



MAKE THE  
**FIRST FIVE  
COUNT**®

White Paper 2013

1 2 3 4 5



# Executive Summary:

## Why Make the First Five Count?

The first five years of life are essential for children's future development yet, each year, more than one million children enter kindergarten without the necessary skills to become successful.<sup>1</sup>

Young learners with undiagnosed disabilities, developmental delays including emotional concerns, and special health care needs are especially vulnerable to falling behind because they require additional supports to address their challenges.

In addition, since children's early experiences set the foundation for later brain development and future skill acquisition, the beginning years reflect an especially important time for nurturing students' growth. During the first five years of life, neural connections form patterns and relationships that serve as the basis for language, reasoning, problem solving, social skills, and emotional well-being.<sup>2</sup> As a

result, it is critical that all children, especially those with disabilities or developmental delays, have access to the appropriate resources to learn, grow, and thrive in their early childhood settings.

Beginning in infancy, early intervention services strengthen children's physical, social, emotional, and intellectual capacities by offering individualized supports that reflect their specific needs. Early identification and early intervention services provide the most valuable approach for promoting children's development during the first years of life. As children grow older, early services also foster the development of more complex skills, including language acquisition, numeracy, balance and coordination, socialization, and cooperative play.<sup>3</sup>

As the nation's largest nonprofit provider of early intervention services, Easter Seals understands the importance of early detection



and intervention for improving the lives of children with autism, developmental delays, and other disabilities. As a result, Easter Seals is spearheading an effort – **Make the First Five Count**<sup>®</sup> – to raise awareness about the importance of early identification, education, and care services for promoting the success of all students. Additionally, Easter Seals intends to mobilize support and resources by fostering a public/private partnership that garners additional funding for early intervention services.



MAKE THE  
**FIRST FIVE  
COUNT**<sup>®</sup>





## A Closer Look at the Problem:

Barriers to early screenings, interventions, and supportive care hinder the optimal development of young children with developmental delays and disabilities. As a result, these children are at increased risk for later school failure.

Every year, more than 25 percent of American children under the age of five enter preschool at risk for developmental delays, behavioral problems, or specific health care needs.<sup>4</sup>

Although millions of young children under the age of 5 with special academic, behavioral, and health care needs can benefit from early services, many of these children never receive the necessary supports to reach their full learning potential.<sup>6</sup> Without the appropriate services to meet their needs, these children often struggle to develop foundational skills critical for later school success.

Fewer than 1 in 5 young children under the age of 5 are properly screened to identify their specific challenges.<sup>7</sup> Additionally, children may spend years in school before health professionals or teachers determine their developmental needs, if at all. Late and absent identification profoundly affects children's academic and socio-emotional development. Young learners with unmet needs continually struggle to keep up in school, connect with their peers, and manage their frustrations.

In many instances, even identified challenges remain unaddressed because too many communities lack the necessary resources to provide direct services and treatments for vulnerable young children. Sadly, 16 percent of children who already have an identified special health care need remain unable to secure appropriate services.<sup>8</sup> In low-income and impoverished communities, where there is a higher prevalence of children with disabilities and fewer services are available, only 25 percent of children with an identified special health care need receive adequate care. Moreover, 45 percent of uninsured children with identified special health care needs also complain of unmet medical needs.<sup>9</sup>

The Federal Maternal and Child Health Bureau of the U.S. Department of Health and Human Services defines children with special health care needs as **“those who have or are at risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”**<sup>5</sup>

Statistics are similarly bleak for children with complex delays such as autism. Almost 1 in every 88 children is identified with some form of autism; a child is newly diagnosed every twenty minutes.<sup>10</sup> Despite rising incidence rates and the availability of validated tools to diagnose autism as early as 24 months, the average age of an autism diagnosis is four and a half years old.<sup>11</sup>



MAKE THE  
**FIRST FIVE  
COUNT**<sup>®</sup>

# What happens when early identification and intervention services are not available?

- **A 20-month-old boy** who clearly displays behaviors associated with autism is not screened and his family struggles with his behavior challenges at home.
  - **A young girl** with learning delays cannot participate in early screening to identify her disability. Her family's needs in assisting in her development are not met. As a result, she fails to receive the appropriate therapy to help her begin school with the foundational skills necessary for success.
  - **A 2-year-old boy** with a speech delay cannot access speech therapy so his family can support his communication development at home, leading to frustration for both the boy and his family.
  - **An 18-month-old girl** with low vision cannot obtain glasses.
  - **A child with Down syndrome** does not receive developmental supports needed to improve his muscle strength to sit up because physical therapy services are not available to him.
  - **A young boy** with social and behavioral challenges is at risk for expulsion from his pre-kindergarten class because he cannot access the services to address his specific needs.
  - **A child with delays** in cognition skills is not screened or identified. Therefore, his family does not receive needed supports and services to improve her school-readiness skills.
- Ultimately, when early interventions and services are not available, young children struggle** to navigate their environment, to live as part of a family, to develop friendships, and to master school readiness skills.

- 3.4 million, or 17 percent of all children, have been identified as having developmental or behavioral disabilities, yet fewer than half of these children were screened before entering school.<sup>12</sup>
- One million, or almost 20 percent of children under the age of 5, do not receive developmental screenings.<sup>13</sup>
- 1 in 5 family households include a child with a special health care need.<sup>14</sup>
- Five million, or 25 percent of all children under the age of 5, are at risk for developmental, behavioral, or social delays.<sup>15</sup>
- More than 1.6 million, or 13 percent, of birth to 3-year-olds have delays that may make them eligible for early intervention services<sup>15</sup>
- Children who do not develop early skills that serve as the building blocks for later school success are less likely to graduate high school or receive high earnings as adults.<sup>16</sup>



# The Larger Cost

Ignoring the needs of millions of our nation's children significantly limits their potential for success as high school students and as adults in the workforce. Moreover, failing to address the challenges of vulnerable students in their early years leads to lasting and negative effects for our nation's economy.

**1.3 million students from the class of 2010 who drop out of high school will cost the United States \$337 billion in lost wages over their lifetimes** - according to *The Alliance for Excellent Education*

The earnings gap between these high school dropouts and high school graduates will amount to nearly \$10,000 each year.<sup>17</sup>

Additionally, new data from the Bureau of Labor Statistics (September 2012) shows the unemployment rate for Americans without a high school diploma is 14.1 percent, which is significantly higher than the 9.1 percent national average.<sup>18</sup> The Bureau of Labor Statistics also reports that students without a high school diploma lack the basic literacy skills needed to fill out a job application.<sup>19</sup>





# The Solution: Invest for Success

When we invest in our children, we change their futures. James J. Heckman, a University of Chicago Distinguished Professor, Nobel Laureate, and expert in the economics of human development, argues that investing in the first five years of children's lives represents a sound commitment to our nation's future.

Professor Heckman writes, "early interventions have much higher economic returns than later interventions for disadvantaged children."<sup>20</sup> His analysis of the Perry Preschool program, which specializes in early care, reveals that early education for vulnerable children results in a 7 to 10 percent annual return on investment. Specifically, early intervention services increase school and career achievement, reduce the need for special education services, lead to healthier lifestyles, and lower crime rates.<sup>21</sup> As an advocate for early education and care, Professor

Heckman strongly recommends we "make greater investments in young children to see greater returns in education, health, and productivity."<sup>22</sup>

The National Institute on Early Education Research reports that **high quality preschool education can substantially increase children's chances of succeeding in school and in life.** Children who attend high quality prekindergarten programs are less likely to be held back a grade, less likely to need special education services, and more likely to graduate high school. They are also less involved in crime and delinquency and less likely to become dependent on welfare. <sup>23,24</sup>



Several studies, including those implemented by the Perry Pre-School in Michigan, the Abecedarian Project in Chapel Hill, N.C., and the Chicago Public School's Child Parent Center Study, also highlight the value of investing in early education programs as a way to promote the success of young children at risk for disabilities and developmental delays. These pilot programs show that early commitment to education and care for young children results in life-long savings. For example, the Chicago study estimates that for every dollar we spend on early identification and intervention services today, we save seven dollars in future costs to society.<sup>25</sup>

Similarly, *The Special Education Expenditures Project*, funded by the U.S. Department of Education, reports that the total expenditure to educate the average student with disabilities is an estimated 1.90 times that spent to educate a student without a disability.<sup>26</sup> Ultimately, by investing in our children through early intervention programs and supports, we can decrease the number of students requiring special education services.

At Easter Seals New Hampshire, nearly half of the young children in early intervention programs enter kindergarten without ever needing additional special education supports. Additionally, at an Easter Seals pre-school in the Bronx, where most of the students come from low-income, non-English speaking families, 20 percent of the preschoolers with identified needs and disabilities enter kindergarten without the need for special education services.

Likewise, in North Georgia, Easter Seals' 2010 Head Start Child Outcomes reported significant progress among 4-year-olds participating in the inclusive childcare program. Serving 2,000 children in 12 centers, the inclusive program offers early intervention services to the 30 percent of children with identified disabilities. In September 2009, 41 percent of the 4-year-olds enrolled in the program were functioning one and two years behind their typically developing peers. By the end of the school year, 94 percent of these children were performing at levels appropriate for their age.



MAKE THE  
**FIRST FIVE  
COUNT**



## Our Call to Congress

Young children can access early identification and early services through a variety of public programs and through private health insurance. However, many public programs are underfunded to meet the current needs of many children. Although Easter Seals advocates for all programs that support the needs of young children and their families, we chose to prioritize only one in the beginning of the *Make the First Five Count* campaign.

The federal early intervention program established by Part C of the Individuals with Disabilities Education Act (IDEA) provides an ideal resource for families of very young children, birth through age two years, with disabilities and developmental delays. Therefore, the first public policy goal of *Make the First Five Count* is to increase funding for Part C of IDEA. By offering critical and coordinated resources for all children and their families, especially those with developmental delays and disabilities, we can ensure that students enter school healthy, supported, and ready for a lifetime of learning.





# Our Call to Parents and Grandparents

**Take a free online screening tool to assess the young child in your life's development—at [MaketheFirstFiveCount.org](http://MaketheFirstFiveCount.org)**

Through generous support from the CVS Caremark Charitable Trust, Easter Seals is now offering parents free access to an online screening tool.

*The Ages & Stages Questionnaires® (ASQ)* from Brookes Publishing lets parents easily and effectively monitor their child's development. It's an important tool for parents and caregivers to make sure their child is reaching his or her milestones — and learn what to do or where to go if the screening identifies a concern.

To date, nearly 3,000 people have taken the online screening — with more than half of the children identified as having some type of delay or concern and provided guidance for seeking appropriate support/services. The tool is now available online in English and Spanish.

In the first year Easter Seals set a goal of increasing funding for IDEA's Part C program by \$100 million, for a total of \$539 million. Our collective advocacy resulted in Congress allocating nearly \$443 million to early intervention services.<sup>27</sup> This modest increase was celebrated in large part because despite the increasing number of children who can benefit from Part C, its funding has remained flat for nearly a decade. Moreover, Government spending on programs for young children with disabilities and developmental delays represents less than 8% of the \$11.5 billion in federal spending for all special education services.

This year, through *Make the First Five Count*, Easter Seals is again calling on Congress to protect and increase funding for Part C of IDEA, with a goal of reaching a total of \$539 million in the years to come.







# Why Make the First Five Count **NOW?**

**Easter Seals' *Make the First Five Count* campaign resonates deeply with the organization's ongoing mission. For nearly 100 years, Easter Seals has improved the lives of young children and families across the United States through early intervention and education services. *Make the First Five Count* speaks to the ultimate goal of Easter Seals: to positively impact the lives of all young children and their families by ensuring that they receive support when it matters most – during the first five years.**

We cannot continue to sit on the sidelines while young children fail to access the services they need to prepare for a bright future. We know what works. We know who needs help. We must act now to ensure that our nation's most important assets- the children- receive the necessary skills and supports to become successful learners.

In recent years, a great deal of legislative and media attention has focused on how to improve our educational system, beginning in kindergarten. Easter Seals knows that kindergarten is too late. The most beneficial and cost-effective outcomes result from early intervention programs, such as those established by Part C, that screen, evaluate and provide early intervention services and supports for eligible children and their families well before they start kindergarten. Thus, through the *Make the First Five Count* Campaign, Easter Seals is advocating for Part C funding to become a significant priority for all Americans.

If you believe all kids deserve a chance to learn, build lifelong skills, and achieve their dreams, speak out today!

Become a part of the solution. Make the first five count. Join us at **[MaketheFirstFiveCount.org](http://MaketheFirstFiveCount.org)**.



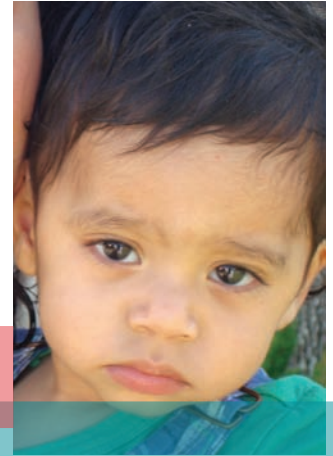
# Five Stories that Count



2



4



1



3



5

Josh, age 3  
Easter Seals  
serving DC | MD | VA

Kai, age 5  
Easter Seals  
Southeastern  
Wisconsin

Audrey & JR,  
ages 5 and 6  
Easter Seals Arkansas

Ben, age 3  
Easter Seals  
Southeast Wisconsin

David & Jacob,  
age 2  
Easter Seals  
Greater Houston



# 1



## Josh, age 3

Easter Seals Serving DC | MD | VA

**“When Josh came to Easter Seals for childcare at age one, we thought he was a typically-developing child. The staff at Easter Seals recognized that might not be the case. They sat me down to take the Ages & Stages Questionnaires® (ASQ). The results confirmed what Easter Seals was already thinking – that Josh has developmental delays,” said Josh’s mom, Rebecca.**

Josh’s ASQ screening results indicated concerns in his communication, gross motor and personal-social skills. After further evaluation, Josh was formally enrolled in Early Intervention services. He’s now receiving on-site speech-language therapy, occupational therapy and physical therapy at Easter Seals to help address his delays and promote his growth and participation in daily routines.

**“I can’t thank Easter Seals enough for the diagnosis and therapy to help Josh overcome his delays. He has such a bright future,” she said.**



MAKE THE  
**FIRST FIVE  
COUNT®**



# Kai, age 5

Easter Seals Southeastern Wisconsin

Kai spent his first 28 months in an orphanage in China. When his new parents brought him home, he didn't walk, speak, or make contact with others, so they sought help from a pediatric specialist. Kai's parents, Scott and Chris, were told that he would be non-verbal and likely would require long-term care. They looked to Easter Seals for help.

Kai began autism services in September of 2010 and showed amazing progress after only nine months. Talking was his first, most noticeable change, from being non-verbal to using over 75 words. He began stating his wants and needs, rather than pointing, and soon started using complete sentences. Because he was able to say what he wanted, Kai had fewer tantrums and more meaningful interactions with family and other children. He began to enjoy activities like looking at books and being read to.

No longer isolated, Kai is now a social butterfly with his friends at school. He's also on target with his academic skills like spelling, counting, reading and writing, and enjoys playing games like Trouble, Sorry, Connect 4 and Chinese Checkers.

Scott and Chris are delighted with their son's progress. **“Not only was our son dismissed from all special education services, except speech therapy,” they said, “but he is functioning at an age-appropriate level. We are so proud of the accomplishments our son has made with the help of Easter Seals! His future looks bright and we are truly grateful!”**





# Audrey & JR, ages 5 and 6

Easter Seals Arkansas

Audrey and JR were both born prematurely at only 26 weeks. After their first three months in the NICU, Easter Seals provided in-home therapy and support services.

Audrey needed extra help learning to crawl, holding herself up on her hands in a sitting position and learning to walk. She made so much progress that, when she turned two, she no longer needed physical therapy. Today, she's running, playing and climbing as a typically developing kid. But she still receives speech therapy to help her with eating, something she's struggled with since infancy.

JR, Audrey's little brother is also an Easter Seals kid. He had physical therapy early on and now does a lot of new things, like jumping and running. He still receives speech and occupational therapy for his developmental delays and is making great progress. He's working very hard to learn to talk.

Audrey's and JR's parents say: **"We are so thankful. Easter Seals has helped us tremendously through such tough times. Audrey and JR have truly amazed us with everything they have achieved in their development."**

Today, both attend preschool and their parents are confident that Audrey and JR will reach their developmental milestones and be ready to enter kindergarten with their peers.



MAKE THE  
**FIRST FIVE  
COUNT**®



# Ben, age 3

Easter Seals Southeast Wisconsin

Ben Jimenez was 18 months old, when his parents noticed delays in his speech. They spoke to their pediatrician about their concerns, and were told that Ben's delays were because he was living in a bilingual family. Not satisfied with this explanation, Ben's parents explored their options and found Easter Seals Southeast Wisconsin's Birth to Three program.

After six months in the Birth to 3 program, Ben is making great progress. When he talks, he speaks in full sentences and is understood by others. And, thanks to his knowledgeable team of speech and occupational therapists, Ben's parents better understand his sensory issues and fine motor-skill needs.

Ben's mom explains, **"Finding out his diagnosis (PDD-NOS) didn't come as a big surprise, it was more like a relief. Our goal is to provide all the necessary interventions as early as possible to be sure he has the best outcomes. Seeing Ben's incredible progress thus far gives us so much hope and great inspiration."**

In fact, Ben is doing so well communicating in his primary language, English, that his parents now hope someday soon he will be able to speak Spanish with his grandparents.



MAKE THE  
**FIRST FIVE  
COUNT**®



# David & Jacob, age 2

## Easter Seals Greater Houston

Susanna Bravo's twins, Jacob and David, were born prematurely and weighed less than 4 pounds together. When they were ready to leave the hospital, they were referred to the Early Childhood Intervention (ECI) Infant Program at Easter Seals Greater Houston. David joined the program right away, but Jacob didn't qualify initially so the Infant Program kept him in their "follow along."

When Jacob was two months old, Susanna listened to her gut instinct that Jacob needed extra support. She learned about the *Ages & Stages Questionnaire*® (ASQ) online screening tool and put it to use for Jacob. The ASQ for Jacob showed delays in his gross and fine motor skills. He was referred to a local Early Intervention program and the evaluation team found the ASQ results were right on target. Jacob began early intervention services along with his brother and is making wonderful progress.

Today, Jacob is crawling and learning to walk independently. Susanna is so grateful for the services her sons receive from the ECI Infant Program at Easter Seals, and she knows the progress they are making is because of their support and teaching her great strategies she can use with Jacob at home.

She knows with the help of Easter Seals and the ASQ to continue to monitor their development, both boys will continue to make progress!



MAKE THE  
**FIRST FIVE**  
COUNT®

# Acknowledgements

**Easter Seals would like to thank the IDEA Infant and Toddler Coordinators Association,** and especially Kate Barry, for their support in developing this Make the First Five Count White Paper. For more, please visit: [www.ideainfanttoddler.org](http://www.ideainfanttoddler.org)

## Notes

1. Getting Ready, "Findings from the National School Readiness Indicators Initiative, A 17 State Partnership," last modified February, 2005, <http://www.gettingready.org/matriarch/d.asp?PageID=303&PageName2=pdfhold&p=&PageName=Getting+Ready++Full+Report.pdf> (accessed May 2012).
2. Ibid.
3. Ibid.
4. Health Resources and Services Administration, "The National Survey of Children with Special Health Care Needs," last modified 2001, <http://mchb.hrsa.gov/chscn/pages/intro.htm> (accessed May 2012).
5. Health Resources and Services Administration, "Children with Special Health Care Needs More Likely to Have Health Care Access Problems," last modified 2011, <http://www.hrsa.gov/about/news/pressreleases/111205cshcnbook.html> (accessed May 2012).
6. Health Resources and Services Administration, "The National Survey of Children with Special Health Care Needs."
7. Data Resource Center for Child and Adolescent Health, "Data Query from the Child and Adolescent Health Initiative," last modified 2007, <http://childhealthdata.org/browse/survey/results?q=257&r=1>. (accessed May 2012).
8. Health Resources and Services Administration, "The National Survey of Children with Special Health Care Needs Chartbook 2005-2006," last modified 2008, <http://mchb.hrsa.gov/cshcn05/NF/4healthcna/services.htm> (accessed May 2012).
9. Ibid.
10. Rice, C., "Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network," Surveillance Summaries March 30, 2012 61(SSO3); 1-19.
11. Centers for Disease Control and Prevention, "Community Report From the Autism and Developmental Disabilities Monitoring (ADDM) Network," last modified 2012, <http://www.cdc.gov/ncbddd/autism/document/ADDM-2012-Community-Report.pdf>(accessed May 2012).
12. Health Resources and Services Administration, "The National Survey of Children with Special Health Care Needs."
13. Data Resource Center for Child and Adolescent Health, "Data Query from the Child and Adolescent Health Initiative," last modified 2007, <http://childhealthdata.org/browse/survey/results?q=236> (accessed May 2012).
14. Health Resources and Services Administration, "The National Survey of Children with Special Health Care Needs Chartbook 2005-2006."
15. Rosenberg, S., Zhang, D. & Robinson, C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*, 121(6) e1503-e1509. doi:10.1542/peds.2007-1680, <http://www.nectac.org/~pdfs/pubs/importanceofearlyintervention.pdf>
16. Alliance for Excellent Education, "About the Crisis," modified 2012, [http://www.all4ed.org/about\\_the\\_crisis](http://www.all4ed.org/about_the_crisis) (accessed May 2012).
17. Ibid.
18. U.S. Department of Labor, "The Employment Situation--September 2012," modified 2012, <http://www.bls.gov/news.release/pdf/empsit.pdf> (accessed September 2012).
19. Ibid.
20. Heckman, JJ, "The Economics of Inequality: The Value of Early Childhood Education," *American Educator* 35, no. 1 (2011); 31-35.
21. Ibid.
22. Ibid.
23. Barnett, WS & Yarosz, DJ, "Who Goes to Preschool and Why Does It Matter?" modified 2007, <http://nieer.org/resources/policybriefs/15.pdf> (accessed May 2012).
24. Espinosa, LM, "High Quality Preschool: Why We Need It and What it Looks Like," modified 2003, <http://nieer.org/resources/policybriefs/1.pdf> (accessed May 2012).
25. National Institute for Early Education Research, "Economic Benefits of Quality Preschool Education for America's 3-and 4-year olds," modified 2012, [http://www.pewtrusts.org/news\\_room\\_detail.aspx?id=19566](http://www.pewtrusts.org/news_room_detail.aspx?id=19566) (accessed May 2012).
26. Chambers, JG, Parrish, TB, & Harr, JJ, "What Are We Spending on Special Education Services in the United States, 1999-2000?" modified 2004, <http://csef.air.org/publications/seep/national/AdvRpt1.PDF> (accessed May 2012).
27. National Early Childhood Technical Assistance Center, [www.nectac.org/partc/partc.asp](http://www.nectac.org/partc/partc.asp)



MAKE THE  
**FIRST FIVE**  
**COUNT**®

*Made possible by*

THE

**SAFWAY** 

FOUNDATION