

Youth with Disabilities in the Foster Care System:

Barriers to Success and Proposed Policy Solutions

> National Council on Disability February 26, 2008

National Council on Disability 1331 F Street, NW, Suite 850 Washington, DC 20004

Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

February 26, 2008

The President The White House Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit this report, entitled *Youth with Disabilities in the Foster Care System: Barriers to Success and Proposed Policy Solutions*. Under its congressional mandate, NCD is charged with the responsibility to gather information on the development and implementation of federal laws, programs, and initiatives that affect people with disabilities.

The goal for our country's youth is to live healthy, happy lives and to become selfsufficient, contributing members of society as adults. However, there are subsets of youth who cannot reach these goals with ease. These youth need additional supports to assist them in their journey toward a healthy adulthood, as they are more vulnerable than the "average" youth and thus are more apt to fall through the cracks during their journey. Youth development researchers have determined that some specific youth populations are more vulnerable than others. This report examines one exceptionally challenged group in particular: older youth (specifically, preteen through young adult) with disabilities who are involved in the foster care system.

The child welfare community generally accepts the fact that while the American foster care system has come a long way in recent years, there is still much to be done to ensure the health and well-being of the children and youth it serves. Likewise, the disability community has seen great improvements in recent years but still advocates for additional needed change. But what is often overlooked among experts in both of these realms is the idea that foster care is indeed both a child welfare issue *and* a disability issue. This is due to the alarmingly high numbers of foster youth with mental, developmental, emotional, learning, and physical disabilities. The purpose of this report, therefore, is to shift the lens through which youth advocates and service providers view the importance of ensuring the well-being of foster youth. This new lens asserts the importance of understanding the prevalence of disability among foster youth and better ascertaining who should be held accountable for this uniquely challenged and often underserved population.

1331 F Street, NW ■ Suite 850 ■ Washington, DC 20004 202-272-2004 Voice ■ 202-272-2074 TTY ■ 202-272-2022 Fax ■ www.ncd.gov NCD stands ready to work with you and the Office of Domestic Policy to ensure that the recommendations within this report become a reality.

Sincerely,

 $G \sim R \gamma \sim Q$

John R. Vaughn Chairperson

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Executive Summary

Youth with disabilities who are also in the foster care system are one of the most vulnerable populations in the United States, yet little attention is focused on the unique challenges they face as they negotiate their way through multiple systems to adulthood. The National Council on Disability (NCD) has decided to delve into the confusing and confounding world faced by these youth, draw attention to their situations, and start a dialogue about how federal, state, and local policies and practices can be more supportive of these young people.

The purpose of this report is to provide policymakers, primarily at the federal and state levels, with information about youth with disabilities in foster care, so that policymakers can begin to understand the characteristics of this population; the challenges they face; how they fare with regard to safety, permanency, self-determination and self-sufficiency, enhanced quality of life, and community integration; and how the complex array of existing programs and services could be better designed to improve these outcomes.

This report will shed light on the poor outcomes of youth with disabilities in foster care, especially with regard to education, employment, and other indicators of well-being. While the federal investment in the multiple systems with which these youth come in contact is significant, the disconnectedness and lack of coordination across programs and agencies call into question the effectiveness of government efforts. The report will therefore describe various policy recommendations for federal and state policymakers that focus on improving coordination, holding systems accountable, developing leadership and the capacity of the system to work more effectively with these youth, improving transitions to adulthood and educational outcomes for them, and better datasharing and information management. A brief summary of these recommendations will follow at the end of the report (Chapter 4).

The goal for America's youth is to live healthy, happy lives and to become self-sufficient, contributing members of society in adulthood. However, there are subsets of youth who cannot reach these goals with ease. These youth need additional supports to assist

them in their journey toward a healthy adulthood, as they are more vulnerable than the "average" youth to fall through the cracks during this journey. This report will examine one exceptionally challenged group in particular: older youth (specifically, preteen through young adult) with disabilities who are involved in the foster care system.

The child welfare community generally accepts the fact that while the American foster care system has come a long way in recent years, there is still much to be done to ensure the health and well-being of the children and youth it serves. Likewise, the disability community has seen great improvements in disability laws in recent years but still advocates for additional needed change. But what is often overlooked among experts in both of these realms is the idea that foster care is indeed both a child welfare issue *and* a disability issue, because of the alarmingly high numbers of foster youth with mental, developmental, emotional, learning, and physical disabilities. The purpose of this report, therefore, is to shift the lens through which youth advocates and service providers view the importance of ensuring the well-being of foster youth. This new viewpoint focuses on the importance of understanding the prevalence of disability among foster youth and better ascertaining who should be held accountable for this uniquely challenged and often underserved population.

Scope of the Issue

At any given point in time in the United States, approximately 500,000 youth are in the foster care system, although nearly 800,000 youth are served by this system per year. Separately, almost 13 percent of all youth ages 6 through 14 have at least one documented disability. Recent reports estimate that youth with disabilities are between 1.5 and 3.5 times more likely to have experienced abuse or neglect than youth without disabilities. Although determining the cause of a disability for an abused young person is often difficult, research has assessed that disabilities are often caused and/or exacerbated by abuse. At the same time, data suggests that youth born with disabilities are more often abused, and also more often relinquished to the child welfare system (either by choice or force). And finally, abuse and trauma also occur *within* the system;

in one study, one-third of foster youth reported some type of perceived maltreatment while in the foster care system. The challenge in determining cause of disability for foster youth is just one of the barriers to ascertaining how to best support this vulnerable population.

Whatever the cause, some troubling patterns regarding disability emerge among foster youth. One acclaimed study of foster youth alumni found that over half of those studied had mental health problems, compared with 22 percent of the general population. Of these people, 25 percent had post-traumatic stress disorder (PTSD), versus 4 percent of the general population, and 20 percent experienced major depression, versus 10 percent of the general population. Social phobia, panic syndrome, and generalized anxiety disorder were also more prevalent among these alumni. Regarding education, it is estimated that 30 to 40 percent of foster youth are in the special education system, a significantly higher percentage than non-foster care youth. And one California study found that 8 percent of foster youth studied had some type of physical impairment. These statistics help illustrate the disproportionality of the numbers of youth in foster care who have disabilities.

Outcomes for youth with disabilities in the child welfare system are overwhelmingly negative as well. Both youth with disabilities and foster youth are more likely to drop out of school and less likely to attain a postsecondary education. One study found that only about 9 percent of youth with disabilities attend four-year colleges, and another 5 percent attend vocational, technical, or business schools. Meanwhile, only about 20 percent of foster youth make it to college, and their rate of completion is around 5 percent. These percentages are staggeringly low. They compare with the national averages of about a 60 percent college access rate for high school graduates and a 20 percent completion rate among adults under age 25.

Other negative outcomes for this population exist as well. By the age of 19, nearly 50 percent of young women in foster care have been pregnant, compared to 20 percent of their non-foster care peers, and 38 percent have been arrested, compared to the national average of about 7 percent. Other studies have estimated that about 22

percent of former foster youth experience homelessness, 33 percent have no health insurance, and only 43 percent are employed—all rates that are much lower than the national averages.

This data indicates that far too many youth with disabilities in foster care are not transitioning into healthy adulthood and are not becoming productive members of society. Unfortunately, these negative outcomes reflect the incompetencies and insufficiencies of the systems, programs, and people that serve these youth. More could certainly be done, at many levels, to ensure success for these youth.

Issue Areas Examined

This report identifies the following main issue areas of utmost importance regarding youth with disabilities in the foster care system:

Federal and state investments in youth with disabilities in the foster care system

Education and training needs

Transitions to adulthood and connectivity issues

Coordination, collaboration, and accountability issues

Issues around the use and sharing of data

Federal and State Investments in Youth with Disabilities in the Foster Care System

Despite the progress that has been made to enhance the laws that affect people with disabilities and foster youth, many believe that still deeper, broader, and smarter investments must be made at the federal and state levels to demonstrate that the future of youth with disabilities in the foster care system is important to everyone. For example, despite the billions of federal dollars spent on foster youth every year, some experts believe that the existing funding structure is too rigid and as a result is hampering states' abilities to truly serve these youth in the ways that are needed. And some assert that this rigid funding structure incentivizes placement into the foster care

system to the detriment of more "family-friendly" supports such as preventative services, reunification, and even adoption. Some think the lack of flexibility most negatively affects youth with disabilities, whose families often do not have enough access to the mental and other health services that may, if provided, make foster care unnecessary.

Another federal funding issue centers on eligibility. Although any child can be placed into foster care, independent of income status, currently a child or youth is eligible for federal foster care funding support only if his or her family meets income eligibility requirements from 1996. This is because the eligibility requirements for foster care support have not updated in more than 10 years, despite program changes and inflation.

Investments could also be made at the federal level in better linking policy with research. An example discussed in this report is the issue of alarmingly high numbers of youth with disabilities in foster care being overinstitutionalized despite research linking negative outcomes with institutionalization, and despite the fact that evaluations of alternate care models have found that family- and youth-centered models are not only more effective and healthier for youth, but also cost significantly less than institution-based care models.

Federal and state investments are also noted as necessary in the realm of recruiting and training foster parents so that they are more inclined and better equipped to care for youth with disabilities. Such investments would help address the disproportionate number of these youth remaining in the foster care system—and especially in institutional settings—for long periods. Better recruitment efforts and high-quality training would enhance these young people's opportunities for permanency and wellbeing and greatly decrease the high rate of recidivism that is strongly correlated with foster youth who have disabilities.

Last but not least, the onus should fall on the Federal Government to do more to reduce the negative stigmas associated with both youth with disabilities and youth who have experienced the foster care system. What both groups have in common is that the

public has almost no understanding of their life situations and characteristics, and that they are stigmatized largely as a result of this lack of understanding. Public awareness campaigns can help increase public understanding and encourage those who work with or on behalf of these youth to be more knowledgeable about the issues that affect them. They can also bring to light the detrimental effects of stigmas on youth.

Education and Training Needs

Time and again, experts in many fields note that success in education is one of the most important indicators of success later in life. Therefore, meeting the educational needs of this vulnerable population should be deemed a top priority by the teachers, caseworkers, foster parents, dependency court judges, and mental health professionals who interact with these youth.

Some of the negative outcomes associated with too many youth with disabilities in foster care have been discussed above. Many believe that these negative outcomes prove that not enough is being done to ensure the educational success of these youth. Thankfully, more is being done now than ever before. The Individuals with Disabilities Education Act (IDEA) works to ensure that the specific needs of each individual student with disabilities are met, while the McKinney-Vento Homeless Assistance Act works to reduce the barriers often associated with homeless and foster youth changing schools often, including issues surrounding enrollment and the transfer of records. However, owing to eligibility issues, the McKinney-Vento Act does not serve all foster youth. And IDEA's processes, although improved in recent years, do not sufficiently consider the special situations of youth involved in the child welfare system, such as experiencing frequent school moves and having no parents to help make decisions on their behalf.

In some cases, federal laws indeed exist to help provide the needed services to students, but not nearly enough money is appropriated to the programs to make enough of a difference. This report discusses the lack of federal support for both mental health services and counseling services for public school students. It argues that these are two important services that can serve both preventative and intervention functions and

should therefore be made available to the youth who need them, which includes youth with disabilities in foster care.

Just as important as primary and secondary school services are access to and success in postsecondary learning opportunities such as college or career and technical training. Because both youth with disabilities and youth transitioning out of the foster care system show negative outcomes for postsecondary education attainment, a larger investment must be made to facilitate their success. One of the main barriers to access is lack of monetary resources, as many youth with disabilities in foster care have low or no incomes. Although the Chafee Foster Care Independence Program's Educational and Training Vouchers Program (ETV) has helped greatly, these limited funds cannot possibly help all youth in need, so additional access to monetary support, such as federal financial aid, is necessary.

Other, nonmonetary barriers to postsecondary attainment exist in the systems themselves. For example, the college application process can be extremely daunting, especially for youth with no supportive adults in their lives. Schools and the Federal Government may not recognize the role they must play in easing this process for youth with significant needs. There is also the concern of low expectations for both youth with disabilities and youth in foster care. These low expectations link back to the stigma issue discussed earlier. Furthermore, not all caseworkers, foster parents, and other adults in "helping" professions are the best information resources for these youth, despite their (often) good intentions. All of these barriers further exacerbate the challenge these youth face as they endeavor to access and succeed in postsecondary learning opportunities.

Transitions to Adulthood and Connectivity Issues

A healthy transition to adulthood for all youth should be the primary concern for all, as far too many negative implications are associated with youth not becoming healthy, productive, economically sufficient adults. Unfortunately, a large number of youth with disabilities transitioning out of foster care end up disconnecting with society and are unable to reconnect for one reason or another. The repercussions felt by these young people, the systems with which they interact, and the country as a whole are indeed profound and long-lasting. Therefore, just as important as education is the need to provide services and supports to youth transitioning to adulthood.

Transition is a daunting experience for youth with disabilities in the foster care system. They often need more services than average youth, require the support of more caring adults in their lives, and must also understand a whole host of laws, regulations, and policies with which most youth usually do not come in contact. They need to know when their Medicaid benefits expire, how to access independent living skills programs, and whether they are eligible for housing, among many other rules and processes. Some youth with disabilities also need to rely on caring adults to help them perform basic functions like eating, bathing, and getting around. Due to the challenging situations of many of these youth as they enter adulthood, many youth development experts believe that youth with disabilities transitioning out of foster care should be eligible for transition services up to age 24, when needed, instead of age 21.

Despite the progress that has been made to ensure the comprehensiveness of services offered to youth as they transition to adulthood, much remains to be done in terms of both *access* to services and the provision of the *right* services. Some experts believe that the services provided are often not pertinent to real-life challenges. Others believe that not enough is being done to incorporate the ideologies of community integration, self-determination, and self-advocacy into the transition curricula. If policy were better linked with sound research, these components might be more regularly connected to the life skills and independent living curricula provided to youth with disabilities and youth transitioning out of foster care. Due to the funding limitations of programs like the Chafee Foster Care Independence Program (CFCIP), not all youth who need these services receive them. As this report discusses, eligibility issues also affect transition services.

The creation of both the CFCIP and the Individualized Education Program (IEP) has been a significant step in the right direction for ensuring healthy transitions for these

young people. But unfortunately, these two systems often operate independent of one another. A recent study has determined that still more must be done to coordinate these two very important services so that these youth have the supports they need to transition adequately.

Coordination, Collaboration, and Accountability Issues

Currently, there is no one federal or state system responsible for youth with disabilities in the foster care system. Instead, separate systems are working toward separate goals with many different procedures. Every now and then, collaborative efforts that are backed with accountability are supported nationally and at the state level, but these collaborations are often limited in time and scope. For this particular group of vulnerable youth, some efforts are being made (and are discussed in this report), but much progress still needs to be made in order to better coordinate services comprehensively for these young people.

An increased federal oversight role is the first crucial step to the delivery of a coordinated system of care. This can be facilitated by the funding of the Federal Youth Coordination Act and the continued (and enhanced) support of the Court Improvement Program and similar efforts. The collaborations and partnerships created through such vehicles must be strategic in nature, as partnerships that are not strategic often do not facilitate positive change. Many youth-serving (and adult) systems are intertwined in the lives of youth with disabilities in foster care, but not all are able to collaborate effectively with one another.

These strategic cross-systems collaborations also require the assistance of high-level state leaders and high-quality accountability systems in order to flourish. This report finds that leadership at the state level should come from a partnership between the highest court system and the executive office.

Another practice that many believe to be effective in fostering a collaborative approach is the adoption of the "youth development" approach across all youth-serving systems.

When systems such as education, child welfare, and juvenile justice are all on board with the same overall goals of helping all youth reach productive, healthy, economically sufficient adulthoods, they provide the opportunity to help all youth flourish, independent of their life situations. Unfortunately, this ideal has not yet been recognized to its full potential nationally.

In order to accomplish true collaboration, it is believed that more cross-training must occur among the adults who interact with and provide supports for these multisystem youth. Right now, there is a dearth of knowledge about disabilities (e.g., how to identify them correctly) among child welfare, school, and delinquency and dependency court personnel as a whole. Likewise, schools and many other systems lack a basic knowledge about the intricate workings of the child welfare system. Lack of awareness about the life situations that these youth confront further hinders their ability to receive the supports that they truly need.

Issues Around the Use and Sharing of Data

In recent years, the child welfare system has seen amazing improvements in the data systems funded by the Federal Government, the type of data collected, and how this data is organized. Likewise, the education system's IEP process has improved immensely in recent years and continues to house data on students with disabilities in public education systems in an effort to provide better targeted services and improve student outcomes.

Despite such progress, many data-related issues persist. For agencies' information systems to help decisionmakers understand the youth who are tracked, with the overall goal of improved services and youth outcomes, the following basic needs have been identified: adequate funding to build capacity; identification, consistency, and accuracy within the systems; improvements in collected information; and cross-systems sharing of data.

Arguably, two of the most important data systems the child welfare system operates are the Adoption and Foster Care Analysis Reporting System (AFCARS) and the Child and Family Services Reviews (CFSR), which provide information about youth served and the adequacies of the agencies that serve them. Despite the cost to maintain these data systems, their importance still outweighs their cost. Without data systems like these, accountability for providing the services that these vulnerable youth need could not be maintained and improvements could not be made. Their capacity must be enhanced in an ongoing manner to continue improving their information collection efforts.

The accuracy of the information that various information systems present must also be ensured in order to gain a better understanding of the situations of these youth and to subsequently serve them better. This includes making information housed in these data systems compatible across the board, such as by using similar terminology and definitions across systems (as feasible) and tracking progress in similar ways.

Using data well also involves holding states accountable for reporting accurately in a timely manner. There is speculation that AFCARS seriously underreports and misreports disability status for foster youth. The implications of inconsistent, inaccurate, and unreliable data are immense. When an accurate picture of an extremely vulnerable population such as this one cannot be assessed, then policymakers and service providers have no idea how many and what types of resources and services must be devoted to them to help them thrive. It is the youth who suffer as a result.

Policy Recommendations

As a response to the issues involved with serving youth with disabilities in the foster care system, this report makes several policy recommendations that can be used as a launching pad for further intensive and detailed discussions with involvement from a wide range of stakeholders, including the youth themselves. The broader points of these recommendations follow:

Provide increased flexibility to states and communities so programs and services can be most effectively structured to meet the needs of youth with disabilities in foster care.

Increase federal support in the departments of Health and Human Services, Education, Justice, and Labor for research and demonstrations to identify effective policies and practices that lead to positive outcomes for youth with disabilities in foster care.

Improve training for foster care parents and increase recruitment of individuals willing to foster youth with disabilities.

Strengthen secondary and postsecondary educational supports for these youth to improve access and success.

Improve access to individualized, comprehensive transition services for youth with disabilities aging out of foster care.

Fund the Federal Youth Development Council, authorized by the Federal Youth Coordination Act, as well as similar federal coordinating efforts.

Strategically increase collaboration among the education, juvenile justice, child welfare, labor, dependency court, and health and mental health systems.

Require states to develop a common youth development approach across multiple systems to improve outcomes for all youth.

Improve training of youth professionals across systems.

Provide resources and technical assistance to help states enhance their data collection and reporting systems.

Introduction

Youth with disabilities who are also in the foster care system are one of the most vulnerable populations in the United States, yet little attention is focused on the unique challenges they face as they negotiate their way through multiple systems to adulthood. The National Council on Disability (NCD) has decided to delve into the confusing and confounding world faced by these youth, draw attention to their situations, and start a dialogue about how federal, state, and local policies and practices can be more supportive of these young people.

There is an enormous overlap of youth with disabilities and young people in the foster care system. Indeed, many advocates for these youth assert that foster care is a disability issue because the prevalence of disabilities among these youth is so high.¹ Yet many individuals and systems associated with youth in the foster care system know little about the disability world and even less about ways to help youth with disabilities become self-sufficient and self-determined adults. The many systems that interface with these vulnerable youth, including family courts, child welfare, juvenile justice, health and mental health, and education, are disjointed, disconnected, and sometimes even at odds with one other. This situation is somewhat a result of the inherent complexities involved in these enormous systems, but blame can also be placed on the lack of a collaborative attitude owing to weak federal and state encouragement.

Much more can be done to guarantee that youth with disabilities in foster care are provided the complete support, encouragement, and assistance they need to ensure their safety, permanency, and well-being.² Additionally, more opportunities can be provided to enable them to meet the adulthood goals of self-determination, enhanced quality of life, and community integration.³ At the same time, it is worth noting that there have already been a plethora of notable system and policy improvements in the care for these youth, most of which have occurred in just the last 15 to 20 years. But while these improvements provide a ray of hope, there is still much left to be done.

The purpose of this report is to provide policymakers, primarily at the federal and state levels, with information about youth with disabilities in foster care, so that policymakers can begin to understand the characteristics of this population; the challenges they face; how they fare with regard to safety, permanency, self-determination and self-sufficiency, enhanced quality of life, and community integration; and how the complex array of existing programs and services could be better designed to improve these outcomes.

This report will shed light on the poor outcomes of youth with disabilities in foster care, especially with regard to education, employment, and other indicators of well-being. While the federal investment in the multiple systems with which these youth come in contact is significant, the disconnectedness and lack of coordination across programs and agencies call into question the effectiveness of government efforts. The report will therefore offer policy recommendations for federal and state policymakers that focus on improving coordination, holding systems accountable, developing leadership and the capacity of the system to work more effectively with these youth, improving transitions to adulthood and educational outcomes for them, and better data-sharing and information management. A brief summary of these recommendations will follow at the end of the report (Chapter 4).

Large numbers of research and policy reports were reviewed and two focus groups were held with a wide range of experts in the disability, mental health, child welfare, juvenile justice, family court, and education fields, including practitioners, administrators, and policy specialists. These meetings occurred in San Diego, California, and Washington, D.C. These focus groups helped identify important policy barriers and recommendations for improving program delivery to youth with disabilities in foster care. Lastly, several people with and without disabilities who had received foster care were interviewed about their personal experiences. Perhaps their stories help frame the need for systemic and comprehensive change more than any article or piece of research can. Quotes from these individuals are inserted throughout the report to illustrate the difficulties they faced as they tried to gain the knowledge, skills, abilities, and attitudes to become self-sufficient and self-determined.

These stories clearly demonstrate how broken the system really is. And it appears that it is not just broken in one or two places for a handful of youth, but it is broken in many places for a large number of young people. The fact that the outcomes for youth with disabilities in foster care are so poor should be evidence enough of the need to take a comprehensive and serious look at federal and state policies and programs that serve them, no matter how challenging this may be. While policy usually deals with discrete problems instead of cross-systems issues like this one, advocates recognize the serious need for the interventions on behalf of these particular youth to be holistically designed to better support them. Significant effort must be dedicated to crafting new approaches and redesigning existing programs to ensure that services are comprehensively and strategically delivered on an ongoing basis. Helping youth with disabilities in foster care reach healthy, productive adulthood requires taking a broad view of the multiple programs and policies and basing them on positive youth development principles so that the programs and policies share common visions and goals.

For most parents, the goal is to help their children become mature, self-sustaining, and happy adults who find productive work, develop meaningful relationships, and earn a living wage. They do this by creating safe, nurturing environments that allow young people to explore, learn, and develop, knowing there are multiple safety nets and caring adults to help when they hit a rocky patch. These are the underpinnings of healthy youth development, and most young people with family supports can negotiate the maze of service providers (e.g., education, mental health) when needed and remain on track.

But youth with disabilities in foster care are at a severe disadvantage in moving toward healthy adulthood for a wide range of reasons, not the least of which may be the disability itself. Having a disability, compounded by the fact that foster care youth may lack a supportive adult network to help them develop personal attributes and abilities and to navigate through some extremely complex systems, blunts or impedes their efforts to develop the educational, occupational, social, personal, and life skills for success. In addition, many of the programs that exist to help youth with disabilities in foster care are not based on youth development principles, or they lack a youth-

centered philosophy. For example, it is not uncommon for youth with disabilities in foster care to be pulled out of school in the middle of class for a court hearing, not only disrupting the learning cycle, but also sending a message to the youth that schooling is unimportant. In a youth-centered system that coordinated its systems, every effort would be made to keep students in class and to arrange for court appearances after school has ended in the afternoon.

Helping young people prepare for successful adult life is a complex undertaking. But helping youth with disabilities in foster care do so requires the commitment, dedication, and hard work of dozens, likely hundreds, of judges, attorneys, health and mental health care workers, caseworkers, educators, advocates, foster parents, and all the other caring adults who come in contact with these youth over the years. Federal and state policies and programs must be structured to recognize this long-term investment across systems and to design a new youth-centered approach. We hope this report will continue the press for positive change.

Chapter 1: Scope of the Issue

Youth with disabilities and youth in the foster care system are two of the populations considered to be at highest risk of not transitioning into and leading successful, healthy, and economically sufficient adult lives. But when youth have disabilities and are *also* in the foster care system, their vulnerability compounds. Even before they become adults, they encounter a tremendous number of barriers to living healthy, safe childhoods and adolescences. Unfortunately, youth with disabilities are overrepresented in the foster care system for many complicated reasons.

The Numbers: Youth with Disabilities and Youth in the Foster Care System

On September 30, 2005, approximately 513,000 children and youth were in the foster care system.⁴ Concurrently, the U.S. Census Bureau has estimated that just under 13 percent of children ages 6 through 14 have at least one disability.⁵ Many of these children and youth overlap.

Research conducted in 1993 by the National Center on Child Abuse and Neglect found that of all children abused, about 17 percent had disabilities.⁶ This rate is about twice the rate for youth without disabilities,⁷ demonstrating the overrepresentation of youth with disabilities who are abused. To look at these statistics the other way around, several studies have also shown that youth with disabilities are anywhere between 1.6 and 3.4 times more likely to be abused, compared with youth without disabilities.⁸

In addition to the severe disproportionality of youth with disabilities in the foster care system, data shows a serious overrepresentation of African-American youth in the system. Indeed, these two groups are by far the most overrepresented groups in the foster care system.⁹ Furthermore, the Council for Exceptional Children reports that African-American children are also disproportionately represented in the special education system.¹⁰ As will be noted later in this section, both youth with disabilities and

African-American youth also stay in the foster care system for longer periods than other youth.

Although studies like the ones mentioned above can estimate rates of abuse for youth with disabilities, determining how many youth with disabilities are actually receiving services in the child welfare system is difficult owing to various methods of determining, assessing, and recording disability information on a state-by-state basis. This important issue will be discussed in more detail in Chapter 3.5.

Abuse and trauma can also happen *within* the child welfare system. This abuse is often caused by foster families, youth workers, and other agency personnel. In one recent study, one-third of foster care alumni self-reported some form of perceived maltreatment ("by a foster parent or another adult") while in the system.¹¹ Abuse can cause disabilities as well. The exact percentage of abuse-caused disabilities is unknown but is estimated to represent a full 25 percent of all developmental disabilities.¹²

This muddled picture of abuse and involvement in the child welfare system for youth with disabilities is partially a result of the fact that precise cause of abuse cannot often be determined. It is further frustrated by the inconsistent and sometimes inadequate reporting methods that states use to record this information. This dearth of clear information has resulted in a serious, nationwide lack of understanding about youth with disabilities in the foster care system.

But despite the challenges of obtaining accurate information about youth with disabilities in foster care, certain information about this population has been collected. For example, one study has determined that between 20 and 60 percent of children entering foster care have developmental disabilities or delays, compared with about 10 percent of the general population.¹³ These include cerebral palsy, developmental delays, learning disabilities, mental and emotional health issues, and speech, hearing, and vision impairments.¹⁴ Foster care alumni studies have also found patterns. The Northwest Foster Care Alumni Study (Pecora et al., 2003) found that more than half of alumni studied had mental health problems, compared with 22 percent of the general

population.¹⁵ Of those studied, 25 percent experienced post-traumatic stress disorder (PTSD), compared with 4 percent of the general population, and 20 percent experienced major depression, compared with about 10 percent of the general population. Other commonly diagnosed mental disorders among these foster care alumni included social phobia, at 17 percent, panic syndrome, at 15 percent, and generalized anxiety disorder, at 12 percent.¹⁶ Regarding physical disabilities, one California study found that 8 percent of foster youth studied had some type of physical impairment, compared with between 1 and 2 percent of the general youth population.¹⁷

Needless to say, disabilities are extremely prevalent among youth who receive foster care, which is what makes these young people's situations and issues enormously worthy of exploration.

Placements and Permanency for Youth with Disabilities in the Foster Care System

In 2005, the average consecutive stay in foster care was just under 29 months.¹⁸ While in care, foster youth may reside in a variety of different settings, including relative family foster care, nonrelative family foster care, kinship care, guardianship care, and institutional settings such as group homes, residential centers, and others. For short periods, most frequently after being removed from home, some youth live in homeless and emergency shelters, hospitals, or trauma intake centers.¹⁹

Reunification with parents is the most common type of placement that foster youth receive upon exiting the system. In 2005, it was estimated that 54 percent of the youth who exited from care were reunified with their families.²⁰ However, reunification does not guarantee stability and permanence, and indeed, a large number of youth leave and reenter the system throughout their adolescence; this includes previously reunified youth. The Child Welfare League of America (CWLA) reports that a full 25 percent of youth who exit out-of-home care will at some point reenter.²¹ This figure is extremely high. Reentry into the system often means that youth are abused again or neglected,

including in cases of reunification with birth parents, a significant issue not to be overlooked.

The U.S. Children's Bureau (via the Adoption and Foster Care Analysis and Reporting System [AFCARS]) reports that 11 percent of foster youth exited to kinship care in 2005.²² This number represents only placements upon *exiting* the system; in reality, about 24 percent of youth live with relatives while they are in the foster care system.²³ Another 18 percent of youth live in institutions such as group homes, residential treatment centers, and different types of hospitals.²⁴ A large percentage of foster youth determined to have disabilities reside in these types of settings. The issue of institutionalization of foster youth with disabilities is discussed in full in Chapter 3.1.

Adoption is considered a "permanent" setting for youth, despite the fact that some adopted youth reenter the foster care system after they are placed with families. According to the Urban Institute, adoptions from foster care increased substantially between 1995 and 2005. In 1995, approximately 26,000 children were adopted from foster care; by 2000, that number had reached 51,000, and it remained steady through 2005.²⁵ (AFCARS data from 2005 reported that 18 percent of foster youth who exited from care that year exited to adoption.²⁶) The number of youth waiting to be adopted is declining as well: In 2000, 132,000 children were waiting to be adopted; by 2005, this number had declined to 114,000.²⁷ Despite these positive trends, research still shows that older youth, especially older youth with disabilities, are remaining in the foster care system longer, on average, than youth without disabilities. According to 2005 AFCARS data presented by CWLA, a full 58 percent of foster youth who exited to emancipation (i.e., "aged out") that year had been in the system for at least the three consecutive prior years. Among foster youth with disabilities, 67 percent of those who exited care via emancipation were in the system for at least three years.²⁸ These numbers clearly show the disproportionality of both older youth and youth with disabilities in the foster care system for extended periods.

Outcomes: Young Adults with Disabilities Entering Adulthood from the Foster Care System

During adolescence, youth in the foster care system with and without disabilities experience more undesirable situations than the "average" youth. As a group, they are less likely to graduate from high school, more likely to come into contact with the juvenile justice system, more likely to get pregnant earlier, and more likely to experience homelessness. Approximately 24,000 youth nationwide transition out of the foster care system via emancipation annually;²⁹ as these youth enter adulthood, these serious issues seldom disappear and are indeed more often exacerbated.

By the age of 19, nearly 50 percent of young women in foster care have been pregnant, compared with 20 percent of their non-foster care peers.³⁰ One study of former foster youth determined that by age 19, 38 percent of the youth had been arrested, whereas nationally, only about 7 percent of youth are arrested.³¹ A full 25 percent of adult prisoners have been in the foster care system at some point in childhood or adolescence.³²

A survey of foster care alumni found only 43 percent of them to be employed, and of those, a full 47 percent were earning wages below the poverty line (i.e., "underemployed").³³ Thirteen percent of these youth were determined to be homeless,³⁴ although other studies have estimated that about 22 percent of former foster youth experience homelessness throughout adulthood.³⁵ Approximately 33 percent of former foster youth have no health insurance, versus 18 percent of the general population.³⁶

Transition to adulthood is an enormously important issue for youth with disabilities experiencing foster care and will be covered more fully in Chapter 3.3.

Chapter 2: Systems That Intersect with Youth with Disabilities in the Foster Care System

Youth with disabilities in the foster care system come in contact with many systems throughout their lives—more than "average" youth. Like all youth, they interact with the **education** system through attending school. It is hoped that, like most young adults, they will interact with the **labor** system when they transition to adulthood and enter into employment. But unlike most youth, they also interact with the **child welfare** and **foster care** systems. Therefore, they also interact with the **dependency court** system. Youth with disabilities will also interact with various **health** systems, and youth with behavioral or mental health issues specifically will interact with **mental health** system services. Lastly, youth with disabilities in foster care have a higher than average chance of coming in contact with the **juvenile justice** system.

Youth with disabilities in foster care are considered "multisystem" youth when they come into contact with multiple systems such as the child welfare, health, mental health, and/or juvenile justice systems.

For these young people, navigating these various systems and fully understanding their place within them is daunting at best, but can be impossible at worst. In order to truly succeed, they require multiple supports and resources, most of which call for the involvement of reliable, caring, knowledgeable, and often persistent adults. And youth who have severe disabilities often require even more support. This report investigates the issues involved in navigating the systems of care that have been developed to assist these vulnerable youth in their journey toward adulthood.

Appendix B lists the major federal programs and funding sources by which youth with disabilities in foster care are most often served via the systems in which they come in contact.

Chapter 3: Challenges and Proposed Solutions

As noted, youth with disabilities in the foster care system may interact with multiple systems throughout their childhood and journey to adulthood, including the child welfare, dependency court, health and mental health, education, juvenile justice, and labor systems. Navigating through these complex systems is much more often a challenge than a smooth ride. Many issues surface, and these issues are often prevalent across multiple systems and agencies. The largest issues for this unique population have been identified as the following:

Insufficiencies in the federal and state investments in youth with disabilities in the foster care system

Inadequacies in the provision of education and training services for these youth

Inadequacies in the provision of transition services and in addressing connectivity issues for these youth

Coordination, collaboration, and accountability issues for the systems involved in serving these youth

Issues around the use and sharing of data and information pertaining to these youth

The next five sections of this report will investigate these five crosscutting issues and propose policy recommendations that can help to address them.

Chapter 3.1: Federal and State Investments in Youth with Disabilities in the Foster Care System

The federal laws that support children and youth in the child welfare system have progressed immensely in the last few decades. As a result of some of these more recently implemented federal laws, foster youth are supported by more systems and policies, in more ways, and for more years. Additionally, with the improvements made to the Individuals with Disabilities Education Act (IDEA) in recent years, more youth receiving special education services are receiving the supports they need.

But these laws are still far from perfect, and as a result, far too many youth are still not being supported in the ways they need. Outcomes for most youth with disabilities in foster care regarding educational attainment, economic sufficiency, and health are still far too bleak. Many believe that deeper, broader investments that must be made at the federal and state levels in order to send a more absolute message that the futures of youth with disabilities in the foster care system, who are often more challenged to succeed than youth without special needs, are of importance to all.

Needed investments involve the following:

- Granting more spending flexibility to the states so that they can make more localized decisions about what is best for their youth
- Altering eligibility requirements at the federal level to better support more youth

Using research to inform policy and practice

Investing in foster parents so that young people's safety, permanency, selfdetermination, and well-being are enhanced

Reducing stigma and increasing knowledge about this population by supporting public awareness campaigns around the issues involved

The specific laws mentioned in this section primarily relate to the child welfare system. However, because such a large percentage of foster youth are affected by disabilities, these laws are extremely pertinent to many youth with disabilities as well.

More spending flexibility must be granted to the states to allow them to address the unique needs of this population.

Through Title IV-E of the Social Security Act, the Federal Government currently spends approximately \$5 billion per year to reimburse states for foster care expenditures on welfare-eligible children and youth.³⁷ Title IV-E is an uncapped entitlement but may be used only for youth in the foster care system. This money made up 65 percent of total federal child welfare spending in fiscal year 2004, while adoption assistance funding (also authorized under Title IV-E) represented another 22 percent. Federal funding that can be used for preventative services (but is not always), which mostly comes from the Title IV-B programs (Subparts 1 and 2) and discretionary programs through the Child Abuse Prevention and Treatment Act (CAPTA), made up only 11 percent of federal child welfare spending in 2004.³⁸ Only the remaining 2 percent of federal child welfare funding was spent on independent living programs,³⁹ a noticeably negligible percentage.

(These percentages do not take into account monies from other federal programs that do not specifically fund child welfare services but are sometimes used for these purposes, such as Temporary Assistance for Needy Families [TANF], the Social Services Block Grant [SSBG], and Medicaid. Funds from programs like these, which are used for child welfare services, totaled another \$5 billion in 2002.⁴⁰)

Despite the billions of federal dollars spent on foster youth, many child welfare experts believe that the funding structure is too rigid and is, as a result, hampering states' abilities to truly serve foster youth. Most argue that better outcomes can be achieved by allocating additional resources to both prevention services (e.g., family substance abuse counseling) and reunification services. Many also believe that the current funding structure, in which the majority of funding goes to the foster care system, actually *encourages* foster care placement over prevention services, reunification, and even

adoption, which are considered more family-centric options.⁴¹ Some, but not all, believe there should be more federal support for kinship care so that youth are not unnecessarily placed into the foster care system when they could be healthily supported by family members instead.⁴²

Flexible spending would expand the list of federally reimbursable child welfare services, thereby allowing states to prioritize their own activities (within certain parameters). Some states are already experimenting with flexible child welfare spending by taking advantage of a limited number of "demonstration waivers" that have been granted to a handful of states for the expressed purpose of testing alternative uses and funding structures for child welfare dollars with the goal of improving foster youth outcomes. These waivers are cost-neutral, meaning that states are allotted the same amount of child welfare funding as they would be normally (e.g., through Title IV-E), but with less strict guidelines on how these funds must be used, although waiver demonstration programs do require rigorous evaluations.⁴³ Examples of activities that are being funded in these demonstration programs include strengthened family assessments; intensive services to reduce out-of-home placement rates; assisted guardianship and kinship permanence; family decision meetings; and improved access to substance abuse and mental health treatment.⁴⁴ Since 1996, 19 states have implemented 27 child welfare waiver demonstrations, which, according to a U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation issue brief, "indicates widespread interest in more flexible funding for state child welfare programs."45

Some child welfare experts also believe that spending flexibility would especially help agencies better serve foster youth with mental, emotional, and developmental disabilities, as it would allow these agencies to devote resources toward newer care models that current research shows are demonstrating positive outcomes specifically for these youth, such as wraparound services and therapeutic foster care.⁴⁶ (Both of these care models are discussed in more detail later in this chapter.)

The Pew Commission on Children in Foster Care has made its own policy recommendations regarding the issue of spending flexibility. It promotes the use and expansion of the federal waiver program and also believes that when states reduce their foster care expenditures, they should be allowed to reinvest their unused funds in other sanctioned child welfare services related to "prevention, treatment, and support once a child leaves foster care."⁴⁷

A specific problem that some experts note as being caused by the current inflexible federal child welfare funding structure is that some parents are effectively forced to place their children into the foster care system when the children require special services that the families cannot afford. This problem indicates that the current funding structure may not be properly supporting services that would help prevent the need for foster care placement, especially for young people with special needs. The Government Accountability Office has reported that in fiscal year 2001, "child welfare directors in 19 states and juvenile justice officials in 30 counties estimated that...parents placed over 12,700 children into the child welfare or juvenile justice systems so that these children could receive mental health services."⁴⁸ The Keeping Families Together Act, which has been introduced several times by Congress but not yet enacted, addresses this issue directly. This act would provide states with grants to build the infrastructure to serve youth with mental health issues more efficiently while keeping them with their families.⁴⁹

One promising strategy being implemented in many states that focuses on providing preventative family service activities with the goal of reducing removals of youth from their homes is called "differential response." Differential response offers local authorities more flexibility in deciding how to respond to reports of abuse and neglect by taking into consideration the severity of the issue, the immediacy of child safety concerns, and individual family needs. In 2007, New Jersey implemented a new Differential Response Pilot Initiative in four counties. "Differential response tells families they do not have to wait for child abuse or neglect to occur before they can get help to keep their children safe, stable and well," said New Jersey Department of Children and Families Commissioner Kevin M. Ryan in a press release.⁵⁰ He continued that it "is about

building and maximizing the use of community resources such as child care, housing assistance, and wraparound services that target families' unique needs."⁵¹ According to the press release, three of the four counties implementing the initiative "will focus on connecting families to emergency housing and utility assistance, domestic violence services, day care, mental health, marital and family counseling, and employment training and placement." One of the priorities of the program is to provide supports for "at-risk families" so that "long-term involvement in government programs can be avoided."⁵²

Some child welfare experts also believe that kinship and guardianship care should be more fully supported at the federal level. According to a report released by Generations United, of the approximately 500,000 young people awaiting placement at any given time, 124,000 (about 25 percent) live with relatives.⁵³ However, in some states, relatives receive federal assistance only if these youth remain in the foster care system—not if the relatives become legal, permanent guardians.⁵⁴ Some think this restriction deters too many of these adults from becoming legal guardians. (Usually, the "guardianship" designation allows a caregiver to access services on behalf of a child or youth, but unlike adoption, after which parental rights are relinquished, a youth's birth parent is able to reclaim custody of the child from a guardian.⁵⁵ The specifics of guardianship laws differ by state.)

Kinship and guardianship care advocates argue that research shows that children and youth placed in the care of relatives are just as safe, or safer, compared with youth placed in unrelated foster families. According to national data, these youth are also less likely to switch caregivers than nonrelative-placed youth (82 percent were living with the same caregivers one year later, versus 65 percent of nonrelative-placed youth).⁵⁶ However, other sources indicate that youth in kinship care do not necessarily fare better than other out-of-home youth in terms of living situations and life outcomes and in some cases actually fare worse. For instance, in 2002 it was found that 54 percent of youth in kinship care were living with families with incomes below 200 percent of the federal

poverty level.⁵⁷ This is one reason why the federal funding of kinship care is controversial.

The Kinship Caregiver Support Act has been introduced several times in recent years by Senator Hillary Rodham Clinton (D-NY) but has not yet been enacted. This act would establish a program to provide federal assistance to states for subsidized guardianship programs to assist relative caregivers and their children. The Child Welfare League of America (CWLA), as well as many other child welfare organizations, endorses this act.⁵⁸ These advocates believe that federal child welfare funding should be flexible enough at the state level to allow for the support of kinship and guardianship care as deemed necessary, and that an investment in kinship care will lead to more positive outcomes for the families who devote their time and resources to taking care of their kin, as well as for the youth themselves. This may be an especially beneficial policy for youth with disabilities in the foster care system, who are generally adopted less often and therefore may be able to find permanency and stability more easily through the kinship care option.

Eligibility requirements for laws pertaining to this population should be reexamined to ensure that they are consistent, current, and supportive.

Although any youth, independent of income status, can be placed into foster care, today a young person is eligible for federal foster care support only if his or her family meets income eligibility requirements from 1996, the last year that the federal Aid to Families with Dependent Children (AFDC) program existed before it was replaced by Temporary Assistance for Needy Families (TANF).⁵⁹ This is because eligibility requirements have not been updated to take into consideration the new law or inflation rates since 1996. As a result, from 1998 to 2005, an estimated 35,000 more children and youth became ineligible for federal foster care assistance because of their family income levels.⁶⁰ In 1998, 53 percent of all American children in foster care were receiving support, whereas in 2005, only 46 percent received it.⁶¹

Because federal law requires states to ensure the protection and care for all of their children, states have been forced to make up the difference between what is required to fund the necessary services and what they receive from the Federal Government. The states lost an estimated \$1.9 billion in federal foster care support between 1998 and 2004, an enormous amount of money for the states to make up.⁶²

This "lookback," what the Pew Charitable Trust's "Kids Are Waiting: Fix Foster Care Now" campaign is calling this policy, ties eligibility to a program that has not been in existence for 11 years as of 2007, affecting the eligibility for federal assistance of families who adopt. Pew asserts that this effect is creating disincentives to adoption for foster youth.⁶³

Most advocates and foster care experts agree that the outdated eligibility requirements are unfair to thousands of families and must be updated to fairly serve all of the lowincome youth and families in need of support, instead of just some of them.

Research should inform policy and practice. Proven best practices should be endorsed, and information about them should be disseminated at the federal and state levels.

More now than ever before, research and data collection increasingly provide us with more accurate and more insightful views into the situations and outcomes of youth with disabilities and youth in the foster care system. And the data that has been uncovered about these populations has both influenced and *been influenced* by practice in multiple fields. With the current focus on accountability and data, more and more programs and practices are now facing more rigorous evaluation to determine their effectiveness and worth. But this research and the insight it brings to multiple systems is all for naught if it is not used to inform and influence policy in a positive way. Many believe that the best means to ensure that research is linked to policy and practice is for the Federal Government to take a primary role in funding not just data collection, but also research that determines promising practices and evaluations that measure programs that implement these practices.

As noted earlier, the Federal Government is already investing in research in the child welfare arena—for example, by evaluating the states whose child welfare agencies are implementing waiver demonstration programs to try innovative methods for serving youth in foster care. Of course, the funding for program and practice evaluations should extend beyond publicly funded programs so that more "out-of-the-box" practices can also be taken into consideration. Research should also be conducted into interventions for specific populations, such as youth with disabilities in foster care.

However, still more can be done at the federal level regarding research. For example, while the Children's Bureau performs data collection, it very rarely funds research. As a result, schools of social work and other research institutions are left to fund and conduct research on their own about youth in the child welfare system. Research and the dissemination of results would be greatly strengthened by support from the Children's Bureau, which could include providing grants and even conducting research.

As an example of the importance of using research to inform policy and practice, the majority of this section focuses on what research is showing to be characteristic of youth with and without disabilities in foster care who are placed in group homes and other institutional placements. It also shares research on promising practices for serving foster youth with behavioral issues and some severe disabilities.

The group home is one type of institutional residence for youth in the foster care system. The purpose of most group home placements is to provide youth with intensive mental health services, including psychopharmacological therapeutic interventions. According to research, the most common reasons for being placed in residential treatment centers are "severe emotional disturbance (clinical depression, PTSD, anxiety disorders, and so forth); aggressive/violent behaviors; family/school/community problems; and physical, sexual, or emotional maltreatment."⁶⁴

In general, only youth with severe mental health and behavioral problems are supposed to be placed in group care. Indeed, group homes are intended to be placements of last resort, as they are considered extremely "restrictive environments" for youth.⁶⁵ Even so,

it has been shown that youth without mental health problems are assigned to group care from time to time as a result of the absence of available foster care placements⁶⁶ (although it is not known how regularly this occurs). Such placements are especially prevalent for older youth, who are traditionally more difficult to place into family care. What this means is that some youth are living in more restrictive settings than they require.⁶⁷ In fact, most child welfare experts believe that most foster youth who have disabilities should be placed in noninstitutional environments, such as family foster homes, whenever possible. The exception is when these youth need specific, intensive services that are accessible only in certain settings.⁶⁸ Some believe that unnecessarily restrictive settings actually worsen certain disabilities and behavior problems in certain situations. In fact, the Surgeon General's 2000 report on children's mental health indicated that "residential treatment has not shown substantial benefit to children and youth with mental health problems," and that research "hints at the possibility that residential treatment may have adverse effects because of the contagion of problem behavior from one child to another."⁶⁹

Research has determined that many negative characteristics are associated with foster youth being placed in group homes and other institutional settings, especially compared with foster youth residing in foster homes, who have been shown time and time again to generally fare better.⁷⁰ According to a recent U.S. Department of Health and Human Services report, 72 percent of institutionalized foster youth experience problems with family, 57 percent experience problems at school, 22 percent suffer skill deficits at school, 66 percent are aggressive, 34 percent have been involved in delinquent behavior, 31 percent have substance use problems, almost half are victims of abuse or neglect, and about 20 percent experience posttraumatic stress.⁷¹ Youth in group homes are more likely than those in foster or kinship care to report that they do not like the people they live with and that they see their biological families less.⁷² They are also less positive in general about their living experiences.⁷³

One study has determined that among young adults who were in foster care for at least one continuous year, those living in family foster care settings ended up functioning

better as adults than those in group care in most areas, including attainment of higher levels of education, lesser likelihood of arrest, fewer substance use problems, higher likelihood of having close friends, and more satisfaction with income levels and their lives in general. However, it is important to note that it is impossible to infer causality regarding these statistics, which means that it cannot be determined that residential placement type *causes* negative characteristics and outcomes, because institutionalized youth may have already been prone to these characteristics before entering their placements.⁷⁴ Nevertheless, these statistics are extremely important, because understanding the barriers that exist for youth in group homes can and should help in developing strategies to address the special needs of these youth.

One of the negative outcomes of group home placement that foster youth advocates say can be confirmed, however, is the fact that fewer youth residing in group homes are adopted. The Child Welfare League of America has determined through studying Adoption and Foster Care Analysis Reporting System (AFCARS) data from 2005 that compared with all foster youth who exited the system in any manner after existing in it long term (three or more years), those who exited *via emancipation* were 7 percent more likely to live in group homes when they exited, and 5 percent more likely to live in another type of institution.⁷⁵ A foster care alumnus and special education teacher in the San Diego Unified School District who teaches foster youth with disabilities notes that this is because parents often adopt after being foster parents first. Also, because fewer parents choose to foster youth with behavior problems, and youth placed in group homes are usually labeled as such, fewer of these youth end up being adopted or even fostered.⁷⁶ "So," this teacher concludes, "one of the major 'outcomes' of group home placement [on many occasions] is the permanent loss of a loving family."⁷⁷

Indeed, according to 2005 AFCARS data, 60 percent of adoptive parents were foster parents first, another 25 percent were relatives, and only 15 percent were "nonrelative," nonfoster parents.⁷⁸ In other words, 85 percent of adopted youth are adopted by relatives or foster parents, while only 15 percent are adopted by nonrelatives who are not foster parents.

Research is now beginning to determine best practices that should be used in group home settings to support youth, as well as alternative practices that can be implemented in place of institutionalization that may better help many of the types of youth who are commonly placed into group homes and other residential settings, including youth with disabilities.

Despite the 2000 Surgeon General's report referenced earlier, which found that group homes are not often beneficial to youth and may even be detrimental to their development, positive findings (from other sources) have also emerged from residential programs—specifically, those that use the following types of exemplary practices:

Family involvement, supervision and support by caring adults, a skillfocused curriculum, service coordination, development of individual treatment plans, positive peer influence, enforcement of strict code of discipline, building self-esteem, family-like atmosphere, and planning and support for post-program life.⁷⁹

However, the Surgeon General's report maintains that evidence shows youth with severe emotional or behavioral disorders to have more positive outcomes when they are provided with "home- and community-based treatments such as multisystemic therapy, intensive case management, and treatment foster care,"⁸⁰ instead of being placed in group homes. "Even for youth in danger of hurting themselves (suicidal, runaways, and so forth), brief hospitalization or intensive community-based services may be a more apt intervention than [residential care]," according to the report.⁸¹

Two of the more often endorsed alternative methods to caring for foster youth with disabilities are therapeutic foster care and wraparound services, as more and more research illuminates their positive effects. Therapeutic foster care is considered the least restrictive form of out-of-home therapeutic placement for children and youth with severe emotional disabilities. Care is provided in private homes with foster parents who have been specially trained in therapeutic care.⁸² Program models vary, but all have in common the following: foster parents are specially trained to handle youth with disabilities, usually only one young person is cared for per home, a higher foster parent

stipend is awarded, and foster parents receive extensive preservice training and inservice supervision and support.⁸³ Therapeutic foster care is often funded jointly by child welfare and mental health agencies.⁸⁴ The Surgeon General's Mental Health Report notes that therapeutic foster care programs are inexpensive to start because of limited facility and staff costs; it also references a study that found that these programs cost half as much as residential treatment center programs.⁸⁵ Although there are not yet many comprehensive studies about therapeutic foster care programs, existing research shows promising trends. All of the studies mentioned in the Surgeon General's report showed that "youths in therapeutic foster care made significant improvements in adjustment, self-esteem, sense of identity, and aggressive behavior. In addition, gains were sustained for some time after leaving the therapeutic foster home."⁸⁶

One of the barriers to serving large numbers of youth with therapeutic foster care is the lack of enough adults who are willing to become therapeutic foster parents, despite the fact that this service is not permanent. This issue may be partially due to how expensive the services are that many youth in therapeutic care need versus how much the state is willing to pay for them. According to the special education teacher in San Diego, "In California, a RCL 12 [Rate Classification Level 12] (moderate to high needs) group home is paid \$5,613 per month [by the state] to care for a youth..." But therapeutic foster parents are "often paid a rate closer to \$700 per month—in spite of the fact that the higher needs of the youth might require a foster parent to work less per week or to take more time off from work."⁸⁷ The teacher asserts that this funding structure ends up favoring institutionalization over more family-centered options by reimbursing institutions at far higher rates than therapeutic foster parents—despite the fact that family-based options are less expensive.⁸⁸

The Surgeon General's report also references the therapeutic group home as a relatively new and thus far promising model of care for youth with serious emotional disturbances. The report recommends that more research be done on this practice.⁸⁹ When federal agencies support the performance of research on alternative care models

like therapeutic foster care, they demonstrate their investment in foster youth, and especially those with disabilities.

"Wraparound services" are considered an approach to care, instead of a program, and are a relatively newly recognized model of care. According to the Surgeon General's Mental Health Report, "the wraparound approach is based on a belief that the child and family should be placed at the center of an array of coordinated health and mental health, educational, and other social welfare services and resources, which a case manager wraps around the patient and family."⁹⁰ Wraparound services have been shown to be beneficial for all youth who have multiagency needs, but recent research indicates that the approach is most effective for children and youth with emotional disturbances.⁹¹ Providing wraparound services involves assembling a team of experts to create an individualized plan of services and then evaluating that plan. The National Wraparound Initiative, an organization that provides resources on the wraparound philosophy and effective practices, is working to create standards for effectiveness around this promising approach to care.⁹² The Federal Government should support more research on wraparound services, as well as the work of organizations like the National Wraparound Initiative, with the goal of more comprehensively serving youth with disabilities without overinstitutionalizing them.

One example of a program that offers community/family-oriented wraparound services is a residential program called the Whitaker School in North Carolina, of which a study was conducted in 2000. This program operates under the "Re-education model," which is "based on systems theory in that emotional conflict is derived from interpersonal and system level problems, such as service provision problems in the mental health system."⁹³ The Whitaker School is particularly targeted to students who have not been treated successfully in more traditional residential care programs. Most of the adolescents in the Whitaker School study had major psychiatric diagnoses such as conduct disorder, attention deficit hyperactivity disorder (ADHD), major depression, and PTSD, and 80 percent had documented abuse on their records.⁹⁴ The success rate (which was based on frequencies of illegal activity, school attendance, and

hospitalization) was found to be 58 percent in this program, which is significantly higher than the success rate of traditional residential programs.⁹⁵

The problems with institutional group care highlighted here, along with the compelling newly emerging evidence that supports alternatives to institutionalization, together illustrate the concern that child welfare research and practice do not always align with the policies and funding structures developed to support youth, and those with disabilities in foster care specifically. The Federal Government should be more involved with relevant research to understand what works for this challenged population and then better align its policies to support practices that are deemed promising.

In addition to supporting research that can help ascertain promising practices for serving youth with disabilities and behavior issues in the foster care system, the Federal Government should actively disseminate the high-quality information that is collected. The Pew Commission on Children in Foster Care recommended this in its 2004 recommendations.⁹⁶ Proper dissemination tactics include providing technical assistance to help program and agency personnel fully understand the nuts and bolts, and the hows and whys, of service and program implementation. Some child welfare advocates and experts also believe that the government should take one step further by rewarding (through monetary incentives) the states and programs that implement the best practices that research has shown to be effective.

One positive step is the development of the various National Resource Centers (NRC) funded by the U.S. Department of Health and Human Services' Children's Bureau. The NRCs conduct free training and technical assistance for states that request it, appear at conferences, collect information, and disseminate information on their Web sites. These efforts should continue to be supported at the federal level to make more information about "what works" readily available to the departments and agencies that support foster youth with disabilities.

An investment in the recruitment and training of foster parents is an investment in safety, permanency, and positive well-being for foster youth.

The adults who commit to serving as caring, nurturing foster parents are the single most valuable component of the foster care system. Indeed, this system is completely dependent on caring people and well-functioning systems to provide youth with disabilities in foster care with the support and services they need to thrive. However, not enough adults make the commitment to care for foster youth, and especially youth with disabilities, which is part of the reason why most of the approximately 20,000 youth transitioning out of the foster care system every year do so unattached to any family. When adults do commit to fostering youth, many feel frustrated about the lack of training, support, and resources they receive to prepare them for success.

To give more foster youth, and especially those with disabilities, the chance to enter into loving, nurturing families, the Federal Government must make a serious investment in the targeted recruitment of foster care parents, as well as in thorough training of foster parents and supporting funding and resources. These investments would assist foster parents greatly while helping to reduce the disproportionality of youth with disabilities who are left in the system for prolonged periods.⁹⁷

According to research, there is no single "profile" of a family willing to foster "difficult" youth.⁹⁸ Studies in the 1970s and 1980s determined that religiously affiliated adults were less likely to adopt African-American children but more likely to adopt children with mental or physical disabilities, that politically liberal adults were more likely to adopt African-Americans, and that single parents were more willing to adopt children with mental disabilities.⁹⁹ However, a more recent study tried to establish whether factors such as education and income levels, marriage status, working in a helping profession, and having social support from family influenced an adult's decision to foster children and youth with emotional and behavioral disorders.¹⁰⁰ Although some patterns were uncovered, significant profiles did not emerge.¹⁰¹

The study also determined that the youth prospective foster parents consider least "desirable" to care for are those with HIV, teenagers, those with fetal alcohol syndrome, drug-exposed infants, youth with physical disabilities or serious illnesses, and youth with serious emotional or behavioral problems.¹⁰² The behavioral problems that these adults determined to be least acceptable were fire starting, behaving destructively, and acting out sexually.¹⁰³ Of course, youth who are less desirable to care for are more likely to remain in the foster care system for several years and are also more likely to be institutionalized.¹⁰⁴ The prevalence of negative outcomes associated with both long-term and institutionalized foster youth means that more targeted investment in healthy, accurate placements, as well as permanency for these youth, is especially necessary.

The authors of the study argue that statistics like those cited above, despite their limits, are crucial for understanding how to recruit foster parents to take on more "challenging" foster youth. Because fewer families are willing to foster youth with disabilities, "it is essential that agencies target recruitment efforts to attract families who are willing to foster children with emotional or behavioral problems."¹⁰⁵ The authors add that inappropriate placements often lead to compromised child well-being and more frequent disruptions when they do not work out.¹⁰⁶

"The fostering of kids with disabilities is often low because the idea is so overwhelming and unfamiliar to [adults]," explains an official at Special Families Foster Care in San Diego, California.¹⁰⁷ The truth is that "many older kids in the foster care system are considered 'unadoptable,' and even 'unplaceable,' if they have a disability, so they are institutionalized," added a program manager in the Juvenile and Family Law Department of the National Council of Juvenile and Family Court Judges.¹⁰⁸ This official asserts that agencies must therefore invest in targeted and comprehensive recruitment strategies to make sure that the right adults are being recruited and matched with the right youth, and that they are trained properly to work comfortably with youth with disabilities.¹⁰⁹

Some advocates in the disability community believe that more should be done to recruit adults with disabilities to care for foster youth with disabilities. Cox et al. (2003) indicate

that targeting recruitment to more adults working in "helping professions" (such as teachers, social workers, and hospital employees) may yield more positive results in terms of matching parents with youth with disabilities and increasing these young people's permanency outcomes.¹¹⁰

Still another issue in the battle to recruit parents to care for youth with disabilities is stigma. Child welfare personnel and prospective foster parents alike have negative perceptions regarding youth with disabilities. When the recruiters themselves hold negative or stereotyped attitudes about children with disabilities, they cannot debunk the stigmas or fears that potential parents may have. A program manager at the Child Welfare League of America believes that partnering foster care agencies with disability organizations may help to reduce stigma at all these levels.¹¹¹

A prevalent issue that both current and prospective foster parents acknowledge involves training and support. As the Special Families Foster Care official noted, many prospective foster parents are overwhelmed by the idea of fostering youth with disabilities. This can partially be attributed to the fact that a large majority of parents are not given any or enough information about disabilities during their foster parent trainings. Even without taking disability information into consideration, the number of training hours mandated by the states for foster parents varies widely and is quite meager in some states. For example, Minnesota mandates only six hours of (basic foster care) training, while Utah mandates 32 hours.¹¹²

One may infer that training programs with fewer mandated hours teach little information about the intricacies of fostering youth with disabilities. However, even more established, national foster parent training curricula often leave out this information. Two widely used training curricula are Parent Resources for Information, Development, and Education (PRIDE) and the Massachusetts Approach to Partnerships in Parenting (MAPP). Neither provides extensive information about disabilities to the foster parents they train. For example, the MAPP curriculum discusses the "effects of maltreatment on development" and "approaches to behavior management," but that is the closest it comes to addressing fostering youth with disabilities.¹¹³ The PRIDE curriculum discusses the "developmental needs of infants and children who have experienced trauma, loss, and separation" in its final training session, but nothing more specifically relevant to disabilities is discussed.¹¹⁴ However, some agencies are working to include disability information in their trainings. A special education teacher in the San Diego Unified School District notes that Special Families Foster Care in San Diego, with whom he is currently training to become a therapeutic foster parent, uses the PRIDE curriculum for its basic foster parent training but also adds specific disability information and other pertinent information to its trainings.¹¹⁵ Clearly, this practice should be replicated more widely so that more parents are familiar and comfortable fostering youth with a variety of disabilities.

Foster parents who support youth with disabilities often share their frustrations with the lack of resources, supports, and training they receive from child welfare agencies. Foster parent Tamara Connor of Topeka, Kansas, states,

Foster families need training in positive behavior supports. They need training on how to entertain and provide stimulation to children with significant disabilities. They need medical training beyond CPR and first aid. The list can go on and on.¹¹⁶

Janel Sheppard is a foster care alumna who suffered greatly when she was placed, during her adolescence, with a range of unsuitable foster parents, including "adults who were drinking heavily, doing drugs, on the verge of divorce, and were at times extremely physically, mentally, and emotionally abusive." She says,

If I could change policy or practice related to foster care, I would change the screening, training, and process for people becoming foster parents. I would [also] make it mandatory for each parent to speak to a former foster parent [to get better acquainted with the realities of fostering a child].¹¹⁷

Cox et al. (2003) also recommend specific training on disabilities so that fewer parents will feel uncomfortable fostering these youth and so that they are fully prepared when they actually do. "Information about how to effectively foster [youth with emotional and behavioral disabilities] should be highlighted during pre- and post-service trainings.... [S]uch trainings should provide information on effective discipline strategies as well as information about how to interpret a child's worrisome behaviors within the context of past trauma."¹¹⁸

While some advocates believe that foster parents caring for youth with disabilities should receive higher stipends (and many states provide higher stipends), Connor believes that additional money alone is not enough. She believes that monetary incentives and adequate training should go hand-in-hand with added support networks and other resources for foster parents fostering youth with disabilities:

I believe the key is training, support, and a team of people working together. I don't believe we [should] just pay foster families more [for fostering youth with disabilities]; I believe that we need to provide support for them. They need staff in their homes providing hands-on training, providing respite, providing therapy, and just dropping by to make sure everyone is OK. The state I live in [Kansas] pays our foster families a lot of money to take care of children with mental retardation and developmental disabilities (MR-DD). It used to be that the state paid less but then also purchased respite/attendant care for foster children. I believe that this was much healthier for everyone; the families are now supposed to purchase it themselves with the money they get, but most do not. [As a result] these families are at a high risk for burn-out. They could probably benefit from a parent mentor match—another foster family to help them understand how to [care for and] include a child with significant disabilities in the family.¹¹⁹

A specific point to reiterate is that ongoing support for foster parents is absolutely crucial, especially for those caring for youth with disabilities. Frequent check-ins and the dissemination of up-to-date resources by foster care agencies can help these parents feel connected to the support structures they need. Both the Federal Government and state officials can make ongoing support a higher priority.

The Federal Government must invest in nationwide public awareness campaigns for youth with disabilities and for foster youth in order to increase public knowledge and help reduce stigma.

Maintaining visibility about a certain issue or population is crucial to inciting any kind of action on its behalf. This is the purpose of public awareness campaigns and other communication tactics that are used to help the public understand a particular issue. Too often, the only information the public receives on a particular topic is the often dramatized and inaccurate information propagated by local newspapers and television news programs, which tend to report on crises, freak occurrences, and other dramatic events in abundance, leading to a narrow and skewed public perspective on an issue. People with disabilities are all too often victims of this negative media attention, but foster youth also experience negative stigmas that stem from the public's general lack of awareness about their life situations.

Public awareness campaigns can help mitigate the negative associations people may have about a particular population. Not only is it important to introduce a crucial issue to the public by way of these campaigns, it is just as imperative to show people *why* they *should* consider a particular issue important to them, for it is this information that often compels people to act. Few policies have been implemented without an initial push from a group of noisy stakeholders, and even fewer have received widespread attention without an adequate base of general public knowledge on the topic, along with its immediate implications. Senator Patty Murray (D-WA) made recommendations in this arena at a recent event sponsored by Casey Family Programs on the educational outcomes of foster youth. She asserted that it is necessary for advocates of the foster care cause to make themselves known to their congressional representatives and to provide them with accurate information about why foster care is such an important issue.¹²⁰

What both youth with disabilities and youth in foster care have in common is that the public has little understanding about their life situations and characteristics, and that

they are stigmatized largely as a result of this lack of understanding. Both groups are also victims of their invisibility to the systems, policies, and institutions that surround and affect them on a daily basis. The consequences of this lack of public understanding begin with the low self-esteem that affects the youth themselves (and the myriad negative outcomes associated with it) and end with the lack of policies and practices to respond to their needs. For these and other reasons, public awareness campaigns and information dissemination for both youth with disabilities and youth in foster care are crucial.

At the same time, it is crucial to note that such campaigns should not seek to *separate* youth with disabilities and foster youth from the general public, but should instead work to help the public better *integrate* them into the community while recognizing their unique individuality.

Currently, few national public awareness campaigns target youth with disabilities in particular. However, the Substance Abuse and Mental Health Services Administration (SAMHSA) launched a national public service advertising (PSA) campaign in late 2006 that was specifically aimed at young adults. The campaign's purpose is to "decrease the negative attitudes that surround mental illness and encourage young adults to support their friends who are living with mental health problems."¹²¹ The campaign's Web site, *www.whatadifference.samhsa.gov*, provides factual information about mental illness, offers advice on supporting friends with mental illness, and breaks down common myths and misunderstandings about those living with mental illness. SAMHSA's campaign is a very important investment by the Federal Government to promote knowledge about an often overlooked and stigmatized issue. More government agencies should follow suit in order to get the word out about other "invisible" issues like this one.

The Silver Ribbon Coalition's Silver Ribbon Campaign for the Brain is a nongovernmental campaign that represents the interests of all of those who are affected by brain disorders or disabilities, such as "anxiety disorders, autism, brain cancer, brain injuries, depressive disorders, mental health, myelin disorders, Parkinson's disease, obsessive compulsive disorder (OCD), psychotic disorders, and rare birth defects," according to the Coalition's Web site, *www.silverribbon.org*.¹²² The goals of the campaign are similar to SAMHSA's but broader in nature. The purpose of the Silver Ribbon Campaign for the Brain is to "promote public awareness of the need for emotional, social, governmental, and research support of these individuals" with the hope that "increasing public awareness will decrease stigma and increase support to result in improved treatment and eventual cures for those affected."¹²³ This campaign, for which supporters wear silver ribbons, has been vital to increasing the awareness of how people with "brain disorders" are stigmatized.

Foster Care Month is the foster care community's awareness campaign. It was initiated in 1988 as an effort to increase recognition and appreciation for foster parents across the country.¹²⁴ Over the years, Foster Care Month (which has always been celebrated during May) became more focused on the issues surrounding older foster youth, especially as they transition out of the foster care system.¹²⁵ Casey Family Programs leads the campaign and is supported by 14 other organizations, notably including the U.S. Department of Health and Human Services' Children's Bureau.¹²⁶ The Foster Care Month campaign credits itself with being a "significant part of the drumbeat that ultimately resulted in the passage of the Chafee Foster Care Independence Act."¹²⁷ The campaign's core messages involve teaching about the magnitude of the issue, the needs of these youth, those affected, the consequences of not supporting these youth, the importance of youth in transition, what the country will look like in the year 2020 if no policies are changed to further help foster youth, and advancing a "call to action." The campaign's call to action involves becoming a caring foster parent and/or spreading the word about why effective foster care policies are important.¹²⁸ An important part of the Foster Care Month campaign is the message that is disseminated about the negative outcomes associated with foster youth who are poorly cared for and poorly transitioned to adulthood, including the issues of "homelessness, poverty, compromised health, unemployment, [and] incarceration."¹²⁹ However, more could be done to expand this message to include more information about why the general public should care about foster youth and how the issue affects everyone directly in one way or another. Additionally, a more strengths-based message would better help highlight the incredible

potential of foster youth and take some of the emphasis away from their vulnerabilities. The Federal Government should take initiative in this area to further this important message and provide an impetus for the states to consider it important as well.

To reiterate, there are some investments, both specific and broad, that could be made at the federal level to better support youth with disabilities in foster care. These critical investments involve granting more spending flexibility to the states, altering federal program eligibility requirements, using research to inform policy and practice, investing in foster parent recruitment and training, and doing more to reduce stigma and increase knowledge about youth with disabilities in foster care. Even small changes in some of these policies could greatly enhance the quality of life for these uniquely challenged youth.

Summary of Policy Recommendations

- 1. More spending flexibility must be granted to the states in order for them to address the unique needs of this population more wholly.
 - a. Flexibility allows states to prioritize their own activities as they see fit.
 - b. More funding can be allocated to family-centric services such as preventative, reunification, and adoption services.
 - c. More funding can also be set aside for alternative models of care, such as wraparound services and therapeutic foster care.
- 2. Eligibility requirements for laws pertaining to this population should be reexamined to ensure that they are consistent, current, and supportive.
 - a. The eligibility requirements for receiving federal foster care support are out-of-date and should be updated to reflect current need.

- Research should inform policy and practice. Proven best practices should be endorsed, and information about them should be disseminated at the federal and state levels.
 - a. Current research should be better reflected in policy.
 - b. According to research, youth should be placed in family settings whenever possible for best outcomes.
 - c. Research is also showing wraparound services and therapeutic foster care to be promising models, especially for youth with disabilities in the foster care system.
 - d. The Federal Government should disseminate high-quality research and provide technical assistance to the fields of child welfare, education, and other systems that intersect with this youth population.
 - e. The Federal Government should encourage the use of scientifically proven best practices, and states and programs should be rewarded when they implement them.
- 4. An investment in the recruitment and training of foster parents is an investment in safety, permanency, and positive well-being for foster youth.
 - a. Better targeting foster parent recruitment efforts by prioritizing placements for youth with disabilities will result in more accurate placements, which leads to increased permanency for these youth.
 - b. Foster parents should receive training on disabilities and caring for youth with disabilities.
 - c. More adults with disabilities should be recruited to serve as foster caregivers.
 - d. Foster parents should receive ongoing support and guidance, especially when caring for youth with disabilities.

5. The Federal Government must invest in nationwide public awareness campaigns for youth with disabilities and for foster youth in order to increase public knowledge and help reduce stigma.

Chapter 3.2: Education and Training Needs of Foster Youth with Disabilities

Education is often looked to as the necessary intervention in the ongoing battles to "close the achievement gaps" and "level the playing field" for all youth. Some even consider access to quality education to be a silver bullet of sorts. The public education system is required to provide a free and comprehensive education to all students, including those who come to school with disparate abilities. Many of these students are challenged with physical, psychological, emotional, and learning disabilities. All students have varying levels of support at home, varying access to preschool, and different socioeconomic levels. Additionally, cultural, ethnic, and language differences are common. The task of helping all of these youth succeed is a tremendous challenge, but one of paramount importance nonetheless. After all, education, which in this report is inclusive of occupational training, has always been, and continues to be, the pathway to economic sufficiency in the United States.

Like every system, the public education system has its limitations, problems, and inefficiencies. Many have argued that the public education system fails to provide quality services to one large portion of the country's youth in particular—disadvantaged youth. This group includes low-income and minority youth; youth with disabilities; youth in the juvenile justice, foster care, and other institutional systems; homeless youth; and other youth who are somehow disconnected, either physically or emotionally, from society. Sadly, many of these youth experience multiple disadvantage factors, further challenging them and complicating their situations. Students in these subpopulations often require services beyond standard academic interventions, such as health- and mental health-related services, mentoring, counseling, substance abuse treatment, conflict resolution skills, self-advocacy skills, and even basic needs such as housing.

Research has shown that students with disabilities, whether they are in the foster care system or not, experience poorer educational outcomes than students without disabilities. Advocates for Children of New York, a nonprofit group that monitors the New York City Public Schools, studied the special education population in the school

district for eight years (between the 1996–97 and 2003–04 school years) to better understand their graduation and dropout rates.¹³⁰ Approximately 15 percent of New York City's students receive special education services.¹³¹ Over the study period, just below 12 percent of students in special education graduated with either a local or Regents diploma.¹³² (Regents diplomas are more rigorous than New York City's local diplomas.) Another 12 percent of students in special education earned individualized education program (IEP) diplomas, which are designed for students with severe disabilities. Students with emotional disturbances had the lowest graduation rates, with only 4 percent receiving local or Regents diplomas.¹³³ (Nationally, youth with diagnosed emotional disabilities have the highest rate of dropping out of school, at 56 percent,¹³⁴ and only a 20 percent chance of enrolling in postsecondary education.¹³⁵) In an Education Week article about the New York City study, the former executive director of Advocates for Children commented, "What we saw was beyond horrendous. A tremendous amount of resources are going into special education services, and the results are not being reflected."¹³⁶ New York City's percentages are exceptionally low compared with the national average, which, although higher, still paint a bleak picture of how special education students fare in terms of high school graduation. According to the 25th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (IDEA), in the 2000–01 school year (SY), 47.6 percent of the students with disabilities ages 14 and older exited school with a regular high school diploma. The report adds that from SYs 1993–94 to 2000–01, there was little change in these outcomes.¹³⁷ This data compares with the national average high school graduation rate for all youth, which is about 70 percent.¹³⁸

Regarding postsecondary attainment, more youth with disabilities enroll in two-year community colleges than any other type of postsecondary school, but this percentage still hovers only around 20 percent.¹³⁹ About 9 percent of youth with disabilities attend four-year colleges, and another 5 percent attend vocational, technical, or business schools.¹⁴⁰ These percentages are staggeringly low compared with national averages. Just under 60 percent of American youth enroll in some type of college immediately following high school.¹⁴¹ Although the IDEA report to Congress reports that 95 percent

of high schools offer "postsecondary education/training applications assistance" and "postsecondary and training institutions counseling,"¹⁴² there appears to be a disconnect between the preparation students with disabilities receive in high school and their postsecondary access and attainment levels.

It is estimated that 30 to 40 percent of foster youth are in the special education system.¹⁴³ Similar to youth with disabilities, students in foster care have lower rates of high school graduation, at 50 percent¹⁴⁴ versus approximately 70 percent for the general population. When foster youth do graduate, they tend to obtain GEDs more often than high school diplomas.¹⁴⁵ Only about 20 percent of foster youth transition successfully to college, and the rate of completion for this cohort is only 5 percent (or less) versus 20 percent for their peers.¹⁴⁶ These dismal statistics highlight the unmet educational need of students in foster care and how compounded this unmet need can be when these youth have mental, developmental, learning, or emotional disabilities. Success in school—and then in life—is an especially uphill battle for these youth, which makes it all the more important that they receive extra supports as necessary.

The following recommendations tackle the myriad barriers to educational attainment that youth with disabilities in foster care face.

The provision of comprehensive, individualized school services in nonrestrictive environments is essential to ensuring the educational success of youth with disabilities in the foster care system.

For too many years, educational expectations for students with disabilities have been low. While the reauthorization of IDEA (P.L. 105-17) in 1997 began to focus on education performance and not just access to education for students with disabilities (states were required to "address the performance of children with disabilities on assessments, dropout rates, and graduation rates"¹⁴⁷), momentum was slow to build in terms of developing rigorous assessment systems. As IDEA 1997 was being implemented, however, a national debate arose on setting academic standards for all students, which resulted in the passage of the No Child Left Behind Act (NCLB) (P.L. 107-110) in 2001. (NCLB is actually the reauthorization of the Elementary and Secondary Education Act of 1965.) One of the principles of NCLB is to ensure that all students become proficient in core academic subjects by 2014.¹⁴⁸ The law requires states to assess students in certain grades annually to determine "adequate yearly progress" (AYP) in meeting proficiency targets, and to disaggregate data on the performance of all students by various indicators, including race, ethnicity, sex, and disability status.¹⁴⁹ The law established the expectation that all children, regardless of status or condition, can learn to high standards.

Because NCLB requires data to be disaggregated by subgroup, schools must report on the performance of students with disabilities and other disadvantaged students (although not youth in the foster care system). Recent reports have consistently indicated that students with disabilities or other disadvantages (such as limited English proficiency) perform at lower levels on standardized tests or other assessments than other groups of students.¹⁵⁰ Because states and schools are not making AYP for these subgroups, educators have refocused efforts to provide the necessary educational services and supports to these subgroups. These efforts include placing more students with disabilities into the general education curriculum and exposing them to grade-level coursework,¹⁵¹ measuring more students with disabilities to highly qualified teachers.¹⁵² Because of these changes, states are beginning to report some incremental improvement in academic performance for students with disabilities.¹⁵³

Equally important to increasing the rigor of coursework for students with disabilities is increasing the expectations of educators and the community about their ability to meet proficiency in core academic subjects. Because expectations have been raised, attitudes about students with disabilities are changing, just as attitudes about the abilities of all disadvantaged students are changing. Students with disabilities are more frequently placed in general education classes and spend less time in "pullout" programs than ever before,¹⁵⁴ which reinforces the notion that these children can be

mainstreamed and meet the same curriculum expectations as any other child. While progress has definitely been made for students with disabilities, barriers still exist to holding high expectations for students who have multiple challenges, such as students with disabilities in the foster care system or students with disabilities who have limited English proficiency. With multiple challenges, these students are harder to serve and require more comprehensive supports.

School counselors are invaluable resources for all students, regardless of achievement level or life circumstance. They can help navigate the often hard-to-understand requirements, regulations, and processes for numerous procedures, such as the college application process or the process for creating an IEP. They also help locate necessary or supportive services, such as after-school programs and tutors, transportation services for youth with physical disabilities, and sexual health counseling. Additionally, they help teachers handle behavior problems they encounter in the classroom. And of immense importance, school counselors provide an ear for students who need to talk to someone they can trust. They are sometimes the most stable adults in a young person's life, especially for highly mobile and disconnected youth such as youth with disabilities in foster care.

However, there are between 3 and 50 times as many students assigned to school counselors as what the profession considers to be appropriate.¹⁵⁵ Schools in low-income neighborhoods are much more likely to have the highest ratios of students to counselors, and as foster youth are disproportionately low-income, this means that most foster youth have little or no access to school counselors.¹⁵⁶

The Elementary and Secondary School Counseling Programs (ESSCP), which reside under Title V of NCLB, provide competitive grants to school districts to create and expand school counseling services that comprehensively include access to not only certified counselors, but also to psychologists, psychiatrists, and social workers.¹⁵⁷ However, this program is extremely underfunded, with only 103 school districts receiving grants in 33 states and the District of Columbia; thus, the majority of schoolaged youth are not being served by this important program.¹⁵⁸ It is also worth noting that

elementary schools have funding priority over secondary schools despite the myriad challenges high school students face.¹⁵⁹ The U.S. Department of Education should increase ESSCP's funding to support more youth, including more secondary school youth, and funding should be targeted to the highest-need school districts. Additionally, schools with counselors should consciously target their time, resources, and expertise to those students who are most in need, which includes youth with disabilities in foster care.

An additional issue around this topic, pertinent to foster youth, is that there is no formal or informal training available to counselors and school psychologists (or administrators and teachers) about the unique educational needs and experiences of students in foster care. Programs like the San Diego County Office of Education, Foster Youth Services' Tutor Connection Program address this deficiency. This program pairs future teachers from California State University, San Marcos (CSUSM) with foster youth. The CSUSM students are taught about the educational needs of foster youth, the impact of trauma on educational progress, and the child welfare system. These future teachers then each provide one-on-one tutoring to a student in foster care as a community service project. This particular partnership includes San Diego County's Foster Youth Services, the county's Health and Human Services Agency, Child Welfare Services, Casey Family Programs, and CSUSM.¹⁶⁰ More programs like this should surely be implemented to increase awareness of the needs of foster youth among educators.

Another extremely important service for foster youth is mental health counseling, as many studies have shown that over half of foster youth have moderate to severe mental health issues.¹⁶¹ While the child welfare system is the main link to mental health services for foster youth, many believe that mental health services should "come to the youth" and be provided in their school settings in order to increase access.¹⁶² San Diego Unified School District is one school district making a move in this direction. The district's Licensed Children's Institutions Program has recently developed several groundbreaking interventions that bring mental health services to the school setting.¹⁶³

Currently, the U.S. Department of Education's Grants for the Integration of Schools and Mental Health Systems, which reside within Title V of NCLB, help to serve this muchneeded purpose. Under this program, collaboration between school districts and mental health systems is mandated in order to "provide, enhance, or improve prevention, diagnosis, and [mental health] treatment services to students," and grantees are required to evaluate their effectiveness in increasing access to quality mental health services.¹⁶⁴ However, this well-intended program is currently funded at only \$4.9 million, enough to award just 20 grants.¹⁶⁵ Funding increases in programs like this would demonstrate the U.S. Department of Education's accountability and dedication to providing the services necessary to give youth who traditionally fall behind, such as those with mental disabilities, a better chance of success in the long term.

IDEA protects and assists students with disabilities in the public education system by requiring access to "a free appropriate public education in the least restrictive environment appropriate to their individual needs."¹⁶⁶ IDEA requires public school systems to develop an appropriate IEP for each eligible student. IEPs are reports that specify the types of services, supports, and environments that a student with a disability needs in order to succeed.¹⁶⁷ The team that develops each IEP usually includes a student's teacher; parents, caretaker, or caseworker; the young student, when deemed appropriate; and a representative qualified to supervise the provision of special education.¹⁶⁸ Because IDEA prohibits caseworkers from making special education decisions on behalf of foster youth, it is often assumed that a caseworker cannot have any role in educational decision-making on behalf of a child.¹⁶⁹ In fact, all caseworkers should help serve as advocates for the education of the youth they serve. Additionally, caseworkers should be working with the dependency courts to ensure that the judge is addressing a young person's education needs.¹⁷⁰ (Often, a Court Appointed Special Advocate [CASA] is called on for this purpose as well.) According to a trial judge in the Arizona Superior Court in Pima County, many courts, like hers, use the Education Checklist that the National Council of Juvenile and Family Court Judges has created, ¹⁷¹ which helps judges understand which questions they should be asking to ensure that the educational needs of the youth are being addressed.¹⁷²

The lack of appropriate individuals to serve as educational advocates, and to hold educational rights, is a recurring problem for systems that serve youth with disabilities in foster care.¹⁷³ IEPs are often delayed or not followed due to an inability to identify or locate the person who holds educational rights.¹⁷⁴ Laws should require an educational advocate for each student in foster care. When necessary, this individual could hold educational rights but could also serve as a support to other appropriate people in the young person's life who could hold these rights but might not have the necessary knowledge to advocate effectively for the child's best interest.

The "least restrictive environment" provision is an extremely important and relevant part of IDEA for youth with disabilities in foster care. The 2004 statute reads,

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.¹⁷⁵

Despite this statute, it is a sad fact that an overwhelmingly large percentage of youth with disabilities in foster care end up in more restrictive settings than are justified. One example of a restrictive school setting is what are referred to as "non-public schools" (NPSs). NPSs are schools run by private entities that provide special education services to students on the basis of their IEPs. Placement into an NPS is considered one of the most restrictive educational placements available. ¹⁷⁶ NPSs are foster youth who have been placed in special education and institutionalized in a group home of some sort pursuant to being identified as unfit to be educated in a regular public school. Although placement into an NPS is appropriate for some foster youth, studies have shown that youth with disabilities are overidentified as needing this type of placement.¹⁷⁷

In 2001, the American Institutes for Research performed a study on educational outcomes for children residing in California's group homes, or Licensed Children's Institutions (LCIs).¹⁷⁸ The study found that 47 percent of the youth in these placements were enrolled in special education, and that 46 percent of them were being educated in NPSs.¹⁷⁹ To give perspective, only 1 percent of special education students who are not foster youth and not in group homes are educated in NPSs, and only 4 percent of foster care youth who are not living in group homes are educated in NPSs.¹⁸⁰ The study also found that residing in a group home or LCI increased the chance that youth with disabilities, and especially those with emotional disturbance, would attend an NPS, versus youth with emotional disturbance who did not live in LCIs.¹⁸¹ (Indeed, most youth in group homes who are placed in NPSs are identified as "emotionally disturbed" under IDEA.¹⁸²) To make matters worse, "Staff visits to group homes revealed that staff reported getting little or no educational information from caseworkers and having great difficulty in getting transcripts from schools," meaning that it was not likely that IEPs were being adhered to for these youth.¹⁸³ The authors of this study suggest that NPSs should be used only as transitional environments that help youth prepare for placement into a public school.¹⁸⁴

A research article published by the National Center for Youth Law explores this issue further. It reports that, in general, independent of education placement type, "Youth [residing] in group homes are frequently educated in substandard, unregulated, and unequal schools."¹⁸⁵ One large concern is the issue of segregation (and isolation), as group homes tend to educate only the youth residing in that particular home.¹⁸⁶ Foster care alumna Samantha Jo Broderick claims that while institutionalized in a group home as a teenager, she was forced to attend a "day school" for severely emotionally disturbed youth where she saw few "outsiders," was allowed almost no privileges, and learned very little because the curriculum reached only the eighth-grade level, which her academic knowledge exceeded.¹⁸⁷

Further complicating, and likely exacerbating, these serious matters of substandard education agencies in California was the fact that financial incentives in that state have

historically encouraged public schools to place youth in NPSs, as they received a *100 percent reimbursement* for each group home-placed foster youth enrolled in an NPS, but *no reimbursement* if they chose to provide the services themselves. But thanks to the 2005 passage of S.B. 1108, state reimbursements to school districts are now linked to a youth's residential placement, not his or her school placement.¹⁸⁸ This means that school districts now have an incentive to educate foster youth in public, comprehensive schools and receive financial assistance to support those youth in the more inclusive settings. School districts should never be provided financial incentives to place youth into extremely restrictive learning environments; students should be placed in them only when absolutely necessary. Schools, along with the laws that support them, should work to adhere to IDEA's standards by keeping youth with disabilities who are in the foster care system in mainstream schools to the full extent possible.

Eligibility requirements of the McKinney-Vento Act should be expanded to include all foster youth, and funding should be increased in an effort to serve more eligible youth.

The average number of school changes per foster youth is three; a large number of these young people actually experience more than seven changes.¹⁸⁹ "Changing schools is particularly disruptive to the education of foster youth, because it reinforces a cycle of emotional trauma and abandonment and repeated separations from adults and friends."¹⁹⁰ Additionally, research suggests that foster youth lose an average of four to six months of educational attainment every time they change schools¹⁹¹—an overwhelming statistic. And higher frequencies of school changes have been linked with lower graduation rates and, hence, lower postsecondary attainment.¹⁹² Therefore, foster youth should remain in their respective schools of origin as long as possible in order to limit the detrimental effects of high school mobility.

The McKinney-Vento Homeless Assistance Act (P.L. 100-77) is the primary federal law focused on the education of homeless youth, who include "children awaiting foster care placement."¹⁹³ The law requires states to have a plan for addressing issues around the enrollment, attendance, and success of homeless youth in school. It allows for these

youth to remain in their schools of origin regardless of where they are living (when feasible) and provides for the funding of transportation services in order to support this allowance.¹⁹⁴ Hence, the McKinney-Vento Act addresses some of the negative effects of high mobility that many homeless and foster youth experience.

The act also eases the transitions of these youth when they do change schools by allowing them to enroll in and attend school immediately, even before their school and immunization records have been transferred.¹⁹⁵ A U.S. Department of Education report recently determined that the McKinney-Vento Act is actually making significant progress toward reducing the barriers to education services for homeless and many foster youth in the districts that receive this program's funding.¹⁹⁶ A trial judge for Division 13 of the Arizona Superior Court in Pima County says that her county uses the act to assist dependent youth with the provision of education services more steadily now that so much recent research has pointed to the negative effects of high school (and home) mobility for foster youth.¹⁹⁷

However, many foster youth advocates, such as Casey Family Programs, agree that the foster care-specific wording of the McKinney-Vento Act, which states that youth who are "awaiting foster care placement" are eligible for services, is too vague, thereby allowing states to take very different approaches to serving these youth.¹⁹⁸ As a result, some states consider all foster youth eligible, including those placed in long-term care, while others consider only youth in emergency shelter or short-term placements eligible.¹⁹⁹ Casey Family Programs believes that this wording should be changed to incorporate all "out-of-home youth," which would include foster youth in any type of placement, such as group homes, foster families, and kinship care, for any length of time.²⁰⁰ The policy director for the National Association for the Education of Homeless Children and Youth says that her organization advocates for the expansion of McKinney-Vento Act eligibility requirements so that states can spend less time determining eligibility for each child and more time making sure that "school is the oasis of stability when everything else is turned upside-down."²⁰¹

Another issue advocates raise pertaining to the McKinney-Vento Act is that its current appropriation of \$61 million creates a highly competitive subgranting process, which means that too many eligible children and youth are left uncovered.²⁰² According to Casey Family Programs, almost half of the 914,225 students identified as eligible (under current definitions) for the McKinney Vento Act in 2005–06 were enrolled in school districts that do not have subgrants.²⁰³ Therefore, the U.S. Department of Education should strongly consider an increase in funding for the act in order to provide all eligible youth with the services they need to succeed in school. Increased support for the McKinney-Vento Act could specifically have a positive effect on youth with disabilities in foster care, who often remain in the system for longer periods and experience many different school and home placements.

Efforts to maintain foster youth in their schools of origin must be strengthened at the state level as well. California's Assembly Bill 490 (A.B. 490), which was passed in 2004, is a promising model of a state program that ensures that foster youth remain in their school of origin to the extent feasible. A.B. 490 requires that foster youth receive equal access to a comprehensive education, which includes the right to immediate enrollment upon changing schools, the right to remain at their school of origin when home placement changes during the school year, access to extracurricular activities and to learning in the least restrictive educational environment, mandated school record delivery to the new school within two days, excused absences for court-ordered activities or court appearances for the youth, and more.²⁰⁴ Other states should strongly consider measures like California's A.B. 490 to better ensure school stability and quality learning experiences for foster youth, especially those with disabilities, particularly when McKinney-Vento Act funding cannot serve all youth in need.

States should invest more actively in addressing and eliminating the barriers to postsecondary learning options that youth with disabilities in foster care face.

Many foster care alumni believe that the Foster Care Independence Act of 1999 is one of the most important recent foster care laws. This law established the John H. Chafee

Foster Care Independence Program (CFCIP), which enables states to provide independent living programs and services to foster youth "aging out" of the foster care system. This law will be discussed further in Chapter 3.3 of this report.

Added to the CFCIP in 2002 was the Educational and Training Vouchers (ETV) Program for Youth Aging Out of Foster Care, which goes beyond CFCIP by providing resources specifically to meet the education and training needs of these transitioning youth.²⁰⁵ CFCIP authorizes \$60 million per year for the ETV program, although in 2005, only \$47 million was actually appropriated to the states. The ETV program provides education and training funds to those foster youth most likely to be in the system on their 18th birthdays (as well as youth adopted at age 16 or later); youth up to age 23 are eligible so long as they are enrolled in a postsecondary education or training program on their 21st birthday.²⁰⁶ The ETV program provides vouchers worth up to \$5,000 per student per year for the cost of attending these institutions. Prior to the ETV program, no federal assistance was specifically available to help foster youth participate in postsecondary education or training programs, although many have been able to participate in federal student financial aid programs for low-income students, such as the Federal Pell Grant Program, depending on eligibility (e.g., must be at least a halftime student).

Foster care alumni who aged out of the system before the ETV program existed communicate their frustration with having a desire to attend college but no known money or supports to make it happen. Melinda Foy, an alumna who turned 18 in the 1980s, says,

My caseworker was great. She drove me to Ferris [State University] to apply for college. However, I was not aware of any services available to help me transition into college. I was fearful of not having enough money to live and [having nowhere to] go for holidays [so I never ended up going to college]. My worker had great intentions, but I was not given proper support.²⁰⁷

Melanie Oyler, another foster care alumna who aged out in the 1980s, has a similar story. She says that she emancipated herself from the dependency system at the age of

17 because there was "no reason to stay" due to the nonexistence of transition (or education) programs for foster youth in the 1980s.²⁰⁸ Oyler did eventually go to college, but it took her eight years to get her associate's degree, all the while working several jobs at once to support herself.²⁰⁹

Although the chance of foster youth (with or without disabilities) attending a postsecondary education or training program has increased since the creation of the ETV program in 2002, the statistics regarding foster youth attending and succeeding in postsecondary programs are dismal, with only 20 percent entering these programs and a mere 5 percent succeeding.²¹⁰ Two major monetary factors can be pointed to as partial causes. First, appropriations for the ETV program are low, hovering around \$45 million on average, and second, most foster youth have low incomes and are cannot afford postsecondary education. As a result of these two factors, only a fraction of eligible foster youth are truly able to take advantage of the ETV program.

Even more troubling is that some of this small amount of allocated ETV funding still goes unused by the states due to administrative issues, creating yet another barrier to access for foster youth with and without disabilities. In 2003, about *30 percent* (\$12.38 million) of the \$42 million appropriated to the ETV program went unused. Wade F. Horn, former assistant secretary for children and families at the U.S. Department of Health and Human Services, commented in a 2007 *Youth Today* article that the funds were not used because the states do not have a full understanding of what the funds can pay for, states have insufficient matching funds, there is inadequate marketing to eligible youth by the states, and staff inexperience and turnover results in confusion about the program's guidelines.²¹¹ The article also notes that in 2003, three states returned more than \$3 million in unused CFCIP funding to the Federal Government for similar reasons.²¹²

Clearly, the Federal Government must invest in state education and awareness for the CFCIP and EVT programs so that the states can do a better job of getting the funds and resources to the transitioning foster youth who need them. Another consideration may be to survey the states to better understand what barriers are preventing them from

disseminating the funds. The administrative process for obtaining the funds, either at the state or local program level, may be challenging or too cumbersome to complete; or the states may not be marketing their "request for proposals" process at the local level well enough to attract applicants.

Of course, foster youth, especially those with disabilities, face other, nonmonetary barriers to attending and succeeding in postsecondary programs. It has already been noted that a third of all foster youth are in the special education system. While special education systems provide students with disabilities many services to help them succeed, it is still a fact that many school districts do not build their special education programs around the goal of college attainment. According to a 2003 University of Minnesota study, in many states, an array of diploma and other exit document options is available to students completing high school. The options "range from honors diplomas, to the standard diploma, to certificates of completion or attendance, and others." ²¹³ Some of these exit documents are specifically for students receiving special education services and are too often less academically rigorous than the average diploma. This fact raises questions about how well-prepared for postsecondary education students who earn these diplomas really are.²¹⁴

Many foster youth also attend alternative high schools (like the NPSs discussed previously), where higher education attainment is not an expressed goal of the program.²¹⁵ As noted earlier, a large percentage of the foster youth in these alternative high school programs have disabilities. Whether youth with disabilities in foster care are in special education or alternative school programs, they all have an uphill battle, as many of them fall victim to low expectations by the adults in their lives, including their foster parents or other caretakers, school counselors, and teachers.²¹⁶ As a result, many youth with disabilities in foster care are not enrolled in college-preparatory curricula during high school, nor are they advised about the myriad postsecondary options available and the financial aid options that exist to help their goals become reality. These students are hence plagued with the idea that higher education is not something "people like them" can pursue. When they do attempt to pursue

postsecondary opportunities, navigating the application and financial aid processes without adult assistance may further hinder their success. These processes can be intimidating even to an educated adult; a foster youth who does not have the benefit of a knowledgeable supporting adult can be overwhelmed by the process and confused by the language in the complex paperwork required to apply for financial aid.

Fortunately, the reauthorization of IDEA in 1997 brought about the addition of mandatory transition planning for students with disabilities (within their IEPs).²¹⁷ Transition plans make recommendations about educational and vocational plans; set goals for an individual's future; identify services needed, such as counseling; and link students with necessary resources upon their exit from high school.²¹⁸ But research shows that the implementation of these transition plans has been slow and inconsistent across states.²¹⁹ Additionally, there is almost no alignment of IDEA's IEP transition plan with the transition plan required by the public child welfare system for foster youth.²²⁰ But coordination between public education and public child welfare is crucial for ensuring that youth with disabilities who are also in foster care receive the assistance and services they need for successful transition.

Ineffective transition planning inhibits many students with disabilities (both foster and nonfoster youth) from receiving the information they need to understand how to pursue higher education and vocational opportunities after secondary school. The National Council on Disability (NCD) also reports that researchers have found six recurring themes regarding the barriers to postsecondary educational attainment for youth with disabilities:

Deficits in study skills such as test preparation, note-taking, and listening comprehension

Problems with organizational skills

Difficulties with social interaction

Deficits in specific academic areas, with reading and written composition being the most frequent

Low self-esteem

Higher school dropout rates²²¹

When youth with disabilities in foster care do make it into a college, technical program, vocational school, or other form of higher education or training program, even more barriers hinder their success. With many financial aid programs, less-than-half-time students and non-degree-seeking students are not eligible for aid.²²² However, many youth with disabilities in foster care are not able to be half-time students. Many must hold jobs concurrently, and some have disabilities that prevent them from taking on fuller workloads. An additional issue is that many institutions of higher education do not provide many services for students with disabilities, such as resource centers, counselors, information on accessibility, and networking opportunities, making institutions unfriendly and daunting places for many students with disabilities. This issue turns out to be a sort of "catch-22" situation: Higher education institutions do not provide services for students with disabilities because many of these youth do not attend them, and many do not attend them because there are no services available for them. These institutions should therefore proactively address this issue by providing the needed services and marketing their availability to prospective students.

Some youth with disabilities in foster care themselves even caution that too often, the adults who help them access college consider college entry to be the ultimate goal, when actually, the achievement of self-sufficiency should be recognized as the true goal.²²³ "Foster youth need independent living plans, and these plans need to be closely linked to accessing jobs and careers, so youth are not just going to college for 'something to do' [when they transition out of the child welfare system]," asserts Richard Devylder, a foster care alumnus who was abandoned by his birth parents upon being born with no arms or legs.²²⁴ He claims that too many foster youth with disabilities are "dumped" into college without enough thought for their independent living needs and plans for self-sufficiency.²²⁵ Foster care alumna Samantha Jo Broderick, who experienced bipolar disorder and depression as an adolescent, agrees. She says that her caseworker fought hard to get her into college, but that she was not ready for the

environment of college because she did not feel prepared enough at that point to be on her own.²²⁶

Both secondary schools and postsecondary educational institutions such as colleges and occupational and vocational schools, as well as caseworkers and educational advocates, counselors, and dependency court judges, must keep this last point in mind when helping youth with disabilities in foster care create their transition plans and assess what skills and services they will need to lead a productive adult life. All of these adults should together be charged with ensuring that each youth's plan is comprehensive enough to lead to healthy, self-sufficient adulthood.

Education plays an enormous role in the success of all young people. Many argue that it should be especially prioritized for traditionally disadvantaged populations, because it is these youth who often end up underserved due to the challenges of meeting their unique needs. Youth with disabilities and foster youth are two such populations, and those who hold both characteristics are even more challenged. The multiple systems that work to ensure their education success must, therefore, more consciously work together to better these young people's educational outcomes. At the same time, other entities, such as systems of higher education and their financial aid programs, must step up to better serve these youth.

Summary of Policy Recommendations

- The provision of comprehensive, individualized school services in nonrestrictive environments is essential to ensuring the educational success of youth with disabilities in the foster care system.
 - Funding for the Elementary and Secondary School Counseling Programs should be increased and prioritized to serve the highest-need school districts.

- b. School personnel such as teachers, principals, and counselors should be trained on foster care issues.
- c. Funding for the Integration of Schools and Mental Health Systems should be supported more fully by the U.S. Department of Education.
- d. Every student in foster care, and especially those with disabilities, should have an educational advocate such as a Court Appointed Special Advocate. Caseworkers and dependency court judges should take more central roles in advocating for foster youth's educational needs.
- e. Nonpublic schools should be used only when absolutely necessary for youth with disabilities in foster care and only as transitional learning environments, not permanent ones.
- Eligibility requirements of the McKinney-Vento Act should be expanded to include all foster youth, and funding should be increased in an effort to serve more eligible youth.
 - a. States should expand eligibility requirements for this act to include *all* foster youth in any type of living placement.
- States should invest more actively in addressing and eliminating the barriers to accessing postsecondary learning opportunities that youth with disabilities in foster care face.
 - a. Funding for the Chafee Foster Care Independence Program's Education and Training Vouchers should be increased to serve more needy youth, and the application process should be simplified.
 - Teachers, caseworkers, and foster parents must raise their expectations for postsecondary learning attainment for youth with disabilities in foster care.

c. Postsecondary education institutions must provide better services and resources and a more welcoming environment for youth with disabilities in foster care.

Chapter 3.3: Transitions to Adulthood and Connectivity

Thousands of foster youth, youth with disabilities, and other vulnerable populations such as youth in the juvenile justice system, youth in poverty, and high school dropouts reach their 18th birthdays and enter adulthood every day. Although many will go on to healthy, productive adulthoods, unfortunately, a large number of these youth fall through the cracks, unable to succeed for one reason or another. The repercussions felt by these young people are profound, with significant numbers drifting into homelessness, unemployment, and the criminal justice system. Concurrently, many of them enter the social and behavioral health care systems in disproportionate numbers, at a dramatic cost to taxpayers. It is indeed a compelling situation for these youth and the adults and systems charged with supporting and assisting them.

The Youth Transition Funders Group Foster Care Work Group,²²⁷ which is committed to helping foster youth make successful transitions to adulthood, identifies four major groups of youth who often "do not make successful transitions" to adulthood:

Those who do not complete high school

Youth deeply involved in the juvenile justice system

Young, unmarried mothers

Adolescents who experience foster placement²²⁸

D. Wayne Osgood, a professor at Pennsylvania State University, identifies seven "vulnerable populations," adding "homeless and runaway youth, youth involved in special education, youth with serious mental disorders, and youth with physical disabilities" to the above list.²²⁹ Many young people experience at least two of these characteristics or situations at least once in their lives, further exacerbating their situations. For example, a recent Vera Institute of Justice study found that foster youth were overrepresented in the juvenile justice system.²³⁰ Although less than 2 percent of New York City's youth population were in the foster care system, foster youth accounted for 15 percent of those admitted into juvenile detention.²³¹

Osgood cites several reasons why transitions to adulthood present exceptional challenges to these extremely vulnerable groups of youth:

Limited abilities, for many youth with disabilities

Unreliable or nonexistent family support, for foster, runaway, and homeless youth

Daunting tasks of transitions, especially for youth with disabilities

Systems exacerbating problems in some cases, especially for formerly incarcerated and special education youth²³²

A further challenge for foster youth in particular is the fact that so many have lived through periods of great instability, with frequent changes in living arrangements and schools. These youth have also experienced multiple social workers and case managers, as well as varying levels of quality in the services they have received.

Young people become disconnected primarily as a result of dropping out of school; running away from their homes, foster care placements, rehabilitations, and detention centers; or merely failing to take part in societal experiences, such as getting a job, spending time with friends, and joining clubs. This population experiences little consistency or permanency in their family situations; thus few, if any, adults have the role of mentoring and guiding these youth. Even when connected to some or all of these institutions and experiences, youth are still at risk of disconnecting, as many foster youth do not have caring adults to encourage, advise, and guide them, and many youth with disabilities can end up feeling isolated, lonely, and even rejected by these societal experiences.

Chapter 3.2 of this report highlighted the dismal postsecondary access and success statistics for youth with disabilities in and out of the foster care system. In terms of employment for youth with disabilities leaving high school, according to one study, although 7 out of 10 youth surveyed claimed to have been employed at some time or another after leaving high school, only 4 out of 10 were actually employed at the time the study was done.²³³ This is "substantially below the 63 percent employment rate

among same-age out-of-school youth in the general population," the report notes.²³⁴ Similarly, almost one-half of former foster care youth have incomes below the poverty line, and they are employed at only a 43 percent rate, on average.²³⁵ Clearly, youth with disabilities and youth in foster care are not faring well in the early years of their transitions to adulthood.

There is a consensus among those who work with these populations that the issues related to disadvantaged youth's transitions to adulthood are routinely overlooked. Many think that this results from the assumption that because youth are given adult rights at the age of 18, they should all be able to live up to the expectations of being adults at that age. However, youth development experts assert that this is an incorrect assumption, and that in fact, the *majority* of 18-year-olds—not just vulnerable populations—do not feel ready for adulthood and self-sufficiency on their 18th birthdays.²³⁶ Although the populations and circumstances listed above are often noted as "unique" in transitions literature, in fact, almost all 18- to 21-year-olds need at least some type of support to help them truly reach self-sufficiency. Indeed, even well-connected and well-resourced college students often need monetary support for tuition, room, and board.

The overall message is that almost all young adults need support systems to help them transition into healthy, productive adulthoods, but that youth at risk of becoming disconnected, and already-disconnected youth, face more barriers to successful transition. Because of their circumstances, these youth require programs and efforts that go beyond what the "average" young person needs. This is especially true for youth involved in the child welfare system, as they are frequently "dropped" from many supports at age 18. "We have no children to spare," reminded Senator Patty Murray (D-WA) at a recent event sponsored by Casey Family Programs that examined the educational needs of foster youth.²³⁷ Her point speaks to the absolute need to ensure the healthy transition of *all* youth to adulthood, no matter how challenging.

No matter how unique each individual's circumstances are, disconnection from the mainstream systems as a whole is not a small issue. Indeed, hundreds of young people

exit out of foster care, get pregnant, drop out of high school, get arrested, and run away from home every day. And a significant number of people with disabilities remain disconnected from society throughout their lives because they do not receive assistance toward community integration. For these reasons, it is obvious that a national, multilevel investment is absolutely necessary if policymakers and other stakeholders are serious about improving the outcomes for these disconnected populations. Though much has been done in the last few years to address the needs of youth in transition from state custody and the needs of transitioning youth with disabilities, much more remains to be done.

Youth development experts assert that the lack of interest and willingness to invest in youth with disabilities in foster care is in part due to the lack of information about the challenges facing this population. Unfortunately, the youth themselves have no natural base of advocacy, since their families are often absent and their professional caregivers are overwhelmed with individual case situations. On this note, the Foster Care Work Group asserts,

The starting point for any reform is changing the public's awareness, and image, of the population. The public and policymakers at the local, state and federal levels must conclude that society has an interest in, and obligation to, helping these youth make it.²³⁸

Changing these attitudes requires providing information to the public at large about the negative outcomes that often occur for this young adult population *and* for the systems with which they interact when proper supports are not in place. For example, the business community must see these young people as future employees who may not have the abilities to acquire and maintain meaningful employment if they are not given access to the skills they need to thrive. Additionally, a targeted campaign must be directed at stakeholders who have a more specific role in working with foster youth and youth with disabilities.

Fortunately, since 1999, the Chafee Foster Care Independence Program (CFCIP) has mandated transition plans for foster youth, and since the 1997 reauthorization of the

Individuals with Disabilities Education Act (IDEA), the individualized education program (IEP) process has included a transition plan for students in special education. While it is commendable that these two mandated systems have been put into place, research is showing that they do not yet work well together, resulting in too many youth with disabilities transitioning to adulthood without adequate preparation. This issue is discussed in more detail below.

Cross-systems collaboration on the provision of transitional services is essential.

The Foster Care Independence Act of 1999 (P.L. 106-169), which established CFCIP, has proven to be an invaluable program for youth aging out of the child welfare system. CFCIP enables states to provide independent living programs and services to these youth until the age of 21.²³⁹ Prior to CFCIP, substantially more youth were dropped from services on their 18th birthdays with no safety net.²⁴⁰ Melanie Oyler, a foster youth in the mid-1980s who emancipated herself at age 17, reflects,

I didn't receive any [transition] support whatsoever. There were no services for youth [in the 1980s], and thus, my being in the State's care at that time did not make sense to me—there was no reason [to stay in the system], and emancipation was my only option to get out of the hell that I was in, and to try and make a "normal" kind of life for myself (i.e., to make my own decisions legally). I fervently wish there had been some support of any kind at all for me, as I struggled immensely with not having anyone to help guide me along and teach me things.²⁴¹

CFCIP, along with its companion legislation, the Educational and Training Vouchers Program (ETV), which provides resources specifically to meet the education and training needs of these transitioning youth, helps provide thousands of foster youth with job skills, life skills, and educational attainment every year. However, states' CFCIP monies are not sufficient to serve all foster youth with transition services. A 2004 General Accounting Office (GAO) survey showed that only about 44 percent of foster youth eligible for independent living services indeed received them, and it is not clear from this report how comprehensive the services actually were when provided.²⁴² Indeed, the independent living services that are provided usually do not offer all of the comprehensive services these youth, and especially youth with disabilities, need to make successful transitions. Mark E. Courtney's renowned 2005 *Midwest Evaluation* of transitioning foster youth showed that, for example, only "23 percent of those studied received training on balancing a checkbook, 25 percent assistance with finding an apartment, [and] 22 percent meal planning and preparation training."²⁴³ Services like these are particularly important for youth with disabilities, who often require more assistance with them than the "average" foster youth.

Despite the resources attached to CFCIP and ETV, youth with disabilities in foster care must still navigate too many challenges and barriers to truly become self-determined or self-sufficient. These young people in particular require a comprehensive, multisystem transition support network. It is unrealistic to imagine that the child welfare system alone can provide the resources necessary to address the employment, education, health care, housing, and family challenges of this population.

Regarding youth in the special education system, since 1997 the IEP process has provided services to develop transitions plan for youth in need. Starting around age 14, a team involving the student and his or her parent(s) (when possible), school personnel, the student's attorney or guardian *ad litem* (when appropriate), and representatives from any agencies that are deemed necessary participants (such as vocational rehabilitation or child welfare) is convened to discuss the youth's plans after high school.²⁴⁴ The team works with the youth to determine what goals are desired and what curriculum and/or special services are needed to support these transition goals. At age 16, this plan is revisited and revised as needed.²⁴⁵ At that stage, the team also discusses what services should be provided until the youth transitions out of high school, including additional classes, access to independent living and/or employment skills, and connections to community organizations and agencies. These services may include those offered not by the school but through other agencies; in these cases, such as if a student requires vocational rehabilitation, these agencies are expected to participate in the IEP transition

planning process and provide the necessary resources when needed.²⁴⁶ Prior to IDEA's reauthorization in 1997, the service links to adult systems were not mandated.²⁴⁷

The creation of both the CFCIP and the IEP transition programs has been a significant step for ensuring healthy transitions of these youth to productive, thriving adulthoods. But unfortunately, these two systems often operate in isolation of one another.²⁴⁸ This lack of coordination results in a one-dimensional approach and often creates yet another missed opportunity for the young person to succeed. Key findings have emerged from a recent study that compared transition plans for youth in special education in the foster care system versus youth only in special education.²⁴⁹ Transition plans for the *foster youth in special education* were 31 percent less likely to include postsecondary education plans than plans for students in special education.²⁵⁰ These plans were also less likely to include goals for developing independent living skills, with only 16 percent of plans having these goals; and they included less advocate involvement, with a family member or foster parent being present for planning meetings only 42 percent of the time.²⁵¹ Additionally, only 31 percent of the transition plans for foster youth in special education indicated that a caseworker had attended the meetings.²⁵²

The study provides several possible reasons why these transition plans for youth in special education and in the foster care system are so deficient. One is that IDEA's IEP process relies heavily on parent participation, without explicitly addressing who must be involved if parent involvement is not an option.²⁵³ At the same time, the role of the caseworker or a guardian *ad litem* is not well defined by IDEA.²⁵⁴ This could be one reason why caseworkers are often not involved, thus leaving the young person without a significant advocate. And as will be discussed in Chapter 3.4, the lack of collaboration between child welfare and schools, as well as the lack of understanding about the child welfare system by educators and vice versa, it is a further challenge to creating collaborative IEP and foster care transition plans that work toward the same goals. Although several improvements that directly affect foster youth were made to the IEP

process during IDEA's 2004 reauthorization, correct implementation at the ground level remains a challenge.

There are positive examples of comprehensive and collaborative transition planning processes, notably within the San Diego Unified School District (SDUSD). The Transition Resources for Adult Community Education (TRACE) program is the school district's community-based program for young adults with disabilities, ages 18–22, which provides services to youth as they transition from public school to adult life.²⁵⁵ According to a program diagnostic resource teacher at SDUSD, individualized services that link education with independent living skills are key for keeping vulnerable youth like those with disabilities in or out of foster care from dropping out of school and becoming disconnected from society.²⁵⁶ The TRACE program ensures that all students, regardless of the severity of their disabilities, are "capable of living, working, and participating in their community."²⁵⁷ TRACE uses a "person-centered planning" approach, and a key component of the program is development of transition goals across multiple "life domains," including "Adult Education, Vocational, Recreation/Leisure, Self-Advocacy, Community, and Domestic Skills." ²⁵⁸ SDUSD links each student's IEP with his or her TRACE transition plan.²⁵⁹

But these cross-systems collaborations should occur not only between systems serving juveniles; they should also be linked with the adult-serving systems to create a continuum of opportunities for the youth involved in them. In particular, they should include links between secondary and postsecondary education systems, the juvenile and adult justice systems, and juvenile and adult mental health systems. Although collaborations between juvenile and adult systems are often challenging, they must communicate with one another in order to better align service delivery choices and goals for the youth they serve. Aligning juvenile and adult services also enhances opportunities for connectivity and community integration in adulthood for youth with disabilities leaving the foster care system.

Collaborations across systems should also be occurring across different sectors, not just systems. Community organizations, youth groups, and businesses all have roles in

helping provide transition services to youth with disabilities in foster care, in addition to the "usual" systems such as child welfare and education. One of the leading national organizations that facilitate these types of collaborations is the Jim Casey Youth Opportunities Initiative, whose mission is "to help youth in foster care make successful transitions to adulthood."²⁶⁰ The initiative encourages an integrated approach that involves the young person in the transition process. It provides grants to states and cities, technical assistance for program development, and coalition-building with multiple stakeholders, including "the private sector, faith-based and community-based organizations, child welfare and workforce development agencies, local governments, and high schools and universities."²⁶¹ Programs like the Jim Casey Initiative are leading the way for communities that want to learn how to create youth-driven systems that depend on healthy collaborations across all sectors, resulting in enhanced services and improved outcomes for youth exiting foster care.

One of the issues surrounding the challenge of creating a collaborative approach is accountability. Chapter 3.4 of this report discusses the importance of cross-systems collaborations and coordination, as well as the importance of determining accountability systems so that systems are required and perhaps even provided with incentives to collaborate. These recommendations also hold true for services related to transitions to adulthood. Some believe that transition services are administered in such a fragmented manner because, as the Foster Care Work Group asserts, while there are indeed some *programs* available to help transitioning youth,

There are no *systems or government agencies*, [emphasis added] like schools and child welfare agencies, which have the responsibility of helping young adults experiencing difficulty in making the transition to adulthood... There needs to be system that has responsibility for reaching out to those not making it, with adequate dedicated resources, in the same way that resources are provided for youth attending college.²⁶²

This network of services could be facilitated by the funding and implementation of the Federal Youth Coordination Act (P.L. 109-365)²⁶³ and by adding explicit language to existing legislation related to the coordination of transitional services among state

agencies and systems. An example of this cross-systems coordination would be a collaboration between schools and child welfare agencies to create comprehensive transition plans that emphasize more specific and individualized personal, career, and education goals for each youth.

Accountability for the services provided by these different systems and entities could also be achieved by the implementation of, and strict adherence to, performance measures. Although many state and federal programs now require programs to be measured on their outcomes, at the ground level many programs do not adhere to these performance measures as strictly as they could.

Transition services for youth with disabilities in foster care should be comprehensive and individualized and offer a full range of appropriate services.

Because of the high prevalence of disconnection from society among foster youth, especially those with disabilities, the Youth Transition Funders Group Foster Care Work Group has developed five overarching program-level recommendations to ensure that foster youth are "connected" by age 25. (Age 25 is considered to be a pivotal age; research has shown that individuals who are not connected to society by this age are at a much higher risk of never connecting at all.²⁶⁴) These recommendations are for programs to "advocate and support educational attainment, facilitate access to workforce development opportunities, provide financial literacy education, encourage savings and asset development, and create entrepreneurship opportunities."²⁶⁵

The Foster Care Work Group adds that that the focus should be on educational attainment for 14- to 17-year-olds, while the focus should be on connections to the workforce for 18- to 24-year-olds.²⁶⁶ "Ensuring that youth complete high school seems to be an especially important factor for successful youth development and adult self-sufficiency," this report asserts.²⁶⁷ These recommendations are also relevant for youth with disabilities.

The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) espouses recommendations for youth with disabilities in and out of foster care in particular. NCWD/Youth has created a guide that can help different stakeholders, including the youth, ascertain what is needed under different circumstances. Under the "Connecting Activities" section of the guide, NCWD/Youth determines that the following services may be needed:

All youth may need: mental and/or physical health services, transportation, tutoring, financial planning and management, post-program supports through structured arrangements in postsecondary institutions and adult service agencies, and connections to other services and opportunities (e.g., recreation).

Youth with disabilities also may need: appropriate assistive technologies, community orientation and mobility training, exposure to post-program supports (e.g., independent living centers), personal assistance services (e.g., interpreters), and benefits-planning counseling.

Foster youth may also need: opportunities to obtain a driver's license, library card, voter registration, birth certificate, or medical records; adults who can serve as adult systems "navigators;" transitional and long-term housing; safety information for personal relationships and independent living; access to financial aid opportunities for college; parenting information and childcare; information on health care; connections to municipalities; and foster care caseworkers making connections in work and community on behalf of these youth.²⁶⁸

The sheer number of these recommendations, and the fact that they require the participation of many individuals and organizations from different systems, illustrates just how complex the support process for youth with disabilities who are exiting foster care is, as well as how much planned orchestration is required.

According to a former employee of the National Council on Disability, the disability community deems another skill necessary for youth with disabilities to obtain during their transitional period: exposure to the independent living philosophy.²⁶⁹ The

independent living philosophy empowers people with disabilities by focusing on building self-determination and self-respect and by working to ensure equal opportunities for them.²⁷⁰ Many disability experts and advocates agree that teaching this philosophy to youth with disabilities is essential to their psychological growth and the key to a healthy adulthood. This philosophy is also important for young people who have experienced foster care. Because the child welfare system has traditionally emphasized child protection, these young people are not often encouraged to be independent or to negotiate situations that include some degree of controlled risk. Therefore, it is important for the ideas of self-determination and personal empowerment to be passed along from child welfare personnel to the youth they serve.

Foster care alumna Samantha Jo Broderick asserts that it is also important to provide not only "access to" or "information about" life skills, as alluded to in the list above, but also *hands-on* skills development opportunities.²⁷¹ She states that the problem with many life skills classes is that they will teach young people the facts, but "the real-life follow-up is nonexistent." Her examples include "actually cooking something, learning to shop at a grocery store with a budget, and riding mass transit," all of which she learned about but never actually attempted to do until she was on her own, at which time she was fearful of trying them.²⁷² Broderick identifies the Ansell-Casey Life Skills Assessment²⁷³ and its connected tool as "a free, but seriously underutilized exemplary resource that typically is not used to its full potential" by agencies and programs that teach life skills.²⁷⁴

Among the "connecting activities" that NCWD/Youth considers highly important are activities that connect youth with disabilities and youth in foster care to their peers, including support networks. Child welfare and disability advocates alike express their frustration with the dearth of support networks available to these young adults. Richard Devylder, a foster care alumnus who was born with no arms or legs, says that his top recommendation is for programs to provide networking opportunities, especially social ones, to youth with disabilities aging out of foster care, because "these are often especially isolated youth."²⁷⁵

Broderick agrees. She claims that the best networking experience she ever received was when her independent living coordinator gave her the chance to attend Destination Future 2001: National Youth Leadership Conference.²⁷⁶ Destination Future is an annual conference administered by the University of Oklahoma's National Resource Center for Youth Services.²⁷⁷ The goals of the conference are to increase youth civic engagement and develop their leadership skills, and to "provide a mechanism for youth in care or recently emancipated from care to inform service providers and policymakers on the issues that impact children and youth in out-of-home care."²⁷⁸ Broderick says that the conference enabled her to connect with other foster youth with disabilities and come to understand that others were in situations similar to hers. She also says that the selfadvocacy skills she learned at the conference were absolutely essential to her growth and entrance into a healthy adulthood, adding that the workshops she attended taught her to transform her curiosity and frustrations into a positive outlet-by becoming a leader in the foster care community.²⁷⁹ Broderick believes that more of these networking and empowerment opportunities should be provided to youth with disabilities aging out of foster care.²⁸⁰

Fortunately, there are now more national networking organizations than ever before for youth with disabilities and youth who are in or alumni of the foster care system, mostly thanks to the World Wide Web. Two national foster care networking groups are Foster Club²⁸¹ and Foster Care Alumni of America. ²⁸² The National Council on Independent Living²⁸³ and the National Youth Leadership Network²⁸⁴ also help many youth and adults with disabilities connect with one another. Support organizations like these provide the essential, although often overlooked, service of networking and facilitating connections among people in similar circumstances.

More should be done to ensure *access* to appropriate transition services for youth with disabilities in the foster care system.

As noted above, individualized, comprehensive, and appropriate transition services that meet all of the needs of the youth who require them are essential. However, *access* to these essential services is often the largest challenge for youth with disabilities involved

in the child welfare system. Many services are truly accessible only to young people who are readily able to seek them out on their own. This is most unfortunate, because youth with disabilities aging out of foster care are often already disconnected from society and therefore not capable of seeking out these services. Young people with disabilities who are transitioning from group homes or other residential programs are even less likely to be able to seek out the unique services they may need, because many such youth are disconnected from their community's resources as a result of their institutional settings.

A systems-level example of the lack of specific outreach to foster youth is the college application process. Federal financial aid forms do not specifically ask applicants if they are in foster care, thereby making it almost impossible for colleges to link foster youth with aid for which they may be eligible.²⁸⁵ (However, many *states* have financial aid programs specifically tailored to foster youth, some of which even completely waive tuition costs.²⁸⁶) Additionally, valuable federal programs such as TRIO and GEAR UP, which assist low-income and first-generation college students, "do not effectively reach out to foster youth or take into account their unique circumstances."²⁸⁷

Another barrier to accessing services exists particularly for foster youth who are identified by the child welfare system as not being eligible for transitional services owing to the (sometimes perceived) severity of their disability. An example is transitional housing programs to which only more "stable" youth may apply. For example, one county-run California transitional housing program's eligibility requirements state that only (18- to 20-year-old) "youth who have demonstrated an ability to live independently" and "who have a legal source of income and/or are working full/part time" may apply for the program.²⁸⁸ Not only is this first requirement extremely subjective, but both requirements end up disqualifying the transitioning foster youth who need services like these the most. To make matters worse, programs like this one often have very long waiting lists, and the youth applicants often do not have access to temporary housing during the waiting time.²⁸⁹ In fact, few model housing programs will seek out and provide appropriate services for the most difficult-to-serve youth, often considered to be

those with mental and emotional disabilities. It is no surprise, therefore, that individuals with these types of disabilities are more likely to experience long-term homelessness.²⁹⁰

This access issue is especially prevalent for foster youth residing in group homes and other institutions (where many youth with disabilities are placed). A special education teacher in the SDUSD who teaches foster youth with disabilities asserts that there is usually an unintended cutoff of services after youth living in group homes age out of care because eligibility requirements give preference to more "connected youth" who have the adult supports available to help them navigate complex systems.²⁹¹ This teacher said that in theory, institutionalized youth should be more connected to accessing services than the average foster youth, as they live with youth workers who are specifically trained to care for them, but in reality, transitions are often extremely abrupt for these youth, because they are linked to supports that often end abruptly when the young person leaves the group home on his or her 18th birthday. "Eighteen years old—payment stops—meaningful adult attention stops. End of story," the official stated.²⁹² He adds that "this shows, rather starkly, how being connected to a 'system' is no match for being connected to other people and/or family."²⁹³

On a personal note, regarding eligibility of services, Samantha Jo Broderick, who transitioned out of the New Jersey child welfare system in 2002, claims that she was denied access to many independent living services while a teenager.²⁹⁴ She believes that she was considered not "stable" enough to ever be able to live on her own because of her bipolar disorder diagnosis. She says she was essentially offered no choice other than a lifetime of institutionalization, despite her assertion that she was mentally and emotionally capable of independent living.²⁹⁵ Broderick's point also brings to light the importance of access to Court Appointed Special Advocates (CASAs) and other advocates for youth with disabilities when they transition out of the foster care system.

Many who study and work in foster care, as well as some foster care alumni themselves, believe that the barriers to accessing services for youth with disabilities transitioning out of foster care can sometimes be attributed to the lack of sufficient training for child welfare workers on the specific needs of these youth. Tom Wolanin of

the Institute for Higher Education Policy reports in *Higher Education Opportunities for Foster Youth* that this may be partially a result of the child welfare system (and therefore its workers) considering preparing foster youth for independent living "something of an anomaly," as,

The dominant thrust of their efforts is to arrange for foster youth to have a permanent place where they will be safe.... The independence program runs against the grain by requiring that foster youth be equipped to care for themselves rather than being placed where others will care for them.²⁹⁶

Whether this reflection is indeed accurate, many believe more efforts should be placed on specifically training more caseworkers on the particular nuances of the transition period. This training should include legal rights and benefits for foster youth with and without disabilities, service and program cutoff dates, the psychological and physical needs of these youth, and knowledge about where these youth can go to access the services they need. One foster care alumna, Melinda Foy, expressed her opinions on this now that she is a foster care worker in Michigan:

As a current foster care worker, I see many problems with our system. Even though we have more services now [than when I was a foster youth in the 1980s], workers are not properly trained for children aging out. I regularly see teenagers in the following situation: Girl, age 18, with a baby; placement is in a foster home. The 18-year-old has no driver's license, no housing, no employment, no education, and no means of income. And the youth workers have no idea what to do with a youth like this, because they are not properly trained. Most workers are not experienced in how to transition children out of the system... Workers and agencies need to understand that teenagers are much more time-consuming. If they are wards of the state, the caseworker is essentially their parent.²⁹⁷

She adds that most of Michigan's foster youth with disabilities who are prevented from becoming independent by the state are "just simply transitioned into the community mental health agencies or adult foster care" instead of being given the help they need to gain self-sufficiency.²⁹⁸ Because these complex systems are so difficult to understand, and because staff turnover is so high, she said the staff never receives the appropriate

amount of training to work well with the youth in these systems. As a solution, Foy says, "I would like to see some workers in each county specializing in children aging out." She believes that every agency should invest in hiring a few caseworkers who specifically work with youth ages 16 and older and who specialize in independent living skills. They should also be trained on disability issues for these youth. Foy says that not only has she used the life skills that she has acquired through trainings and conferences for her own benefit, but she has also been able to "empower" the foster youth she now oversees by sharing the information with them:²⁹⁹

When I saw the need in my county, I started an IL [independent living] group for my caseload. The group meets monthly to track IL progress on such things as obtaining driver's training, Social Security cards, birth certificates, etc. We also explore all options of education and much more. Youth who participate in these support groups are empowered to succeed.³⁰⁰

To fully invest in both access to and the provision of transition services for youth with disabilities in foster care, a state must commit to this investment head-on and devote the necessary resources to make serving all of these youth a reality. As noted earlier, this is a challenge for most states, which usually do not receive enough CFCIP and ETV funds to help all youth. Nonetheless, a few states are overcoming the hurdles and leading the way. Most important, these states began with an acknowledgment and understanding of the unique issues facing these youth. One of these examples is North Carolina, which runs NC LINKS, a statewide foster care independence program. The goal of NC LINKS is

[t]o build a network of relevant services with youth so that they will have ongoing connections with family, friends, mentors, the community, employment, education, financial assistance, skills training, and other resources to facilitate the transition to adulthood.³⁰¹

CFCIP mandates that all foster youth between ages 16 and 18 be provided transition services, so NC LINKS provides these services, but North Carolina's counties are also urged to serve 13- to 15-year-olds, as well as 18- to 21-year-olds.³⁰² NC LINKS is devoted to seeking out those youth who need services most. Additionally, a "positive

youth development" approach is used for service delivery, which means that county agencies encourage each young person's active participation in the decision-making process for their individual service plans.³⁰³ NC LINKS is an outcomes-based program, which is unique; it has identified seven outcomes around its goals that the Federal Government uses to measure its success.³⁰⁴ North Carolina allocates \$2.1 million of federal and state CFCIP monies to finance the NC LINKS program provided by each county.³⁰⁵ The state sets aside an additional \$400,000 to reimburse counties for additional services; this extra, more flexible funding ensures that all of the services needed to help youth exiting care can be provided.³⁰⁶ This includes services provided for those youth with disabilities. Many other states should follow North Carolina's lead in providing comprehensive services for a broader age range of foster youth in order to better ensure the futures of more youth in need.

It is clear that removing the barriers and systemic challenges to accessing transitional services would greatly enhance the ability of youth with disabilities aging out of foster care to obtain these services. Addressing these challenges includes removing the unrealistic requirement that many programs have for youth to seek out the services themselves, and investing in the extra efforts needed to bring the services to those who need them. Only then will it be possible to reach those who most need the supports.

Youth should be eligible for needed transition services beyond age 21.

An additional access issue pertains to age eligibility requirements for the transition services that are available. Right now, the CFCIP program requires states to use a portion of their funds for services for former foster youth ages 18 to 21, and states may even spend up to 30 percent of their funding on housing assistance for these youth.³⁰⁷ This is a very positive step toward providing transitional services to youth who have aged out of the system. Still, some youth development experts believe that these services should be extended to youth past the age of 21, perhaps to 23 or 24, as many young people, such as youth with disabilities and English-language learners, still need these services at older ages.³⁰⁸ While high-quality independent living services programs

help most youth become independent, healthy, productive adults by age 21, the need to continue these services for youth beyond age 21 should be recognized.

Some states are already leading the way in these efforts, such as California, which recently implemented the Transitional Housing Program for Foster/Probation Youth (THP-Plus). THP-Plus is a transitional housing placement opportunity for emancipated foster youth, ages 18 to 24, who have emancipated the child welfare system. The goal of THP-Plus is to provide a "safe living environment" while helping youth achieve self-sufficiency so that they can learn life skills upon leaving the foster care system. Counties in California electing to participate in the program must provide supervised independent living housing and support services.³⁰⁹

Connecticut runs an independent living program through the Department of Children and Families, Adolescent Services, in which youth up to age 24 are eligible to receive aftercare services. Aftercare services include access to alumni groups/workshops, referrals to housing, employment, counseling, and education, and access to a directory of community resources.³¹⁰

It is ideal for all youth to receive all of the transition and independent living supports they need by the age of 21 and be able to live healthy, economically sufficient lives by that age. However, this ideal is not often the reality for those youth in particularly challenging life situations, such as youth with disabilities leaving foster care. These youth often need ongoing supports for longer periods to be able to thrive. For this reason, both the child welfare and vocational rehabilitation systems should make the necessary services available up to age 24 for those who need them.

Summary of Policy Recommendations

- 1. Cross-systems collaboration on the provision of transitional services is essential.
 - a. The IEP transition planning process and the Chafee Foster Care Independence Program process must be better aligned to help youth with

disabilities in foster care transition to adulthood and achieve selfsufficiency.

- b. Juvenile and adult systems should increase collaboration efforts to streamline transitions for youth with disabilities aging out of foster care.
- c. Community organizations and the business sector should play stronger roles in providing transition services.
- Transition services for youth with disabilities in foster care should be comprehensive and individualized and offer a full range of appropriate services.
 - a. Transition services should include exposure to the independent living philosophy, hands-on life skills opportunities, and networking opportunities.
- 3. More should be done to ensure *access* to appropriate transition services for youth with disabilities in the foster care system.
 - a. Colleges and other postsecondary learning institutions should better reach out to youth with disabilities.
 - b. Transition plans must take into account access to housing for both youth with disabilities and foster youth.
 - c. Institutionalized youth with disabilities in foster care are at great risk of being disconnected from society's networks and should therefore be provided access to even more connecting services.
- 4. Youth should be eligible for needed transition services beyond age 21.
 - a. State child welfare agencies should make transition services available for youth with disabilities up to age 23 or 24 when deemed appropriate.

Chapter 3.4: Coordination, Collaboration, and Accountability Across Systems

We need to address the compartmentalization of the government entities responsible for foster children. At present, there is no one state agency with authority for children in foster care. The disjointed governmental 'parenting' of foster youth creates a failure to share information and a lack of coordinated decision-making.

This 2005 quote³¹¹ by a former member of the Pew Commission on Children in Foster Care speaks to the serious need for cross-systems collaboration to better hold all stakeholders accountable for America's foster youth. Many think that these collaborative efforts must start with an endorsement from the Federal Government in order for the states to be able to first envision and then operationalize such a considerable task. Legislation such as the Federal Youth Coordination Act (FYCA) (P.L. 109-365), passed in 2006, as well as other programs, can help the Federal Government to facilitate the implementation of such endeavors. But coordination is needed at the local agency, school, and program levels as well in order for this vision of multilevel, multisystem accountability to become a reality.

The following recommendations pertain to the serious need for coordination, collaboration, and accountability structures across the myriad systems that impact youth with disabilities in foster care. Specifically, the recommendations speak to the need for a strengthened federal oversight role, strategic systems collaborations, and stronger federal- and state-level leadership and accountability structures. They also advocate for a cross-systems streamlined youth development approach, better cross-training for the adults who work with these young people, and enhanced and coordinated efforts in identifying abuse and disabilities quickly so that services can be provided in a timely manner.

A strengthened federal oversight role is necessary for an effective collaboration and accountability among youth-serving entities.

The primary purposes of FYCA are to create a federal coordinating body to facilitate interagency coordination and collaboration and to support state-level coordination efforts. It was created by the White House Task Force for Disadvantaged Youth, which was charged with developing recommendations to strengthen the federal response to the needs of children and youth, with a focus on coordination and accountability.³¹² FYCA establishes a Federal Youth Development Council (FYDC). If this FYDC were to be implemented, its membership would be made up of 11 federal department secretaries and heads of agencies; representatives from youth-serving nonprofits, foundations, and faith-based organizations; and various youth.³¹³ The FYDC's agency heads and department secretaries can and should be the states' points of contact at the federal level for technical assistance and oversight issues regarding the creation of strategic state-level agency collaborations. Although FYCA has not yet been funded, efforts are being made in Congress to appropriate \$1 million to the Act in 2008.³¹⁴

Despite the lack of funding for FYCA, there are federal and state efforts to increase cross-systems collaboration. One important piece of progress was the tripling of the Court Improvement Program's (CIP) authorized funding in 2005 from \$10 million to \$30 million.³¹⁵ This program was originally authorized in 1993 through what is now referred to as the Promoting Safe and Stable Families (PSSF) program and expanded in 2001.³¹⁶ It provides grants to the highest court in each state (plus the District of Columbia and Puerto Rico) to test new approaches to improving juvenile and family court performance. These grants allow the court systems to assess their foster care and adoption laws and judicial processes and to develop and implement plans for system improvement. Some typical CIP activities are the development of mediation programs, creation of linked agency-court data systems, implementation of "one judge/one family" models, and improvement of representation for children and families.³¹⁷

The tripling of CIP's funding in 2005 was due to the addition of two new grants (at \$10 million each) to the program.³¹⁸ One of these grants provides funds to courts for data collection and analysis, with the goal of strengthening the court's role in ensuring safety and well-being for youth in the foster care system. The other grant provides funding for the cross-training of legal, judicial, and child welfare agency staff at the same time.³¹⁹ These new grants are discussed in more detail in other sections of this report. What is most important about all three of these CIP grants is their strengthened requirement for cross-systems collaboration between child welfare and the juvenile courts at a minimum, but also among other systems when desired by the states.

It may be too early to tell if these new grants and their emphasis on collaboration are truly helping more foster youth achieve safety, permanency, and well-being, as their implementation did not begin until 2006. However, an extremely promising step was taken in April 2006, when, in a rare yet outstanding move, representatives from 49 of the states' highest courts and child welfare agencies met to develop action plans to improve outcomes for their foster youth.³²⁰ Additionally, some states have already begun implementing statewide interagency task forces and commissions to tackle their action plans.³²¹

With this type of help and endorsement from the Federal Government, states are more empowered to enforce collaborations across agencies and departments such as child welfare, education, dependency courts, labor, health, and juvenile justice in an effort to streamline and improve services to vulnerable youth. Without this federal endorsement, few incentives would exist to encourage this type of endeavor, which takes immense effort, not to mention a strong willingness to put the efforts of the collaborative before the individual needs of each department involved.

Collaborations at the state level, such as those mandated under the CIP, should lead the way to the development of *local* interagency workgroups, each of which could work both independently and collectively to focus on different uniquely challenged groups of youth. These local workgroups would be accountable to the state commissions and work to inform them about specific issues facing the vulnerable youth in their communities. Youth with disabilities in and out of the foster care system are examples of these types of unique, underserved groups. Workgroups that focus on such populations would ideally include representation from the state agencies and departments mentioned above, but would also include the parents and youth involved in these systems. This representation would ensure that those who are most knowledgeable about certain issues could share this information with other departments, thereby enhancing their knowledge base exponentially and better enabling them to work collaboratively.

Samantha Jo Broderick, an alumna of the New Jersey foster care system, is currently working in that state's Department for Children and Families. Regarding the impact that high-quality systems collaboration has on youth, she said, "I would ideally see the barriers come down between child welfare, mental health, juvenile justice, substance abuse, and special education, so that funds could creatively support multisystem, [otherwise referred to as] 'deep end,' kids."³²²

For the Federal Government to best perform its oversight role in facilitating the coordination, collaboration, and accountability efforts at the state level, some key practices must be instituted. These more specific recommendations follow.

Strategic state and local level coordination and collaboration efforts must be considered a priority.

Collaboration, especially at high levels, is difficult. Therefore, it should be managed strategically, with much thought to which systems collaborations would yield the most beneficial results. Some experts in the foster care field believe that the "hub" of collaboration should be the highest state dependency court system, but that this system should work very closely with the state executive offices.³²³ One of the primary tasks of the Adoption and Safe Families Act of 1997 (ASFA) is to increase the accountability of the child welfare system, which inherently promotes more collaboration of the dependency courts with the child welfare system. The goals of this collaboration are to promote timely permanency for foster youth and to ensure the safety and well-being of

abused and neglected children and youth.³²⁴ While this act has greatly streamlined collaborations between the dependency courts and child welfare, in order to truly reach the act's goals, both the courts and the child welfare agencies have to rely on the cooperation of other systems, such as the health and mental health systems, juvenile justice (when necessary), and the education system (specifically, the child's school).

Some of these cross-systems collaborations are easier than others. The juvenile justice and dependency courts naturally tend to collaborate with one another most often, especially in counties where both dependency and delinquency courts are administered by the same court system, such as Pima County, Arizona.³²⁵ Not all counties and states use this administrative approach, but "others should definitely follow suit," because it eases this necessary collaboration, commented a trial judge in Division 13 of the Arizona Superior Court in Pima County.³²⁶ Of course, this model does not work for all states. Another promising model that both New York and California are using is to have an office of children within the state court system.³²⁷

The dependency courts are required to collaborate with both the health and mental health systems. This interaction, which is facilitated through child welfare, enables the courts to obtain crucial medical information about the children for whom they must work to provide suitable placement and services. But these systems do not necessarily collaborate in a streamlined manner. When the collaboration is working well, Child Protective Services (CPS) alerts the appropriate agencies that a child has been removed from the home, and the child receives mental and physical assessments in a timely manner, usually within *24 to 72 hours of the removal*. The purpose of these assessments is to determine what services the young person needs, such as special education services, mobility equipment, or mental health counseling. Assessments also help determine which type of placement (e.g., kinship care, group home) is most appropriate. When assessments are done on time and the voices of all critical partners and stakeholders, including the youth and their families, are heard, the first hearing can be held a few days after a child's removal from the home. Ideally, the judge has all the

information necessary by the time of this hearing and is therefore able to make an educated decision on behalf of the young person at that time.

But when this collaboration is *not* working well, collaboration between CPS and the health and mental health systems is usually not streamlined and the health assessments may not happen in a timely manner. In this situation, the judge may lack the appropriate information to make knowledgeable decisions on behalf of the youth at the first hearing. This can leave the young person in a state of uncertainty for weeks or even months, with little access to needed services. This situation especially negatively affects dependent youth with disabilities. The timely assessments of these young people's mental and physical health, coupled with the rendering of services to address their needs in these areas, are often crucial to their livelihood. This breakdown of collaboration between child welfare and the health systems is largely a result of lack of capacity for large caseloads at child welfare agencies, which are notoriously underfunded, but it can also result from a dearth of system accountability. An official in the Juvenile and Family Law Department of National Council on Juvenile and Family Court Judges (NCJFCJ) recommends that the Federal Government work through legislation to better align the mandated timelines for the dependency courts, child welfare, and the health and mental health systems, so that ASFA can reach its intended goals.328

As noted earlier, the CIP grants help states reach these goals and should therefore be supported by the U.S. Department of Health and Human Services. A promising way in which some states are choosing to operationalize their CIPs is through the Model Dependency Courts Initiative, whose funding is earmarked through Congress to NCJFCJ through the Office of Juvenile Justice and Delinquency Prevention.³²⁹ This project is currently being administered in 21 states and the District of Columbia. Through it, NCJFCJ provides training and technical assistance "to improve the courts' handling of child abuse and neglect cases to ensure more timely decision-making in permanency planning."³³⁰ According to the official at NCJFCJ, a key component of these improvement plans is to foster cross-systems collaboration.³³¹ In 1997, Pima

County in Arizona became a Model Court implementation site.³³² Since then, many positive changes have occurred in the system. Before the implementation, it took dependent children an average of 3.2 years to move through the court system; with the Model Court program, the average is now 1.6 years.³³³ Before Model Court, the first meaningful hearing for the dependent youth did not occur until 90 days after filing a dependency petition—now, a Preliminary Protective Hearing is held between five and seven days after a youth is removed from the home.³³⁴ Thanks to Pima County's success, according to the Pima County trial judge, the Model Court process has been made the standard for dependency cases in every Arizona county.³³⁵ This official believes that efforts such as the Model Court program are best practices that the Federal Government should continue to fund.³³⁶

An important role of the dependency court system is to determine how a child or adolescent's well-being will be ensured—and education is a large part of a child's wellbeing. Disabilities and other characteristics that have an impact on decisions regarding education services are identified during the health and mental health assessments. From these assessments, a team (usually involving caseworkers, attorneys representing parents and child, mental health specialists, and education liaisons) determines what education services are needed and where the child can best access them. A high-quality assessment of necessary services is best facilitated when schools collaborate with the courts by submitting school records to them, sitting at the table to discuss what the child needs, and willingly helping to provide the necessary services. However, according to the official at NCJFCJ, this collaboration is tricky, because "the education community and its individual schools are relatively autonomous, so getting key decision-makers to sit at the table with juvenile and family courts to address policy issues is a major challenge."³³⁷ But as the chief executive officer for Casey Family Programs asserted at a Capitol Hill briefing on educating foster youth, "The child welfare and education systems must work together and do what they have to do to help foster youth."³³⁸ The onus is on both of these systems to ensure that appropriate education services are provided for foster youth, but the courts can play a larger role by taking advantage of the tools that have been created (most notably, by NCJFCJ and Casey

Family Programs) to help judges understand the questions they should be asking about a youth's education plan.³³⁹

Another barrier to collaboration with education on behalf of serving youth with disabilities in the foster care system involves the delinquency courts. Abused or neglected youth are more likely than nonabused and nonneglected youth to be arrested as juveniles, at 27 percent versus 17 percent, respectively.³⁴⁰ Additionally, the National Center for Mental Health and Juvenile Justice asserts that "the prevalence of mental disorder among youth in the juvenile justice system is two to three times higher than among youth in the general population."³⁴¹ As evidenced by these statistics, a large number of young people with disabilities in the foster care system are also coming into contact with the juvenile justice system. Indeed, some advocates regard the juvenile justice system as the "dumping ground" for troubled youth, many of whom have emotional disturbances, developmental delays, and learning disabilities, and who teachers consider too difficult to manage.³⁴² Some of these youth are also foster youth. Two major policies may be exacerbating the problem of "dumping" youth into the juvenile justice system when they are believed to be "acting out." One is the No Child Left Behind Act (NCLB); the other is "zero tolerance" policies, which many school districts around the United States have adopted.

Some believe that the stringent guidelines of NCLB, which place sanctions on schools whose subgroups of students (broken down by race, disability status, and English proficiency level, among other groups) do not make "adequate yearly progress" (AYP), are creating a "culture of exclusion" in the public schools.³⁴³ They say that the law's high-stakes testing provision ends up benefiting schools that push out students who are not high achievers so that they will not bring down the school's achievement levels.³⁴⁴ Students who are excluded are disproportionately those with mental and emotional disabilities³⁴⁵—some of whom are foster youth. These youth are at high risk of being removed from school, often by the police, and transferred to the juvenile justice system. Foster youth are more apt to end up in the justice system, according to the NCJFCJ official, as they usually have no caretakers to make placement decisions on their

behalf.³⁴⁶ "Identified as 'troublemakers,' these kids are even more difficult to get back into school once they are out," she added.³⁴⁷ According to her, this is especially true for older adolescents.

Often these youth are not welcomed back because of the schools' zero tolerance policies. "Zero tolerance" refers to a policy that enables schools to punish students harshly after any type of first infraction—frequently by means of expulsion. It was originally introduced as a response to students bringing guns to school, but the policy can be used however a school sees fit; there are no legal guidelines that must be followed. Many individuals and organizations think that zero tolerance policies not only fail to reduce bad behaviors, but that they actually harm students by expelling and punishing them instead of working to deal with the real causes of the negative behavior. According to an American Bar Association (ABA) juvenile justice policy brief,

Zero tolerance has become a one-size-fits-all solution to all the problems that schools confront. It has redefined students as criminals, with unfortunate consequences... Zero tolerance is theoretically directed at students who misbehave intentionally, yet it also applies to those who misbehave as a result of emotional problems, or other disabilities, or who merely forget what is in their pocket after legitimate nonschool activities.³⁴⁸

Disability rights and advocacy groups, including the National Council on Disability, agree with ABA's stance and add that the policy most negatively affects students with disabilities by pushing more of them into the juvenile justice system.³⁴⁹

This "culture of exclusion" consequence is more likely to be diminished when the education, juvenile justice, and dependency court systems work to educate each other and then develop a streamlined process for managing these youth that puts the youths' best interests at the forefront.

Other important collaborations between the juvenile and adult systems and the community as a whole must occur to improve the lives of youth with disabilities in the foster care system. These collaborations include linking efforts between the child

welfare system, independent living centers, IEP transition plans, and labor systems to ensure a streamlined effort toward connecting youth to the adult world upon their exit from juvenile systems of care. They also include a conscious effort to integrate these youth into the communities in which they live, as many youth with disabilities are not fully provided the necessary integration services and opportunities.

Large percentages of both foster youth and youth with disabilities enter adulthood unemployed and without the skills they need to acquire gainful employment.³⁵⁰ The Federal Government has been attempting various methods of addressing this important problem. A recent attempt is a series of demonstration projects initiated by the U.S. Department of Labor's Employment and Training Administration (ETA). In 2004, ETA awarded grants to five states (California, Illinois, Michigan, New York, and Texas) to implement programs to improve educational, employment, and self-sufficiency outcomes for youth transitioning out of foster care.³⁵¹ A major piece of these projects involved collaborations between child welfare agencies and community organizations and businesses. An ongoing evaluation of the program has already shown that "frequent and structured opportunities for ongoing communication among lead agencies, community partners, and youth are critical to creating an effective program."352 While it is too early to tell if these projects will truly have a positive impact on foster youth's self-sufficiency, these types of collaboration-centered investments are crucial for building cross-systems competencies, which will should result in enhancing these young people's lives.

Taking the success of these demonstration projects into consideration, another promising way to enhance state-level collaboration of the systems that interact with youth with disabilities in foster care entails involving state-level boards such as the Workforce Investment Act's (WIA) Workforce Investment Boards (WIBs). WIA requires state WIBs to include the governor, two members of each chamber of the state legislature, elected officials, and representatives appointed by the governor from the business sector, labor organizations, state agency heads, as well as "individuals with experience in delivering programs and youth services."³⁵³ At the local level, WIBs

usually include representatives from local business, education providers, labor organizations, community-based organizations (including those serving individuals with disabilities and veterans), economic development agencies, and "One-Stop" program partners.³⁵⁴ To promote more comprehensive collaborations at the state level, however, agencies that are not usually involved with the WIBs, such as the state child welfare agencies and dependency courts, should participate. This way, the views of the child welfare sector regarding workforce issues for young adults would be taken into consideration at the state level.

It is imperative to designate a systems-level leader of these coordination efforts, and then to create an accountability system that supports the leadership.

Cross-systems collaboration benefits not only the agencies, organizations, and departments that work on behalf of youth with disabilities in foster care, but also the youth themselves, which of course is the end goal. But collaboration cannot be maintained without a system of accountability in place to ground it.

Accountability systems must always be headed by a leading body that is well connected to all of the systems around it. In the case of coordinating systems that interact with youth with disabilities in foster care, some experts see the natural systems-level leader of these efforts as the dependency courts—and more specifically, the highest state court, often the state's supreme court.³⁵⁵ "When the courts act as leaders, systems improve," asserted a trial judge in the Arizona Superior Court in Pima County.³⁵⁶ From her viewpoint, judges are in the unique position of being able to "rise up above the fray" and see the broad picture of what needs to happen to make things better for the dependent youth. Judges are also in a position to use federal law—in the form of ASFA—to help them work more collaboratively with the child welfare system, she noted.³⁵⁷ But as mentioned previously, this leadership should be jointly managed with executive office to make this leadership even stronger.

It is this Arizona judge's opinion that to complete the accountability structure, the courts must have, in addition to their jurisdiction over the child welfare system, similar control over the health and mental health systems.³⁵⁸ Historically, dependency court judges have not had leverage over these systems.³⁵⁹ Aligning this accountability through federal law would further ensure that foster youth, and especially those with disabilities, receive the services they need in the timeliest manner possible. This official stipulated that judges are indeed responsible for child well-being, despite not being direct service providers, and that they can demonstrate their responsibility by using their authority to ensure that "the agencies that *are* [directly] responsible for child well-being fulfill that responsibility."³⁶⁰ However, she added that no system can or should be solely responsible for ensuring the well-being of foster youth; every system must do its part.³⁶¹ This point of view further illustrates the importance of joint leadership with the executive office in order to strengthen the role of the courts in ensuring child well-being.

Another way the Federal Government can enhance the accountability of these crosssystems collaborations is by improving the data systems in place to better monitor child welfare systems and the youth outcomes they produce. These data systems include the Child and Family Services Reviews (CFSRs), the Adoption and Foster Care Analysis and Reporting System, and the State Automated Child Welfare Information Systems. The CFSRs in particular are and should continue to be used as a vehicle for ensuring accountability. The purpose of this system is to ensure that the child welfare agencies and courts are working to enhance the safety, permanency, and well-being of foster youth.³⁶² The new data-focused CIP grants³⁶³ can help strengthen all of these data systems and should therefore continue to be supported and monitored by the Federal Government. All of these data systems are discussed in more detail in Chapter 3.5.

Developing a common and streamlined youth development approach across all systems and programs will enable policymakers and service providers to improve outcomes for all youth.

Although coordinating services across systems is extremely important, the *approach* taken by these systems is just as important to improving the outcomes for youth with disabilities in the foster care system. Multiple systems work to improve outcomes for youth in different arenas. Because the goals of these systems vary, their approaches and processes naturally vary as well. However, the varying processes often create a barrier to cross-systems collaboration. This report argues, however, that *all* systems and programs are capable of instilling the "youth development" approach into their curricula, independent of individual program purpose. These systems and programs, foster parent trainings, institutions where youth may reside, incarcerated youth programs, and many more. This report further argues that infusing the youth development approach into multiple systems and programs would better facilitate cross-systems collaboration.

The youth development approach is a comprehensive, promising method that is broadly used by youth-serving programs to improve developmental and social outcomes for a wide variety of young people, including those with disabilities.³⁶⁴ Ideally, this approach would have an increased chance of effecting positive change on a broader level if it were infused into every system and program that comes in contact with youth. However, *truly* comprehensive youth development systems that reach across multiple systems and sectors are challenging to accomplish and therefore almost never exist in their entirety in a community.

Despite the challenges, many organizations have created "frameworks" that can help to incorporate the youth development approach into and across programs and systems. The National Collaborative on Workforce and Disability for Youth (NCWD/Youth), an interagency workgroup, has developed "Guideposts for Success" to help families,

institutions, and the youth themselves through the transition to adulthood. These "Guideposts" make specific recommendations about what types of youth development services and activities all youth need, what youth with disabilities may need, what foster youth may need, and even what youth in foster care with disabilities may specifically need.³⁶⁵ For example, services and activities that these latter youth in particular may need include being "engaged in creating, modifying, and integrating their Individualized Education Program, Transition Plan, Independent Living Plan, Individualized Plan for Employment, and/or other [school-based] individualized planning tools." The services also include enabling youth with disabilities in foster care to learn "how to access and make connections to and between the child welfare system and various disability programs and services."³⁶⁶

NCWD/Youth has also put forth recommendations for the "Five Areas of Youth Development"—working, learning, thriving, connecting, and leading.³⁶⁷ According to NCWD/Youth, *all* youth thrive when all five of these areas are incorporated into the programming of youth-serving entities, especially if the involvement of youth with disabilities is facilitated with *conscious* consideration (by addressing access issues, hiring willing and knowledgeable staff, and partnering with other disability organizations to stay in tune with these young people's needs).³⁶⁸

New Ways to Work is another organization that has set up a framework to incorporate the youth development approach. Its framework, entitled "All Youth – One System," differs slightly in that the four content "elements" of a comprehensive youth-serving system—Academic Achievement, Career Preparation, Community Services and Supports, and Youth Leadership—are supported by a fifth element: a Comprehensive Youth Development Approach.³⁶⁹ New Ways to Work recently updated its "All Youth – One System" framework to consider the needs of both foster youth and youth with disabilities. Like many other approaches, the framework requires cross-systems collaboration to serve youth in a comprehensive manner. It demonstrates once again that ensuring self-sufficiency for all youth, including foster youth and youth with disabilities, is everyone's job.

Although rare, positive examples of communities infusing the youth development approach across many different systems do exist. The Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs funds the development of Healthy & Ready to Work state model programs, which focus on the healthy transitions of children and youth with special health care needs.³⁷⁰ These programs use a youth development framework to reach their goals of healthy community integration and employment for youth with disabilities.³⁷¹ Several states have received demonstration grants for these projects in recent years. One example is Maine's Adolescent Training Partnership. This program's goal was to use collaborations between several different partners (such as juvenile and adult education, labor/workforce development, health care, independent living centers, and parent organizations) to promote successful transitions of youth into adulthood and employment. The program's 2001 evaluation showed that it enhanced the well-being of these youth.³⁷² Opportunities like these should be nationally supported and made available to all states and local communities.

Youth workers should be trained across fields to better understand and provide for the diverse needs of youth with disabilities in foster care.

This recommendation asserts that when communities (and states) coordinate their systems by adopting the same approach to helping vulnerable youth, the improvement in cross-systems collaboration help provide all youth with the tools they need to thrive. This recommendation by nature necessitates the implementation of a more comprehensive training structure for all adults who work on behalf of youth.

Youth involved in multiple systems, such as youth with disabilities in foster care, often require complex services. Providing high-quality assistance to these youth calls for the expertise of youth workers who are knowledgeable about a range of issues, including mental health deficiencies, substance abuse, disabilities, and child abuse. They must understand the ins and outs of processes such as creating IEPs, accessing transitional housing, applying for Medicaid, understanding a dependent child's legal rights, and

navigating the juvenile justice system. While no one youth worker is expected to know everything about all these things, more could be done to raise the competency levels of the many types of adults who come in contact with multisystem youth, including teachers, caseworkers, mental health specialists, school counselors, and even employers. Of course, this approach also includes helping foster and adoptive parents to learn about disabilities, a topic that is discussed in Chapter 3.1.

For example, teachers should know the basics about how the foster care system works so that they are familiar with the general situation of foster youth when they have them in the classroom. This knowledge-sharing across the schools and child welfare agencies would help limit the confusion and frustration that teachers often feel when a child is called to appear in court in the middle of the school day. (Conversely, if caseworkers and dependency judges had a better understanding and appreciation of the fact that frequent school day interruptions have a damaging effect on the education of youth, they might be less inclined to schedule hearings between 8:00 a.m. and 2:00 p.m.) Teachers should also be provided with basic information about the causes and symptoms of disabilities, such as learning disabilities, developmental delays, and post-traumatic stress disorder (PTSD), the latter of which is extremely prevalent among foster youth.³⁷³ This basic knowledge can help educators identify disabilities early on and enable them to help the student access appropriate services. Some experts even believe that both disabilities and the foster care system should be taught as part of the curriculum for teaching degrees.³⁷⁴

Equally important is the need for child welfare workers such as caseworkers and CPS workers to understand and be able to correctly identify disabilities so they can work to help these youth in the best ways possible. According to a brief published by the Institute on Community Integration at the University of Minnesota, "Only 19 state child protection systems collect data related to disability in their state registries, and only seven require child protection workers to be trained in recognizing and entering disability data."³⁷⁵ The authors of this brief recommend the following:

While all child welfare workers need not become experts in disability services, they should know enough about disability issues to recognize when a child is in need of disability screening, and know who to collaborate with in the disability field."³⁷⁶

Tamara Connor, who has been a foster and adoptive parent for 18 years for multiple youth with disabilities, feels very strongly about caseworkers being trained on disability issues, the lack of which she sees as an enormous and perpetuating problem. She said,

Our typically developing children usually have a voice; those with disabilities often do not. They often have therapy available to them; those with disabilities often do not. And our social workers know how to interact with typically developing children—but they often don't have a clue how to support children with disabilities.³⁷⁷

Foster care alumna Samantha Jo Broderick added another point regarding educating caseworkers about disabilities—educating them on sensitivity issues.³⁷⁸ She argues that many foster youth are victims of being labeled by their caseworkers and other adults in their lives, which can have an extremely debilitating effect on how youth with disabilities in foster care see themselves. Broderick said that she herself was a victim of this type of labeling, and that the single most positive message she received from a caseworker was, "You're normal," which she never heard from anyone during her life in care until the age of 17, upon her fourth entry into an emergency shelter.³⁷⁹ As an adult, Broderick now understands that she had formed a picture of herself based on how all of the adults in her life—including group home, shelter, and other institution staff; several abusive caregivers; and caseworkers—had labeled her. (Broderick was diagnosed with bipolar disorder and depression when she was a teenager.)³⁸⁰ As a result of her personal experiences, Broderick advocates for teaching sensitivity issues to caseworkers, educators, and other adults who work directly with youth with disabilities in foster care.

The new CIP grants administered by the PSSF program that focus specifically on the cross-training of individuals working with multisystem youth are a hopeful new investment that should be supported to communicate the importance of an adequately trained workforce.³⁸¹

Systems must collaborate to ensure that abuse, neglect, and disabilities are identified more accurately and quickly, so that youth are connected with the services they need in a timely manner.

A point from above that is worth reiterating is the importance of identifying disabilities in children and youth as early as possible so that the systems that interact with youth can provide services and other supports in a timely manner. Foster youth often do not have advocates (like parents) in their lives to ensure that necessary supports are being provided at all times. The only way to ensure that foster youth receive the necessary support is through cross-systems communication.

Strong collaboration between the courts, child welfare, and the health and mental health systems is crucial to cross-systems communication. When medical assessments are accomplished as soon as a child or adolescent is removed from the home, the judge and the team (of experts and other stakeholders working on behalf of the child) are better able to make timely, educated decisions about the services that should be provided, such as mental health counseling, the creation (or alteration) of an IEP, or certain medications.

The issue of identifying disabilities accurately and quickly crops up often in the realm of education. As noted in Chapter 3.2, about one-third of all foster youth receive special education services.³⁸² But some experts believe that one-third is an underestimate of the true number of foster youth who need these services, because child welfare workers not trained to identify disabilities, know what type they are, and know what services are needed.³⁸³ On the other hand, other experts think that these youth are being either *over* identified or *mis* identified as needing special education services when they are merely having trouble adapting to a new school environment.³⁸⁴ These experts tend to agree that "disability" is label that professionals such as educators overuse when they do not know or are not inclined to find out what is really going wrong for the youth.³⁸⁵

A similar argument exists for diagnosing learning disabilities in children and youth. The Child Welfare League of America warns against misdiagnosing learning disabilities as other types of mental health issues:

Even though some three million school-age children are classified as having specific learning disabilities (LD), this category of special need is often widely misunderstood. Surveys of both parents and educators confirm that many people mistakenly link LD with mental retardation and disorders of mental health and believe that, left alone, children are likely to outgrow LD over time.³⁸⁶

The Learning Disabilities Association of America confirms that LDs cannot be cured or "fixed," and that they are often misidentified; however, the organization notes that people with LDs can achieve success in life, work, and school with the proper supports.³⁸⁷

An important issue pertaining to the identification and understanding of disabilities with abused youth pertains to ensuring that the caseworkers, child protective service workers, caregivers, and other adults working closely with the youth understand that young people with disabilities may have difficulty communicating their abuse to others. An official at the Chadwick Center for Children and Families in San Diego, an emergency shelter for abused and neglected children, comments that (especially young) children with emotional or developmental disabilities cannot always effectively communicate their trauma or abuse.³⁸⁸ An unfortunate consequence is that authorities do not always consider these youth to be reliable sources of information and therefore do not trust them to give accurate information. As a result of this lack of knowledge about the effects of mental and emotional disabilities on children's communication capabilities, adults may either become frustrated and give up on trying to obtain information, or not believe the young person's claims because of his or her disability status.³⁸⁹ Both of these responses can result in CPS finding cases to be unsubstantiated.

Foster care alumna Samantha Jo Broderick has personal experience with authorities not trusting her testimonials owing to her disability.³⁹⁰ She said that her claims of sexual

abuse by both foster family members and treatment facility staff were "ignored or determined to be unsubstantiated" by authorities because of her mental health diagnosis.³⁹¹ Broderick believes that these authorities considered her to be lying. She added that she was also strongly discouraged by authorities from reporting intrasystem abuse by way of verbal threats and physical attacks, causing her to recant out of fear.³⁹² Situations like these are more often avoided when CPS workers and other authorities have a better base of knowledge about the effects of abuse and varying disabilities on communication, trust, and other factors.

In conclusion, there are a multitude of reasons why cross-systems collaboration and accountability is a huge piece of improving the systems that most affect youth with disabilities in foster care. It is in the young people's best interest that systems work together to share information and streamline their processes so that the varying and often immense needs of these youth can be met in a timely and orderly manner. It is imperative that the Federal Government aid with this collaboration by helping to develop a sound accountability system across multiple agencies that is supported by high-quality leadership and accurate national data systems. These endorsements at the federal level would be both valuable and effective for reaching the goal of improving outcomes for youth with disabilities in the foster care system.

Summary of Policy Recommendations

- 1. A strengthened federal oversight role is necessary for effective collaboration and accountability among youth-serving entities.
 - a. The Federal Youth Coordination Act, which supports the Federal Youth Development Council, should be funded to provide stronger management over the laws that affect youth with disabilities in foster care.
 - b. Programs that encourage high-level collaboration, such as the Court Improvement Program, should continue to be supported at the federal level.

- 2. Strategic state and local level coordination and collaboration efforts must be considered a priority.
 - a. Timelines for assessing, placing, and providing services to youth with disabilities in foster care should be consistent and aligned across agencies and programs.
 - b. The dependency court and child welfare systems must collaborate with schools to ensure that youth with disabilities in foster care are not being disproportionately placed into the juvenile justice system.
 - c. Child welfare agencies and schools must collaborate with the workforce system to help youth with disabilities aging out of foster care access job skills and employment.
- 3. It is imperative to designate a systems-level leader of these coordination efforts, and then to create an accountability system that supports the leadership.
 - a. The dependency court system can and should act as a systems-level leader in the effort to better care for youth with disabilities in foster care.
 - b. An accountability system can be built on existing data and reporting systems such as the Child and Family Services Reviews.
- 4. Developing a common and streamlined youth development approach across all systems and programs will enable policymakers and service providers to improve outcomes for all youth.
- 5. Youth workers should be trained across fields to better understand and provide for the diverse needs of youth with disabilities in foster care.

- a. Teachers and other school personnel should be educated about the foster care system in order to better understand what is needed to work with foster youth.
- b. Child welfare and dependency court personnel should be educated about disabilities so that they are better able to meet the needs of these youth when they enter the child welfare system.
- 6. Systems must collaborate to ensure that abuse, neglect, and disabilities are more accurately and quickly identified, so that youth are connected with the services they need in a timely manner.

Chapter 3.5: Using and Sharing Data

Because youth with disabilities in foster care come into contact with many systems throughout their lives, more information is collected about them than about the average person. Most systems, such as child welfare, juvenile justice, education, and health and mental health, maintain files on the children, youth, and adults who pass through them. Even so, very little research is available on the experiences of youth with disabilities in the foster care system. While raw data on these youth frequently exists, the challenge is to make the data useful in ways that will inform policy and practice. One of the most basic challenges is identifying which children in a particular system are in foster care and which have disabilities. When it is feasible to identify these youth, another challenge is ensuring that this data is organized in a way that is useful to policymakers and other stakeholders.

In recent years, child welfare data systems have improved dramatically. In the 1990s, the Federal Government, through the U.S. Department of Health and Human Services (HHS), made resources available to states to develop Statewide Automated Child Welfare Information Systems (SACWIS). SACWIS is a case management system that caseworkers use to house information and run reports on the youth who come in contact with the child welfare system, including youth with disabilities in foster care.³⁹³ HHS requires states use SACWIS to submit data semiannually on children in foster care and those who have been adopted, for purposes of the Adoption and Foster Care Analysis and Reporting System (AFCARS).³⁹⁴ States also submit data on reports of abuse or neglect through the National Child Abuse and Neglect Data System (NCANDS).³⁹⁵ Another rich source of information about the child welfare system is the Child and Family Services Reviews (CFSRs). This review process, done by states together with HHS, is designed to collect information about how child welfare systems are functioning to serve families.³⁹⁶ Reports produced through this process draw on data from a variety of sources to consider a state's progress and compliance on several federal indicators. The CFSRs are useful to improving both the administration of the programs that serve youth in the child welfare system and the outcomes of the children and youth themselves, in terms of safety, permanency, and well-being.³⁹⁷

Other systems collect and house data as well. Similar to the child welfare data systems, these other systems are nuanced and are missing pertinent information. As mentioned in Chapter 3.2, the individualized education programs (IEPs) kept on students with disabilities in public education systems help track these youth in order to provide services and improve student outcomes, but neither NCLB's nor IDEA's reporting systems collect information on youth in foster care. Juvenile justice departments maintain files on the youth who go through them, but these systems may not consistently collect information on which youth are in foster care and which have disabilities. And of course, health and mental health records are maintained for youth with disabilities in foster care; however, with these records as well, youth in foster care might not be consistently identified.

Despite the numerous and ever-improving data systems in place, there are still many unknowns about youth with disabilities in the foster care system. For example, it is extremely difficult to assess which of a young person's disabilities are caused by abuse and which are intrinsic to his or her impairment. This unknown information is inherently hard to decipher but is further complicated by many (especially abused or traumatized) young people's inability to communicate, as well as by inadequate disability assessments that may result from untrained personnel or other complicating factors.³⁹⁸ Nonetheless, improvements can be made to various systems to enable them to uncover important information about these youth.

For information systems to truly act as tools for helping the youth with whom they come in contact, with an overall goal of improving services and youth outcomes, the following basic principles must be in effect:

Adequate funding to build capacity Identification, consistency, and accuracy Improvements in collected information Cross-systems data sharing

These principles are discussed below, with accompanying recommendations.

The Federal Government must continue to support the development and improvement of data systems and provide assistance to states for their use.

Data systems housing information on youth served by public service systems are generally supported by the Federal Government. SACWIS is an example of a federal data system that requires federal funding and support. HHS provides a 75 percent match per year to states during their planning, design, development, and/or installation of SACWIS, and a 50 percent match after the implementation for the operation of the system.³⁹⁹ Currently, most states are running operational SACWIS systems, many more are still developing and improving their systems, and a few are still using non-SACWIS models, meaning that not all states are currently using the SACWIS system but will likely be in the near future.⁴⁰⁰ This continued funding (currently at about \$2 billion, but rising as more states implement systems⁴⁰¹), coupled with technical assistance to state child welfare agencies, is absolutely necessary to help all states build and maintain the systems they need to house pertinent information about dependent children and youth.

AFCARS is another data system that warrants continued support at the federal (HHS) level. AFCARS compiles case-level information on all children and youth in foster care, as well as on youth who are adopted under the auspices of a state's child welfare agency. This includes demographics information and specific information about foster care system entry and exit dates and types of exits.⁴⁰² It is one of the reporting systems that is enabled by SACWIS. States are required to submit AFCARS data semiannually to the Administration for Children and Families at HHS.⁴⁰³ In 2003, the Child Welfare League of America (CWLA) responded to an HHS request for comments regarding the improvement of AFCARS; some recommendations included "an ongoing process for state input, flexibility to make changes to the system without legislative intervention, and improvements of data quality (the reliability, validity, relevance and appropriate application of the AFCARS data)."⁴⁰⁴ CWLA also noted the importance of funding to support these changes in order to avoid unfunded mandates.⁴⁰⁵ AFCARS is an

extremely important reporting system, because it provides a nationwide picture of the children and youth in foster care and those who have been adopted. Federal monetary investments in its improvements are investments in the overall effort to help these vulnerable youth succeed. Technical assistance and training can further help agency administrators input AFCARS information accurately and analyze the reports meaningfully. More recommendations pertaining to AFCARS follow.

In general, it is important that the Federal Government continue to invest in existing data systems so that states have the capacity to utilize them. Without federal support, this responsibility falls to the states, many of which are already cash-strapped and would not be able to keep a truly useful system afloat without assistance.

Reporting methods and definitions should be made consistent across programs and information systems.

As mentioned above, one of the barriers to assessing the situations of youth with disabilities in foster care is the fact that too much about this population is unclear. This barrier directly affects agencies' ability to provide necessary services to these young people. Because the child welfare system's current data systems do not enable agencies to gain a full understanding of this vulnerable, complex population, policymakers and other stakeholders cannot truly assess what is needed to help these youth, nor can they allocate appropriate funds to programs that can respond to those needs.

Consistency of reporting methods and terminology definitions is one extremely important piece of achieving reliability in the data that systems collect and upon which stakeholders base decisions. As mentioned, each state submits AFCARS reports to HHS twice a year. Although AFCARS reports have been required since 1995, it was not until 1998 that penalties were implemented for noncompliance, resulting in more complete and consistent reporting from 1998 on⁴⁰⁶—relatively recently. In these reports, states submit information on 45 adoption data elements (or variables) in one report and 89 foster care data elements in the other. Foster care data elements include gender,

birth date, race, ethnicity, number of previous stays in foster care, service goals, availability for adoption, and dates of removal and discharge.⁴⁰⁷ Seven of these data elements pertain to disabilities, or "special needs." Disabilities assessed include "Mental Retardation, Visually or Hearing Impaired, Physically Disabled, Emotionally Disturbed, and Other Diagnosed Condition" (which includes chronic illness such as HIV/AIDS and other disabilities that states include).⁴⁰⁸ Clinical diagnoses by "qualified professionals" are required to categorize a youth as having a disability.⁴⁰⁹

Some experts believe that the list of disability choices needs to be updated and that terminology should be examined for accuracy and perhaps be made more specific.⁴¹⁰ Some states agree. In the Washington State AFCARS Assessment Review Findings, the state reviewers comment that the disability-related data elements do not offer enough answer choices to help caseworkers best describe a youth.⁴¹¹ For each disability listed, such as "mental retardation," caseworkers can note only whether the youth has been diagnosed with it (coded "Yes") or not ("No"). Definitions of the disabilities, including severity indicators, are limited and are therefore interpreted differently by different states.⁴¹² For example, an analysis of 2003 data from AFCARS of foster youth documented as having "mental retardation" found that more than 12 percent of Wyoming youth were reported as having this disability, versus less than 1 percent (0.27%) of New Jersey youth.⁴¹³ It is unlikely that two states house such radically different youth in their child welfare systems; therefore, different states are likely. Without consistency in terminology and definitions, the coded data has limited meaning.

As a result of this issue, researchers speculate that AFCARS may underreport the prevalence of disabilities.⁴¹⁴ Underreporting is an enormous barrier to obtaining accurate information about youth with disabilities in the foster care system, further impeding systems' abilities to provide services to these youth. Underreporting may result when disability assessments are not done consistently, not done at all, or not reported correctly, as in the above example of Wyoming and New Jersey. According to a researcher working with the Child Welfare Research Program at the Urban Institute,

"If assessments for disabilities are not done or not done systematically, then children with disabilities who are not assessed might not be identified."⁴¹⁵ To explain further, in AFCARS, the data element to indicate disabilities offers states the option of noting that the child has not been assessed for a disability; in the group that is not assessed, those who have disabilities would not be identified. As a result, states that do not assess all or most children may undercount the number of youth in their foster care systems with disabilities.⁴¹⁶ To improve this situation, state departments of human services should require their health and mental health systems to perform assessments for disabilities on all youth in foster care.

A research newsletter published by the Institute on Community Integration at the University of Minnesota sums up these issues and their implications well:

Federally mandated data collection [in 2003] identified only 11 percent of children in care as having a developmental or medical condition, a proportion far lower than would be expected given prevalence in the general population, much less the higher incidence of disability caused by abuse or neglect. In 1999, Washington State reported no children in foster care had disabilities and Florida reported 21 of 34,254; that same year North Dakota reported 46.7 percent of children in foster care had disabilities... If we don't know who has and who does not have a disability and where they are, how can we be sure we're providing them with what they need?⁴¹⁷

This issue also pertains to recording the data accurately and completely at the local level for AFCARS reporting purposes. If caseworkers do not enter information about disabilities and the results of assessments into the data system, ACFARS information will be less complete. Similarly, when local agencies submit data element information for the youth they serve, they must not only have the same understanding of the terms that are used—especially for sensitive issues like disability status—but they must also commit to reporting the information accurately and collecting all existing information to ensure an accurate report.

Fortunately, by now, most states are doing well at submitting information for each data element and for each child. Yet not all states are consistent, and the inconsistencies

result in incomplete information about youth in the child welfare system. For example, in 2004, while Virginia submitted information for every child in the child welfare system on every data element relating to disability (9,641 out of 9,641), New York submitted disability information on *none* of its 49,530 youth in the child welfare system.⁴¹⁸ Some of the reasons may be that disability information is not be available, the data may be inaccurate, or disabilities may be reported inconsistently or in a way that is not usable for AFCARS. Despite this serious reporting issue, it is encouraging to see that most states are reporting correctly, and states with issues like New York's are in the minority. To continue to improve reporting, caseworkers at child welfare agencies must be required to fill out all SACWIS fields, including all disability fields.

In the education arena, two major laws require significant data reporting on youth with disabilities. NCLB requires schools and states to report on academic outcomes on standardized tests for various subgroups of students, including students with disabilities, and these reports are drawing attention to these students' instructional needs.⁴¹⁹ IDEA requires schools and states to report on various educational outcomes for youth with disabilities, such as the number of students with disabilities who earn regular or special high school diplomas, who are expelled from school, and who have testing accommodations, as well as the disproportionality of racial or ethnic groups in special education, and post-high school outcomes.⁴²⁰ As noted previously, neither law requires the identification of youth in foster care, so while these laws shed light on the academic performance of students with disabilities, there is no way to know at an aggregate level how many students with IEPs are in foster care or how they are performing on a range of indicators. Both laws should consider expanding their data collection requirements to include this subpopulation.

The implications of inconsistent, inaccurate, and unavailable data are immense. When an accurate picture of youth with disabilities in foster care cannot be provided, then policymakers have no idea how many and what types of resources and services must be devoted to these vulnerable youth to help them thrive. It is the youth who suffer as a result.

Therefore, whenever feasible, all systems that come into contact with youth with disabilities in foster care should contain fields in their data systems that providers must fill out to indicate both the foster care and disability status. This information would substantially improve the ability to analyze and paint a more accurate picture of these youth as they navigate through the various systems. This idea may not be feasible yet. Providers in other systems may not always know a young person's status in these two areas, since most cross-systems communications are still quite weak. Confidentiality also may pose a problem; systems may not want to include information about foster care status because of sensitivity concerns. The Federal Government should examine these issues to assess how to better collect accurate information about multisystem youth like youth with disabilities in foster care.

The information collected through the Child and Family Services Reviews should be enhanced to better incorporate the unique needs of youth with disabilities.

Apart from the AFCARS data, for which improvement recommendations have been discussed in the previous pages, the CFSRs can and should continue to be enhanced in order to assess more deeply and accurately the compliance of the state child welfare agencies and the outcomes they are producing for youth with disabilities in the foster care system.

HHS has been reviewing the state child welfare systems since 1994, when an amendment regarding state system compliance was added to the Social Security Act.⁴²¹ But it was not until changes to these reviews were made in 2000 that HHS's review process started focusing not only on agencies' systems competencies but also on the youth outcomes that resulted from the states' efforts. This newer review system, the CFSRs, is administered by HHS's Children's Bureau.⁴²² AFCARS is a substantial data source for this review process. Another important addition to the review process in 2000 was the implementation of federal assistance to the states to enhance their capacity to produce positive outcomes among the children and youth they serve. This process is called states' Program Improvement Plans (PIPs).⁴²³

The CFSRs cover the following seven indicators that are relevant to safety, permanency, and well-being outcomes:

Safety

Children are, first and foremost, protected from abuse and neglect.

Children are safely maintained in their homes whenever possible and appropriate.

Permanency

Children have permanency and stability in their living situations.

The continuity of family relationships and connections is preserved for families.

Family and Child Well-Being

Families have enhanced capacity to provide for their children's needs.

Children receive appropriate services to meet their educational needs.

Children receive adequate services to meet their physical and mental health needs.⁴²⁴

The CFSRs also measure competency in seven "systemic factors":

Statewide Information System

Case Review System

Quality Assurance System

Training

Service Array

Agency Responsiveness to the Community

Foster and Adoptive Parenting Licensing, Recruitment, and Retention⁴²⁵

For each of the outcomes, the needs of youth with disabilities are particularly salient. In terms of safety, youth with disabilities are more at risk of maltreatment⁴²⁶ and therefore may be more at risk than other youth of being abused in foster care or once they are reunified with their parents or adopted. Regarding permanency, it may be more difficult to find adoptive homes for youth with disabilities or to put in place the needed services to support the child's biological parents in caring for the child, should reunification be the goal. Finally, in terms of well-being, youth with disabilities have very specific developmental needs that will need to be addressed, particularly if they are making the transition to adulthood and aging out of the foster care system. For all of these reasons, the CFSRs may want to look specifically at youth with disabilities as a special population within the child welfare system.

The first "round" of CFSRs was done with all 50 states, the District of Columbia, and Puerto Rico from 2001 to 2004. At that time, no state or territory was found to be in "substantial conformity" in all of the 14 outcome and systems competency areas.⁴²⁷ In fact, the median state performance was in substantial conformity in only 6 of the 14 areas, with no state achieving conformity in more than 9.⁴²⁸ Therefore, since 2004, all of the states and territories have been working to implement their PIPs, which target the specific areas with which each state needs the most help.⁴²⁹

The less-than-optimal results of the first round of CFSRs show that much work still needs to be done on all of these outcomes. A 2004 GAO report shows that states are confronting barriers to implementing their PIPs in order to reach procedural compliance.⁴³⁰ The most common challenges affecting PIP implementations were insufficient funding and staff; states must stretch their existing, often meager resources to implement new and sometimes costly strategies. Regarding this important issue, CWLA argues that "without new, dedicated federal resources to assist states [in

implementing] the needed improvements... states will continue to struggle to fully meet the needs of the children in their care and comply with federal expectations[.]"⁴³¹

Youth remaining in the foster care system for long periods is still a serious issue nationwide, especially for older youth with disabilities and African-American youth.⁴³² CWLA believes that one thing that can be done to help is to further improve the CFSRs in an effort to better assess these permanency issues, better hold states accountable for them, and continue to invest at the federal level in helping states with these improvements. The organization believes that these efforts will lead to more healthy permanency outcomes—as well as better safety and well-being—for all foster youth, including disadvantaged youth. In a 2006 statement submitted to the Senate Finance Committee on the "Progress Achieved and Challenges Ahead for America's Child Welfare System," CWLA notes,

The CFSR process is important but the measurements used in the CFSR process can be improved. The scope and reliability of measurable outcomes need to be refined to improve comparability among states and to also produce measures that reflect good practice in the field. The current measures fall short in these areas.⁴³³

The Pew Commission on Children in Foster Care joins CWLA with this suggestion. In 2004, the Pew Commission made its own highly regarded recommendations regarding improving outcomes for foster youth; one of its propositions was that the "CFSRs should include more and better measures of child well-being [and] use longitudinal data to yield more accurate assessments of performance over time[.]"⁴³⁴

Now in round two of the CFSRs, HHS is making efforts to obtain feedback from child welfare experts such as CWLA and the Pew Commission about the status of the CFSR process, and the American child welfare system as a whole, via public hearings and requests for statements and comments. This is a positive step toward helping to make this hugely important review system the best it can be, so that states can be held accountable and foster youth can thrive as a result of their actions.

An additional recommendation for the second round of the reviews is to take the desired outcomes of the disability community into consideration as well. These include ensuring that people with disabilities are self-determined, are well-integrated into their communities, and are experiencing enhanced quality of life. These outcomes notably parallel the desired outcomes for foster youth, which are safety, permanency, and well-being. If these outcomes were more consciously taken into consideration for the youth with disabilities in the foster care system, these young people's unique needs would likely be supported more fully.

Information and data must be shared across systems whenever feasible.

Chapter 3.4 of this report dealt with the serious need for the different systems and agencies that come in contact with youth with disabilities in foster care to work collaboratively with one another. An incentive for making this happen, and easing the process, would be to facilitate the sharing of data and information across these entities. The often-cited barriers to information sharing include technical capability barriers; lack of understanding about what information sharing is legal; and negative, fearful, and uninspired attitudes toward this kind of data sharing. Therefore, cross-systems information sharing would need to involve both the technical elements that help data systems interface more easily and organizational and attitudinal elements to enhance cross-systems communications, trust, and basic attitudes toward sharing. The sharing of data across systems faces a plethora of challenges, but nonetheless it holds great importance in the effort to better track, understand, and care for youth with disabilities in the foster care system.

As discussed in Chapter 3.3, too many youth with disabilities, and too many youth in foster care, become "disconnected" from society during their journey to adulthood. All types of disconnected youth are extremely challenging to track, because they are inherently not attached to any systems or programs that would maintain information about them. As a result, almost no research has been able to grasp a full picture of what these young people's outcomes truly look like, and specifically, how youth with

disabilities in the foster care system have fared. Mark E. Courtney and Amy Dworsky's *Midwest Evaluation of the Adult Functioning of Former Foster Youth* (2005) is one of the only reliable longitudinal studies that has succeeded in following a cohort of foster youth from when they were in the foster care system in their teens to the years after they exited.⁴³⁵ (The *Northwest Foster Care Alumni Study* examined former foster youth between the ages of 20 and 33.⁴³⁶)

One of the largest challenges for tracking foster youth is that they are a highly mobile population. They change both residences and schools often, as noted in Chapter 3.2. For this reason, and because youth in foster care, especially those with disabilities, have a greater chance of becoming disconnected from society during their journey to adulthood, tracking them across the systems they encounter is of crucial importance. Tracking these youth helps us to better understand their circumstances. In turn, this understanding enables agencies and programs to "bring the services to the youth"—a task that is often needed but rarely possible.

One way to carry out this task is to institute statewide and/or countywide ("comprehensive") data systems that bridge the necessary departments and agencies, such as education, child welfare, juvenile justice, and health and mental health. These comprehensive data systems would improve the interface between the individual systems and ideally would hold all pertinent and relevant information about all foster youth in the state, including detailed information about disabilities. A former Pew Commission member supports this idea with the assertion that "communication networks that enable organizations and data systems to 'talk' to one another must be developed. Without meaningful data and the ability to track children's progress, children and families will continue to pay the price of our inattention."⁴³⁷

Some states are already investing in data systems that "talk" to one another. Kansas has recently augmented a preexisting database that had initially housed information about foster youth with IEPs but now houses education, child welfare, and juvenile justice information for *all* foster youth in the state. An official at the Children & Family Services department in Kansas's Social and Rehabilitative Services commented about

the system's functionality, saying, "When the system is working well, schools know much more about the students [who are foster youth] and are able to provide services to them faster."⁴³⁸

An approach to identifying this population when systems are not able to "talk" to each other is to link administrative sources using a common identifier, if available (e.g., a Social Security number), or probabilistic matching techniques that use available information such as names and birth dates to determine the likelihood that two cases are the same. For example, the Urban Institute, together with the University of California-Berkeley and the University of North Carolina, is conducting a study for HHS's Office of the Assistant Secretary for Planning and Evaluation (ASPE) that uses Social Security numbers to link foster care data with unemployment insurance data and assess outcomes for youth aging out of foster care.⁴³⁹

One other example is an analysis done by researchers in Utah. At the state's Department of Human Services, researchers linked foster care data with data from several other agencies, including the Department of Workforce Services, the Department of Health, the Board of Regents (higher education), and the Department of Public Safety, to identify a variety of outcomes for youth transitioning out of foster care.⁴⁴⁰ This methodology could be very applicable if the population of youth with disabilities in foster care were identified in a particular state's SACWIS system and then linked to other agency data using Social Security numbers or probabilistic matching techniques. Agencies would need to work together to develop data-sharing agreements and support the analysis, but this approach may be less resource intensive than redeveloping or reorganizing data systems to talk to each other.

Sharing information across the child welfare, dependency court, and education systems is often cited as one of the most necessary, as well as challenging, collaborations of all. Further complicating the situation is the fact that many youth workers and educators are not clear on what types of information can be legally shared and with whom. A helpful guidebook titled *Mythbusting: Breaking Down Confidentiality and Decision-Making Barriers to Meet the Education Needs of Children in Foster Care*, by Kathleen

McNaught of the American Bar Association's Center on Children and the Law, is an important tool that should be used to clarify this point.

Mythbusting examines the barriers caused by lack of information and unclear regulation language that hinder the child welfare and education systems from interacting on behalf of foster youth. The book sums up this issue as follows:

Child welfare and education systems share responsibility to ensure children in the child welfare system receive an appropriate education.... However, confidentiality rules and regulations that control the release of education and child welfare records are often unclear, and can hinder the appropriate transfer and disclosure of information.⁴⁴¹

One of the biggest of these "confidentiality regulations" is the Family Educational Rights and Privacy Act (FERPA). The most basic definition of FERPA is the following:

FERPA is a federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education. FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level.⁴⁴²

Specifically, FERPA requires schools to obtain a parent's written permission in order to release a student's school records (with certain exemptions, as indicated below). It is important to know that FERPA and IDEA define "parent" differently. FERPA defines parent as a "parent of a student and includes a natural parent, a guardian, or an individual acting as a parent in the absence of a parent or guardian," while IDEA's definition includes foster parents, relatives with whom the child lives, and surrogate parents.⁴⁴³ Because "parent" is defined broadly under FERPA, child welfare workers can technically be considered parents for purposes of FERPA (but not for IDEA), meaning that they may indeed access students' educational records.

In addition, contrary to popular belief, one of FERPA's "exceptions" to the written parental consent mandate is that school records may be released without these

permissions to "comply with a judicial order or lawfully issued subpoena."⁴⁴⁴ This means that judges can order the release of these records if they are needed to make decisions about a dependent child or young person's education. Another exception exists for "organizations conducting certain studies for or on behalf of the school."⁴⁴⁵

Other pertinent laws with confidentiality are the Child Abuse Prevention and Treatment Act (CAPTA), which includes requirements related to confidentiality for youth who have been abused or neglected, and the Adoption Assistance and Child Welfare Act (AACWA), which requires confidentiality of information for youth receiving assistance under Titles IV-E and IV-B of the Social Security Act.⁴⁴⁶ According to *Mythbusting*, numerous "myths" surround the question of which records and information for foster youth can be shared across systems, and with whom. These misunderstandings about FERPA, CAPTA, and AACWA can severely hinder an institution's ability to help youth with or without disabilities in the foster care system. But misunderstandings can be avoided easily if the Federal Government invests in disseminating information about legal information sharing so that "lack of information" no longer creates a major barrier to helping these youth. Schools, caseworkers, judges, and all other stakeholders absolutely must be able to navigate these protection laws in order to help, protect, or ensure youth's well-being.

In addition to "information-sharing myths," another barrier to sharing information is attitudes toward sharing. Creating and working with data systems that interface with each other requires extra training for those who must input and disseminate accurate and timely information. But sharing data also usually requires more frequent interagency meetings, which can be difficult to schedule and which can fall off the radar if those involved are neither mandated nor inspired to attend regularly. And last but definitely not least, consensus about the goals of data sharing across systems can be difficult to reach, as different systems have different accountability measures and laws by which abide, as well as different visions of success. "Remember that systems don't collaborate for altruistic reasons," reminded a judge at Arizona's Superior Court in Pima County.⁴⁴⁷

need to ensure that there will not be a negative impact from *not* doing it.⁴⁴⁸ Therefore, mandates, incentives, and of course funding support may be necessary steps to help alter agency representatives' mind-sets about the importance of sharing data.

McNaught of *Mythbusting* adds that states and/or counties must formally "establish the *importance* of sharing education information with the child welfare system" to encourage the community to essentially "buy in" to the effort.⁴⁴⁹ Florida is highlighted in the book as a positive example; the state passed a statute in 2004 requiring interagency agreements among education, child welfare, and other key stakeholders. McNaught reports that "this law has led to the establishment of the first-ever statewide interagency agreement in Florida"—no small victory.⁴⁵⁰

When states and counties invest in tracking their most vulnerable youth, such as youth with disabilities in the foster care system, with the goal of not letting them fall through the cracks, they send the message that these youth are important. Having the capability to track these youth across systems means having the capability to help connect them to the services they need in a timely and organized manner. But these connections cannot be accomplished unless systems are capable of and actively working to communicate with one another and share information. For this to happen, the Federal Government must make a serious commitment to the effort by infusing collaborative language into legislation and funding the technology and training that can make this data sharing a reality. Specific recommendations include investing in resources to support states in developing systems that talk to each other, supporting research that links data using common identifiers or Social Security numbers, and supporting training for administrators on confidentiality issues around data sharing.

Summary of Policy Recommendations

1. The Federal Government must continue to support the development and improvement of data systems and provide assistance to states for their use.

- a. Funding for the Statewide Automated Child Welfare Information Systems (SACWIS) and Adoption and Foster Care Analysis and Reporting System (AFCARS) should be increased, and enhanced technical assistance support should be provided to states to improve data collection and analysis.
- 2. Reporting methods and definitions should be made consistent across programs and information systems.
 - a. All data-reporting systems should include indicators of disability and foster care status when possible.
 - b. Terminology and definitions pertaining to disability status, as reported by AFCARS, must be updated and made more specific to facilitate clear, consistent reporting of disability status for youth in foster care.
 - c. The Individuals with Disabilities Education Act (IDEA) and No Child Left Behind (NCLB) should consider expanding their data collection requirements to include foster care status.
- The information collected through the Child and Family Services Reviews (CFSRs) should be enhanced to better incorporate the unique needs of youth with disabilities.
 - a. The information collected through the CFSRs should be expanded to include well-being indicators for youth with disabilities.
 - b. In general, the continued support and enhancement of the CFSRs to include better measures of well-being helps more youth achieve permanency in a timely manner.
- 4. Information and data must be shared across systems whenever feasible.

- a. Building statewide and/or countywide multiagency data systems would enhance the sharing of vital information on all youth.
- States and counties should implement mandates and provide incentives to agencies and departments in order to encourage cross-systems data sharing.
- c. Employees of various agencies should have a general understanding of information protection laws so they are aware of the types of information that can be legally shared across systems.

Chapter 4: Policy Recommendations

Improving the various programs and systems that affect youth with disabilities in foster care can help lead these young people to self-determination, enhanced quality of life, and community integration, as well as ensure their safety, permanency, and well-being. This report contains numerous recommendations for national, state, and local policymakers as well as practitioners in the various systems. However, the recommendations highlighted in this section have broader systemwide implications. It is strongly recommended that these recommendations be used as the launching pad for further intensive and detailed discussions about this policy issue with involvement from a wide range of stakeholders, including youth.

Provide increased flexibility to states and communities so programs and services can be most effectively structured to meet the needs of youth with disabilities in foster care. More flexibility awarded to state child welfare agencies can lead to more help where it is needed for preventative services, alternative care models, transition services, and school-based mental health programs, among many other appropriate services for youth with disabilities in foster care. Allowing a percentage of funds from one program to be shifted to meet the purposes of another is one possible approach; allowing waivers and block granting of funds is another.

Increase federal support in the departments of Health and Human Services, Education, Justice, and Labor for research and demonstrations to identify effective policies and practices that lead to positive outcomes for youth with disabilities in foster care. High-quality research and program evaluations should be supported at the federal level to demonstrate which programs and policies are truly effective for youth with disabilities in foster care.

Improve training for foster care parents and increase recruitment of individuals willing to foster youth with disabilities. State child welfare agencies should increase their efforts to identify and recruit adults who are willing to foster or adopt the highest-need youth, including youth with disabilities, to reduce the high numbers of these youth

left in the system for long periods. Training programs for foster parents should include a focus on working with youth with disabilities and should provide ongoing support to help these adults best support these youth.

Strengthen secondary and postsecondary educational supports for these youth to improve access and success. The U.S. Department of Education and state education agencies should provide additional services to high school students with disabilities in foster care when needed, such as school-based mental health services and counseling, with the goal of helping them attain higher graduation rates. In addition, students with disabilities should always be educated in the "least restrictive environment" possible. Finally, these education agencies should increase access to and success in postsecondary learning opportunities by removing the monetary and nonmonetary barriers that stand in the way of youth with disabilities in foster care.

Improve access to individualized, comprehensive transition services for youth with disabilities aging out of foster care. State child welfare agencies should enhance the transitional supports that are available for these youth to improve their life outcomes. They should also extend the availability of transition services to youth with disabilities through age 24 when necessary to enable them to lead healthy, self-sufficient lives.

Fund the Federal Youth Development Council, authorized by the Federal Youth Coordination Act (FYCA), as well as similar federal coordinating efforts. This council is charged with developing an interagency plan to implement federal youth policy more strategically for disadvantaged youth, such as youth with disabilities in foster care. Federal support of FYCA and its council would greatly facilitate a stronger federal role in serving these youth, as well as more cross-systems collaboration efforts involving the many systems that interact with these youth.

Strategically increase collaboration among the education, juvenile justice, child welfare, labor, dependency court, health, and mental health systems. Efforts should be made to increase collaboration among all of these systems so that youth with

disabilities in foster care can achieve greater well-being in their adolescence and into adulthood. State dependency court systems can serve as leaders in many of these collaboration efforts, and cross-system accountability measures should be developed.

Require states to develop a common youth development approach across multiple systems to improve outcomes for all youth. The youth development approach is broad enough to be applicable to multiple youth-serving programs. Research indicates that this approach is successful in helping a full range of youth, including those with disabilities, achieve self-sufficiency and self-determination, as well as educational, employment, and developmental skills.

Improve training of youth professionals across systems. Multiple federal and state agencies can and should encourage and support cross-training of professionals who work with youth with disabilities in foster care so that all service providers have an understanding of both the foster care system and disabilities. The cross-training should include adults working in schools, child welfare agencies, health and mental health agencies, youth development programs, and many more. This measure will help these adults better address young people's needs in a timely manner.

Provide resources and technical assistance to help states enhance their data collection and reporting systems. Federal agencies that require data collection and reporting, particularly the departments of Education and Health and Human Services, must better ensure that information is being collected and recorded at the local level in a consistent and timely manner so that youth are tracked accurately. Additionally, youth with disabilities in foster care could be better assessed if all data systems tracked both disability and foster care statuses and if child welfare agencies were specifically asked to report on the well-being of youth with disabilities.

Appendixes

Appendix A: Glossary of Relevant Terms

Children's Shelter (or Receiving Home):

An emergency shelter to which children are taken by police or child welfare workers after being removed from the home, while decisions are made about their future placements. A child's stay may be as short as one night or as long as 30 days, and sometimes longer. Some shelters house more than 100 children and youth at a time.

Family Foster Home:

A family with agency-certified foster parents, often not related to the youth who is placed there. Placements are temporary; some of these fostered youth are adopted by their foster families, while most are reunited with their birth parents eventually.

Foster Family Agency:

A private agency, often a nonprofit organization, that recruits, trains, and supervises specially trained foster parents. These foster parents are certified by the Foster Family Agency, not directly by the county government.

Group Home:

Generally, a six- to eight-bed home that provides care for youth taken out of their homes. (However, some group homes are much larger, with 100 beds or more.) Most group homes provide intensive mental health services and other special services.

Kinship Care:

Temporary care for youth taken out of their homes, provided by the youth's relative(s). Adults who provide kinship care are not usually licensed.

Nonpublic School (NPS):

A school run by private entities that provides special education services to students based on the needs enumerated in their IEPs. Placement into an NPS is considered to

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be one of the most restrictive educational placements available. NPSs are often affiliated with group homes.

Residential Treatment Center:

A facility whose primary purpose is to provide individually planned programs of mental health treatment in conjunction with residential care for seriously emotionally disturbed children and youth.

Therapeutic Foster Care:

A type of care provided in private homes by foster parents who have been specially trained in therapeutic care. It is considered the least restrictive form of out-of-home therapeutic placement for children and youth with severe emotional disabilities. Typically, each therapeutic foster home cares for only one youth.

Wraparound Services:

An approach that places the child and family at the center of an array of coordinated health and mental health, educational, and other social welfare services and resources. Wraparound services are a relatively new approach to working with youth with disabilities, especially those with emotional disturbances.

Appendix B: Relevant Federal Programs and Systems

Program Name	Purpose	Abbreviation
Adoption and Foster Care Analysis and Reporting System	Data system that collects case-level information on all youth in foster care, as well as on adopted youth.	AFCARS
Adoption and Safe Families Act	Established timelines and conditions for filing termination of parental rights (1997).	ASFA
Adoption Assistance and Child Welfare Act	Requires states to develop procedural systems for case management, permanency planning, and foster care placement (1980).	AACWA
Americans with Disabilities Act	Prohibits discrimination against persons with disabilities (1990).	ADA
Architectural Barriers Act	Requires that buildings constructed with public dollars be made accessible to those with disabilities (1968).	ABA
Child Abuse Prevention and Treatment Act	Provides funds and technical assistance for child abuse prevention and intervention services and research (1974).	САРТА
Child and Family Services Reviews	Federal review process that assesses the state child welfare agencies' systems competencies and their resulting youth outcomes.	CFSR
Carl D. Perkins Career and Technical Education Improvement Act	Funds programs, services, and activities designed to improve career and technical education programs, especially for high-need youth (1984).	Perkins Act
Court Improvement Program	Gives flexible grants to state courts to test new approaches toward improving the juvenile and family court systems.	CIP
Education and Training Vouchers Program for Youth Aging out of Foster Care	Part of the John H. Chafee Foster Care Independence Program. Provides resources specifically to meet the education and training needs of youth aging out of foster care.	ETV
Elementary and Secondary	Provide grants to school districts to create and	ESSCP
School Counseling Programs Family Educational Rights and Privacy Act	expand school counseling services. Protects the privacy of student education records (1974).	FERPA
Federal Youth Coordination Act	Facilitates interagency collaboration and supports state-level coordination efforts on behalf of disadvantaged youth (2006).	FYCA
Grants for the Integration of Schools and Mental Health	Mandate collaboration between school districts and mental health systems in order to provide,	(None Used)

Systems	enhance, and improve mental health treatment services to students.	
Indian Child Welfare Act	Strengthens the role of tribal governments in determining the custody of Native American children (1978).	ICWA
Individualized Education Program	Mandated by the Individuals with Disabilities Education Act. Individualized document that describes the personal and academic goals for a youth in special education, as well as any supports that are needed to help achieve those goals.	IEP
Individuals with Disabilities Education Act	Guarantees youth with disabilities the right to a free appropriate public education in the least restrictive environment (1975).	IDEA
John H. Chafee Foster Care Independence Program	Offers assistance to help current and former foster care youth achieve self-sufficiency (1999).	CFCIP
<i>McKinney-Vento Homeless Assistance Act</i>	Ensures that homeless youth (including those awaiting foster care placement) have access to free and appropriate education (1986).	McKinney-Vento Act
<i>Medicaid (Title XIX of the Social Security Act)</i>	Provides health care coverage for children and their parents, the elderly, and people with disabilities.	Medicaid
National Child Abuse and Neglect Data System	National data collection and analysis system used to track abuse and neglect.	NCANDS
No Child Left Behind Act	Mandates stronger accountability of all public K–12 schools, with the goal of proficiency for all students (2001).	NCLB
<i>Promoting Safe and Stable Families Act</i>	Provides more flexible funding to the states for foster care prevention efforts; established the Court Improvement Program (2006).	PSSF
Social Security Act, Title IV-E and Title IV-B	Provide federal support for foster care, adoption assistance, and prevention programs.	Title IV-E and Title IV-B
Statewide Automated Child Welfare Information Systems	Case management system that caseworkers use to house information and run reports on youth in the child welfare system.	SACWIS
Temporary Assistance for Needy Families	Provides financial assistance and supportive services to high-need families.	TANF
Workforce Investment Act	Provides workforce investment services and activities through local One-Stop Career Centers (1998).	WIA

Appendix C: Promising Practices and Exemplary Programs

Bridges...from School to Work

The Bridges program is sponsored by the Marriott Foundation for People with Disabilities. Bridges develops and supports mutually beneficial job placements to meet the workforce needs of local employers and the vocational goals of young people. The program is designed to assist youth with disabilities, both in and out of school; youth who are pregnant or have a child; youth in or transitioning out of foster care; and urban and minority youth. Bridges assists in training youth while also providing employers support with issues such as communication, supervision, and discipline. A unique career development plan is created and built on each youth's individual interests, long-term goals, and needs and obstacles. http://www.marriott.com/bridges/default.mi

Destination Future

Destination Future is an annual youth leadership conference for youth in or transitioning out of foster care. Young people ages 16 through 20 who demonstrate leadership abilities are encouraged to attend. Attendees participate in small-group discussions that focus on issues pertaining to out-of-home care. They are encouraged to voice their opinions about policy issues that affect them and become advocates for the foster youth cause. http://www.nrcys.ou.edu/conferences/df06/index.html

Foster Youth ePassport

Recognizing the need for foster care youth to have transportable, complete, and accurate school and medical records, ePassport offers an Internet-based solution. A secure online management tool keeps track of young people's immunizations, drug allergies, school admissions, and more, and it allows records to be updated and managed in real time. Data tracked by ePassport is accessible 24 hours a day, seven days a week, which can expedite traditionally long processes such as receiving medical care and enrolling in school. http://www.connectforkids.org/node/481

NC LINKS

The goal of NC LINKS, a state-run program for North Carolina youth transitioning out of foster care, is to build a network of relevant services for youth so that they will have ongoing connections with family, friends, mentors, the community, employment, education, financial assistance, skills training, and other resources to facilitate the transition to adulthood. NC LINKS, provided by the North Carolina Division of Social Services, offers an Independent Living Program as well as an Education and Training Voucher Program. Because of North Carolina's commitment to serving youth for as long as possible, NC LINKS begins offering its services to youth at age 13 and extends services through age 21 for those who request them. http://www.dhhs.state.nc.us/dss/links/index.htm

Pima County, Arizona, Model Dependency Court Program

Started in 1997, the Pima County Model Dependency Court Program was one of the first Model Courts in the country. The primary goal of the program is to design and manage dependency court processes that result in active judicial oversight, timely case processing, and shorter temporary placements for dependent children and youth. Since the program's start, initiatives that have been implemented successfully include the following: improving collaboration with Child Protective Services and the behavioral health system to enhance the timeliness of health assessments and the delivery of appropriate services, improving dependency data collection systems to streamline case management and enhance reliability, and increasing the use of alternative dispute resolution tactics. http://www.supreme.state.az.us/dcsd/improve/model.htm

Transition Resources for Adult Community Education (TRACE)

TRACE is San Diego Unified School District's program for students with disabilities, ages 18 through 22, who are transitioning out of high school into adulthood. According to its Web site, "The purpose of TRACE is to ensure that every student, regardless of the severity of his or her disability, is capable of living, working, and participating in [the] community." TRACE uses the "person-centered planning approach" to ensure that

students are involved in making their own decisions about their futures. Topics addressed in TRACE include accessing adult education and vocational programs, seeking out recreational opportunities like clubs and community centers, learning to self-advocate, using community services like public transportation, and learning domestic skills like cooking and budgeting. http://www.sandi.net/depts./specialed/trace.htm

Treehouse

Treehouse provides services for foster care youth in King County, located near Seattle, Washington. The Treehouse vision is to create a place for foster youth to thrive and to have "a safe place to dream." Emphasis is placed on community supports, as the program seeks the help of community members and organizations to achieve its mission. Services are focused on providing key material needs such as clothing, learning opportunities such as tutoring, and enrichment activities such as summer camp. http://www.treehouse4kids.org

Whitaker School

The Whitaker School in Butner, North Carolina, is a long-term treatment program for adolescents with emotional disabilities, ages 13 through 17. A large percentage of the Whitaker School's students have been diagnosed with posttraumatic stress disorder, depression, and/or attention-deficit hyperactivity disorder. In this nonmedical alternative program, "staff mobilizes the home community resources to build a network of services to meet the students' individual needs and the needs and expectations of the family, school, and community," according to the school's Web site. Adolescents attending the Whitaker School are provided individual guidance on increasing academic, social, and behavioral competencies that can be transferred into less restrictive environments. http://www.dhhs.state.nc.us/mhddsas/whitaker.htm

Youth Connections

Youth Connections extends the services for youth leaving foster care or other state custody by offering a support system to bridge the path from youth to adulthood. It is a

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partnership between Monroe Harding and the Tennessee Department of Children Services. These organizations work in conjunction with the Vanderbilt Institute for Public Policies, Tennessee Youth Advisory Council, Nashville Career Advancement Center and Teaching Kids to Dream. One service offered is the Jim Casey Opportunity Passport[™], which helps youth learn about financial management, the banking system, saving money for education, insurance, and health care. In addition, foster youth gain streamlined access to educational, training, and vocational opportunities. Life skills classes and mentors assist in resume writing, job coaching, and employment training. Information on housing is made available, as is furniture assistance. http://www.tnyouthconnections.net

Youth Empowerment Services (YES)

Begun in 1999, YES is a partnership of the San Diego field office of Casey Family Programs, the San Diego Workforce Partnership, and ACCESS, Inc., a local nonprofit provider of youth and employment training programs. Its goal is to help young people ages 14 through 21 develop the skills to get and keep a job so they are able to live on their own after foster care. More than a dozen programs and services are offered, including Youth to Youth (foster care alumni mentor current foster youth), Pre-Employment Traineeship (for 13- through 16-year-olds), physical and mental health services, education support, Door of Hope Project (for pregnant and parenting teens), internships, and driving school. http://www.access2jobs.org/Programs/ Programs.htm#Program1

Appendix D: Mission of the National Council on Disability

Overview and purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific duties

The current statutory mandate of NCD includes the following:

Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.

Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.

Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other

officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.

Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).

Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.

Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.

Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.

Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special

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rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers served and current activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that people with disabilities who are members of diverse cultures fully participate in society.

Statutory history

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

Endnotes

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⁷ Id.

⁸ Cheryl A. Larson and Lynda Anderson, *Children with Disabilities and the Child Welfare System: Prevalence Data*, 19, 1 Impact (University of Minnesota, Institute on Community Integration), Fall/Winter 2005/06, at 6, available at http://ici.umn.edu/products/impact/191/over6.html (viewed on March 5, 2007).

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¹⁹ For definitions of these different types of residences, see Appendix A.

²⁰ United States Department of Health and Human Services, Administration for Children and Families, Children's Bureau, *The AFCARS Report* (Fiscal Year 2005), available at

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²⁸ African Americans are also disproportionately represented in the foster care system for prolonged amounts of time. According to CWLA's assessment of 2005 AFCARS data, of all the exits from foster care that year (for any reason, including emancipation, adoption, reunification, guardianship, and kinship care), 28.3 percent of these youth were African American, but when just *exits to emancipation* are viewed for African Americans, whites, and Hispanics, *35.3 percent* of African Americans exited this way, meaning that a disproportionate number of long-term African-American foster youth remained in the system until they aged out at 18. The Child Welfare League of America addresses disproportionality issues for adolescents, youth with disabilities, and African Americans in the following source: O. Jane Morgan et al., *Long-Term Foster Care: The Forgotten Child*, Child Welfare League of America Conference, (unpublished presentation), CWLA, (February 26, 2007) (given to author by Kelly Mack, Program Manager, CWLA, on March 20, 2007). Also see Endnotes 9 and 97 about this topic. ²⁹ United States Department of Health and Human Services, Administration for Children and Families, Children's Bureau, *The AFCARS Report* (Fiscal Year 2005), available at http://www.acf.hhs.gov/programs/cb/stats_research/afcars/tar/report13.htm (viewed on February 20, 2007).

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Brief, August 2005, at 17; United States Department of Health and Human Services, Administration for Children and Families, Children's Bureau, *Summary of the Title IV-E Child Welfare Waiver Demonstrations* (April 2006), available at http://www.acf.hhs.gov/programs/cb/programs_fund/cwwaiver/summary_demo2006.htm (viewed on February 18, 2007).

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⁶² Id.

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⁶⁴ Richard P. Barth, *Institutions vs. Foster Homes: An Empirical Base for a Century of Action*, University of North Carolina at Chapel Hill, School of Social Work, at 7 (June 17, 2002).

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⁶⁶ Id.

⁶⁷ Id.

⁶⁸ Barth recommends that group homes specifically be used for only the following types of youth: youth who have run away from foster care, youth who are destructive or self-destructive, and youth who are moving back into the community from more restrictive settings such as juvenile detention centers or psychiatric hospitals. *Id.* at 24–25.

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²⁷³ The Ansell-Casey Life Skills Assessment (ACLSA) is an evaluation of youth independent living skills. It is anonymous and is "appropriate for all youths regardless of living circumstances, whether with one parent, in foster care, in group homes or in other places." Learn more about ACLSA and download the tool at www.caseylifeskills.org.

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²⁷⁵ Richard Devylder, Remarks at the National Council on Disability Executive Board Meeting, San Diego (January 31, 2007).

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²⁸¹ Foster Club offers three separate Web sites, one for children, one for adolescents, and one for adults, which provide targeted resources for each of these groups. They are used primarily as networking tools for children and adolescents and provide research

articles, media kits, position papers, as well as advocacy and support tools on the adult Web site. All three sites include information on foster youths' rights. For more information, visit www.fosterclub.org.

²⁸² Foster Care Alumni of America is a membership organization with several statewide chapters that work to convene foster care alumni as well as advocate on behalf of policies and practices that affect them. For more information, visit www.fostercarealumni.org.

²⁸³ The National Council on Independent Living provides members with tools for effective independent living advocacy, as well as a members-only "peer-to-peer" online message board, among many other services. For more information, visit www.ncil.org.

²⁸⁴ The National Youth Leadership Network is completely governed by individuals under age 28 who have disabilities and promotes the inclusion of young leaders with disabilities by advocating for policies that support them. It also runs quarterly Web casts for youth with disabilities to network with one another. For more information, visit www.nyln.org.

²⁸⁵ Thomas R. Wolanin, *Higher Education Opportunities for Foster Youth*, Institute for Higher Education Policy, at 40 (2005).

²⁸⁶ Id.

²⁸⁷ *Id.*, Executive Summary at vii.

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²⁸⁹ Email Interview with Jerry Hobbs, Teacher, San Diego Unified School District (April 18, 2007).

²⁹⁰ "While only four percent of the U.S. population has a serious mental illness, five to six times as many people who are homeless (20–25 percent) have serious mental illnesses." National Resource Center on Homelessness and Mental Illness, *Why are so many people with serious mental illnesses homeless?*, available at

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²⁹⁷ Email Interviews with Melinda Foy, Foster Care Alumna (April 18, 2007 and May 9, 2007).

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²⁹⁹ Id.

³⁰⁰ *Id*.

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³⁰² *Id.*

³⁰³ North Carolina Department of Health and Human Services, Division of Social Services, *Family Services Manual, Chapter IV, Section VIII*, at 1 (October 2006) (Provided by the Division of Social Services; on file with author).

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³⁰⁸ The Youth Transition Funders Group is dedicated to promoting programs and policies that serve youth through age 24 with the hopes of ensuring their connectivity to society by age 25. See www.ytfg.org for more information. YouthBuild is one organization that serves youth through age 24 owing to its belief that many youth still need services past age 21. See www.youthbuild.org for more information. California's Conservation Corps admits youth up to age 25 to its program. See www.ccc.ca.gov for more information. Youth Service America, a national resource center that partners with thousands of organizations committed to increasing the quality and quantity of volunteer opportunities for young people, also serves youth through the age of 25. See www.ysa.org for more information.

³⁰⁹ California Department of Social Services, Children and Family Services Division, Children and Youth Permanency Branch, Independent Living Program Policy Unit, *Transitional Housing Program for Emancipated Foster/Probation Youth (THP-Plus)* brochure, available at http://www.childsworld.ca.gov/res/pdf/THP-PlusBrochure.pdf (viewed on May 2, 2007).

³¹⁰ Connecticut Department of Children and Families, *Policy Manual: Adolescent Services*, *Aftercare*, available at http://www.dir.ct.gov/dcf/Policy/Adoles42/42-5-5.htm (viewed on May 2, 2007).

³¹¹ William C. Vickrey, Editorial, *A better life for foster youth*, San Francisco Chronicle, May 18, 2005, at B-9, available at http://www.sfgate.com/cgi-bin/article.cgi?file=/c/a /2005/05/18/EDGHUCQLRB1.DTL (viewed on March 12, 2007).

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³¹⁴ Norm Coleman (R-MN) and Deborah Stabenow (D-MI), Letter to Tom Harkin, Chair, Subcommittee on Labor, Health and Human Services and Education, and Arlen Specter, Ranking Member, Subcommittee on Labor, Health and Human Services and Education (April 20, 2007), available through the National Collaboration for Youth Web site, at http://nassembly.org/ncy/documents/04092007LETTERFYCAFunding.pdf (viewed on July 3, 2007).

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³²² Email Interview with Samantha Jo Broderick, Statewide Youth Coordinator, New Jersey Department for Children and Families (April 17, 2007).

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http://www.chapinhall.org/article_abstract.aspx?ar=1355 for full access to all of the reports pertaining to this study.

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⁴⁴⁶ Kathleen McNaught, *Mythbusting: Breaking Down Confidentiality and Decision-Making Barriers to Meet the Education Needs of Children in Foster Care*, American Bar Association Center on Children and the Law, at 29–30 (January 2007).

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⁴⁴⁸ *Id.*

⁴⁴⁹ Kathleen McNaught, *Mythbusting: Breaking Down Confidentiality and Decision-Making Barriers to Meet the Education Needs of Children in Foster Care*, American Bar Association Center on Children and the Law, at 43 (January 2007).

⁴⁵⁰ *Id*.