

Forgotten Children



A Case for Action for Children and Youth with Disabilities in Foster Care

A Project of United Cerebral Palsy
and Children's Rights, 2006

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About United Cerebral Palsy

United Cerebral Palsy is one of the nation’s leading organizations serving and advocating for the more than 54 million Americans with disabilities. Most UCP consumers are people with disabilities other than cerebral palsy. Through its nationwide network, United Cerebral Palsy offers services to individuals, families and communities such as job training and placement, physical therapy, individual and family support, early intervention, social and recreation programs, community living, state and local referrals, and instruction on how to use technology to perform everyday tasks. For more information, visit www.ucp.org or call (800) 872-5827.

About Children’s Rights

Children’s Rights is a national organization advocating on behalf of abused and neglected children in the U.S. Since 1995 we have used legal action and policy initiatives to protect children and create lasting improvements in foster care, adoption and child welfare. For more information, visit www.childrensrights.org or call (212) 683-2210.

Acknowledgements

The partnership between United Cerebral Palsy and Children’s Rights would not be possible without the commitment of Loreen Arbus, a national Trustee of United Cerebral Palsy, who saw the need and cared enough to initiate and support this effort.

Children’s Rights and United Cerebral Palsy also would like to thank the diverse group of United Cerebral Palsy affiliates who have added their voices to this collaboration, and to recognize Sara Munson at Children’s Rights, the primary author of this comprehensive literature review.



A Case for Action

On any given day, there are more than half a million children and youth in foster care in the United States, and studies suggest that at least one-third have disabilities, ranging from minor developmental delays to significant mental and physical disabilities.¹ This population continues to increase as technology enables growing numbers of children to survive disabling medical conditions and as more children are being recognized and identified as having disabilities.² Evidence suggests, however, that the special needs of this population are not being met in foster care systems across the country, and that these children experience worse outcomes than other children in foster care.³

In 2004, two national organizations committed to improving the lives of vulnerable children, United Cerebral Palsy and Children's Rights formed an alliance to improve policy and practice for children and youth with disabilities in foster care. Through this partnership, United Cerebral Palsy and Children's Rights are identifying promising service delivery approaches for meeting the needs of this population and developing policy and legal advocacy strategies to address major systemic problems that negatively affect these children's safety, well-being and opportunity to grow up in permanent families. The joining of forces of the child welfare and disability service and advocacy communities at the national, state and local levels is a critical step in beginning to address these issues.⁴

This report provides a summary of the research and other available information regarding children and youth with disabilities in foster care. It documents the critical needs of the children and youth themselves and the status of the systems that serve them, detailing the range of issues that provide the foundation for the partnership between United Cerebral Palsy and Children's Rights.

The Kids

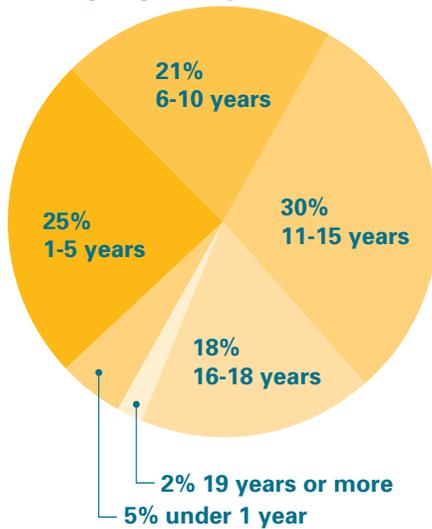
Of the more than 500,000 children and youth in foster care, almost one-third are under age five and one-fifth are over the age of 16. Almost half are placed with non-relative foster families, one-fourth live with relatives, and one-fifth are living in group homes or institutions. Forty percent have been in foster care for more than two years.⁵ Many of these children and youth have disabilities.⁶

There are 119,000 children and youth in foster care who are waiting to be adopted. Their average age is eight; more than one-third are under the age of five, and more than one-third are over the age of 11. They have been in foster care an average of nearly four years.⁷ The majority of these children and youth have disabilities.⁸

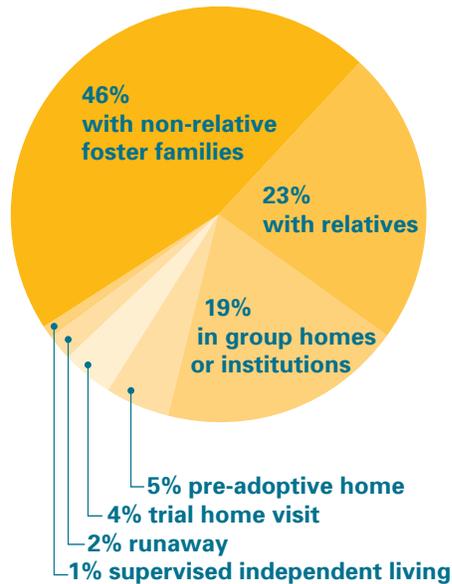
A Profile of Children in Foster Care

Age

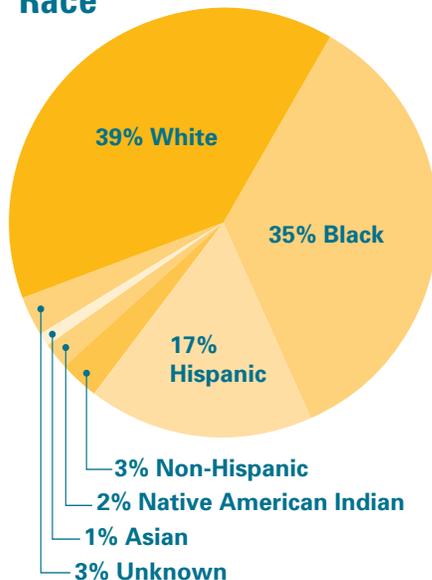
Average Age = 10 years



Placements



Race



Length of Time in Care

40% have been in foster care for more than 2 years

Gender

Slightly more males than females

Source: US Department of Health and Human Services, 2005

The Unmet Needs

A growing body of research has revealed that increasingly, children and youth in foster care have physical, mental health or developmental problems.⁹

Although the issues facing children and youth with disabilities in foster care have yet to come to the forefront of child welfare planning, service delivery or evaluation,¹⁰ there is a developing body of literature that clearly highlights the critical need for this type of discussion and focus.¹¹

Most of the children who enter foster care have been exposed to conditions that undermine their chances for healthy development.¹² Research indicates that children and youth in foster care are in worse health than those who are homeless or those living in the poorest sections of our inner cities.¹³ They have a higher likelihood of chronic medical problems, lifelong psychiatric and behavioral issues, as well as permanent physical, cognitive and developmental disabilities than children in the general population.¹⁴

Whether they experience maltreatment that results in disabilities, or are victims of maltreatment because of their disabilities,¹⁵ children who enter foster care with special needs, on average, already have experienced more than 14 different environmental, social, biological and psychological risk factors before coming into care.¹⁶

While there have not been systematic national studies of the prevalence of disability among children in foster care, individual studies in various states and localities have highlighted a range of potential challenges. These studies have found the following:

- **40% born low birth weight or premature;**¹⁷
- **80% prenatally exposed to substances;**¹⁸
- **30-80% with at least one chronic medical condition [e.g., asthma, HIV, TB];**¹⁹
- **30-50% with dental decay;**²⁰
- **25% with three or more chronic health problems;**²¹
- **30-60% with developmental delays;**²²
- **50-80% with mental and behavioral health problems;**²³
- **20% fully handicapped;**²⁴
- **30-40% receiving special education services.**²⁵

Children and youth with these types of special needs experience disproportionately poorer foster care outcomes. When compared to children and youth without disabilities, those with disabilities in foster care:

- Are less safe, and more likely to be maltreated;²⁶
- Are more likely to be on psychotropic medications;²⁷
- Have poorer educational experiences and outcomes, including higher rates of school transfer, absenteeism, tardiness, grade retention, achieving poor grades, dropping-out, performing below grade level, receiving low state testing scores, exemption from state testing, suspension and expulsion, enrollment in vocational training, placement in more restrictive classrooms, and lower rates of doing homework, receiving help with schoolwork from caregivers, being enrolled in college preparatory courses, receiving a high school diploma, or participating in postsecondary education;²⁸
- Are more likely to be institutionalized;²⁹
- Experience more placement instability;³⁰
- Have longer lengths of stay;³¹
- Have lower rates of achieving permanency, including lower probability of reunification with their birth families, guardianship with relatives or adoption,³² and higher rates of re-entry into care;³³
- Have fewer opportunities for positive adult functioning, including higher rates of homelessness, substance abuse, unemployment, receiving public assistance, criminal justice involvement, non-marital childbearing, being violently or sexually assaulted and having mental health problems following discharge from foster care.³⁴

Systemic Challenges

Foster care is supposed to provide a safe haven for abused and neglected children.³⁵ Unfortunately, too many children in foster care experience further harm.³⁶ Children in foster care may not receive adequate health or mental health care or appropriate educational support. They may bounce from foster home to foster home or be placed inappropriately in institutional settings. Due to a range of systemic challenges, children with disabilities are at even greater risk for negative experiences in foster care and poor life outcomes.

The sections below describe various systemic issues in child welfare that affect children with disabilities.

Identifying the Population

Child protection investigators and foster care caseworkers are not typically provided with sufficient training, tools and support to ensure the identification and assessment of children and youth with disabilities.³⁷ This may result in underreporting, inappropriate placement decisions and inadequate provision of services for children and youth with disabilities in foster care.³⁸

Federal, state and county data tracking systems have not accurately captured information regarding the disability status of children and youth in foster care.³⁹ Children's disabilities are not consistently evaluated and defined within and between systems, and services and outcomes are not monitored consistently or recorded at all in some states.⁴⁰

Hence, it is difficult for frontline workers, advocates, researchers, policy makers and government officials to fully define this population, understand their unique needs and ensure tailored services and supports to adequately meet those needs.

Foster Parents

All children and youth in foster care need safe, committed caregivers who are able to meet their physical, emotional and social needs.⁴¹

In most communities, however, foster and adoptive parent recruitment, preparation, training and support do not focus on the specific needs of children and youth with disabilities.⁴² Thus, foster and adoptive parents are routinely under-prepared for the challenges associated with caring for children and youth with disabilities. They may not have received training to help them effectively parent children and youth with different disabilities, or advocate for their special medical and educational needs. They often lack basic information about the special needs of the children who are placed in their homes, and are not provided with information regarding special programs and services that may be available in their area. More often than not, they are also under-supported, lacking access to respite care, in-home assistance and other specialized programs.⁴³

These challenges increase the likelihood of frequent moves for children and youth with disabilities, decrease the possibility that foster parents will provide permanent adoptive homes for these children and increase rates of adoption disruption and dissolution.⁴⁴

Health Care

All too frequently, children and youth with disabilities in foster care do not receive access to comprehensive assessments, immunizations and consistent medical, dental, mental health and other specialty care.⁴⁵

In many instances, health care providers are not willing to accept Medicaid or to serve these at-risk youth, and children are placed on lengthy waiting lists for much-needed services.⁴⁶ In addition, services are frequently not located in the communities in which children are placed, resulting in increased use of costly emergency department visits to address non-emergent health care issues.⁴⁷



Education

While studies have estimated that 30-40 percent of children and youth with disabilities in foster care may qualify for special education services, for a number of reasons, only 16 percent may actually receive the full array of services outlined in their Individualized Education Plans.⁴⁸

Although children and youth with disabilities are entitled to special services and supports, they routinely are denied many of these accommodations because they lack consistent educational advocates. Despite increased attention to this issue, there continues to be a lack of clarity regarding the respective roles and responsibilities of caseworkers, foster parents and birth parents when working with school systems to meet the educational needs of these children and youth. All too frequently, birth parents are not included in educational planning activities; foster parents do not understand the importance of their role; and caseworkers do not have the time to participate in regular meetings.⁴⁹

In addition, children and youth with disabilities in foster care may not receive timely testing and accommodations due to their frequent placement changes.⁵⁰ Research indicates that school placements routinely are delayed 2-4 weeks due to problems in the transfer of the student's educational records.⁵¹ Once records are received, students with disabilities in foster care frequently do not receive credit for prior work, given different requirements among different schools.⁵² Hence, students with disabilities in foster care often find themselves placed in markedly different settings [e.g., regular versus special education, self-contained versus integrated, etc.] simply due to a move from one school to another.

Transition to Adulthood

Youth with disabilities transitioning from foster care to adulthood frequently do not receive critical services and supports to ensure their safety, stability and well-being. They typically lack coordinated transition plans and do not have access to further education and training opportunities. They may receive little help finding jobs and have few dependable mentors. They are likely to receive little or no assistance finding housing, arranging for their health and mental health care or establishing themselves in their communities.⁵³

Framgedted Systems and Lack of Information

These challenges are further exacerbated by a general lack of information-sharing, collaboration and communication among child welfare and the many systems that can serve and support children and youth with disabilities in foster care, including the health care, court, early intervention, education, disability and mental health systems.⁵⁴ These gaps can result in poor health and well-being outcomes for non-disabled children in foster care and have the potential to be catastrophic for children and youth with disabilities in foster care.⁵⁵

Promising Approaches

The literature highlights a range of approaches and recommendations, summarized below, for addressing some of these longstanding challenges. Currently, however, many of these strategies have not been fully implemented, adequately funded or universalized among all foster care systems.

The United Cerebral Palsy and Children's Rights collaboration seeks to share this existing information, and to build upon these innovations in order to develop a more effective and comprehensive approach to improving the lives of children with disabilities in foster care.

Strategies for improving services for children and youth with disabilities in foster care include:

• *Adopt Health Care Standards*

- Direct all agencies to adopt and meet standards for health care for children and youth in foster care that reflect those put forth by the Child Welfare League of America (1988), the American Academy of Pediatrics (1994, re-affirmed in 2002), and the American Academy of Child and Adolescent Psychiatry (2001);⁵⁶

• *Ensure Timely and Comprehensive Evaluations*

- Ensure that an initial medical screening of all children and youth entering foster care occurs within the first 24 hours;⁵⁷
- Require a comprehensive assessment within 30 days for all children and youth entering foster care, focusing on physical [including medical, dental, vision, hearing], behavioral, emotional, cognitive, relational, educational and other environmental domains;⁵⁸

• *Manage Records More Effectively*

- Universalize the medical home model for all children and youth in foster care, whereby dedicated Foster Care Clinics, staffed by pediatric health care professionals who understand the effect of foster care on children and youth, provide initial health screening, comprehensive medical and dental assessment, developmental and mental health evaluation, and ongoing primary care and monitoring of health status for all children and youth in foster care;⁵⁹
- Implement and utilize education/medical passports to ensure the documentation and exchange of information among caregivers, providers and decision-makers;⁶⁰
- Establish health care management professionals or teams at foster care agencies, with a broad mandate to gather children's health care information, assure appropriate medical consents, coordinate access and approval for health care services, educate staff, other professionals and caregivers and ensure the integration of medical plans into safety and permanency plans;⁶¹

• *Increase Specialized Services*

- Develop mechanisms to recruit, train and reimburse "preferred" health care professionals for serving children and youth in foster care, as well as offer incentives to providers to encourage acceptance of foster care clients;⁶²
- Institute mandatory referral to Early Intervention for all children in foster care under age three;⁶³
- Increase the range of specialized, therapeutic, medical or treatment foster care programs that provide children and youth with disabilities with a team of specially trained foster parents, respite caregivers, medical professionals and social workers;⁶⁴
- Generate awareness and strengthen targeted recruitment efforts to highlight the need for foster and adoptive families willing to care for children and youth with disabilities;⁶⁵
- Design integrated support and service systems for transitioning youth to reflect the specific needs and experiences of youth with disabilities;⁶⁶

• **Improve Training Programs**

- Create specialized training programs for investigators, caseworkers and other child welfare professionals to ensure the identification and documentation of disabilities;⁶⁷
- Expand current models of foster parent training to address caring for children and youth with disabilities, including identifying and understanding different disabilities, locating and accessing appropriate providers, and developing skills in medical, disability rights and educational advocacy;⁶⁸
- Organize comprehensive cross-systems training to ensure information-sharing and collaboration between child welfare, education, health care, court and other systems;⁶⁹

• **Collect and Assess Data**

- Infuse disability status and evaluation in all child protection risk assessments;⁷⁰
- Mandate data collection, tracking and reporting regarding disability status, services and outcomes for all children and youth in foster care.⁷¹

Conclusion

This review of available literature and research indicates that there has not been nearly enough attention paid to the specific issues facing children and youth with disabilities in foster care, even though the risk factors facing this population are monumental. Their health care is often compromised, and their educational experiences are frequently damaging. Their opportunities for placement with permanent families and lifelong connections with caring, committed adults are severely lacking. Their community experiences often are defined by isolation and frequent relocation. And when it comes time to move to an adult life with more independence, there may be little or no help available to them during this crucial transition.

Without intervention and assistance at all levels of the system and without the development of innovative partnerships to address these longstanding issues, these barriers will remain.

Children's Rights and United Cerebral Palsy are dedicated to continuing our efforts to improve policy and practice for children and youth with disabilities in foster care.

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Isabelle's Kids



A National Initiative of United Cerebral Palsy

About Isabelle's Kids

Isabelle's Kids, a national initiative of United Cerebral Palsy, endeavors to empower children and youth with disabilities to live without limits. Named in honor of UCP co-founder Isabelle Goldenson, Isabelle's Kids addresses the countless challenges faced by children and youth with disabilities, including school, friends, play

and growing up with self-confidence. United Cerebral Palsy, through its national network of affiliates, encourages, supports and mentors a new generation of leaders with disabilities to contribute to their communities and achieve their dreams. For more information, visit www.ucp.org/isabelleskids.