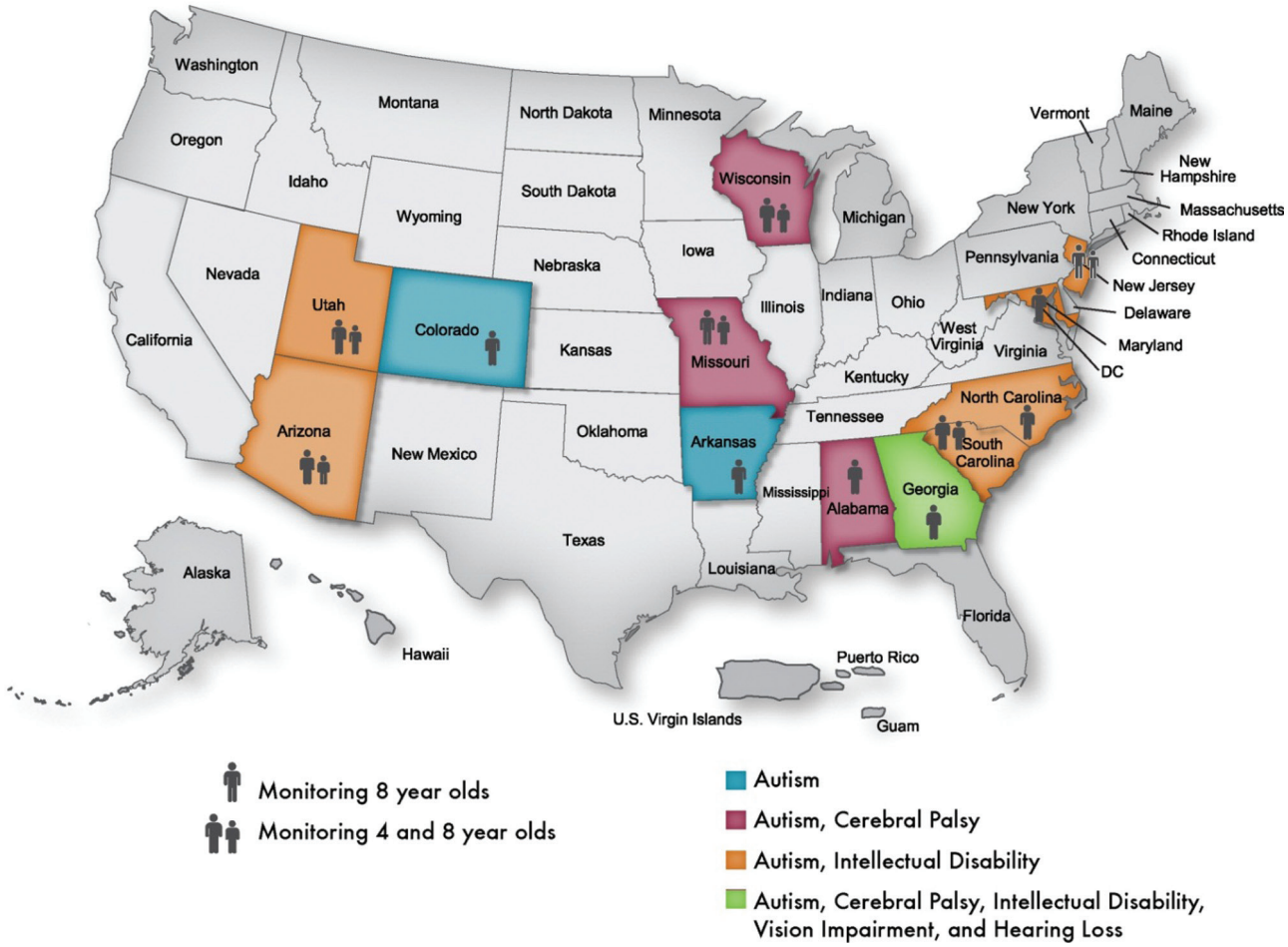
- Trained abstractors review and abstract selected records at multiple data sources in the community that educate, diagnose, treat, and provide services to children with developmental disabilities.
- Abstracted information from all data sources for a given child is then reviewed by trained clinicians who determine if the child meets the criteria for CP.

What are the advantages of this method?

The ADDM CP Network provides the most complete picture of the prevalence of CP in the US, and its overall CP estimates are similar to those of other US studies [7]. The ADDM CP Network's methods are population-based, which means that we look across thousands of children from diverse communities across the country. Rather than tracking CP only among children who, for example, visit a specific clinic, we can look at all children in a certain community who have received a variety of both health and education services.

By tracking CP in the same way over time, we can find out whether more, fewer, or the same number of children are being identified with CP. Also, tracking CP at sites that are part of the overall ADDM Network allows us to not only look at CP but also the other developmental disabilities tracked by the ADDM Network, including ASD. This provides a fuller picture of the characteristics of children with CP and can suggest areas for further research on risk factors and causes.

Current ADDM Network Sites, Surveillance Years 2010 and 2012



What else is the overall ADDM Network doing?

The overall ADDM Network continues to collect data to provide ASD prevalence estimates every two years. CDC also provided supplemental funding to six ADDM Network sites to track the prevalence of ASD among younger children (4-year-olds) using ADDM Network methods.

CDC has leveraged its existing ASD and developmental disabilities tracking infrastructure to establish the ADDM CP Network and learn more about CP. The ADDM CP Network continues to track the prevalence of CP in four sites. Some ADDM Network sites also study the prevalence of other developmental disabilities, including intellectual disability, hearing loss, and vision impairment.

In addition to prevalence reports, the ADDM Network has published many findings on the potential risk factors for developmental disabilities and characteristics of individuals identified with developmental disabilities. You can search a list of publications on our website: www.cdc.gov/ncbddd/developmentaldisabilities/articles.html

Overall Results

Part of US Population included in the ADDM CP Network

8-Year-Old Children: 147,112

Cerebral Palsy (CP) Prevalence, 2008

Number of 8-year-old children identified with CP: **451**

Total average prevalence of CP: **3.1 per 1,000 (or 1 in 323)**

Range of prevalence estimates across sites: **2.5 per 1,000 (Missouri) to 3.6 per 1,000 (Georgia)**

Sex

Boys: **3.6 per 1,000**

Girls: **2.5 per 1,000**

Race/Ethnicity

White, non-Hispanic: **2.7 per 1,000**

Black, non-Hispanic: **3.9 per 1,000**

Hispanic: **2.4 per 1,000**

American Indian/Alaska Native: **1.7 per 1,000**

Asian/Pacific Islander: **1.3 per 1,000**

Documented CP Diagnosis

The majority of children identified with CP by the ADDM CP Network had a CP diagnosis documented in their records.

Children with cerebral palsy who had a diagnosis documented in their records: **98.4%**

CP Subtypes

Spastic: **77.4%**

Non-Spastic*: **8.4%**

Other**: **14.2%**

*Includes dyskinetic, ataxic, hypotonic, and dyskinetic-ataxic

**Includes spastic-ataxic, spastic-dyskinetic, and cerebral palsy not otherwise specified

Co-Occurring Developmental Disabilities

Children with CP who were identified with autism spectrum disorder: **6.9%**

Children with CP who were identified with epilepsy: **41.0%**

Walking Ability†

Walk independently: **58.2%**

Walk with hand-held mobility device: **11.3%**

Limited or no walking: **30.6%**

†Walking ability data available for 74.7% of the children identified as having CP

Network Information

States Participating in ADDM CP Network, 2008

Alabama, Georgia, Missouri, and Wisconsin

For more information, please contact:

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How Can The Data Be Used?

We need to know how many children have CP, so that appropriate plans can be made to support children with CP and their families. Understanding the number and characteristics of children with CP is key to promoting awareness of the condition, helping communities coordinate service delivery, and identifying important clues for further research.

Awareness and Policy

Understanding how many children have CP is key to increasing awareness of this condition. This information can be helpful when a community is working together to address the needs of families living with CP. It can also be used on a national level to promote awareness. In 2013, for example, March 25th was officially designated "National Cerebral Palsy Awareness Day" by the US Congress. ADDM CP Network's CP prevalence estimates were used to generate support for the official designation.

Service Provision and Planning

Knowing the number and characteristics of children with CP can help providers and educators plan and coordinate service delivery. For example, among children with CP who walk with a handheld mobility device or who have limited or no walking ability, motor function often gets worse in adolescence and young adulthood[8]. Information from the ADDM CP Network on the number of children who walk with a handheld mobility device or have limited or no walking ability and who may experience a decline in motor function can help families and communities plan for services related to treatment, education, and community participation.

Research and Coordination

Understanding the characteristics of children with CP can provide important clues for further research. For example, the causes of CP in most affected children are unknown. Information from the ADDM CP Network on the higher prevalence of ASD among children with CP suggests that the two conditions share risk factors and might help direct research into the causes of CP.

A Doctor's Perspective

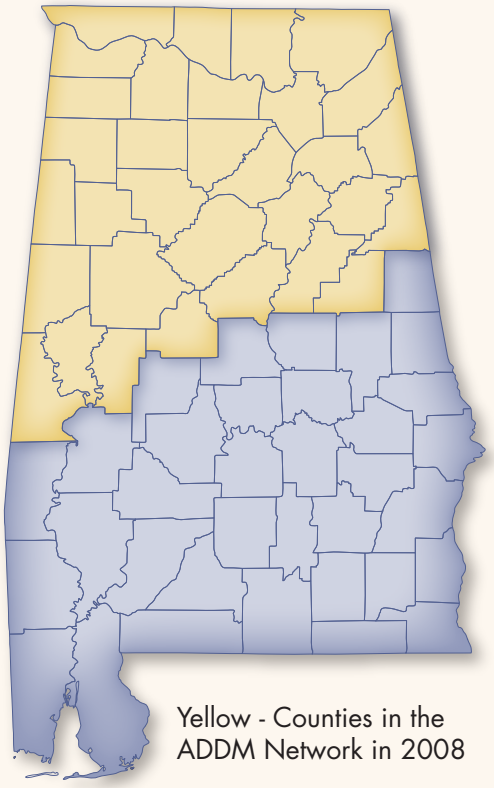
"As a clinician, accurate information is so important. CP is often misunderstood--there are many false assumptions--and our partners at CDC can help us get answers. CDC's data have also been very helpful when we have gone and talked to Congress. These prevalence numbers are critically important to us."

-Dr. Lisa Thornton, a pediatrician who specializes in physical and rehabilitative medicine and who serves on the board of Reaching for the Stars and as past co-chairman of the advocacy committee for the *American Academy of Cerebral Palsy and Developmental Medicine*

State Results and Resources

Alabama

The Alabama Autism Surveillance Program (AASP)



Yellow - Counties in the ADDM Network in 2008

SITE INFORMATION

Part of Alabama Included in ADDM CP Network, 2008

32 counties: Bibb, Blount, Calhoun, Cherokee, Clay, Cleburne, Colbert, Cullman, DeKalb, Etowah, Fayette, Franklin, Greene, Hale, Jackson, Jefferson, Lamar, Lauderdale, Lawrence, Limestone, Madison, Marion, Marshall, Morgan, Pickens, Shelby, St. Clair, Sumter, Talladega, Tuscaloosa, Walker, and Winston

Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old Children: 36,566

White: 67.0%

Black: 25.4%

RESULTS

Cerebral Palsy (CP) Prevalence, 2008

Number of 8-year-old children identified with CP: 118

Total prevalence of CP: 3.2 per 1,000

Boys: 4.0 per 1,000

Girls: 2.4 per 1,000

Race/Ethnicity*

White: 2.9 per 1,000

Black: 4.1 per 1,000

Documented CP Diagnosis

Percentage of children identified with CP by AASP who had a CP diagnosis documented in their records: 99.2%

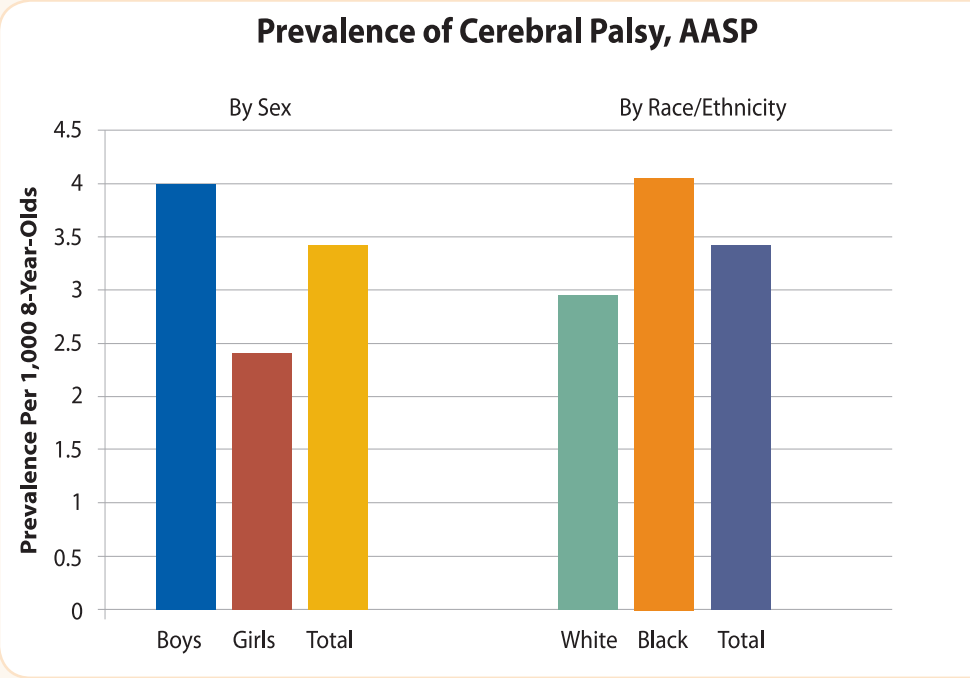
CP Subtypes

Spastic: 87.3%

Non-Spastic: 3.4%

Other: 9.3%

*Does not include racial/ethnic groups with less than 10 children with CP



Alabama

The Alabama Autism Surveillance Program (AASP)

AASP tracks the number of 8-year-old children in the population with autism spectrum disorder, CP, or both. This tracking system provides an accurate count of the number of children in Alabama living with these disorders. The investigators are members of the Department of Health Care Organization and Policy in the School of Public Health at the University of Alabama at Birmingham (UAB) and are working as agents of the Alabama Department of Public Health. The AASP is a joint undertaking with CDC, the Autism Society of Alabama, and other Alabama state partners, agencies, and organizations that serve children with developmental disabilities and their families. The AASP has completed the 2002, 2004, 2006, and 2008 surveillance years and will continue to collect data for the 2010 and 2012 surveillance years.

Does AASP conduct community outreach?

Through their partnership with the Autism Society of Alabama, AASP staff provide workshops and trainings for parents, teachers, and primary health care providers to increase recognition of the early signs and enhance their ability to identify and diagnose autism spectrum disorder. In addition, AASP's partners are actively engaged in trainings that help providers and parents recognize developmental disabilities sooner.

What are some of the resources available in Alabama for children with developmental disabilities, their families, and the professionals who serve them?

- The Alabama Parent Training & Info Network for Children with Disabilities provides information and services to families with children with disabilities. For more information, visit http://alabamaparentcenter.com/2012/ALPTI/index.php
- United Cerebral Palsy (UCP) provides services to individuals with CP and other disabilities and has local chapters across Alabama, including:
  - UCP of East Central Alabama (www.ecaucp.org)
  - UCP of Greater Birmingham (ucpbham.com)
  - UCP of Huntsville & Tennessee Valley (www.ucphuntsville.org)
  - UCP of Mobile (www.ucpmobile.org)
  - UCP of Northwest Alabama (ucpshoals.wordpress.com)
  - UCP of West Alabama (www.ucpwa.org)

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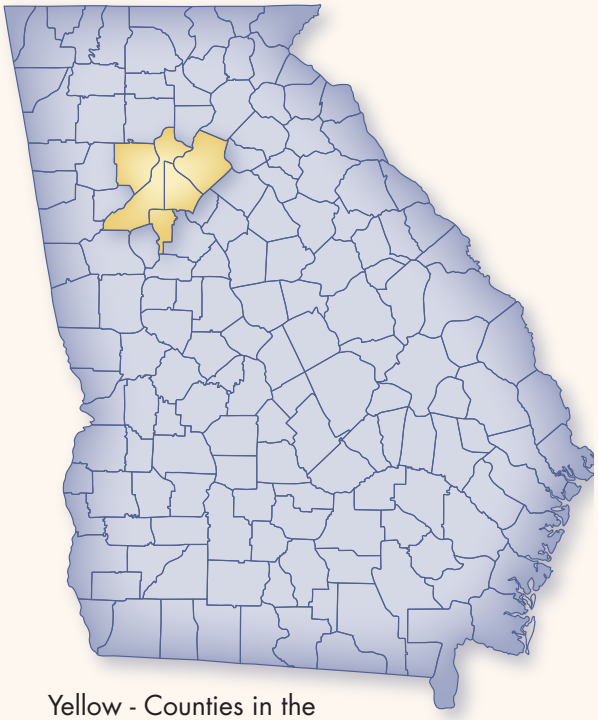
"Being a part of the ADDM CP Network has provided the opportunity to expand our understanding of CP more broadly than if we were working as a single site in Alabama. Also, the local staff and community providers who share data for the project have been dedicated to working together and with us. Because of the willingness of our partners to share information and the care our data collectors and analysts use in handling that information, we can confidently present our findings. The team at AASP is grateful for the opportunity to make a unique contribution to the field of developmental disabilities."

-Dr. Martha Wingate

Georgia

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)



Yellow - Counties in the ADDM Network in 2008

SITE INFORMATION

Part of Georgia Included in ADDM CP Network, 2008

5 counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett

Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old Children: 50,427

White: 37.1%

Black: 41.0%

Hispanic: 15.6%

RESULTS

Cerebral Palsy (CP) Prevalence, 2008

Number of children identified with CP: 180

Total prevalence of CP: 3.6 per 1,000

Boys: 4.3 per 1,000

Girls: 2.8 per 1,000

Race/Ethnicity*

White: 3.2 per 1,000

Black: 4.1 per 1,000

Hispanic: 2.5 per 1,000

Documented CP Diagnosis

Percentage of children identified with CP by MADDSP who had a CP diagnosis documented in their records: 100%

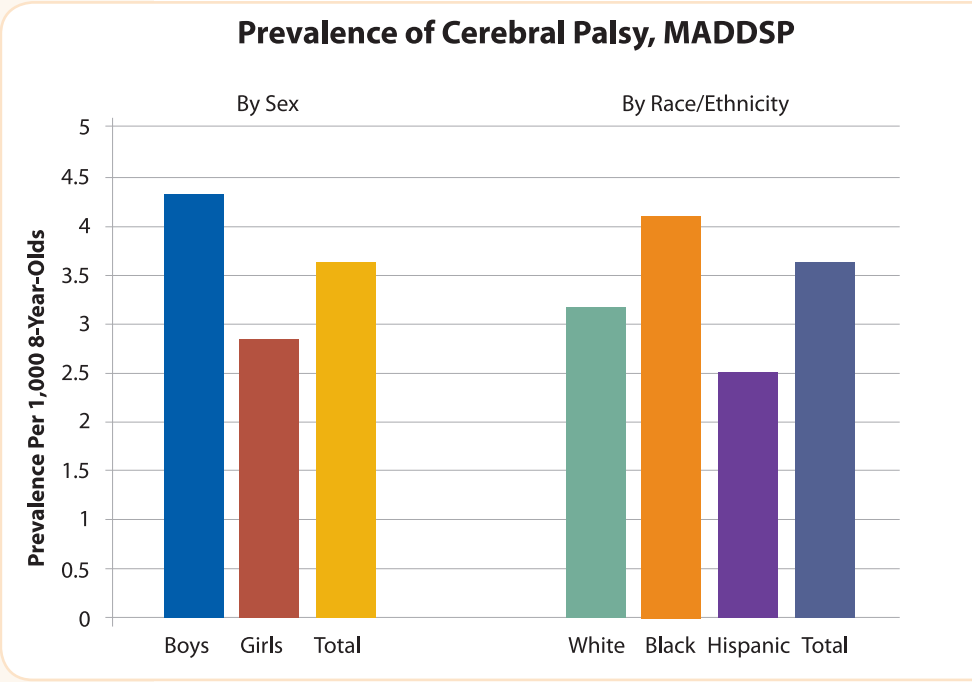
CP Subtypes

Spastic: 71.7%

Non-Spastic: 13.9%

Other: 14.4%

*Does not include racial/ethnic groups with less than 10 children with CP



Georgia

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

MADDSP tracks the number of 8-year-old children living in metropolitan Atlanta who have developmental disabilities. The Centers for Disease Control and Prevention (CDC) established MADDSP in 1991 to track the number of school-age children with CP, hearing loss, intellectual disability, and vision impairment. Autism spectrum disorder was added as a fifth disability in 1996. Since 2000, MADDSP has served as the model for and been a site in the ADDM Network, which tracks autism spectrum disorder and other developmental disabilities in multiple communities across the United States. MADDSP has contributed a wealth of information on the characteristics, risk factors, costs, and overall impact of developmental disabilities.

Does MADDSP conduct community outreach?

MADDSP partners with community organizations, such as Reaching for the Stars, to host CP awareness events in Georgia. MADDSP staff also provides workshops and trainings for parents, teachers, and primary health care providers to increase awareness and recognition of the early signs of developmental disabilities.

What are some of the resources available in Georgia for children with developmental disabilities, their families, and the professionals who serve them?

- CDC's *Learn the Signs. Act Early*. program is an effort to raise awareness about developmental milestones and the importance of early screening and intervention. Visit www.cdc.gov/ActEarly for more information.
- FOCUS offers support to children and teens with significant developmental or physical disabilities and their families. To find out more, visit www.focus-ga.org or call 770-234-9111.
- Parent 2 Parent of Georgia offers a variety of services to Georgia families of children with disabilities, including parent support and training in both English and Spanish. Visit their roadmap to services at http://roadmap.p2pga.org or call 1-800-229-2038.
- The Georgia Department of Behavioral Health and Developmental Disabilities provides support services to people with developmental disabilities. For more information, contact your Regional Office or call the Georgia Crisis and Access Line at 1-800-715-4225. You can also visit their website at http://dbhdd.georgia.gov
- United Cerebral Palsy of Georgia delivers a wide range of supports for people living with CP and other developmental disabilities. To find out more, visit http://ucpga.org or call 770-676-2000.

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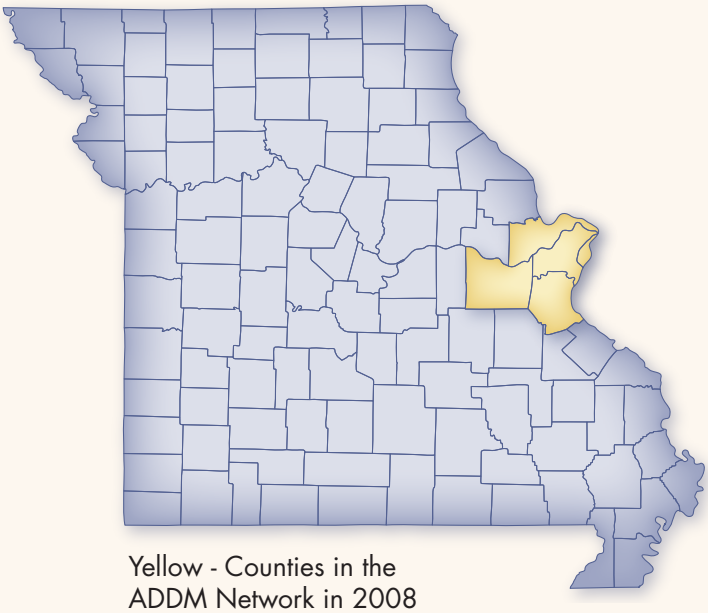
"Since its inception in 1991, MADDSP has made significant advances to our understanding of CP and other serious developmental disabilities. MADDSP's contributions would not have been possible without the support of the many education and clinical providers in the metropolitan Atlanta community that are committed, as we are, to improve the lives of children with CP. We are grateful for their partnership."

-Dr. Kim Van Naarden Braun

Missouri

The Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM)



Yellow - Counties in the ADDM Network in 2008

SITE INFORMATION

Part of Missouri Included in ADDM CP Network, 2008

5 counties: St. Louis, St. Louis City, Franklin, Jefferson, and St. Charles

Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old: 25,668

White: 69.0%

Black: 24.0%

RESULTS

Cerebral Palsy (CP) Prevalence, 2008

Number of children identified with CP: 64

Total prevalence of CP: 2.5 per 1,000

Boys: 3.2 per 1,000

Girls: 1.8 per 1,000

Race/Ethnicity*

White: 2.3 per 1,000

Black: 2.1 per 1,000

Documented CP Diagnosis

Percentage of children identified with CP by MO-ADDM who had a CP diagnosis documented in their records: 96.9%

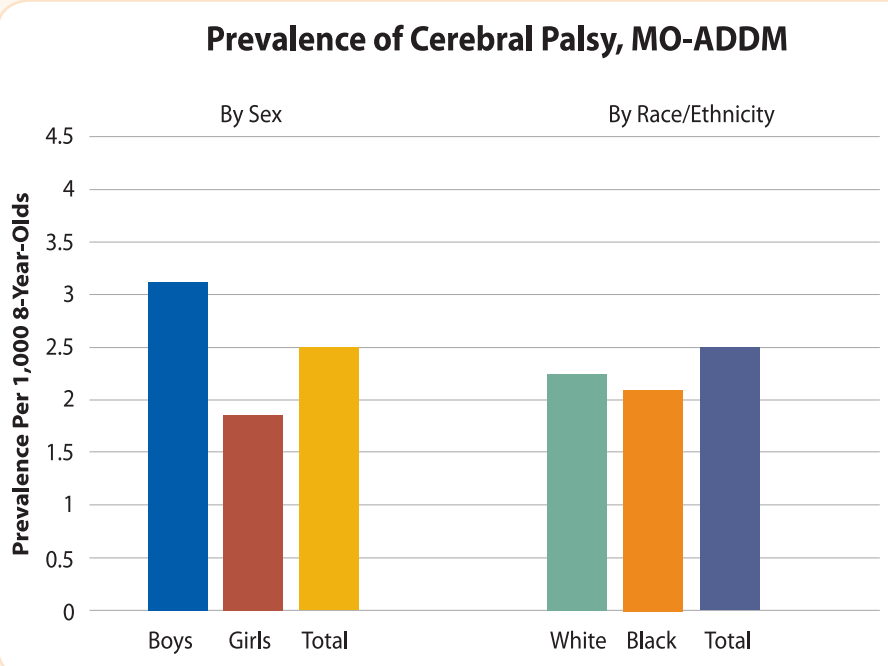
CP Subtypes

Spastic: 78.1%

Non-Spastic: 4.7%

Other: 17.2%

*Does not include racial/ethnic groups with less than 10 children with CP



Missouri

The Missouri Autism and Developmental Disabilities Monitoring Project (MO-ADDM) Program (MADDSP)

MO-ADDM tracks the number of 8-year-old children with autism spectrum disorder and/or CP and co-occurring epilepsy. The goal of this project is to generate accurate, population-based prevalence estimates of autism spectrum disorder and CP among 8-year-old children living in the metropolitan St. Louis area. MO-ADDM is a joint undertaking comprised of investigators at the School of Medicine at Washington University, the Missouri Department of Health and Senior Services, the CDC and other Missouri state and local partners.

Does MO-ADDM conduct community outreach?

MO-ADDM investigators offer lectures at the two main children's hospitals on diagnosis of autism spectrum disorder, as well as its early signs and symptoms. Investigators also work with other stakeholders in Missouri to develop educational programs for therapists and special education teachers.

What are some of the resources available in Missouri for children with developmental disabilities, their families, and the professionals who serve them?

- The Missouri Department of Mental Health's Division of Developmental Disabilities (http://dmh.mo.gov/dd/) coordinates services in Missouri.
- United Cerebral Palsy (UCP) provides services to individuals with CP and other disabilities and has local chapters across Missouri including UCP of Greater Kansas City (www.ucpkc.org), UCP Heartland (www.ucpheartland.org), and UCP of Northwest Missouri (www.ucpnwmo.org).
- Washington University's Intellectual and Developmental Disabilities Research Center (WUIDDRC) is focused on improving care for children with developmental disabilities through research, advocacy, and clinical services. Find out more at http://iddrc.wustl.edu.
- Washington University's Division of Child and Adolescent Psychiatry (http://wuchild.wustl.edu) provides leading edge psychiatric care and research opportunities.

For more information, please contact:

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"The ADDM CP Network data are a vital tool for public health officials and clinicians in the Saint Louis region and further our understanding of the epidemiology of CP. The local CP data also provide additional understanding regarding the co-occurrence of CP and autism spectrum disorder and suggest that autism spectrum disorder may occur more frequently in CP, especially in specific subtypes. This type of knowledge is crucial to be able to identify autism spectrum disorder and other co-occurring conditions in high risk patients as soon as possible and optimize planning for services and supports for families in our region."

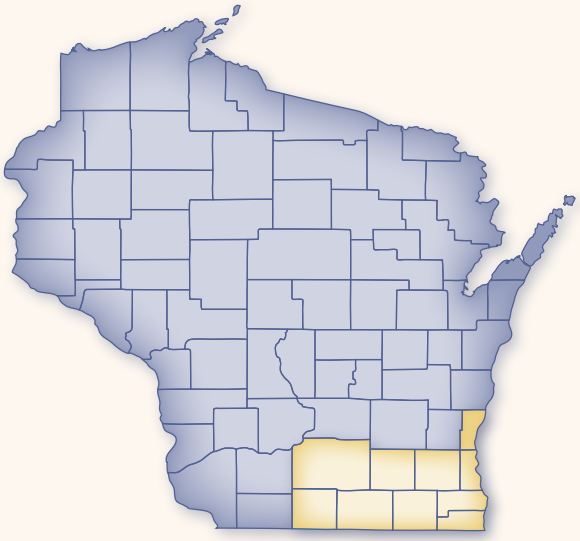
- Dr. Janice E. Brunstrom-Hernandez

Associate Professor of Neurology and Pediatrics at Washington University School of Medicine,

Director of the Pediatric Neurology Cerebral Palsy Center at St. Louis Children's Hospital

Wisconsin

Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS)



Yellow - Counties in the ADDM Network in 2008

SITE INFORMATION

Part of Wisconsin Included in ADDM CP Network, 2008

10 counties: Dane, Green, Jefferson, Kenosha, Milwaukee, Ozaukee, Racine, Rock, Walworth, and Waukesha

Population of 8-Year-Old Children in Study Area, 2008

8-Year-Old Children: 34,451

White: 65.2%

Black: 16.9%

Hispanic: 13.7%

RESULTS

Cerebral Palsy (CP) Prevalence, 2008

Number of children identified with CP: 89

Total prevalence of CP: 2.6 per 1,000

Boys: 2.6 per 1,000

Girls: 2.6 per 1,000

Race/Ethnicity*

White: 2.2 per 1,000

Black : 4.5 per 1,000

Hispanic: 2.1 per 1,000

Documented CP Diagnosis

Percentage of children identified with CP by WISADDS who had a CP diagnosis documented in their records: 95.5%

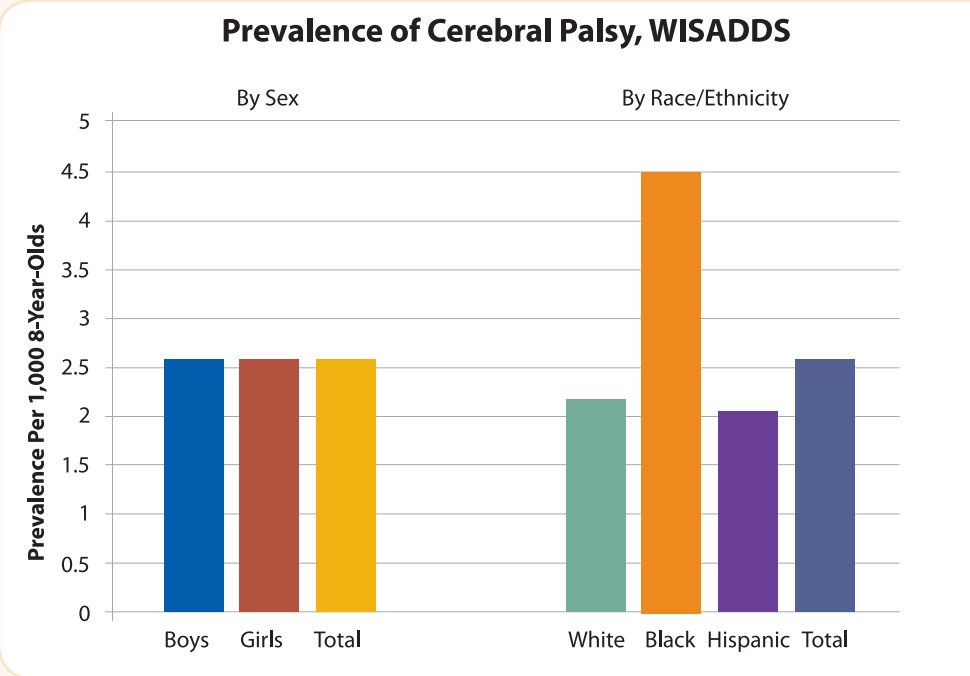
CP Subtypes

Spastic: 75.3%

Non-Spastic: 6.7%

Other: 18%

*Does not include racial/ethnic groups with less than 10 children with CP



Wisconsin

Wisconsin Surveillance of Autism and other Developmental Disabilities System (WISADDS)

WISADDS was established in 2003 as an ADDM Network site in collaboration between the Wisconsin Department of Health Services and investigators from the Waisman Center and Department of Population Health Sciences at University of Wisconsin-Madison. WISADDS tracks the prevalence of autism spectrum disorder and CP. In addition to tracking prevalence, this program contributes information on the characteristics and risk factors for CP, including:

- Racial disparities in functional limitations among children with cerebral palsy, (www.ncbi.nlm.nih.gov/pubmed/22081059)
- Classifying gross motor function among children with cerebral palsy, (www.ncbi.nlm.nih.gov/pubmed/21133973)
- Relationship between multiple births and cerebral palsy, (www.ncbi.nlm.nih.gov/pubmed/19360679)

Does WISADDS conduct community outreach?

This project offers workshops where occupational and physical therapists in Wisconsin learn how to classify gross motor functioning in children with CP. This project also sponsors trainings in early identification of developmental disabilities for pediatricians and other pediatric health care providers serving Wisconsin. The goal is to improve the ability of providers to recognize early signs of CP and autism spectrum disorder and make appropriate referrals.

What are some of the resources available in Wisconsin for children with developmental disabilities, their families, and the professionals who serve them?

- Wisconsin promotes CDC's *Learn the Signs. Act Early.* campaign in an effort to raise awareness about developmental milestones and the importance of early screening and intervention. Visit www.ActEarly.wisc.edu for more information.
- Wisconsin Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) provide confidential information, referral and follow-up so all families of children and youth with special health care needs and providers have access to complete and accurate information. The Regional Center staff regularly provide training related to early identification, autism spectrum disorder, developmental screening, and community-based resources. To find out what is available in your area, visit www.dhs.wisconsin.gov/health/children/overview/index.htm
- *Finding Your Way: A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities* is another valuable resource that provides brief descriptions of programs, services, and systems of support available in Wisconsin. You can download the booklet at www.waisman.wisc.edu/connections/pdfs/FindingYourWay.pdf
- Wisconsin First Step is a 24-hour hotline and searchable online database for families and providers who support the needs of children and youth with special needs: call 1-800-642-7837 or visit www.mch-hotlines.org
- United Cerebral Palsy (UCP) provides services to individuals with CP and other disabilities and has local chapters across Wisconsin including UCP of Greater Dane County (www.ucpdane.org), UCP of Southeastern Wisconsin (www.ucpsew.org), and UCP of West Central Wisconsin (www.ucpwcw.org).

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"Before the publication of the ADDM CP Network findings, we had no way of estimating how many children in Wisconsin have CP, and no information on their levels of functioning. Now we have both kinds of information, which can be used for planning purposes and to improve the lives of children with CP and their families."

-Dr. Maureen Durkin

A Community Perspective

Stories from the ADDM CP Network States

Making An Impact On Local Communities: CDC's Cerebral Palsy Awareness Events

Dr. Stephen Dantzig speaking with an attendee during the event's book signing

Since 2007, CDC has hosted events to raise awareness of CP and engage local communities that collaborate with CDC on CP tracking. Most recently, we partnered with the Alabama ADDM Network site, along with their local partner, United Cerebral Palsy of Greater Birmingham, to host an event on March 26, 2013 in Birmingham, Alabama.

> We have always had great relationships with our community partners, but working on the event together has opened doors for some interesting research and collaborations to come.
>
> *-Dr. Julie Preskitt, Assistant Professor at University of Alabama at Birmingham's School of Public Health and staff member of the Alabama ADDM site*

> It was wonderful to share my life and perhaps offer some hope to the audience members who either have CP or have children with CP.
>
> *-Dr. Stephen Dantzig, Keynote Speaker*

As a school psychologist, professional photographer, author, and adult with CP, the keynote speaker Dr. Stephen Dantzig shared his multifaceted perspective on issues from talking for the first time to parents about their child's need for special education services to aging with a disability. Several other speakers spoke of their personal and professional connections to CP, including Dr. Gary Edwards, CEO of United Cerebral Palsy of Greater Birmingham, Dr. David Allison, Associate Dean for Science at University of Alabama at Birmingham, Dr. Marshalyn Yeargin-Allsopp, Chief of CDC's Developmental Disabilities Branch, Dr. Martha Wingate, Principal Investigator of the Alabama ADDM Network site, and Congressman Spencer Bachus of Alabama.

CDC will continue hosting events with partners in the ADDM CP Network communities across the US to bring greater attention to CP and strengthen community relationships. We also will continue to highlight the inspirational stories of families and individuals living with CP, and the providers and champions working to support them. On the following pages, we present stories from Dr. Stephen Dantzig and from members of the ADDM CP Network communities.

ADDM CP Network: An Individual/Provider's Perspective

Stephen Dantzig, PsyD

Stephen is a school psychologist, professional photographer, and author of several articles and books, including *Get Up, Your Bus Is Here: Living My Life With Cerebral Palsy*. He is also a nationally renowned lighting expert, owner of the Hawaii School of Photography, and was the keynote speaker for CDC's 2013 Cerebral Palsy Awareness event in Birmingham, Alabama.

What inspired you to become a photographer?

I have been in love with photography since my father gave me my first pocket camera when I was 8 years old! Creating images that did not exist a split second ago is still fascinating. Photography also gave me an opportunity to compete with my classmates on a level playing field. I couldn't play sports and my drawing is pretty bad, so photography not only opened the arts up to me, but allowed me to be judged purely on my images and not based on some other criteria. I am at my best behind a camera.

When you were growing up, what do you feel was your greatest obstacle? What was your greatest strength?

The second part of that question is easy: My parents were my greatest strength when I was growing up. They allowed me to do things and try things just like any other kid. They got me a large tricycle when I couldn't ride a two-wheeler so I could cruise the neighborhood like other kids. They got me into bowling leagues. They allowed me to go on skiing trips in junior and senior high school. They were very active in my academic progress and never let me slack off. The list goes on and on. My biggest obstacle as a kid, perhaps ironically, was learning that it was OK to accept and even ask for help in certain situations. I felt that I failed if I couldn't do whatever "IT" was without help.

Now that you are an adult, what is your greatest obstacle and your greatest strength?

The biggest obstacle that I face as an adult with CP is coping with a changing body and deteriorating motor skills. I am part of a generation of people with CP who we need to study. We are living longer now so we are learning more about aging with CP. CP is not supposed to be degenerative. The damage to the brain that caused the disability is supposed to be static and unchanging. The reality for me and for many others is quite different: I simply cannot move as "well" as I used to and there is a lot more pain from muscle spasms (painful cramps of a muscle). The aging process can be rough on all of us, but it can be particularly tough on those with prior physical difficulties. My greatest strength as an adult is my stubbornness—though my fiancée may not agree! I refuse to let my increasing physical challenges or other issues stop me.

What is the most important thing that people should know about CP?

People with CP are people first. Look at the person, then assess the disability.

What is the most important thing that individuals and families living with CP should know?

Having any kind of limiting disability stinks…but YOU don't stink as a person for having a disability or having a child who is disabled. Encourage and fight for as much independence as is possible, but accept reality. Denying reality does not change it.

ALABAMA: A Champion's Perspective

Gary Edwards, PhD

Gary has been with *United Cerebral Palsy (UCP) of Greater Birmingham* for 30 years and currently serves as Chief Executive Officer (CEO). UCP of Greater Birmingham provides programs and services to more than 3,000 infants, children, and adults with disabilities in Birmingham, Alabama and the surrounding counties.

Do you use CDC's information on the number and characteristics of children with CP?

It's a constant thing that I use. When we were planning whether we should open up a physical medicine and rehabilitation clinic, it helped us to answer, 'What is the specific number of clientele that really could benefit from this?' It's very critical in my strategic planning.

In promoting early intervention services, I use CDC's data with legislators and other policymakers to tell them, 'OK, this is the potential number of people that we will be serving'. And in employment - I use CDC's data to let policymakers know we have potentially this many people with disabilities exiting school and coming into the employment market.

What inspires you to continue working on behalf of individuals with CP and other disabilities?

When a family has a child with disability, especially a child with CP, their dreams for that child are shattered. What we see our role as is to help families dream new dreams.

It's also the people that are waiting on their services. What can I do to reach the people and the families that are not being served? That keeps me pushing every day.

What is the most important thing that people should know about CP?

People with disabilities can be and should be an integral part of all of our communities. Here at UCP we envision a world where disabilities are understood to be a common part of human existence - neither defining nor limiting.

What is the most important thing that individuals and families living with CP should know?

We are here for you. We will be here forever. We will become part of your family and you will become part of our family. I've been here long enough to see the kids we were serving as children are now here as adults.

And you are not alone. We are with you on this journey of life. And it's not going to be easy. We are trying to build all the supports that we can. There is hope; you just need to dream new dreams.

GEORGIA: A Sibling's Perspective

Leighton Jordan

Leighton is the sister of a young man with CP and represented Georgia in the Miss America 2013 pageant. Among her many activities, she volunteers for the *Sibling Support Project*, an organization focused on increasing the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.

What was it like growing up as the sibling of an individual with CP?

While my brother struggles with many different disabilities, CP and deafness are the most challenging ones he faces. Growing up as his younger sister, I had a hard time understanding why I had to fold his clothes, make his bed, make his food, tie his shoes, comb his hair (and the list goes on). Most of the time I embraced helping him, but sometimes I viewed it as unfair. Looking back, of course, I now realize the only person who had it "unfair" was my disabled brother. CP affects the right side of my brother's body, making daily tasks extremely trying and cooking an egg nearly impossible.

Through my brother's CP, I have learned the precious gift of patience. His walking slower than most, taking longer to get dressed, and showing perseverance in physical therapy showed me some things aren't meant to be rushed. While it has frequently been difficult, trying, and frustrating growing up with a sibling who has CP, it has also been rewarding, life-changing, and educational.

How does having a sibling with CP impact your life today?

Having a sibling with CP makes me grateful for the things I can do in life. It makes going to the ballet studio exciting and going to the gym more than just a daily task. It makes me realize how much we take for granted the "easy things" in life, such as tying a shoe, throwing a ball, and brushing our teeth. I am also cognizant that, as our parents age, I will likely have a lifelong role participating in my brother's care. This will affect not only me, but also the family that I plan to start in the future.

What advice do you have for siblings and other family members of individuals with CP?

To first and foremost realize it is okay to be frustrated and/or upset about a family member's disability. It is also normal to feel guilty about feeling frustrated! While these emotions are hard to face, they must be confronted, accepted and communicated if one wants to make the most of their situation. Secondly, it is essential to accept what you've been given in life and make the most of it. I have chosen to view my brother's disabilities as a blessing, and that, in itself, has helped me embrace every circumstance my family faces. I know I have a crucial "job" in my brother's life: to love him, accept him, push him, and help him. I am here to be his best friend at all times, because there are many times when feels he has no friends other than myself.

MISSOURI: An Individual/Provider's Perspective

Stephanie Marten, MSN, RN

Stephanie is an adult with CP and a clinical nurse coordinator with the *Pediatric Neurology Cerebral Palsy (CP) Center* at Washington University School of Medicine and St. Louis Children's Hospital in Missouri.

How did you first become involved in the field of CP?

I am an identical twin and was born three months prematurely. My parents recognized I had a disability when my twin sister began crawling at eight months and I was not crawling. They were eventually told I had CP. At age three, I had my first orthopedic surgery and began preschool where I had physical, occupational, and speech therapy three to four days per week.

My time in elementary school was unique in that I was the only child in my building with a disability. However, I was always included and did not feel different in anyway. The school did make some special adaptations, but it was truly a wonderful and positive experience.

I have always been aware of my disability, but I feel that it doesn't define me. After high school, I attended nursing school. I was a former patient of Dr. Brunstrom-Hernandez, the Director of the CP Center where I now work. After I finished my nursing degree, she offered me a position in the CP Center as her clinical nurse.

What inspires you to continue working in this field?

Every day I get to interact with patients and their families who work tirelessly to find ways to succeed in life. CP can make some everyday tasks very hard, but the kids and their parents and caregivers don't give up.

What is the most important thing that people should know about CP?

Many people with CP are capable of living a full and productive life, but they may need help with adaptations, modifications, and strategy along the way.

What is the important thing that individuals and families living with CP should know?

Anyone with a disability needs to know that they can accomplish nearly anything if they really want to. They may have to work hard and go about things a little differently than someone without a disability, but they should never give up on their dreams.

WISCONSIN: A Parent/Provider's Perspective

Sandra Tierney, PhD, MSW

Sandra is the parent of a child with CP and the Board President of *Gio's Garden*, a non-profit organization in Wisconsin whose mission is to nurture and strengthen families with special needs children by increasing their access to needed services. Before becoming a full-time mother and advocate, Sandra worked for 14 years in depression research.

How does having a child with CP impact your life today?

Every aspect of our lives is shaped by the over 1200 hours a year it takes to take our daughter with CP to her more than 200 appointments with 9 doctors and 5 therapists; deal with insurance; find needed equipment and services; do therapy with her at home; address her behavioral issues; spend extra time on her school work; supervise almost everything she does to maintain her safety and maximize her independence; and make the extra time for her to do things other kids do so quickly and easily. It means staying where we have supportive family and have learned how to navigate systems; giving up my career because of my family's needs; and becoming an advocate for families with children with special needs. It has forced us to acquire new skills and re-focused our lives. It has made us intentional parents who constantly think about how we can keep our daughter's needs from taking over our family while making sure her brother's needs are also met. It has brought us closer together as a family, taught us the value of family and community, and helped us learn to cherish every little thing about both of our children.

What inspires you to continue working on behalf of children with CP?

Having a child with special needs changed everything: because I now know the effect raising a child with special needs has on the entire family and how hard it is to learn about and access the multitude of needed services, I feel compelled to help other families through this process any way I can. My husband and I have all the advantages a parent of a child with special needs could hope for - supportive family and friends, relevant education and training, a good income, and good insurance - yet we have still experienced challenges. If we have not had an easy time of it, how do families who are not as fortunate as we are do it? And how could I sit back and watch that happen when the focus of the career I gave up for the sake of my special needs family had been resilience, stress, and coping?

What is your vision for the field of cerebral palsy?

I would love to see CP awareness increased as well as significant progress made in new treatments. Having treatments that could actually cure aspects of CP, not just treat the symptoms would be fantastic.

What is the most important thing that people should know about cerebral palsy?

Although CP is a disorder that can impact any and all aspects of a person, it does not define who that person is. He or she still wants a high quality of life and parents of kids with CP want the same thing for and to do the same things with their kids that other parents want.

Questions and Answers

Does this mean that the prevalence of CP is 1 in 323 children in all US communities?

The ADDM CP Network sites do not make up a nationally representative sample, but in 2008 their combined areas represented approximately 4% of 8-year-olds in the US. It is important to remember that the estimate of 1 in 323 is an average based on data collected from four sites and that prevalence estimates from the four sites ranged from 2.5 per 1,000 8-year-old children in Missouri to 3.6 per 1,000 8-year-old children in Georgia.

How does the information in this report compare to information collected by the ADDM CP Network for 2002 and 2006?

The prevalence of CP has remained relatively stable over time. Past prevalence estimates from the ADDM CP Network of 1 in 276 for 2002 and 1 in 303 for 2006 are similar to the current estimate of 1 in 323[9-10].

The characteristics of children with CP have also stayed much the same over time:

- CP has been 1.5 times more common among boys than girls.
- Among racial and ethnic groups, Black children have been more likely to have CP.
- The proportion of children in each CP subtype group and at each level of gross motor function has remained fairly constant.
- The prevalence of co-occurring ASD has been between about 7% and 8%.
- From 2006 to 2008, the prevalence of co-occurring epilepsy only increased from about 35% to 41%.

How does the prevalence of CP compare with other developmental disabilities?

About 15% of children in the US have a developmental disability[7]. Conditions such as attention-deficit/hyperactivity disorders (8%), learning disabilities (7%), and communication disorders (6%) are more common than CP.

How can I tell if my child's development is on track?

You can follow your child's development by looking for developmental milestones - that is, how he or she moves, plays, learns, speaks, and acts. Developmental milestones are things most children can do by a certain age. Talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

Learn more about developmental milestones and get free milestone checklists at CDC's *Learn the Signs. Act Early.* website, www.cdc.gov/ActEarly

What should I do if I think my child might have CP?

As a parent, you know your child best. If your child is not meeting the motor or movement milestones for his or her age, talk with your child's doctor and share your concerns. Do not wait.

For tips on how to share your concerns with your health care professional, visit www.cdc.gov/concerned

Can CP be prevented?

In most cases, we don't know why children develop CP. Some preventable risk factors for CP have been identified. For example, babies with severe jaundice can be treated with special lights (phototherapy) to stop the development of kernicterus, a known cause of CP. Similarly, routine vaccination of babies prevents many cases of meningitis, another known cause of brain damage that can, in turn, cause CP. Making sure that children are properly buckled in car seats or booster seats can help prevent head injury during a car accident; head injury is another cause of CP.

What kinds of treatments can help children with CP?

There is no single best treatment for children with CP. After a CP diagnosis is made, a team of health professionals works with the child and family to develop a plan to help the child reach his or her full potential. Before deciding on a treatment plan, it is important to talk with your child's doctor to understand all the risks and benefits.

Common treatments include:

- Medicines
- Surgery
- Braces
- Physical, occupational, and speech therapy

What is IDEA?

As administered by the US Department of Education, the Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities[11]. IDEA also provides for evaluation of children who might have been or be at risk for developmental disabilities.

- Part C of IDEA deals with early intervention services for infants and toddlers with disabilities (birth- age 2) and their families.
- Part B of IDEA deals with special education and related services for children and youth (ages 3-21).

Even if your child has not been diagnosed with CP, he or she may be eligible for IDEA services. Visit the IDEA website for more information: http://idea.ed.gov

Where Can I Get More Information?

The resources that follow will help you learn more about CP and find services for children and adults with CP and their families.

General Information about CP

CDC's CP Information Center
www.cdc.gov/cp

Check out a full range of resources for parents, providers, and researchers at this site. Also, learn what CDC is doing to better understand CP.

American Academy of Pediatrics Healthy Children
www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/pages/Cerebral-Palsy.aspx

Get more information on CP's signs and symptoms, treatments, and associated problems.

MEDLINEplus
www.nlm.nih.gov/medlineplus/cerebralpalsy.html

Access a range of resources on CP from clinical trials to disease management to coping (some materials available in Spanish).

National Dissemination Center for Children with Disabilities (NICHCY)
http://nichcy.org/disability/specific/cp or 1-800-695-0285

Access NICHCY's CP fact sheet that covers topics such as signs of CP and treatment, as well as tips for parents and teachers (available in English and Spanish). Call the toll-free number for information and referrals over the phone.

National Institute of Neurological Disorders and Stroke (NINDS)
www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm or 1-800-352-9424

Learn more from NINDS' brochure on CP that includes information on early signs of the condition, diagnosis, causes, treatment, and where to go for more information (available in English and Spanish).

Developmental Milestones and Early Identification

CDC's *Learn the Signs. Act Early.*
www.cdc.gov/ActEarly or 1-800-CDC-INFO

Find out if your child's development is on track and learn the signs of developmental delays, get examples of what to say to health care professionals, and get tips about what to do if you have to wait for an appointment (available in English and Spanish).

Motor Delays: Early Identification and Evaluation
http://pediatrics.aappublications.org/content/131/6/e2016.full

Learn more about early identification and evaluation of motor delays in this report from American Academy of Pediatrics.

Services and Supports for Children and Adults with CP and Their Families

American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)
www.aacpdm.org

Learn more about AACPDM and find a healthcare provider in your area who is a member of AACPDM: aacpdm.execinc.com/edibo/ReferralDirectory

CP Parent
www.cpparent.org

Connect with this online group of parents, caregivers, and others who work with children with CP.

Children's Hemiplegia and Stroke Association (CHASA)
www.chasa.org

Find information and resources for children who have hemiplegia, hemiparesis, or hemiplegic CP and their families.

The Early Childhood Technical Assistance Center (ECTA)
Use ECTA to find state contacts for early intervention programs for infants and toddlers from birth to 3 years old (Part C Programs http://ectacenter.org/contact/ptccoord.asp) and preschool special education for children from 3 to 5 years old (state Section 619 http://ectacenter.org/contact/619coord.asp).

Easter Seals
www.easterseals.com or 1-800-221-6827

Learn more about the services, education, outreach, and advocacy that Easter Seals provides for people living with ASD and other disabilities like CP.

Family Voices
www.familyvoices.org or 1-888-835-5669

Learn more about this national network that provides information and supports for parents raising children with special health care needs, disability, or both. For contacts in your state, go to: www.familyvoices.org/states

My Child Without Limits
www.mychildwithoutlimits.org

Find resources for families of young children from birth to 5 years old with developmental delays or disabilities, including CP. A "Guide to CP" can also be downloaded from this site.

Parent Technical Assistance Center Network
www.parentcenternetwork.org/parentcenterlisting

Find local training and assistance for the families of children with disabilities and other special health care needs at Parent Centers across the US.

Providing a Primary Care Medical Home for Children and Youth with Cerebral Palsy
http://pediatrics.aappublications.org/content/128/5/e1321

Learn more about the aspects of care specific to CP in this report from the American Academy of Pediatrics.

Reaching for the Stars (RFTS)
www.reachingforthestars.org or 1-855-240-7387

Learn more about RFTS, an organization that is committed to advocacy, education and driving research to serve the needs of children with CP and the individuals involved in their care.

Scope
www.scope.org.uk/help-and-information/cerebral-palsy/ageing-and-cerebral-palsy

Access a fact sheet on aging and CP.

Sibling Support Project
www.siblingsupport.org

Connect to resources for the siblings of people with special health, mental health, and developmental needs.

Technical Assistance and Dissemination Network
www.tadnet.org

Access links to a variety of websites and online resources that focus on special education issues, such as policy, technology, curriculum, and parent trainings.

United Cerebral Palsy (UCP)
www.ucp.org/resources/one-stop-resource-guide or 1-800-872-5827

Learn more about UCP and access their One Stop Resources Guide where visitors can locate organizations in each state to help answer questions about healthcare, home modifications, or financial assistance.

Research

Cerebral Palsy International Research Foundation (CPIRF)
www.cpirf.org

Learn more about CPIRF, a not-for-profit organization that funds research and educational activities related to the cause, cure and evidence-based care for those with CP.

Cerebral Palsy Research Registry (CPRR)
www.cpregistry.org

Learn more about CPRR, a multi-institutional collaborative effort to improve our understanding of CP.

Clinical Trials
www.clinicaltrials.gov or 1-800-411-1222

Access a searchable database that provides patients, family members, and the public with information about current and ongoing clinical research studies.

Other Federal Agencies

Department of Education
www.ed.gov

Find resources to assist with the educational needs of children with CP.

Disability.gov
www.disability.gov

Access comprehensive information on disability programs and services in communities nationwide.

Food and Drug Administration
www.fda.gov

Learn about drugs that the FDA has approved to treat children with CP.

National Council on Disability
www.ncd.gov

Find out more about disability-related issues on civil rights, cultural diversity, education, emergency management, employment, financial assistance & incentives, health care, housing, long term services and supports, technology, transportation, and youth perspectives.

Office of Special Education and Rehabilitative Services
http://www2.ed.gov/about/offices/list/osers/index.html

Learn more about the Department of Education's support to parents and individuals, school districts, and states in three main areas: special education, vocational rehabilitation, and research.

*We provide links to web pages if you want to learn more about a topic or organization. Some of these pages are on the CDC website and others are on outside websites. Links to organizations outside of CDC are included for information only and do not indicate any form of endorsement or approval from CDC or the Department of Health and Human Services (HHS). CDC has no control over the information at these sites. The views and opinions of these organizations are not necessarily those of CDC or HHS.

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www.facebook.com/CDC

www.flickr.com/photos/CDCsocialmedia

https://twitter.com/DrBoyleCDC -or- http://twitter.com/CDCgov

http://www.youtube.com/user/CDCStreamingHealth

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Learn more about cerebral palsy, the most common motor disability in childhood.

http://www.cdc.gov/cp

National Center on Birth Defects and Developmental Disabilities

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