

## Child Development

### Improve Developmental Outcomes of Children

#### What Is the Problem?

- Childhood is the ideal time for interventions that promote lifetime health and development. Unfortunately, poor outcomes are experienced by too many children with conditions such as Attention-Deficit Hyperactivity Disorder (ADHD), Tourette syndrome, spina bifida, fragile X syndrome (FXS) or muscular dystrophy.
- Children who experience poverty are also at risk for poor developmental outcomes, which can be improved through early identification and intervention.
- More than 15 million children in the U.S. are living in poverty, and the number is increasing. Children living in poverty are at significantly higher risk for poor health outcomes and for:
  - Behavior and emotional problems.
  - Lower IQ.
  - Language delays.
- Nearly one in 10 school-aged children in the U.S. (5.4 million children) has been diagnosed with ADHD, and rates have been increasing during the past decade. Children with ADHD are also likely to have emotional and behavioral problems and may face many challenges such as:
  - Difficulty in establishing peer relationships.
  - More frequent and severe injuries.
  - Difficulty with their emotions.
  - Difficulty in learning.
  - Difficulty with their behavior.
- The annual financial and societal costs of ADHD on the juvenile and criminal justice systems are approximately \$42.5 billion (Pelham, W.E., E.M. Foster, and J.A. Robb, The economic impact of attention-deficit/hyperactivity disorder in children and adolescents. *J Pediatr Psychol*, 2007. 32(6): p. 711-27.t).



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- Tourette syndrome (TS) can impact a person's health, education, employment, family and social relationships, and has wide-ranging effects on their physical, mental, and emotional well-being.
  - At least 148,000 children and their families are living with TS in the U.S.
  - Boys are 3 times more likely than girls to have TS.
  - [80% of children with TS](#) also have a mental, emotional or behavioral condition—including ADHD, anxiety, depression, and developmental delays.
- Fragile X syndrome (FXS) is the most commonly known cause of inherited intellectual disability, but is difficult to diagnose early.
- Each year, about 1,500 babies are born with spina bifida. Spina bifida may cause physical and mental disabilities that range from mild to severe. In 2009, the lifetime medical cost for a person with spina bifida was estimated to be \$460,923.
- One of the most common forms of muscular dystrophy in children, Duchenne muscular dystrophy (DMD), is usually fatal in the teens or early 20s, most commonly due to severe respiratory or heart problems, or both. Individuals living with DMD may be impacted by muscle and bone weakness as well as digestion and nutrition concerns throughout their lives.

## What Do We Know?

- A positive impact has been documented through *Legacy for Children*<sup>TM</sup>, an evidence-based program whose aim is to improve child outcomes by promoting positive parenting among low-income mothers of infants and young children. Compared with families that did not participate, mother-child bond was stronger, and children performed better on intelligence measures and showed fewer behavior problems.
- Improving the health of people with ADHD could substantially reduce costs to the health care system. It could reduce both the [\\$31.6 billion](#) spent each year on health care costs, and the costs associated with time lost from work and school among children and adults with ADHD and their family members.
- Mental, emotional and behavioral symptoms can complicate the diagnosis and treatment of TS, and create extra challenges for people with TS, their families, educators, and health professionals.
- For families of a child with FXS, research indicates that about 16 months typically passes between professional confirmation of a developmental delay and the diagnosis of FXS. More than one third of families reported that they had more than 10 visits to the doctor before they received the FXS diagnosis.

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- Children with spina bifida can live life to their full potential and become productive members of society. Programs to improve physical and mental health will increase independence and social participation, which will benefit people with spina bifida throughout their lives.
- Improving screening and diagnosis for muscular dystrophies will improve the services patients and families need across the life course.

## What Can We Do?

- Translate research into practice by broadly disseminating Legacy for Children™ through existing programs, such as Early Head Start and measuring the program's impact on child health and development.
- Improve the understanding of risk behaviors and impact of ADHD to develop better prevention and intervention strategies so that the health and long-term outcomes of children with ADHD improves.
- Provide credible health information on recognition, diagnosis, co-occurring conditions, and management of TS for people with TS, their families, health care professionals, teachers, and the public.
- Promote better understanding and earlier identification of FXS and to promote best possible outcomes for children and their families.
- Conduct research on unhealthy lifestyles among adolescents and young adults with spina bifida, analyzing data to determine whether spina bifida magnifies the risk of adverse health outcomes.
- Study the transition from adolescent healthcare to adult health providers among individuals with Duchenne or Becker muscular dystrophy. Additionally, determine factors associated with a successful transition such as managing personal finances, and moving towards independent living.

## Accomplishments

- Provided the first outcome results from NCBDDD's Legacy for Children™. The public health approach to positive parenting showed:
  - 16% fewer children exhibited hyperactivity.
  - 9% fewer children with social-emotional problems.
- Demonstrated that NCBDDD's Legacy for Children™ can be successfully implemented in existing Early Head Start programs, resulting in more efficient use of resources.

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- Published findings on the increasing occurrence of ADHD in the Morbidity and Mortality Weekly Report (MMWR).
- Presented preliminary results from a longitudinal study of children with ADHD that showed that children with ADHD:
  - Are more likely to engage in behaviors where they can hurt themselves as compared to children without ADHD.
  - Had below average academic performance in reading and writing skills.
- Detected challenges in the accurate identification of TS and investigated ways to tracking through ongoing collaborative research to better define the impact of TS.
- Developed the report, Bridging the Gap Between Tourette Syndrome and Public Health in collaboration with the TS community - including individuals, providers and researchers. This report describes the public health issues around TS, highlighting the health, education, employment, and social outcomes that can be improved by public health research, practice and partnerships.
- Launched the first comprehensive website addressing FXS and fragile X-associated disorders. In conjunction with National Fragile X Awareness Day in July, a web feature on FXS was published on CDC's homepage.
- Through NCBDDD, the National Task Force for Early Identification of Childhood Neuromuscular Disorders is shortening the time between first signs of symptoms and diagnosis for a range of neuromuscular disorders in children age 6 months to 5 years. The Task Force has launched an educational website ([www.childmuscleweakness.org](http://www.childmuscleweakness.org)), which is anchored by point-of-care tools and videos to assist providers in the early identification of childhood muscle weakness. Children who get help sooner have a better chance of having a full and productive life.
- The Spina Bifida Association launched its [Preparations website](#), giving families and individuals living with spina bifida a hands-on tool with specific guidelines to promote a

## Did you know?

Fragile X syndrome (FXS) is the most common known cause of inherited intellectual disability. FXS affects both males and females, however, females often have milder symptoms than males. The exact number of people who have FXS is unknown, but it has been estimated that about 1 in 5,000 males are born with the disorder.



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successful, independent adulthood. This partner website is based on CDC's Life Course Model, that considers developmental progress across life stages, and shifts attention from clinical measures to a focus on participation--how people fare in the real world.

- In the past year through funding from NCBDDD, the Tourette Syndrome Association (TSA) improved the knowledge about TS among health care professionals and educators to help them serve children better. Almost 3,000 professionals were reached, with 90% reporting an increase in knowledge of TS. Exhibits reached an additional 2,600 professionals.

## Looking to the Future

- We are leading the effort to develop the first-ever CDC report on children's mental health. The report will be published in the Morbidity and Mortality Weekly Report (MMWR) and will summarize what is known about the incidence of a number of mental health conditions in children.
- Legacy for Children™ (Legacy) is a public health program that engages parents and promotes evidence based strategies to improve the health and well-being of children living poverty. We will use the information learned from the rigorous evaluation of Legacy's impact, process, and costs to help inform public policy on early childhood intervention programs, children's health and well-being, and address health disparities in children at risk for poor health and developmental outcomes.
- The Project to Learn about ADHD in Youth (PLAY), an ongoing longitudinal study on ADHD, will develop new knowledge on the occurrence of childhood ADHD, secondary conditions, health risk behaviors, treatment, and symptoms experienced over time.
- We will work for implementation of important changes to the recent revised ADHD diagnostic and treatment guidelines, an activity that NCBDDD collaborated with the American Academy of Pediatrics:
  - Expand age range of coverage from 6-12 years to 4-18 years of age.
  - Expand scope that considers behavioral interventions and directly addresses problem-level concerns in children based on the Diagnostic and Statistical Manual for Primary Care (DSM-PC), Child and Adolescent Version.
  - Create a system to guide the clinical care process.
  - Integrate with the Task Force on Mental Health to foster stronger ties to families and mental health clinicians, to intervene early, and to foster good mental health.
- We will continue to work with partners to increase awareness and understanding of Tourette syndrome among health and education professionals and the public. Providing education and outreach activities at both the community and national level will help reduce stigma and

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improve access to care, aid with timely diagnosis, and ultimately help children with TS lead healthy and productive lives.

- We are developing and evaluating the implementation of care guidelines for specific muscular dystrophies. The first guidelines for Duchenne muscular dystrophy were developed through an international expert panel process and published in *Lancet Neurology* in 2010. The Duchenne muscular dystrophy guidelines will inform development of evidence-based guidelines and best practices for four additional forms of muscular dystrophy. In most cases, these will be the first guidelines ever developed for these complex conditions, giving clinicians and families a critical resource.
- Building from a previous pilot study, we will continue to support research on fragile X syndrome. Data collection will be expanded to include information about school progress, behavioral interventions, medication use, and transition to adulthood and independent living.
- Determine the impact of urinary tract infections and renal complications among individuals with spina bifida, looking at end stage renal disease, monitoring of renal function, and the importance of quality urologic care.

## Stories

### Impact of Partnership

My heartfelt thanks go to the CDC and the Tourette Syndrome Association for providing such wonderful educational opportunities to our TS families in Louisiana. Without the Youth Ambassador program, my son's life would likely be on a very different track right now. The training gave him the confidence and the boost in self-esteem at a time when he desperately needed it, and he has continued to "pay it forward" with his presentations in schools and youth groups. –Mother of a son with TS

### Angela and *Legacy for Children*<sup>™</sup>

Angela was one of the 600 mothers enrolled in the first study of *Legacy for Children*<sup>™</sup>. Watching the other children in the *Legacy for Children*<sup>™</sup> program helped Angela understand what to expect of her daughter, Lara. Helping other parents practice new parenting skills reinforced her own skills and helped define her career track. "It never would have crossed my mind to want to help others [as a profession] – I never realized what an influence I was to other people." Sharing parenting experiences with the other mothers created a community that supported Angela's desire for the best possible life for her children and persisted beyond the three years of the *Legacy for Children*<sup>™</sup> program.



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Angela developed a strong connection to the idea of “parents are the child’s first teachers” and consequently changed her interactions with her children, including her discipline decisions. She learned to be an advocate for Lara’s academic success. As a result, at the age of five, Lara was enrolled in a magnet school a year ahead of her peers. In general, Angela reported that *Legacy for Children™* helped her to think more about her influence on her children. Mothers quickly develop a deep connection to their *Legacy for Children™* group, and participation rates have stayed high since the first group session. “*Legacy for Children™* opened my eyes to thinking through the long-term effects of what I do, rather than just at that moment.”— Angela, a *Legacy for Children™* mother



## Building a Better Roadmap: The Spina Bifida Multi-Site Study

Nancy went for her five-month ultrasound to find out whether she was expecting a boy or a girl. “They kept repeating the ultrasound over and over. I knew from a mother’s instinct, and from being a nurse, that something was wrong. The doctor walked in and said your son’s going to have spina bifida. I had briefly studied spina bifida in nursing school, only hearing about the worst-case scenarios, so immediately I thought that’s what my child would be facing.”

Nancy was referred to a high risk obstetrician and the spina bifida clinic at Children’s Hospital of Alabama in Birmingham. At her prenatal consultation in the clinic she went with questions about her son’s prognosis. “The pediatric neurosurgeon told me to put away all my questions and said I don’t know, I don’t know.” Nancy and her husband were very scared and shaken.

Nancy shares that the staff at Children’s Hospital were wonderful, “...but the lack of research when Clark was born meant there were so many ‘don’t knows.’ It would have been so helpful to have a better roadmap based on research. More spina bifida research would give parents definite steps to take at each milestone to ensure the best results for their child. It would also help manage the secondary conditions. Every issue is just as important as the next. Some families might deal more with neurological symptoms, while others struggle daily with bowel and bladder concerns. Nutrition and physical activity are also important when it comes to living with the condition. Clark is ambulatory and goes to the gym but it’s still very difficult for him to get his heart rate up. I’m constantly watching his weight. For us, the closest accessible sports are an hour and fifteen minutes away. There are not enough resources available.”

Clark is now twelve years old. He walks with braces. He takes piano lessons and will start guitar lessons soon. He loves watching college football and he’s the assistant coach of his younger brother’s soccer



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team. He likes to hang out with his friends. Although spina bifida impacts his life every day, Clark does not let it define who he is. Nancy continues, “Clark had a shunt put in at two weeks and then a revision at two years, but since then no shunt malfunctions.” She crosses her fingers and knocks on wood when she talks about how lucky they’ve been because shunt problems are common with spina bifida.

“We want there to be more knowledge of all aspects of spina bifida and the best way to manage it. Everything is so intertwined,” Nancy says. “Any time there is an opportunity that is non-invasive for Clark to be involved in the research, we do it because we know that in the long run the research will help us and all the other families affected by spina bifida, as well as those to come. Clark is proud to be part of the research. I know for some families the research they’d like to have is on the neurological side because they’re dealing with frequent shunt revisions or their child has symptoms from tethered cord syndrome. Also every parent I’ve spoken with who has a child that’s a little bit older says their child seems to show other neurological symptoms like an increased emotional response, like wearing their emotions on their sleeve or a lack of motivation. Without more research in this area, it’s difficult to say if these behaviors are related to puberty, depression, or perhaps the effects of hydrocephalus.”



Each year, about 1500 babies are born with spina bifida. Health issues and treatments for people with spina bifida will be different for each person. Some health issues and treatments related to spina bifida include hydrocephalus, tethered cord, limited mobility and physical activity, incontinence, skin sores, and latex allergy. The 2009 estimate of medical costs for the first year of life for a child with spina bifida was \$52,415 and the lifetime medical cost was estimated to be \$460,923.

NCBDDD began funding data collection from Children’s Hospital of Alabama as part of the Multi-Site Study in 2008. Today there are 17 spina bifida clinics across the country sending their de-identified patient data to NCBDDD for analysis. The clinics use an electronic medical record (EMR) specially designed for spina bifida and developed by NCBDDD and its partner the Spina Bifida Association, to collect information about patients’ clinical experiences. This information includes the type of spina bifida diagnosis, mobility, surgeries, pressure sores, education and employment, and insurance coverage, as well as other clinical information. Using the EMR also guarantees that all clinics in the study provide registry information in the same way, ensuring that NCBDDD has standardized and reliable data for research.

As part of the Nurse First program she’s launched, Nancy gives presentations on spina bifida to nursing students. As both a nurse and a mother of a child with spina bifida she says, “If I talked about spina bifida in depth, and covered all the topics, it would take me six months of continuous talking. So if NCBDDD did research on spina bifida nonstop for the next twenty-five years, there would still be more to know.”

NCBDDD is the only organization in the United States designing the infrastructure and conducting the clinical research to build a better road map for living with spina bifida.

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In collaboration with our partners, we are learning which health care services may be most beneficial, with the goals of health and condition self-management, success in developing relationships, and success in learning so that participation in society throughout life can be relevant and meaningful. The first findings from this study will be shared with health care providers and families beginning in 2012.

## Featured Videos

[The Spina Bifida Experience: Developing Independence](#)

[The Spina Bifida Experience: Managing Your Own Medical Care](#)



## Notable 2011 ncbddd scientific publications

- Bitsko RH, Cortese MM, Dayan GH, Rota PA, Lowe L, Iversen SC, Bellini WJ. **Detection of RNA of mumps virus during an outbreak in a population with high two-dose measles-, mumps-, and rubella vaccine coverage.** J Clin Microbiol 2008;46(30): 1101–3.
- Fairman AD, Thibadeau JK, Dicianno BE, Parmanto B. **Implementing a specialty electronic medical record to document a life-course developmental model and facilitate clinical interventions in spina bifida clinics (a review).** Pediatr Clin North Am 2010;57(4):959–71.
- Kronk R, Bishop EE, Raspa M, Bickel JO, Mandel DA, Bailey DB Jr. **Prevalence, nature, and correlates of sleep problems among children with fragile X syndrome based on a large scale parent survey. Sleep 2010;** Swanson ME, Sandler AD eds. Spina bifida: health and development across the life course. An Issue of Pediatric Clinics (The Clinics: Internal Medicine). Maryland Heights (MO): Elsevier, 2010.
- Swanson ME, Sandler AD. Preface. **The natural history of spina bifida.** Pediatr Clin North Am. 2010;57(4):xv–xvi
- Swanson ME. **Need for the life course model for spina bifida (A Review).** Pediatr Clin North Am. 2010;57(4):893–901.
- Visser SN, Bitsko RH, Danielson ML, Perou R, Blumberg SJ. **Increasing prevalence of parent-reported attention-deficit/hyperactivity disorder among children — United States, 2003 and 2007.** Morbidity and Mortality Weekly Report. 2010;59(44):1439–43

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