

Impact

Feature Issue on Children with Disabilities in the Child Welfare System

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Carolyn Johnson was a child with a disability who grew up in foster care. Today, as a mom she works hard to create a strong and loving family environment for her own children. See story below.

Growing Up in Foster Care: Carolyn's Story

by Carolyn Johnson, as told to Jennifer Hall-Lande

My childhood was spent in the foster care system. The first time I went into foster care I was seven years old. Throughout my childhood and teenage years, I was in over seven foster care and group home placements. As I look back at those years, it feels like a mixture of good and bad experiences.

One of the most difficult parts of foster care was not knowing what was going to happen to me. There was always a sense of uncertainty and confusion. I often felt scared and alone. It would be hard for any child to go through the foster care system, but having a disability made it more difficult for me to understand what was going on in my life. The only time that I really remember my social worker was when she came to my house to take us away. I do not recall a social worker talking with or visiting me in the foster home. It was important to know what was happening in my life. I needed someone to explain the situation to me in a way that I could understand, someone I could trust and talk to about things. Sometimes it felt like the foster homes were just in it for the money. It felt like they did not care about me or that I had a disability. In one foster home, her son hurt me. When I told my foster mom, she whooped me for telling on him. If a social worker had come to the home, I would have told her about what had happened to me.

Being separated from my siblings was another painful part of being in foster care. I was the oldest in my family followed by my brother and baby sister. My brother and I were always placed in the same home, but my sister was always in a different foster home. At that time, most foster homes only wanted babies or very young children.

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From the Editors

When children with disabilities and their families become involved with the child welfare system – with child protective services and/or permanency services – there is often a steep learning curve for the system as to how to best serve them. As complex as the needs are of any child removed from his or her family because of abuse or neglect, or because the family is unable to continue caring for the child, the needs of children with disabilities are even more complicated because they involve multiple systems – the disability services and child welfare services systems. These two systems don't necessarily communicate with each other in a way that supports their work on behalf of children with disabilities who have been removed from their family home or who are at risk for such removal, and they may not have adequate access to expertise in one another's areas of focus. In this Impact issue, we examine the presence and needs of children with disabilities who are in the child welfare system, barriers to be addressed by the two systems and those who work in them, and strategies for moving forward in better meeting the needs of such children and their families.

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Supporting Family Life for Children with Disabilities: What We Know and Don't Know

by Nancy Rosenau

The simple truth that young children need a close relationship with a nurturing parent for physical and emotional well-being has been known intuitively for as long as humankind has organized itself in families. It has been affirmed by child development experts and researchers. It was theorized by John Bowlby in the 1950s, subsequently studied under the term "attachment," and is now supported by an enormous body of empirical evidence (Cassidy & Shaver, 1999; Carlson, Sampson & Sroufe, 2003). The

Children with disabilities experience more removals from their parents, more residential settings, longer time in care, fewer goals of family life, and less achievement of the goals of family life than their non-disabled peers in the child welfare system.

best description I've seen of this necessary relationship is Stanley Greenspan's (1997):

Every child needs a safe, secure environment that includes one stable, predictable, comforting, and protective relationship with an adult, not necessarily a biological parent, who has made a long-term personal commitment to the child's daily welfare and who has the means, time, and personal qualities needed to carry it out. (p. 264)

Children with Disabilities and Family Disruption: What's Known, Unknown

In the child welfare system, the need of children for family has been built into policy and mandated by federal legislation since 1980 under the term "permanency planning." Permanency planning is a set of goal-directed, time-sensitive activities to create conditions to allow the safe resumption of care by a birth family after removal, or permanent placement with another family when return is not possible. Despite the importance attributed to a nurturing parent-child relationship, children with disabilities have been differentially assured this singularly important developmental imperative. Several very thorough, must-read publications on children with disabilities summarize the now well-established facts (Bruhn, 2003; Marge, 2003; Rosenberg & Robinson, 2004):

- Children with disabilities are at increased risk of maltreatment compared to nondisabled children.
- Children with disabilities have an increased likelihood of suffering maltreatment multiple times in multiple ways by multiple perpetrators.
- Some disabilities are caused by maltreatment.
- Some children are unwanted because of their disabilities and are relinquished; others are desperately wanted but relinquished to obtain otherwise unavailable services.
- Children with disabilities are more likely to live in congregate care where subsequent maltreatment is more likely.
- Children with disabilities experience more removals from their parents, more residential settings, longer time in care, fewer goals of family life, and less achievement of the goals of family life than their non-disabled peers in the child welfare system.

In short, too many children with disabilities get into care, too few get out, and too often they're in the wrong place while there. What contributes to this state of affairs? In a number of senses, we "don't know."

We don't know in the sense of having factual information. Despite recognizing the prevalence of children with disabilities in child welfare systems, we don't know who they are, where they live, or what their experiences are. Studies widely report children with disabilities are over-represented in the child welfare system. Estimates range from 14% to 64% depending on methodology and definitions, but the data is hard to interpret. Take the following examples identified from data in a national reporting system (see Bruhn, 2003). Federally mandated data collection identified only 11% 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% of children in foster care had disabilities. Either children with disabilities were not identified in Washington or Florida, or they weren't living in foster care. Either children in North Dakota are maltreated at enormous rates or North Dakota is reporting children that other states don't count as having disabilities. If we don't know who has and who doesn't have a disability and where they are, how can we be sure we're providing them with what they need?

We also don't know in the sense of having awareness. We don't distinguish to what extent behaviors of children with disabilities are consequences of maltreatment rather than intrinsic to their impairment. Knowing is complicated by

children's inability to communicate and by inadequate evaluations that have difficulty distinguishing underlying conditions. The behavioral consequences of maltreatment are increasingly understood to include aggression, poor sense of personal safety, inappropriate sexual behavior, self-abuse, poor hygiene, extreme withdrawal, and running away.

The common thread in promising practices is that they direct resources to surround an anchoring family – one with the requisite time, means, and personal qualities to care for the child – with the support and expertise they need.

The behavioral consequences of early loss of an attachment figure are also increasingly understood to include delayed speech and language development, sensory integration difficulties, behavioral stereotypies, and inattention/hyperactivity (Zeanah, 2000). The list of behavioral consequences of maltreatment and attachment loss is suspiciously similar to the descriptions of many children with disabilities. When children with disabilities are described as aggressive, impulsive, withdrawn, overly friendly, or sexualized, their behaviors are attributed to their disability. Lodged in a child welfare service system that doesn't know about disabilities, the thing that is least known is identified as the causative agent. If behavior is assumed to be a manifestation of a disability rather than a traumatic experience, will we provide the right response?

While child welfare has been struggling to provide permanency for chil-

dren for 25 years, the disability sector is coming to permanency planning more recently, with a few notable exceptions like Michigan, Pennsylvania, and Texas. Texas, for instance, has legislation to assure all children in disability services non-family living arrangements have a permanency plan that is reviewed every six months. While this legislation was passed 20 years after the protections afforded children in the child welfare system, many states don't yet even offer that protective policy in their disability services.

Supporting Family Life for Maltreated Children

Our collective response to children with disabilities is too frequently placement in settings to get "specialized treatment" to prepare them for community life. Treatment methodologies are written so they can be implemented by interchangeable staff. Treatment is seen as modifying the behavior of the child, rather than modifying the relationships available to the child. The relationships children need are not interchangeable, but rather require the security of a unique attachment to heal wounds of separation and maltreatment. The answer is not preparing for family life and the relationships it offers – the answer is family life and the relationships it offers.

There are some hopeful trends in child welfare in relation to supporting family life for children who have challenges as a result of maltreatment:

- Prevention services. A number of initiatives are demonstrating successful ways to work with troubled families to prevent removing a child by providing intensive in-home intervention tailored to unique family needs.
- Therapeutic foster care. An intensive version of foster care that is demonstrating success with children with emotional or behavioral issues placed with families who are carefully chosen, specifically trained, and partnering in teams with clinical expertise.

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The Risks of Maltreatment for Children with Disabilities

While the risk factors that contribute to child maltreatment in all children apply to children with disabilities too, the presence of a disability increases both the risk of maltreatment and the impact of maltreatment in the following ways:

Child

- Greater dependence on caregivers for their personal needs and longer-term dependence on caregivers because they may be less in charge of their own bodies;
- Physical, cognitive, emotional/mental health disabilities that interfere with being able to understand, resist, or tell someone about abuse;
- More likely to have their symptoms of abuse or neglect ignored because their symptoms are confused with those of the disability itself; and
- Greater isolation and fewer chances to socialize that may contribute to low self-esteem and less opportunity to learn how to prevent or end abuse.

Family

- Higher costs for caring for their child with special needs, including medical care, therapy, equipment, transportation, and childcare;
- More social isolation;
- More emotional stress and time pressures to coordinate care for their child's behavioral, medical, or educational needs;
- Lack of programs for parents of children with special needs; and
- Differing cultural values and beliefs about disability and the need for intervention.

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Seven Keys to Supporting Children with Disabilities in the Child Welfare System

by Nora Baladerian

Children with disabilities represent at least 15% of the child population in the United States (Committee on Education and the Workforce, 2005). How many are receiving services in the child welfare system is unknown, as disability is not universally recorded. It could be estimated that there is an equal representation in the system as in the population, yet two other important factors may cause an adjustment in this assumption. The first is that child abuse involving children with disabilities occurs at approximately 3.5 times the rate of abuse

reported (Davis, 2000). Thus, while we don't know precisely how many children in dependency services have disabilities, we do know they are there, they are in need of such services, and that there may be many more in need of services than come to the attention of the system. Child welfare systems need to have protocols, practices, and procedures in place to assure excellence in service delivery for this population.

Barriers to such excellence have included a scarcity of training and educational programs preparing child welfare staff to recognize a child's disability. Further, requirements of child welfare workers do not include assessment for disability unless specific services such as foster care placement are called for. Documentation of the child's non-medical health care needs has not been mandatory. Yet the needs of children with disabilities for services matching their disabilities certainly are there.

Types of Disabilities Encountered in Child Welfare

Disabilities can be identified within nine categories: sensory, communication, mobility, intellectual, social, psychiatric, medical, orthopedic, and respiratory. A child may have one or more of these disabilities. "Developmental disability" is a category of disability defined by law as interrupting the normal developmental process. The Developmental Disabilities Act of 2000 (P. L.106-402) provides the federal definition, while most states have their own definitions designed to identify children who may qualify to receive supportive services. The federal law states: "Developmental disabilities are severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of

major life activities: capacity for independent living, economic self-sufficiency, learning, mobility, receptive and expressive language, self-care, and self-direction." Developmental disabilities represent approximately 3-5% of all disabilities found among children and adults.

Children may be born with a disability, or may acquire a disability as a result of illness, accident or abuse. Studies show that of those children who have survived severe neglect, 52% retain permanent disabilities (Baladerian, 1990). Child abuse victims in general may acquire mental health conditions including posttraumatic stress disorder, anxiety disorders, depression, and dissociative disorders in addition to other consequences such as difficulty learning, and engaging with social skills. Adjustment disorders of all types may ensue. It must be noted that such conditions are often ignored when the child has a significant disability of another type.

Attitudinal and Knowledge Barriers

Most people in the disability field agree that the most prominent barrier is negative societal attitudes. Individuals with disabilities are perceived as being valued "less than" their non-disabled counterparts. In fact anyone with a "difference" from what society values for height, weight, verbal fluency, youthfulness, beauty, athleticism and so forth is somehow seen as "less than."

When one is among the "highly valued" in society, it can be difficult to understand why it is so important to those labeled "less than" to assure that services are available, or why announcing that one's services are available to that population is even needed. Yet, individuals with disabilities and their families are well aware that generic services are often denied to them. For example, a

There is a huge gap between the child welfare and disability service systems that needs to be closed. There is no apparent lack of willingness, only a need for a mechanism for making collaboration happen.

of children without disabilities (Sullivan & Knutson, 1998, 2000). Secondly, underreporting of abuse of both children and adults with disabilities is an enormous problem; researchers estimate that less than 30% of many types of abuse is ever reported (Protection and Advocacy, Inc., 2003). For example, it's estimated that 90% of people with developmental disabilities will be sexually assaulted over the course of their lives – and children with any type of disability are almost twice as likely to experience sexual abuse as nondisabled children – but only 3% of the assaults will ever be

child sexual assault survivor with intellectual disabilities may be denied mental health services with this statement at the mental health center – “We don’t serve children with mental retardation” – although their service is provided to all other survivors of sexual assault. Why not? In part, just plain prejudice, usually based, like any other prejudice, in lack of personal experience with individuals with disabilities. In part, a lack of understanding of the needs of the child. In part, a failure to procure training in how to serve children with intellectual disabilities. There may also be fear on the part of practitioners about individuals with disabilities, as well as fears regarding their own skills.

Yet, it is the mission of the child welfare system to serve all children. Conversely, those agencies that focus their services to children with disabilities are frequently unaware of the many services provided by child welfare. There is a huge gap between these two service systems that needs to be closed. There is no apparent lack of willingness, only a need for a mechanism for making collaboration happen!

Strategies for Excellence in Service

In order to remedy this problem, and equip child welfare professionals and systems to not only serve children with disabilities equitably, but with excellence, the following seven strategies are recommended. Implementing these within one’s own community will strengthen both sides of the service delivery system in that disability service providers will be included in ongoing planning and service delivery of child welfare services, while child welfare professionals will be included in ongoing service delivery and planning of disability related support services. The seven strategies are:

- Nothing about us without us
- Spirit and letter of the ADA
- Teach disability awareness
- CREDO (Compassion, Respect, Empathy, Dignity, Open-mindedness)

- Recognize when you don’t know and ask
- Use the Web and listservs
- Meet monthly with disability services

Nothing About Us Without Us

“Nothing about us without us” is a theme of self-advocates. The perspective of individuals with disabilities cannot be overestimated. Including individuals with disabilities in all phases of service delivery planning can save enormous amounts of time and money. By “building it right” from the start, costly modifications to physical site and service delivery products are avoided, not to mention the time and effort expended to doing things twice. The implementation of this is to include qualified individuals with a variety of disabilities, and those who represent children with disabilities, in all planning for physical sites; in all planning for service delivery procedures, protocols, and policies; in board membership; and in training activities.

Spirit and Letter of the ADA

In 1990, the Americans with Disabilities Act was passed, with final compliance to be in place by July 1994. Yet, many organizations and agencies still lag behind. It is not just the letter of the law that requires compliance, but also the spirit of the law that needs to be adopted by all who serve members of the public. Full ADA-guided accessibility refers to implementation of both the spirit and letter of the law and at the agency-level can include adding “serving people with disabilities” into all informational and promotional materials for clients, the public and potential employees; assuring comprehensive physical accessibility throughout agency sites (and wherever else services are offered); and assuring comprehensive program accessibility throughout all services that are provided. Help with accessibility compliance is available to agencies from qualified ADA compliance support agencies

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A Need for Shared Expertise

Services for children with disabilities and their families include special education, health care, family support (including respite care), advocacy, vocational training, and independent living as children mature. Historically, these services have functioned separately from the child protective system, with little recognition by either about the vulnerability of children with disabilities for maltreatment. Key gaps include:

- *Lack of screening for disabilities at time of intake into the child protective system;*
- *Lack of awareness of and training on recognizing and reporting maltreatment among disabilities services, special education services, and advocacy organizations;*
- *Lack of awareness and training about disabilities among maltreatment investigation, assessment, and treatment services;*
- *Differing eligibility requirements and age cut-offs for disabilities services and the child protective system;*
- *Prevention services (parenting support groups, respite, child abuse hotlines) that do not address the needs and concerns of families of children with disabilities;*
- *Few crisis and long-term placement options for children with disabilities.*

People with expertise in disabilities and cultural competency need to be included in identification, investigation, assessment and treatment of maltreatment through appointments to review committees, staff positions with assessment and treatment centers, and consulting on individual cases and on prevention programs.

Programs serving children with disabilities and their families must become aware of the relationship between disabilities and maltreatment; address maltreatment of children with disabilities through prevention, intervention and advocacy; and develop cross-cultural competence.

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Children with Disabilities and the Child Welfare System: Prevalence Data

by Sheryl A. Larson and Lynda Anderson

Several studies have examined the characteristics of children with disabilities and/or the relationship between disability and participation in the child welfare system. According to the National Child Abuse and Neglect Data System (NCANDS), in 2003 an estimated 906,000 children were determined to be victims of abuse or neglect by child protective services agencies in the United States (a rate of 12.4 children per 1,000; U.S. Department of Health and Human

care as children without a disability.

While the NCANDS data are very helpful in understanding abuse and neglect from a broad systems perspective, official reports acknowledge its limitations in measuring abuse and neglect specifically among children with disabilities. Several other studies provide more specific information about children with disabilities. For example, one study cross-referenced school records, the foster care system records, and police databases for 50,000 children ages 0-21 in Nebraska to examine the extent to which children who were considered by schools to have a disability were at increased risk of experiencing maltreatment (Sullivan & Knutson, 2000). In that study, 9% of children who did not have disabilities and 31% of children who had disabilities were found to have experienced reported maltreatment. The study concluded that children with disabilities are 3.4 times more likely to be maltreated than their peers who did not have disabilities.

Another study examined the characteristics of children involved in 1,249 cases of substantiated maltreatment from a national sample of 35 Child Protective Services agencies (Crosse, et al., 1992). Data for this study were collected from caseworkers responsible for the cases. That study reported that "the incidence of maltreatment... among children with disabilities was 1.7 times higher than the incidence of maltreatment for children without disabilities" (p. vi). In all, 36 children with disabilities per 1,000 had been maltreated. Among children with disabilities who had been maltreated, caseworkers expressed their opinion that the presence of a disability contributed to or led directly to maltreatment for 47% of the children.

A third study examined whether the experience of being maltreated as a

child is associated with later entry into the special education system. A seven-year longitudinal study of 8,000 children whose families received Aid to Families with Dependent Children found that among children who were not already receiving special education services at the time they were abused, children who had experienced substantiated maltreatment were 1.9 times more likely to enter special education than children who did not experience substantiated maltreatment (Jonson-Reid, Kim, Porterfield, & Han, 2004). This was true even after controlling statistically for the presence of medical conditions that pose a developmental risk at birth. This study suggests that not only are children with disabilities at higher risk of entering the child welfare system, but that children who enter the child welfare system are at higher risk of having or acquiring disabilities requiring special education services.

The studies cited above report experiences of children who had contact with the child protection system for some reason. They do not examine the general population of children with disabilities. The 1994/1995 National Health Interview Survey on Disability (NHIS-D), on the other hand, collected nationally representative information from 202,560 people in nearly 100,000 households. In that study, the estimated prevalence of intellectual or developmental disabilities (ID/DD) amongst persons not living in group homes or institutions was 38.4 per 1,000 for children ages birth to five years, and 31.7 per 1,000 for children ages 6 to 17 years (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2001). An estimated 939,617 children ages birth to five years, and 1,452,359 children ages 6 to 17 years had ID/DD in 1995 (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2001). In addition, many more children

Whichever numbers are used, it is clear that the child welfare system must be prepared and equipped to support and serve substantial numbers of children with disabilities.

Services, 2005). In that study, children with disabilities accounted for 6.5% of all child victims. However, this is considered to be an undercount because not every child receives a clinical diagnostic assessment by child protective services. Children identified as having disabilities were 1.57 times more likely to have experienced abuse or neglect and were 1.51 times more likely to experience recurring abuse or neglect as children without disabilities. Approximately 57% of victims, and 25% of children involved in cases not determined to be abuse, received services as a result of an investigation or assessment. Children with disabilities who were abused or neglected were 89% more likely to receive services and twice as likely to be placed in foster

had substantial functional limitations in self-care, expressive or receptive language, learning, mobility, and self-direction, but did not have ID/DD (Anderson, Larson, Lakin & Kwak, 2002). The estimated prevalence of substantial functional limitations but not ID/DD was 39 per 1,000 for children ages 6 to 17 years (an estimated 1.8 million children). Children younger than six with substantial functional limitations were included in the ID/DD group.

The NHIS-D asked questions about both disability status and about services people received. Among children with ID/DD or functional limitations, 10% received social work services through school (Anderson, Larson, Lakin & Kwak, 2002). An estimated 11% of children with ID/DD (an estimated 263,000 children) and 6% of children with functional limitations but not ID/DD (an estimated 108,000 children) received social work services in other settings. The NHIS-D did not specifically ask whether the social work services received were provided by the child protection system or whether they were provided through the human services system.

As noted earlier, several of the reviewed studies reported that children with disabilities were more likely to experience abuse or neglect than were other children. Factors reported to be associated with an increased risk of child sexual abuse include gender (girls are at higher risk), age (older children are at higher risk), disability (children with disabilities are at higher risk), and family constellation (the absence of one or both parents is a significant risk factor) (Putnam, 2003). Factors reported to increase the risk of physical abuse or neglect include younger age, lower socioeconomic status, teenage parents, parents who abuse substances, single parents, and parents with cognitive limitations (Putnam, 2003; Kaplan, Pelcovitz & Lebruna, 1999). The NHIS-D data describe the extent to which these and related risk factors are present among children with disabilities living with their families or in other non-institutional settings. For example, children with ID/DD

were significantly less likely to live with both parents than other children (61% versus 70%). They were also significantly more likely to live in families with below poverty level incomes (Larson, Lakin, Anderson & Kwak, 2001). Furthermore, more than 30% of families of children with disabilities reported that the child's disability caused parents to make one or more of the following accommodations: not accepting a job offer, changing work hours, working fewer hours, quitting work, changing sleep habits, turning down a better job, changing jobs, or having severe financial problems (Anderson, Larson, Lakin & Kwak, 2002). The presence of a child with a disability increases stress for many families, and for some families the combination of stressors and other family characteristics or problems leads to involvement with the child welfare system.

These studies show that having a disability puts a child at increased risk of abuse or neglect. It also puts the child at increased risk of participating in the child welfare system and the foster care system. Furthermore, the experience of abuse or neglect increases the risk that children who had not previously been receiving special education services will receive those services. The NCANDS study estimated that approximately 59,000 children with disabilities had experienced abuse or neglect in 2003. This is lower than the estimated 86,000 children with intellectual or developmental disabilities or the estimated 151,000 children with any type of disability who could be expected to have experienced abuse or neglect if the incidence of abuse of 36 per 1,000 in the Crosse study is combined with the estimated prevalence of intellectual or developmental disabilities (2.39 million children) or estimated prevalence of any type of disability among children (41.9 million children) from the NHIS-D. Whichever numbers are used, it is clear that the child welfare system must be prepared and equipped to support and serve substantial numbers of children with disabilities. This may require increased cooperation between child protective

service systems and disability service systems at both the state and local levels. This cooperation should address the provision of supports that can help prevent abuse and neglect in at-risk families, such as respite care, parent education and training, and other supportive services.

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Serving Children with Disabilities in the Child Welfare System: Barriers and Strategies

by Elizabeth Lightfoot and Traci LaLiberte

There are a number of barriers to providing services to children and youth with disabilities in the child welfare system. This article describes three that have the greatest impact: the need for greater disability competence on the part of child welfare service providers, the need to overcome systemic barriers, and the need for increased empirical knowledge. While there is limited research into best practices for serving children with disabilities and their families who are involved in the child welfare system, there are some important positive strategies that are being successfully used in a number of locations to address these barriers; this article presents three such strategies.

Need for Disability Competence

One barrier to serving children with disabilities is the lack of disability competence on the part of child welfare workers. They typically receive little training on disability issues in their formal education, and disability has not been a popular continuing education topic in the realm of child welfare. Because of the lack of disability competence, child welfare workers who have cases involving people with disabilities may find challenges relating to their lack of knowledge. In fact, in a recent survey of child protection managers and supervisors, workers most often cited specific factors related to the disability of an individual as a barrier to serving children with disabilities in the child welfare system (Lightfoot & LaLiberte, in press). Child protection employees cited such disability barriers as communication challenges, behaviors associated with particular disabilities, and the chronic nature of some disabilities, such as mental illness. However, the focus on a specific disability may actually reflect the lack of disability competence by workers within child welfare agencies. In this

same survey, child protection managers and supervisors discussed the lack of disability knowledge by their workers and allied professionals, such as law enforcement and court personnel, as another key barrier to serving people with disabilities. Because of their lack of knowledge and skills in relation to disabilities, child protection workers may perceive that issues surrounding a particular disability are the problem. However, from a social model view of disability, the barrier is not the disability itself, but is rather the lack of knowledge of professionals on how to work with people with disabilities and accommodate their needs.

Systemic Barriers

Even for child welfare workers who have the knowledge and skills in serving children and youth with disabilities, there are a number of systemic barriers impacting their ability to provide appropriate services. A top systemic barrier is lack of financial resources and funding to provide families of children with disabilities the support that they need to parent their children. In addition, there is a shortage of child welfare providers who have expertise in both child welfare and disabilities, and those specialized providers that do exist often have long waiting lists.

Another systemic barrier relates to the multitude of systems with which a child with a disability interfaces. A family involved in the child protection system is often receiving mandated services from the child protection system, along with voluntary services from the disability service system. These two systems not only have different philosophies, but also have separate legislation, rules, and bureaucratic procedures. Because these two systems are generally not well-integrated, the resulting red tape is a serious barrier to obtaining services. Further, the federal and state laws mandating child protec-

tion services usually are not written with disability accommodations such as extended timeframes or modified parenting classes in mind. For example, the timeframes mandated by the Adoption and Safe Families Act placement can cause barriers in working with children with disabilities because a longer timeframe may be needed to obtain services or for the family to otherwise comply with an order from child protection. Such accommodations are often not provided.

Rural areas often have additional barriers to services, including lack of service providers, especially specialized providers such as child psychologists, specialized parenting classes or accessible foster care (Lightfoot & LaLiberte, in press). The services that are available are often a long distance from where many families live. Parents of children with disabilities frequently have to drive long distances to access needed services, and those without private transportation may be unable to receive the supportive services they need. A final rural concern is that child welfare agencies in rural areas may not have a critical mass of cases involving children or youth with disabilities that is necessary to develop expertise in disability issues.

Too Little Empirical Knowledge

A final barrier is the general lack of empirical knowledge about prevalence of children with disabilities in the child welfare system and appropriate strategies and services to meet their needs. While many professionals in the child welfare and disability arenas would anecdotally point to the high rates of maltreatment involving children with disabilities, there have only been several studies actually measuring the prevalence of such abuse (Sullivan & Knutson, 2000; Westat, 1993). Only 19 state child protection systems collect data related to disability in their state registries, and only 7 require

child protection workers to be trained in recognizing and entering disability data (Bonner, Crow, & Hensley, 1997). There is even less information on how child welfare agencies serve clients with disabilities and no empirical studies on child protection strategies that are effective for families with a child with a disability.

Increasing Disability Competence

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. Trainers on disability competency are available in many communities through disability advocacy and resource organizations, as well as state or county disability services agencies. Further, some social work departments at local colleges and universities can provide staff training in serving people with disabilities in the child welfare system. Some agencies have increased their disability competence by the use of specialty child protection workers or units (Lightfoot & LaLiberte, in press) with particular training and expertise in disability issues. For agencies that have specialty workers or units, all child protection cases involving people with disabilities are handled by these experts.

Collaborating

Currently, the greatest need is for increased collaboration among personnel in the child welfare and disability fields. Informal collaboration with disability professionals is the most common way that child welfare workers gain information and skills needed in serving clients with disabilities (Lightfoot & LaLiberte, in press). These informal collaborations can involve a child welfare worker simply asking a question regarding resources, or could involve a disability worker aiding a child welfare worker in assessing risk of maltreatment. Some public child welfare agencies also have formalized such collaboration. Some agencies have two case workers – one from the child protection

unit and one from developmental disabilities unit – working together on all cases involving a child with a disability who has an open child protection case. Other child protection units team all of their cases with someone in the disability unit, which can aid in identifying children who may be eligible for disability services. When these types of collaborative efforts work well, the workers can overcome some of the systemic barriers mentioned above.

Conducting Further Research

Finally, there needs to be further research on children with disabilities involved in the child welfare system. Federal regulations should be changed to require child welfare agencies to report on the number of children with disabilities involved in the child welfare system, and the outcomes of these children's cases. This would provide data that could enable researchers to further address the resource and services barriers.

Conclusion

In order for children with disabilities involved in the child welfare system to achieve the best possible outcomes, the system must provide accessible, appropriate services to these children and their families. The strategies in this article provide a starting point.

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Family Support Strategies

The following are some strategies that may be useful in supporting struggling families and preventing out-of-home placement of children with disabilities:

- **A Support Family.** *A Support Family provides family life for a child when their birth family is unable to provide it or provide it full-time. Within disability services, it is a way to provide shared parenting as an alternative to residential placement for a child whose family is considering voluntary out-of-home placement; it may be a valuable prevention strategy for use by the child welfare system, as well. A Support Family differs from a foster family in that it is recruited specifically for a child with disabilities and makes a long-term commitment to that child, birth parents can share parenting with a Support Family through mutual agreement without giving up their rights, and the Support Family is trained to care for the particular child placed with it.*

- **Respite.** *Respite programs provide temporary care by trained individuals for children with disabilities. They give the family a break from caregiving, reduce family stress, and create time for other activities. Respite may be in-home or out of home; among the out-of-home options are respite in the provider's home, a day care center, a group foster home, and homes of a circle of families that provide respite for each other.*

- **Parent Training and Support.** *Parent training and education programs, support groups, and other family support services through disability and other human service organizations/agencies can assist parents with learning about the disability of their child, building skills in caring for their child, attending to the whole of family life, and finding peer support with other parents of children with disabilities.*

Information on Support Families adapted from *Options for Parents*, Every Child Inc., Austin, Texas, www.everychildtexas.org/optionsparents.shtml. Information on respite adapted from *FactSheet Number 2, Respite for Children with Disabilities and Chronic or Terminal Illnesses*, National Resource Center for Respite and Crisis Care Services, www.archrespite.org/archfs02.htm.

Child Welfare Services: How Children with Disabilities Move Through the System

by Traci LaLiberte and Elizabeth Lightfoot

When a child with a disability enters the child welfare system as a result of a report of abuse or neglect in their home environment, a complicated collaboration must take place between professionals who understand disability and those whose responsibility is child protection. Children with complex medical needs who require specialized daily

process children with disabilities and their families go through when engaged in this traditionally involuntary service system. The structure of child welfare services varies from state to state, and in some states from county to county or region to region. However, all child welfare agencies carry out four similar tasks: intake, investigation and assessment, ongoing services, and permanency services. For each of these tasks, child welfare workers need access to expertise in disability. Workers who do not themselves have such knowledge should involve experts in the disability field – which may include professionals from medical and disability services areas, disability advocacy agency staff, individuals with disabilities and their families, researchers, and others – when working with children or youth with disabilities. This collaboration between child welfare personnel and those experienced with disability is essential to ensuring that children with disabilities and their parents get effective, appropriate, and fair services.

Intake Services

During intake, the child welfare agency receives a report of suspected child abuse or neglect by either a person mandated by law to report such abuse, a family member or a community member. The child welfare worker seeks to obtain as much information from the reporter as possible and creates a formal report for the agency. It is important at this stage of the intake process for information regarding the disability of a child or youth to be included in the report so that the child welfare staff can plan for appropriate, accessible services. At the point of intake, child welfare staff will make a decision to accept or not accept the report, based upon its fit with the agency's mission and the state

statutes to which the agency is accountable. If the report is accepted, child welfare will investigate the case for validity of the allegations.

Investigation and Assessment Services

During investigation and assessment, the child welfare worker gathers information about the current allegation of abuse and/or neglect and assesses the current functioning of the family. The child welfare worker should be in contact with all family members, the reporter if possible, and any other important contacts, such as school personnel, day care providers, medical providers, therapists, other service providers, and law enforcement. Often during the investigation and assessment period, child welfare workers rely on disability experts inside or outside the social services agency. Disability experts can provide consultation on communication techniques for interviewing children with communication disabilities, appropriate care for children with certain types of disabilities, and accommodation issues. Children may need to see a medical provider or other specialist to determine the nature of marks, bruises, or other physical conditions that are pertinent to the allegations, and child welfare workers may need to seek out providers who specialize in the care of children with disabilities.

Child welfare workers generally use a risk assessment tool to guide them in making assessments. On such tools, the presence of disability can represent an increased potential for abuse in a family; however, the presence of appropriate service providers or other supportive activities, such as participation in parenting or advocacy groups, can offset this risk. Child welfare workers will typically ask questions related to the child or

When a child with a disability enters the child welfare system, a complicated collaboration must take place between professionals who understand disability and those whose responsibility is child protection.

health care, children with mobility limitations who need wheelchair-accessible environments and assistance with moving about, children with cognitive disabilities who need individual-specific support and interaction in their everyday routine, as well as children with other types of disabilities, all call upon the child welfare system to understand and respond appropriately to their needs. Conversely, to support such children within the child welfare system requires the participation of those with expertise related to the child's disability. This necessitates understanding how the child welfare process works and how disability service providers, advocates, and other professionals should be involved.

The following presents an overview of the child welfare system and of the

youth's disability to determine if an increased risk of maltreatment is present. An example of such questions include (Wahlgren, Metsger & Brittain, 2004, p. 230):

- What kind of kind of physical demands result from the child's disability?
- What is the financial impact of the child's disability?
- How do family members react to the child's disability (e.g., rejection, guilt, jealousy, feelings of inadequacy)?
- Are there cultural or religious factors that would shape family perceptions (Wayman, Lunch, & Hanson, 1990)?
- To what/where/whom does the family assign responsibility for their child's disability (Wayman et al., 1990)?
- How does the family view the role of fate in their lives (Wayman et al., 1990)?
- How does the parent or caregiver respond to the child with special needs?
- How does the family view their role in intervening with their child? Do they feel they can make a difference, or do they consider it hopeless (Wayman et al., 1990)?

Based upon the investigation and assessment process, child welfare workers make a determination regarding abuse or neglect. The determination can result in the case being (a) substantiated and the family is provided ongoing services in the presence of abuse or neglect; (b) substantiated and closed if the risk for abuse or neglect is no longer present; (c) unsubstantiated and closed if the abuse or neglect did not occur; and (d) unsubstantiated and the family is provided services when abuse or neglect is not present but the family is at-risk. Some child welfare agencies do not provide for the last determination due to fiscal restraints or agency mission. At times, the risk assessment may indicate a need for the immediate removal of a child from the home.

Ongoing Family Services

During ongoing family services, the child welfare worker provides families with services with the goal of restoring the family to a situation in which the children can be safely cared for in their own home. During this phase, the children may be living at home, in temporary foster care or some other appropriate residential setting. In cases that involve a family member with a disability, disability professionals are critical to the services provided to the family. For children with disabilities, the disability professionals may play a crucial role in assisting the child welfare agency to access and secure funding for appropriate resources, such as respite care, personal assistance or home modifications. They may also help in locating or designing accessible family services, such as parenting skill training geared towards parenting children with disabilities, or in finding foster care providers experienced in caring for children with disabilities. If a parent has an intellectual disability, the disability expert's assessment of parental functioning and safety is often critical to the case decisions made by the child welfare worker. Observations and information offered by disability professionals may be used by child welfare workers in ongoing case management, risk assessments, decisions of removal, decisions to return children home, designing case plans, and decisions to close cases.

Permanency Services

When a child welfare agency determines that parents are unable to change sufficiently to take care of their children safely and in a timely manner, the child welfare system provides permanency services. The Adoption and Safe Families Act dictates the amount of time a parent has to make the necessary changes to have their child returned to their care. If they aren't able to meet the indicated timeframe, their parental rights will likely be "terminated." The agency will pursue a permanency hearing in court, requesting either a transfer

of guardianship or the termination of parental rights. During this phase, child welfare provides services primarily to the child, while services to parents may cease. Child welfare workers must find a permanent setting in which the child can live. In cases involving a child with a disability, this means the worker will rely heavily on the disability professionals involved in the case to articulate the child's needs (in addition to the child and family) and to aid in the search for an appropriate permanent placement.

In addition to the four common child welfare tasks, some public child welfare agencies have embraced child welfare reforms and also offer services such as alternative response and family group decision making. These services provide child welfare agencies with different ways of interacting with families to achieve positive outcomes for children and their families. Alternative response provides the agency flexibility in responding to a family where the risk is lower and the provision of services to that family may bring about a stable and safe situation. For a family with a child or youth with a disability, this form of child welfare intervention may be all they need to receive assistance and services. Family group decision-making typically involves extended family members in the case planning process in an attempt to use resources within their own familial structure to plan for the safety and well-being of the children. Again, this approach may be beneficial to families in which a child or youth has a disability. Extended family members may brainstorm ways in which they can come together to support the child and the parents.

Cross-System Collaboration

Collaboration between child welfare professionals and other key professionals is critical throughout a family's child welfare involvement. Disability and other key professionals should be contacted for collateral information in the early stages of a case in order to gather information regarding the child's and

[LaLiberte, continued on page 38]

Child Welfare Legislation Affecting Children with Disabilities

The following summarizes some of the federal laws that apply to children with disabilities who have been removed from their families either temporarily or permanently, or who are in families that can benefit from prevention or intervention efforts in order to continue parenting their children with disabilities. On the following page is information about another significant federal law, CAPTA.

- **Adoption and Safe Families Act of 1997 (ASFA, P.L. 105-89).** ASFA has three primary goals: child safety, permanency, and child well-being. ASFA marks the shift away from “family preservation” in the child welfare field to a focus on accountability and outcomes. A significant aspect of the legislation directs child welfare workers and agencies to make what is termed “reasonable efforts” to prevent unnecessary removal of a child and to reunify children with their parent(s). Specific criteria were also set for cases in which child welfare professionals were not required to provide reasonable efforts (e.g. parent has murdered or attempted to kill a child, or has had parental rights to another child terminated). Another key aspect of the ASFA legislation is the minimum timelines for reunification. When a child has been removed from their caregiver, in addition to temporary custody hearings, a permanency hearing must be held within 12 months. For children remaining in foster care for 15 or 22 months, it’s mandatory for child welfare professionals to file for termination of parental rights. Exceptions to these timeframes include the child is in the care of a relative, the child welfare agency documents a compelling reason why filing is not in the best interest of the child, and the child welfare agency has not provided to the child’s family the services deemed necessary to return the child to a safe home consistent with the time period in the case

plan. States can legislate shorter reunification times.

Sections specifically addressing children with special needs include provision for health insurance coverage for children with special needs for whom there is in effect an adoption assistance agreement or whom the State has determined cannot be placed with an adoptive parent(s) without medical assistance because the child has special needs for medical, mental health, or rehabilitative care; and provision for adoption assistance payments to continue for children with special needs who were eligible at the time of an adoption that has now been dissolved – the eligibility may continue into the next adoption.

In relation to children with disabilities, it is also important to note that the timeframes for reunification in this legislation can present a hardship. For children with disabilities it often takes considerable time to locate or create services tailored to meet the individual’s needs. If a parent needs to participate in those services in order to work toward reunification, the time it takes to begin services still counts against their 12- or 22-month permanency timeframe. In cases such as these, child welfare workers would need to advocate in court for the parent to have additional time for reunification because these circumstances are beyond the control of the parent.

(Information based on “Major Federal Legislation Concerned with Child Protection, Child Welfare, and Adoption” from the National Clearinghouse on Child Abuse and Neglect Information, <http://nccanch.acf.hhs.gov/pubs/otherpubs/fedlegis.pdf>, and on text of the Act at <http://frwebgate.access.gpo.gov>)

- **Social Security Act Adoption Assistance. Title IV-E** is the federally funded adoption assistance program

that provides financial support to adoptive parents of children with special needs. The definition of special needs, under section 473(c) of the Act, varies by state but must meet three criteria: (a) the child cannot or should not be returned to his/her parental home, (b) there is a specific factor or condition that makes it reasonable to conclude that adoption assistance will be necessary to facilitate adoption – possible factors include presence of a disability; and (c) reasonable but unsuccessful efforts have been made to place the child without adoption assistance. For children identified by a State as “special needs,” those who meet the requirements for **Title XVI Supplemental Security Income** benefits at the time of adoption are among those eligible for adoption assistance; children eligible for SSI have significant disabilities (these commonly include Down syndrome, deafness, blindness, and cerebral palsy).

(Information based on “Title IV-E Eligibility & Benefits” and “Adoption Subsidy Definitions–United States” from the North American Council on Adoptable Children, <http://www.nacac.org>)

- **Foster Care Independence Act of 1999 (P.L. 106-169).** The Foster Care Independence Act and the Chafee Program provide for permanency planning specific to the needs of adolescents in out-of-home care. They provide financial assistance to states for child welfare agencies delivering independent living training to youth, transitional living programs for emancipated youth, and Medicaid coverage extending to age 21.

(Information based on “Foster Care Independence Act of 1999” from the Child Welfare League of America, <http://www.cwla.org/advocacy/indlivhr3443.htm>)

Children with Disabilities and the Child Abuse Prevention and Treatment Act

by Kim Musheno

The incidence of disability among abused and neglected children is staggering. Too often, disability and child abuse follow two intertwined pathways. First, children with disabilities are particularly vulnerable to child abuse, and some studies have demonstrated that children with disabilities are almost four times more likely to be victims of maltreatment than children without disabilities (Sullivan & Knutson, 1998). Second, many cases of abuse and maltreatment

The Child Abuse Prevention and Treatment Act (CAPTA, P.L. 108-36) is one of the only federal programs that provides funding for prevention activities.

contribute to the development of childhood disabilities. According to one study by the National Center on Child Abuse and Neglect, over a third of substantiated cases of maltreatment led to acquired disabilities (National Center on Child Abuse and Neglect, 1993). Preventing child abuse and neglect is integral to promoting the health, well-being, and maximum potential of all individuals, including individuals with disabilities.

The Child Abuse Prevention and Treatment Act (CAPTA, P.L. 108-36) is one of the only federal programs that provides funding for prevention activities. The Keeping Children Safe Act of 2003 amended CAPTA and was signed into law on June 25, 2003. One of the key provisions is authorization for grants to states to (a) support collaboration among public health agencies, the child

protection system, and private community-based programs; (b) provide child abuse and neglect prevention and treatment services; and (c) address the health needs, including mental health needs, of children identified as abused or neglected. This entails prompt, comprehensive health and developmental evaluations for children who are the subject of substantiated child maltreatment reports. Some of the other important provisions successfully incorporated include:

- New eligibility requirements and support for training, technical assistance, research, innovative programs addressing linkages between the child protective system, and community-based health, mental health, and developmental evaluations.
- Support for research on effects of maltreatment on child development and identification of successful early intervention services.
- Support for research on voluntary relinquishment to foster care of low-income children in need of health or mental health services.
- Provision for referral of a child under age 3, in a substantiated case of abuse or neglect, to early intervention services funded under the Individuals with Disabilities Education Act (P.L. 105-17, IDEA) Part C.
- Language replacing statewide networks with community-based and prevention focused activities throughout Title II.
- Language replacing “family resource and support program” with “programs and activities designed to strengthen and support families and prevent child abuse and neglect (through networks where appropriate).”
- Emphasis on the importance of respite as a critical component of child abuse and neglect prevention in Title II.

- Inclusion of families of children with disabilities, parents with disabilities, and organizations who work with such families is strongly emphasized throughout Title II, particularly in the eligibility section.

One of the most important but somewhat controversial changes mentioned above is the requirement that States develop provisions and procedures for referral of a child under the age of 3 who is involved in a substantiated case of child abuse or neglect to early intervention services funded under Part C of IDEA. Part C is a component of IDEA under which states have created their early intervention services system for infants and toddlers with disabilities and their families. In spite of the fact that many of the children in the child welfare system are eligible for Part C, the rates of their referral to the early intervention program have been very low. However, the current early intervention system is struggling to serve the families now enrolled. The new CAPTA requirements will substantially increase the workload for providers of Part C evaluation and intervention services. Currently, Part C serves about 227,000 children (2% of the population under 3) nationwide (U.S. Department of Education, 2000). Rough estimates suggest that an additional 167,000 children would need to be screened for eligibility for early intervention services as a result of the CAPTA amendments. And, from that number, approximately 44,000 could be enrolled in the Part C program (Rosenberg & Robinson, 2003).

Without additional resources to the Part C and CAPTA state agencies, the promise of the CAPTA amendments will not be realized. In addition to the increased numbers of children that Part C will assess and serve if referrals from child protection are regularized, the

[Musheno, continued on page 39]

Out-of-Home Placement and the Developmental Disabilities Service System

by *Charlie Lakin*

The Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272) made permanency planning national policy. This policy was designed to respond to the sense of Congress that too many children and youth were being placed outside their family homes; that too many once placed never returned home; and that too many were growing up without the social, cultural and developmental benefits of family living. At its foundation permanency planning is a commitment to honoring the important role of family life in child development.

Within developmental disability service systems permanency planning for children and youth with disabilities has been promoted for the social, cultural, and developmental benefits of family life, and as a means of overcoming an unfortunate history in which out-of-home placements for children with intellectual and/or developmental disabilities (ID/DD) were common and widely viewed as beneficial to both the family and child. These placements occurred through both the developmental disability and child welfare service systems.

Beginning in the mid-1970s a number of social reforms began to give substance to the idea that children with disabilities, like their non-disabled peers, deserved the benefits of family life. These reforms, which took foothold primarily within the developmental disability service system, included Supplemental Security Income (SSI) for low-income families of children with disabilities (1974); free and appropriate educational programs for children with disabilities in their own communities (1976); a range of state family support and subsidy programs with respite care, personal care, and other services and cash assistance; and a rapidly growing number of children, youth and families supported within Medicaid Home and Community Based Services (1981).

A quarter century after its introduc-

tion as national policy, permanency planning remained an important concept in the formulation of Healthy People 2010, a national initiative to establish goals and specific objectives with regard to health in the United States. The overarching goals of Healthy People 2010 are: "1) increasing the quantity and quality of life for Americans, and 2) eliminating the disparities in health among us" (National Center on Birth Defects and Developmental Disabilities, 2001, p. 1). Among the 13 objectives established for national performance in effective support of persons with disabilities is "Objective 6.7: Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles" (p. 89). The specific measurable national objective established around permanency planning was "Objective 6.7b: Reduce to zero the number of children aged 17 years and younger living in congregate care facilities" (p. 89). Congregate care facilities were defined as "settings in which children or adults with disabilities live in a group of 4 or more people with disabilities, in order to receive needed supports and services" (p. 89).

In an effort to establish the national performance related to Objective 6.7b, in June 2005 state developmental disabilities program agencies were requested to report the numbers of children (0-14 years), youth (15-18), and young adults (18-21 years) with ID/DD in "out-of-home residential placements." Out-of-home residential placements were defined as individuals receiving residential supports who are not living with parents or other relatives. State reports included children placed out-of-home by developmental disabilities programs, and did not necessarily include children with ID/DD placed through the child welfare system.

Between June 1977 and June 2005 children and youth with ID/DD in out-of-home placements through the develop-

mental disability service system decreased from an estimated 90,942 (36.7% of all persons in residential settings) to an estimated 26,395 (6.2% of all persons in residential settings). To be sure these changes were the product of important national and state commitment to families of children with ID/DD. Braddock et al. (2005) report that \$1.98 billion in service and subsidy expenditures were provided for various family supports and cash assistances in FY 2004, excluding SSI and Medicaid health benefits. While such statistics give reason for satisfaction, the number of children in congregate care settings far exceeds the national objective and the rate of decrease appears to have slowed substantially in recent years. In 1997, an estimated 26,028 persons with ID/DD 21 years or younger received out-of-home residential supports (.98 per 1000 persons 21 and younger in the general population); in 2005 the number was 26,395 (about .90 per 1000 persons 21 years and younger). Along with the modest decrease in the number of out-of-home placements indexed for population, there was also a decrease in the proportion of persons 21 and younger among all persons receiving out-of-home residential services for persons with ID/DD (from 7.6% in 1997 to 6.2% in 2005). The trend toward decreasing numbers of children 14 years and younger continued between 1997-2005 (from an estimated 10,243 to 7,926), but was offset by an increase in the number of youth 15-21 in out-of-home settings.

In general, then, it appears that within the developmental disability service delivery system great progress has been made in the past three decades in reducing out-of-home placements of children and youth with ID/DD, and, unfortunately, this progress has substantially slowed or halted in recent years, depending on the measure selected. The nation clearly has considerable distance to go in accom-

plishing its national permanency planning objective for young people with disabilities, especially in light of the data from the U.S. Children's Bureau reporting that child welfare agencies have placed children with disabilities more than twice as often in foster care than children without disabilities (U.S. Department of Health and Human Services, 2005a), and that there is a scarcity

of appropriate placement options through the child welfare system for children with ID/DD (U.S. Department of Health and Human Services, 2005b).

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A Statement in Support of Families and Their Children

The following statement was developed by advocates and parents in 1986 at a meeting sponsored by the Center on Human Policy at Syracuse University, and still stands today as a clear assertion of the importance of family for children with disabilities.

These principles should guide public policy toward families of children with developmental disabilities and the actions of states and agencies when they become involved with families:

- **All children, regardless of disability, belong with families and need enduring relationships with adults.** When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and pursuit of adoption for children when reunification is not possible.

- **Families should receive the supports necessary to maintain their children at home. Family support services must be based on the principle "whatever it takes."** In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

- **Family supports should build on existing social networks and natural sources of support.** As a guiding principle, natural sources of support, including neighbors,

extended families, friends, and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

- **Family supports should maximize the family's control over the services and supports they receive.** Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.

- **Family supports should support the entire family.** Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents, and siblings.

- **Family support services should encourage the integration of children with disabilities into the community.** Family support services should be designed to maximize integration and participation in community life for children with disabilities.

- **When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family.** Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, due to family crisis or other circumstances, children

must leave their families, efforts should be directed at encouraging and enabling families to be reunited.

- **When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued.** In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibility of "open adoption," whereby families maintain involvement with a child, should be seriously considered.

- **While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families.** After families and adoptive families, children should have the opportunity to live with foster families. Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. As a state or agency sponsored program, however, foster care seldom provides children the continuity and stability needed in their lives. While foster families may be called on to assist, support, and occasionally fill in for families, foster care is not likely to be an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships.

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Understanding Adoption Subsidies: An Analysis of AFCARS Data

Adoption subsidies are perhaps the single most powerful tool by which the child welfare system can encourage adoption and support adoptive families. The federal Adoption Assistance Program was created by Congress in 1980 to ensure that families adopting foster children with special needs could do so

The federal Adoption Assistance Program was created by Congress in 1980 to ensure that families adopting foster children with special needs could do so without reducing or exhausting their resources.

without reducing or exhausting their resources. This federal adoption subsidy program entitles all families adopting children from foster care with special needs, who cannot meet their needs, to obtain subsidy support. Federal expenditures for adoption assistance have grown rapidly since the program was created, from less than \$400,000 in fiscal year 1981 to \$1.3 billion in fiscal year 2002, and are expected to approach \$2.5 billion by FY 2008.

Little is known about the factors associated with the receipt and amount of subsidies. Data from the Adoption and Foster Care Analysis and Reporting System (AFCARS) offer an opportunity to examine how states use adoption subsidies to help achieve goals of permanency and well-being for children. Of particular interest to this study are patterns of subsidy receipt, the role of federal support for adoption subsidies under Title IV-E of the Social Security Act, and the relationship between adoption

subsidies and adoption outcomes, including the rate of adoptions among eligible children and the timeliness of adoption.

The analyses presented in this report [for full report see <http://aspe.hhs.gov/hsp/05/adoption-subsidies/>] explore patterns of subsidy receipt, and how subsidies are related to adoption outcomes such as the rate of adoptions among eligible children and how quickly eligible children are adopted. Questions of interest include the extent and funding of subsidies; the relationship between children's characteristics, foster care experiences, and subsidy receipt and amount; and variations among states in subsidy practice. These analyses use AFCARS data representing all adoptions from foster care during the years FY 1999 to FY 2001, with additional data from the AFCARS foster care file for 2001. Three types of analyses are presented:

1. Descriptive analyses of both national trends and variations among states;
2. Correlations among state-level measures, examining relationships among state subsidy practice and adoption outcomes; and
3. Multivariate analyses addressing the relationship of child, family, and state characteristics to subsidy receipt and subsidy amount.

At the national level, subsidy practice shows some clear patterns in relation to characteristics of adopted children and adoptive families. However, the variations among states are also striking. The following key findings represent both national patterns and variations among states:

- Nearly all children adopted from foster care in recent years received an adoption subsidy. Nationally, 88 percent of children adopted in FY 2001 received an adoption subsidy, with subsidy receipt ranging from 13 percent to 100 percent across states. Nearly all adopted children (88 per-

cent) were identified as having special needs, the primary bases for providing a subsidy. The special needs definition used in adoption varies by state, but includes both disabilities and other factors, such as age, that make finding an adoptive home more challenging.

- The median monthly subsidy amount was \$444 per month. At the state level, median subsidies ranged from \$171 to \$876 monthly. Although states have the option of offering payment agreements that don't start immediately, providing the basis to award a subsidy in the future if the child's needs change, very few adopted children were shown as having an

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adoption assistance agreement with what appeared to be a placeholder payment of \$0 or \$1.

- Among newly adopted children receiving subsidies, 84 percent received federal adoption assistance through Title IV-E. States with higher rates of Title IV-E eligibility provided subsidies to more children. Multivariate analyses found associations between Title IV-E eligibility and subsidy receipt and

amount. States with higher federal matching rates (indicating lower state per capita income) offered lower subsidy amounts, suggesting that even augmented federal contributions did not offset limited financial resources within these states.

- Children's age and special needs status influenced subsidy receipt and amount. Older children were more likely to receive subsidies, and to receive larger subsidies; race and ethnicity did not influence subsidies. Boys received slightly higher subsidies than did girls.
- Pre-adoptive relationship and other characteristics of adoptive families influenced children's subsidies. Children adopted by foster parents were more likely to receive subsidies than others. They also received higher subsidies than children adopted by

relatives. Children adopted by single females received higher subsidies than those adopted by married couples.

- Analyses found some support for associations between subsidies and adoption outcomes. State-level analyses show a significant correlation between subsidy receipt and the percent of each state's eligible children who are adopted. Multivariate analysis found that children living in states where the median time to adoption was longer were more likely to receive subsidies, and received higher subsidies. Possibly, states are using subsidies strategically to address the backlog of waiting children in foster care and meet their adoption goals.

The limitations of the AFCARS data set suggest that more compelling analy-

ses may be possible using state administrative databases, with greater opportunities to compare children's foster care and adoption experiences. These analyses, however, make use of AFCARS to provide an overview of how adoption subsidies are used to encourage permanency for children.

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Information on Adoption Subsidies in Each State

The National Adoption Information Clearinghouse Web site offers information on state-funded adoption assistance programs in each of the states. The clearinghouse (<http://naic.acf.hhs.gov>), a service of the Children's Bureau, Administration for Children and Families, U.S. Department of Health and Human Services, provides details on the following for each state:

Who is Eligible for Adoption Assistance?

- What specific factors or conditions does your State consider to determine that a child cannot be placed with adoptive parents without providing financial assistance? ("What is your State definition of special needs?")
- What are the eligibility criteria for your State-funded adoption assistance program?
- What is the maximum amount a family may receive in non-recurring adoption expenses from your State? (Adoptive par-

ents can receive reimbursement of certain approved, "one-time" adoption expenses incurred in the process of finalizing a special needs adoption).

- Does your State enter into deferred adoption assistance agreements? (In some States, adoptive parents can enter into an agreement in which they choose to defer the receipt of a Medicaid card, the monthly monetary payment, or both and can elect to receive the Medicaid card and/or monetary payment at another time.)
- When may adoption assistance payments and benefits begin in your State?
- How are changes made to the adoption assistance agreement in your State?

Post-Adoption Services

- What types of post adoption services are available in your State and how do you find out more about them?

Medical Assistance

- What mental health services are provided by your State?
- Does your State provide additional finances or services for medical or therapeutic needs not covered under your State medical plan to children receiving adoption assistance?

Fair Hearings

- What is your State's process for applying for a fair hearing? (A fair hearing is a legal, administrative procedure that provides a forum to address disagreements with agency decisions).

Web/Internet Links

- What is your State Web address for general adoption information?
- What is your State Web address for adoption assistance information?
- What is your State Web address for State-specific medical assistance information for children?

Description adapted from http://naic.acf.hhs.gov/parents/prospective/funding/adopt_assistance/.

Youth with Disabilities Aging Out of Foster Care: Issues and Support Strategies

by Katharine Hill and Pam Stenhjem

The transition from high school to adult life can be exciting, but also challenging and even frightening. Young people are expected to live independently, continue their education, pursue careers, establish relationships, and participate in their communities. Meeting these goals is only part of the picture for youth with disabilities; additional social, academic, health, and environmental barriers must also be addressed (Lehman, Hewitt, Bullis, Rinkin & Castellanos, 2002; Cameto, 2005). Add foster care to this

reflect the same basic needs and goals for youth. The Individuals with Disabilities Education Act (IDEA) ensures youth with disabilities receive individualized supports and services to successfully complete high school and transition to postsecondary education, employment, and adult life. The Individualized Education Program (IEP) plan ensures formation of concrete goals with measurable outcomes based on each individual's future plans (NCSET, 2002). IDEA's definition of transition planning implies a comprehensive process addressing all life domains, including a "coordinated set of activities" planned and implemented by a transition team of education and service representatives, the parent/caregiver, and ideally the youth themselves (Lehman, et al., 2002; Cameto, 2005).

The John H. Chafee Foster Care Independence Program of 1999 doubles the amount of money available to states for independent living services, provides increased flexibility for development and implementation of Independent Living Programs (GAO, 2004), and supports outreach programs, education and employment assistance, daily living skills training, individual/group counseling, and service coordination. A required, transitional independent living plan supports youth to: develop critical competencies; obtain education, career counseling, physical/mental health care, and housing; develop relationships with caring adults; access community resources, public benefits, and services; and acquire daily living skills (Pokempner & Rosado, 2003). Up to 30% of program funds can pay for room and board. Education and Training Vouchers up to \$5000 per year are also available. States must coordinate Chafee programs with runaway, homeless youth, and housing programs; workforce agencies; disability services; and tribal entities (GAO, 2004).

IDEA and Chafee requirements are complimentary and have the potential to strengthen one another when combined. Best practice would dictate that these federal requirements and planning processes be coordinated when planning for the transition of foster youth with disabilities.

Youth with Disabilities in Foster Care

The prevalence of youth with disabilities in long-term foster care mandates specific attention and action. Although Chapin Hall's 2005 longitudinal Midwest Study of youth aging out of foster care excludes youth with developmental disabilities or severe mental health problems, nearly half the youth report receiving special education services (Courtney, 2005; Courtney, Terao, & Bost, 2004). Ironically, disabilities are rarely studied in relation to child welfare and are even less frequently considered in the transition from care (Geenen & Powers, 2006).

The National Evaluation of Title IV-E Independent Living Programs found foster youth with disabilities are less likely to be employed, graduate from high school, have social support, or be self-sufficient compared to non-disabled peers (Westat, 1991). In general, they have poor school performance, lag behind in academic achievement, and experience significant challenges to academic success (Geenen & Powers, in press). Although many foster youth have disabilities and should receive special education services, multiple moves, school changes, and inconsistent adult advocacy for comprehensive and appropriate IEPs means this is often not the case (Badeau, 2000).

A comparison of the IEP/ITPs (Individualized Transition Plans) of 45 foster special education students with the IEPs of 45 special education students not in

As foster youth with disabilities age out of the child welfare system, coordination of transition planning among key agencies and systems is imperative.

mix of challenges for youth with disabilities and successful outcomes can be significantly jeopardized. Youth aging out of foster care must first address basic, critical needs such as housing or medical care that youth in stable situations do not face (Osgood, Foster, Flanagan & Ruth, 2004). Foster youth experience many disruptions growing up and often require extensive supports in transition to adulthood (Massinga & Pecora, 2004). This article addresses the unique needs of foster youth with disabilities and best practices in the transition planning process.

Impact of Legislation

Federal legislative mandates protecting youth with disabilities as well as those in foster care are very compatible and re-

care (Geenen & Powers, in press) indicates the foster youth were significantly less likely to have independent living and postsecondary education goals. Foster youth and educational advocates rarely attended IEP meetings and low wage jobs with little opportunity for advancement were the norm. In addition, IEPs indicated very few extracurricular activities and lack of self-determination training, person-centered and career planning, and mentoring activities. None of the IEP plans made any reference to the transition planning process occurring in the child welfare system.

Youth Aging Out of Foster Care

Aging out of foster care is challenging for a variety of reasons, including lack of family/caregiver support, confusion about services, and lack of thorough, realistic planning. Child welfare typically focuses on temporary child removal as

Foster youth with disabilities aging out of care require careful, coordinated planning that aligns the IEP with the National Resource Center for Youth Development's four core principles and CWLA Standards of Excellence.

well as reducing time spent in foster care. Nevertheless, numerous children spend considerable time in foster care, many remaining until emancipation with approximately 20,000 adolescents leaving foster care each year (GAO, 1999).

Foster youth in the Midwest Study faced a broad spectrum of challenges when aging out (Courtney et al., 2005).

Almost 63% were not enrolled in an education or training program and only 11% were enrolled in a 2- or 4-year college. Fewer than half were employed, and for those who were, employment was sporadic, rarely providing financial security. Less than half received independent living services and only 50% received education services. Twenty-five percent did not have enough to eat and one in seven had been homeless. Nearly half of the females were pregnant by age 19 and were more than twice as likely to have at least one child. Thirty-three percent had been arrested in the last year and 23.7% spent at least one night in a correctional facility (Courtney et al., 2005).

Foster and Gifford (2004) found approximately one-third of youth leaving foster care were receiving public cash assistance within two years. Other studies indicate youth who leave care are more likely to struggle with drug and alcohol abuse (Massinga & Percora, 2004) and to be suspended from school or expelled (Courtney, Terao, & Bost, 2004). Thirty to forty percent of foster youth have chronic medical problems (GAO, 2004) and twice as many have repeated a grade, changed schools, or enrolled in special education as compared to their peers.

Supporting Youth with Disabilities

As foster youth with disabilities age out of the child welfare system, coordination of transition planning among key agencies and systems is imperative. Frey, Greenblatt & Brown (2005) states:

“Aging out” without a permanent family and/or adequate preparation for adulthood is a crisis. It is a personal injury to each and every youth in care and a public emergency for our national child welfare system. (p. 1)

Transition planning has evolved from a systems-driven approach to the current best practice of youth-driven, strengths-based transition planning (Lehman, et al., 2002; NCSET, 2004). The Child Welfare League of America's (CWLA; 2005) recently-released transition standards

compliment requirements within IDEA: youth involvement, healthy and safe environments, healthy relationships, learning by doing, creating community partnerships, interdependence, and feedback and self-assessment. In addition, the National Resource Center for Youth Development has identified four core principles for successful transition from foster care (Kessler, 2004) that also align with and enhance IDEA and CWLA standards: 1) positive youth development promoting self-determination, communication, and problem-solving skills; 2) collaboration that includes functional linkages among child welfare systems, schools, medical/mental health services, foster care providers, and other human service and community agencies; 3) cultural competence that extends beyond race and ethnicity to disability, sexual orientation, religion, and gender and reflects diverse backgrounds, strengths, unique cultural issues, and traditions of youth and their families; and 4) family and community connections that are maintained and strengthened through participation in the transition planning process.

Foster youth with disabilities aging out of care require careful, coordinated planning that aligns the IEP with the National Resource Center for Youth Development's four core principles and CWLA Standards of Excellence. Youth must learn self-determination skills through formal goals on their plan and be actively engaged as leaders in the planning process (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). Consistency in planning, especially for those that transfer between numerous foster placements, must be addressed.

Additional recommendations to improve the transition of foster youth with disabilities include:

- **Concrete, Integrated Transition Plans.** Transition plans must contain specific goals, action steps, and clear responsibility designation to ensure success. Service needs and agencies must be integrated and build upon supports and services available,

[Hill, continued on page 39]

Caring for Children with Special Needs: The Reeves Family's Experience

by Paula Reeves

Our family is pretty unique. Our children are a mix of races and abilities, ranging from age 2 to 31 years. And there are lots of them – 11 to be exact. Even now when we travel in a pack of eight we cause lots of neck craning. Most people make admiring comments, but occasionally the looks are not friendly and are more along the lines of “the circus just arrived.” We are quite used to it, although my husband, Mark, prefers anonymity and sometimes feels like the bug under the

help of the Internet and interstate foster and adoptive care systems. Our family began with our first biological son Conor in 1980. Three years later we adopted Chad, who has Down syndrome and was eight at the time. Seven months after that Jonathan was born. In 1984, Kelsey joined us at four months of age, and in 1986 Melissa arrived from Korea at 13 months of age. We settled in for awhile before Christopher joined us as a foster newborn and became Reeves #6 in 1990. In 1997, Shannon joined us at 11 months of age and we knew she would bring some challenges with her. Over the next year or two Shannon was diagnosed with cerebral palsy, a seizure disorder, and a visual impairment. She had a gastrostomy-tube permanently placed for feeding and received the general diagnosis of developmental disability. She has been, by far, our most physically challenging child and the most beautiful blue-eyed blond who has all of us, especially daddy, in the palm of her hand.

We jumped on the fast-track adoption train again in 2001, adding the first of our four African-American children. Ella was just six months old and came from Michigan. She is quite precocious and has a charismatic personality. Without Ella we may never have cracked Callie's shell. Callie came in 2003 at two-and-a-half years of age. As a consequence of spending the first nine months of her life in intensive care without family to cheer her on we have been dealing with reactive attachment disorder. She is an inspiration as she shows the strength of the God-given human spirit to survive, and to learn to love, express emotion, and trust after knowing nothing but a lack of all those. The end of 2004 brought us our first sibling group, although not biological. Jacob was two years old and Christian was seven years old. They were foster siblings in a very loving foster home. They were both premature little

ones. Jacob has since caught up in his developmental milestones, but Christian continues to deal with delays in all areas of development. He learned to walk shortly before coming to our family because, according to his foster family, Jacob walked and sibling rivalry got the best of him.

As you can imagine it takes more than just Mark and I to meet all their special needs. Having so much experience helps, as does having adult and teen children who are nonplussed by their siblings' extensive needs. For us, this is normal. Even so, it can be exhausting to identify support needs, locate providers, and start services for each new arrival. This can be challenging for us even though we know where to go for the help we need. We have learned many valuable positive and challenging lessons in our years of fostering and adopting children who have disabilities.

We have worked primarily with public child welfare agencies; however we have worked with private agencies as well. Perhaps the most difficult part of our foster and adoptive processes was working simultaneously with social workers from two different systems: child welfare and disability services. When you add the out-of-state component, things become even more complex. The adoption or foster care workers typically worked in different buildings than the disability workers. Sometimes all the workers did a good job of communicating with each other (and us) and other times it was cumbersome and challenging. Our best experiences were when we had a “team” because we could all discuss our child's needs, address barriers, and work on conflicts that arose due to multiple system involvement. The team consisted of the child welfare worker, the disability worker, a previous foster parent (if there was one) who knew our child's support needs, and us.

We have had many social workers, medical providers, and other professionals involved in our lives and the lives of our children over the years. We have watched policies and funding change, and for the changes that improved our lives, I am grateful. However, some made no sense or are too complicated.

magnifying glass. Generally, we forget what a sight we must be.

We became foster and adoptive parents in the early 1980s and have continued caring for children for almost 20 years. We have cared for about 25 children through foster placements. Most of these children have had special needs. We have also adopted nine children. Some of the children we have adopted were our own foster children, others were in foster care with some of our friends and still others we found with the



The Reeves family children: (left to right in back) Shannon, Chad, Kelsey, Chris with Callie, Conor with Christian; (left to right in front) Melissa, Jacob, Jonathan and Ella.

Another challenge we faced many times was being asked by child welfare agencies to consider fostering or adopting a child without sufficient information to make a decision. We've had enough experience to know what we can handle and what we cannot handle. Without the proper information, our decision is impossible to make and a placement might be made and consequently disrupted simply because we were not given the full picture. We were told one time that we had been chosen for an adoptive placement for a child we knew nothing about. After asking just three questions I knew our family could not serve that child well. Lots of time could have been spared had the social worker simply given us some basic information in a phone conversation.

Medical aspects of the children's care can be complex, entailing both positive and challenging experiences. Christian and Jacob had a fabulous social worker in Texas who was extremely conscientious and sent us every piece of paper ever written about them. The University of Minnesota's U Special Kids program – a Department of Pediatrics program that provides care coordination to children with complex medical problems – graciously condensed piles of Christian's medical reports into a seven-page medi-

cal profile. This was very helpful for communicating with other support service providers. A challenging part to providing care for our children is handling all the paperwork and learning the funding streams. Adoption subsidies provide monthly stipends for the care of the children. Medical Assistance provides financial support for the children's medical needs. When we adopted Christian and Jacob we had to work through two state systems. Although Minnesota agreed to provide Medical Assistance for the boys, formal applications still had to be submitted and six weeks passed before they were approved. Meanwhile, due to their medical issues and prescription needs, we spent about \$500 out-of-pocket. We were fortunate to have the resources to cover those expenses while waiting for reimbursement, but not all adoptive and foster parents do.

When we adopted Shannon we had written into her adoption subsidy contract that she might need a ramp one day to get her into our home. As she grew and the need arose, we approached the state subsidy office (yet another governmental agency) about our need for a ramp. They informed us that two estimates would be required before they would assist in the payment. The two contractors said an elevator was the only

alternative for our house as our entry was too steep. Then, the subsidy office referred us to a consultant specializing in accessibility to reassess the situation. We had to attend several subsequent meetings only to be told that subsidy dollars couldn't be used to pay for an elevator. This meant we needed to finance \$30,000 (which we did) as a second mortgage on our home. Only then did our county disability worker inform us that we might be able to get a different type of funding to pay for the elevator. Funding was available through a one-time grant, available only if there is excess money in the county budget at the end of the year. Ultimately we were able to work within the system to get a \$20,000 reimbursement. That experience was very frustrating, expensive, and time-consuming. Why wasn't the accessibility consultant involved from the start? Why didn't we know about the one-time grant funds? All we wanted was to help our daughter safely enter her home.

We have had many social workers, medical providers, and other professionals involved in our lives and the lives of our children over the years. We have watched policies and funding change, and for the changes that improved our lives, I am grateful. However, some changes made no sense or are too complicated. Many of us who parent special needs kids are, frankly, too tired at the end of the day to send e-mails or call our representatives. We look to the social workers to advocate for good outcomes for our kids.

As I personally hit the half-century mark I am heartened by how far we have come and am hopeful as to what lies ahead in our children's lives. What we do for the "least of these" as a society will tell the story of what kind of human beings we were.

Paula Reeves and her family live in Burnsville, Minnesota.

Serving Children and Youth with Disabilities: A N.C. Social Work Supervisor's Perspective

David Fee is a social work supervisor in the Mecklenburg County Youth and Family Services, Mecklenburg, North Carolina, which includes the city of Charlotte. In this interview, he talks about his experience serving children and youth with disabilities in the county child welfare system.

Q. Briefly describe your child protective services (CPS) context.

A. The Mecklenburg County Department of Social Services has a separate division that covers child protective services: Youth and Family Services (YFS). The YFS agency has three basic divisions – Investigations, Family Intervention, and Permanency Planning. I work in the Permanency Planning Unit. Permanency Planning is responsible for all aspects of a child's care, especially placement. We have 10 teams of social workers, plus a specialty unit that deals with teenagers with significant mental health needs. I supervise a team of permanency planning social workers that varies between four and six in number. At any given time, Mecklenburg County has about 1,000 children in custody. The number of children and youth with disabilities in placement are unknown.

Q. From your observations as a supervisor, what are the things that CPS workers struggle the most with when it comes to working with families and kids with disabilities?

A. Most of our social workers do not have a basic awareness of disability issues. They lack appropriate vocabulary such as “person-first language.” When one disability-related intervention is put in place, it is tempting to assume that the entire situation has been resolved. Workers also struggle when children are reunified with parents whose understanding of disability issues is also inadequate. Our social workers are not equipped to educate them. Disability resources are not well known within child welfare. Col-

laboration appears to be somewhat lacking between the two systems so workers are not “armed” with the resources and information they need to serve families with children who have disabilities. Social workers receive plenty of training in substance abuse, sexual abuse, the legal system, working with families, etc. I'm not aware of any formal training on disabilities except what they receive in college or graduate school.

Q. What is your role in supporting CPS workers so they are prepared to work with youth with disabilities?

A. My role is to assist them in finding “experts” who are knowledgeable in providing appropriate services to children with disabilities. When a worker on my team encounters a case involving a child with an educational disability, I refer that worker to our staff educational liaisons. If a worker has a case involving a child with a physical disability, I refer the worker to our agency nurses who assist with cases involving medical issues. The local Area Mental Health Authority is our main resource for assisting children with disabilities related to their mental health. Developmental disability social workers, who also work for the county, assist us in cases where the child or youth has an intellectual or developmental disability. Overall, I think my agency has adequate resources and working relationships with disability providers, but worker awareness and training are still inadequate.

Q. What are systemic barriers to successful services for children with disabilities who are in the CPS system?

A. We face numerous systemic barriers. Five appear to impact us on a daily basis. First, we don't have many disability advocacy organizations, or at least ones that interact with us in child protection. Instead of coming together to help children, we seem to work in isolation. Second, we are often bound by court orders

that mandate a service that is not readily available. Our agency is then put in the position of trying to create that service or “force” a provider, such as another county agency, to create the service. This can result in an adversarial rather than collaborative relationship. Third, we need to collaborate with the county developmental disability workers; these workers are located in another building and the staff is largely unknown to the child protection staff. Fourth, our agency is affected by budget shortages and high caseloads (like everyone else) and it is more difficult for us to create specialized services that may be needed by children with disabilities that we serve. Lastly, and perhaps most importantly, is the lack of disability awareness and training for child protection workers.

Q. What can you do as supervisor to address these barriers?

A. I would like to maintain a library of disability resources in my office. Workers would have the ability to reference disability-related text to increase their knowledge on the issues that children and youth with disabilities face, their needs, and ways to provide appropriate services to them. I would also like to make better use of the Internet for the same purpose; social workers are on the go constantly, and surfing for information is a luxury they cannot usually afford. I can do more of that and share the most updated disability information with them. I also intend to make better use of our monthly unit meetings to teach my workers about disability awareness, person-first language, and basic communication approaches that can be used when working with children with disabilities, such as intellectual and developmental disabilities.

David Fee may be reached at 704/336-6659 or feeda@co.mecklenburg.nc.us. He was interviewed by Traci LaLiberte of the Institute on Community Integration.

Observations of a Child Protection Supervisor in Connecticut

by Janis Courter

I have been a social worker in the child welfare field for nine years, working primarily in child protection investigations and in permanency planning for children. I supervise a child protection unit in Meriden, Connecticut, and over the years have worked with numerous families with children who have disabilities. Child welfare services in Connecticut have evolved over time. In the past 15 years, our staffing has doubled and our caseloads have been cut in half due to a federal court order. With more time to spend with each family, service delivery has improved; this is a positive step for all families, especially those with children with disabilities with whom it often takes extra time to identify and meet the needs of the children. However, we also continue to face many challenges.

Challenges and Strategies

There are five primary challenges I've experienced in working with children with disabilities and their families as they are involved with our child welfare system:

- **Parental issues and needs.** Often the issues associated with a child's disability are in addition to other challenges faced by the families that come into contact with our child welfare system, such as domestic violence, substance abuse, unemployment, and/or poverty. For parents who are unable to manage the challenges they face, physical abuse, severe neglect, and sexual abuse of their children may occur. We often see parents who do not have sufficient emotional or financial support to raise their child who has a disability.
- **Lack of specialized providers.** Even with increased state funding over the past several years, we lack the resources necessary to provide adequate care to our children with

specialized needs. There is a need for more specialized and community service providers equipped to meet the special needs of children with disabilities and their families.

- **Provider turnover.** Many of our provider agencies use interns who change agencies every year. Children become comfortable and trust one therapist, and then that person leaves and another comes in to start over. This cycle is damaging to the many children who have a difficult time trusting and confiding in adults. The provider's limited budget forces them to make the difficult choice between having continuity of care and being sensitive to children with disabilities.
- **Lack of appropriate foster homes.** We are in need of foster homes who are prepared to care for children with various types of disabilities. There is a lack of families who are willing to accept children with specialized needs into their homes. Recruiting foster homes is currently a challenge nationally and the challenge to recruit foster homes to care for children with disabilities is more severe.
- **Training for child welfare staff.** Our child protection staff does not receive a great deal of training related to working with children with disabilities. As new workers are hired, these cases are difficult for them to manage and often take a great deal of their time as they try to learn about the child's disability, services options, and conduct all other case management activities.

Some of the strategies that we use to successfully address these challenges, are the following:

- **Flexible funds.** Flexible funds are one way we can assist families to obtain services which otherwise are not

contracted through the child welfare department. Flexible funds are part of our annual budget set aside for family expenses such as rent, security deposits, and furniture. Flexible funds can also be used to tailor existing services to meet the needs of the child and family.

- **Alternatives to foster homes.** To address the foster home shortage for children with disabilities, we have sought extended family members who are willing to care for children. They are often aware of the child's needs and how best to meet them. We also have implemented "Safe Homes," group care facilities where children go for the first 45 days of their placement and are evaluated for placement needs. Recommendations identify the types of things that we must look for in a suitable foster home or other placement.
- **On-the-job training.** On-the-job training is used to assist workers who are not experienced with children with disabilities and their families. New workers often collaborate with workers who have experience working with children and youth with disabilities. These workers serve as a sort of "mentor" and direct the less experienced workers to needed resources.

Conclusion

The children in my care rely on me for support, protection, safety, and comfort. Children and youth with disabilities have unique needs and we must continue to strive for better services and outcomes for these children and their families.

Janis Courter is Social Work Supervisor with the Department of Children and Families, Meriden, Connecticut. She may be reached at 203/238-8413 or janis.courter@po.state.ct.us.

Serving Youth with Disabilities in Minnesota: Two Case Worker's Experience

by Timothy B. Zuel and Marilee Bengtson

Billy,* a 12-year-old with developmental disabilities, was picked up by the police for the third time in as many weeks at 3 a.m. while attempting to sleep at a bus shelter. He was brought to the 24-hour Child Protection intake shelter. His speech was very difficult to understand and he only responded in two- or three-word phrases. He was easily agitated during the interview and looked tired. The Child Protection worker noted that Billy appeared disheveled, wore dirty clothes, and had an unpleasant odor.

Through Child Protection involvement Billy was placed out of his home, and referred to receive services and case management from county Disability Services. The hope was that more and specialized resources could be gained through Disability Services. While under the care of the child welfare system, Billy was increasingly aggressive and continued to run. Until his order to permanent foster care, he had 13 different placements over a three-year period. All the while attempts were being made to structure a community-based support system that would allow him to reside in his family home with supports and services.

Billy did not fit into the practice model for Child Protection due to his disabilities, and he did not fit into the model for disability case management due to his Child Protection involvement. We struggled to adjust, dug deeper and deeper into resources, and often came to blows with our enormous bureaucracy filled with payment streams, processes, and procedures. In reviewing this case, several issues became clear to us involving the interaction of child welfare services and youth with disabilities.

The first challenge we encountered with Billy was the high number of disrupted placements. It was clear to us that the resources of the foster care system and other residential providers were not equipped to meet the complicated needs

*"Billy" is a composite of a number of youths' stories

of adolescents with developmental disabilities. Ten of the thirteen placements were temporary emergency shelters and Billy resided there until his behavioral issues resulted in his being removed from the programs. The focus became just finding a bed for Billy as opposed to locating an appropriate placement that would meet his needs. The placement issue was more complicated by the fact that for most of the Child Protection case, the option of a long-term community group home was closed since the child welfare system's legally prescribed goal is reunification with the family. It became evident early on that even though Billy's family was concerned and willing, they could not meet his needs.

Another challenge was the needed yet complicated interactions between multiple systems including child welfare, the public schools, medical professionals, and disability services. With data privacy, and each system having its own set of rules to govern it, coordinating services was difficult. It also was evident to all the systems involved that there was a lack of early intervention for Billy when he was young and first identified as having a developmental disability. The first known comprehensive assessment was requested by the child welfare system when he was 13 to satisfy a requirement for residential consideration. His needs, and support for his family in trying to help meet those needs, would have been much easier to address when he was a young child rather than an aggressive teenager.

The child protection system model is based on reaction to specific safety events. Meeting a child's need for ongoing services and developmental assessments is voluntary on the part of caregivers. A family's reluctance or inability to engage in services for a child's developmental needs can have the potential to profoundly impact the child's life. This is

especially true for children with disabilities. This raises the larger question: Should the child welfare system mandate early intervention services for this population?

Due to legal issues within the child welfare system, Billy was unable to be placed voluntarily; the case required court supervision from the initial Child Protection intervention. Most disability services are engaged in voluntarily. Billy's family had always been resistant to outside services, therefore Child Protection made involvement with Disability Services a requirement for the case plan. The failure to fully engage in disability services became part of the Child Protection legal argument for neglect by the family; however that took 18 months to document and prove. During this time the court required reunification efforts and that impeded the ability to find a long-term stable placement. Ultimately the court ordered the family to make use of Disability Services.

Throughout this case the two systems struggled to find appropriate services for Billy while at the same time satisfying their respective, sometimes conflicting, program policies. To better meet the needs of youth such as Billy, child protection units could have a developmental disabilities social worker attached. This simple programming change would help navigate the landscape of legal, resource, medical, payment streams, and policy hurdles. Furthermore, juvenile courts could be better trained as to the special needs and services available to youth with developmental disabilities. Finally, we urge the identification and service/support intervention for these children at a very early age.

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Specialized Training on Maltreatment and Disability: VCU's Web Curriculum

by Peggy O'Neill

Early identification of abuse and neglect, intervention, and appropriate treatment are crucial to insure the health and safety of children and youth with developmental disabilities. Unfortunately, it can be more difficult to recognize maltreatment of these individuals, and treatment options are limited. Young people with disabilities may be unaware that they are experiencing abuse, since they are often taught to be compliant with anyone in authority. They may also be unable to communicate what happened to them, or they may be afraid to tell for fear of retaliation, loss of care, or institutionalization. If they do tell someone, they may not be understood because of communication difficulties, or they may not be believed because of doubts about their cognitive or mental abilities. Isolated from mainstream society, children and youth with disabilities just may not have anyone else to tell.

The Partnership for People with Disabilities, a University Center for Excellence in Developmental Disabilities (UCEDD) at Virginia Commonwealth University, became involved in developing training about abuse and neglect of people with developmental disabilities in 1997. In that year, a multidisciplinary group of parents and professionals in Virginia who were alarmed about reports of abuse of children with disabilities in schools and institutions formed the Virginia Coalition on Abuse and Disabilities. As they uncovered more stories of maltreatment, it became clear to this group that the systems for protecting vulnerable children and adults were ill-prepared to provide adequate services for people with disabilities. The Coalition specifically asked parents, educators, law enforcement officers, and child protective services workers what they needed to know about abuse and neglect of children with disabilities. Based on their input, and with the support of the

National Center on Child Abuse and Neglect, a comprehensive curriculum, *Abuse and Neglect of Children with Disabilities: A Collaborative Response*, was developed. The two-day interdisciplinary training has been offered in Virginia since 1999, with the joint support of Virginia's Departments of Social Services, Education, and Criminal Justice Services. The Partnership received further requests from others who needed training about maltreatment of people with disabilities, including justice and courts professionals, health professionals, and other human services professionals. In response, three additional training curricula were developed by the Partnership, including courses on children with disabilities in the justice system (*Reaching Out to Community Kids*), women with disabilities (*Violence Against Women with Disabilities: The Response of the Criminal Justice System*), and a comprehensive Web-based course on maltreatment issues, *Abuse and Neglect of Children and Adults with Developmental Disabilities: A Problem of National Significance*.

The Web Curriculum

Developed with the support of the Administration on Developmental Disabilities, the Web course – *Abuse and Neglect of Children and Adults with Developmental Disabilities: A Problem of National Significance* (www.maltreatment.vcu.edu/info/) – was created in collaboration with seven states' UCEDDs, and five states' Protection and Advocacy agencies. They facilitated a national review and pilot-test of the curriculum, which became available online in spring 2005. This comprehensive, interactive course features self-paced instruction; video interviews with children and adults with developmental disabilities, their caregivers, and disabilities specialists; an extensive bibliography; helpful resources; links to relevant

Web sites; and a seminar discussion guide for use with groups. A wide range of topics are addressed, including scope and significance of the problem, overview of developmental disabilities, communication issues, risk factors, family and cultural issues, special considerations in the use of medications, recognizing sexual abuse, assessment and documentation, reporting, follow-up and treatment, prevention, and resources. Continuing education credits are pre-approved for nurses, social workers, certified counselors, rehabilitation counselors, psychologists, and other professionals who complete the course.

Outcomes of the Training

Nearly 200 professionals from 24 states and 2 other countries have registered for the course. Evaluation comments from participants who have completed the course indicate that this online training is relevant and useful for professionals from a wide variety of disciplines. Participants report that they especially appreciate the comprehensive information, extensive resources and links to other sites, and easy-to-use format. Among comments on evaluations are, "I would recommend this course to everyone employed in the human services field!" and "This course is packed with useful information that I know will assist me in providing better services to families and children we serve."

Peggy O'Neill is author of the course and Abuse and Disabilities Coordinator, Partnership for People with Disabilities, Virginia Commonwealth University, Richmond. She may be reached at 804/827-0194 or poneill@vcu.edu. To view the annotated course outline and sample module, visit the course Web site at <http://www.maltreatment.vcu.edu/info/>.

Competencies for Child Welfare Caseworkers Serving Children with Disabilities

by Judith S. Rycus

Children who have developmental disabilities, emotional disturbance, mental illness, or severe behavior problems are increasingly being served by child welfare agencies. Most of these children who enter the child welfare system do so as victims of abuse or neglect, while others need temporary or permanent out-of-home placement because their parents cannot care for them. As a group, they are generally described in the child welfare literature as having “special needs.” They can present significant challenges to their families, caregivers, and service providers, and if their special needs and conditions are not appropriately addressed and treated in a timely manner, these conditions often become more pronounced over time, permanently impacting long-term development and well-being (Rycus & Hughes, 1998).

While early identification and timely intervention can greatly improve the likelihood of positive developmental outcomes for these children, accessing appropriate developmental and remedial services can be a significant challenge for families and agencies. Identifying and coordinating specialized medical care, developmental assessment, special education, respite care, psychological or psychiatric services, financial assistance, recreational programs, and supportive family counseling is a complex and often daunting undertaking (Children and Family Research Center, 2004). Many child welfare agencies depend on community providers and other service systems to meet the specialized needs of these children and their families. Unfortunately, in many communities, specialized services may be unavailable, underdeveloped, poorly coordinated, or inconsistently applied (Rycus & Hughes, 1998). This creates additional challenges for workers who have case management responsibility for these families.

The Importance of Competency-Based Training

One essential strategy for improving child welfare services to children with disabling conditions is to provide specialized training to the caseworkers and supervisors who serve them. While a variety of training resources have been developed for this purpose, the child welfare profession has yet to uniformly support training at the scope and depth necessary to serve these children most effectively. A comprehensive, competency-based training model provides the formal structure to support the development and delivery of timely and relevant training to staff serving children with special needs and their families.

Competencies are statements that incorporate the knowledge and skills necessary for the performance of job tasks (Rycus & Hughes, 2000). They are derived from a job/task analysis that determines the specific knowledge and skills necessary to achieve organizational and case-related outcomes in a manner consistent with standards of “best practice.” Competencies are used for a variety of purposes. They support the assessment and priority ranking of each worker’s individual training needs, with the highest priority needs occurring when considerable development is needed in competencies that are highly relevant to a worker’s job. Supervisors use needs assessment data to devise individualized training and development plans with their staff. And, compiled needs assessment data for an entire unit, agency, or service system enables training developers to design and provide workshops and other training resources to address high priority needs in a timely manner.

Sequentially organizing competencies by their levels of learning (Rycus & Hughes, 2001) also promotes development of the most suitable training strat-

egies to address each competency area. Classroom training and self-directed learning can help workers acquire the necessary knowledge base and understanding of a particular topic. However, to develop and master new skills, learners must apply their knowledge in the real world. Training to develop workers’ skills requires opportunities to model and practice new approaches and behaviors, to receive constructive feedback, and to be positively reinforced and supported by the work environment. Appropriate training strategies include educational supervision, coaching, peer supervision, interactive distance learning, and shadowing professionals who have mastered the skills.

Proposed Competencies for Child Welfare Caseworkers

In 1985, the Institute for Human Services (IHS) began development of competencies that delineate the array of knowledge and skills essential to provide effective child welfare services to children with special needs. Child welfare and developmental disability professionals worked together to review relevant research, identify activities essential to recognizing and serving these children, and articulate the specialized knowledge and skills needed to perform those activities. The competencies were used to develop standardized training for child welfare caseworkers and supervisors in identifying and serving children with a variety of disabilities.

It is important to note that training in these specialized competencies must be based on a solid foundation of core-level knowledge and skills. Children with special needs are fundamentally no different from other children served by the child welfare system. They need safety, stability, nurturance, stimulation, love, and support in permanent families. Effective

work with these children and their families first requires mastery of universal child welfare skills: family engagement and empowerment, safety and risk assessment, comprehensive family assessment, case planning and service provision, placement prevention, family reunification, case management, and interviewing. With that caveat, the following are key specialized competencies identified for child welfare case workers serving *children* with developmental, behavioral, and emotional disabilities:

- Caseworker understands how developmental disabilities, emotional disorders, and behavior problems in children and youth can be both a consequence of child abuse or neglect, and a stressor to which some parents may respond with abuse or neglect.
- Caseworker understands the importance of early identification and intervention to help children and youth with developmental, emotional, or behavior disorders develop to their potential.
- Caseworker knows the nature and indicators of the primary developmental disabilities, including mental retardation, cerebral palsy, epilepsy, autism, and pervasive developmental disorder (PDD).
- Caseworker knows the potential impacts of fetal alcohol syndrome (FAS)/fetal alcohol effects (FAE), attention deficit/hyperactive disorder (ADD/ADHD), and prenatal drug exposure on children's development and behavior.
- Caseworker knows the nature and indicators of emotional and behavioral disorders common in maltreated children and youth, including depression, anxiety, insecure or disordered attachment, aggression, impulsivity, and anti-social behavior.
- Caseworker can observe the development and behavior of children and youth, and recognize developmental delays or disabilities, emotional and behavior disorders, and abnormal patterns of development.
- Caseworker can refer children for comprehensive developmental assessment, and can use this information to plan and access individualized medical, educational, social, developmental, and recreational services.
- Caseworker knows the prevalent negative stereotypic attitudes and misconceptions regarding persons with developmental disabilities or mental illness, how these attitudes and stereotypes can interfere with the provision of effective services, and the benefits of normalization in promoting children's development.
- Caseworker can identify children with developmental, emotional, or behavioral conditions who are at heightened risk of abuse, neglect, or placement disruption in their families, and can determine when out-of-home care is the only option to assure a child's safety and well-being.

In addition to the competencies above, the following are competencies for serving *families* of children with developmental behavioral, and emotional disabilities:

- Caseworker understands the impact of families' cultural backgrounds on beliefs about and responses to developmental disabilities, emotional disorders, and behavior problems, and can provide culturally sensitive interventions within each family's own community and cultural context.
- Caseworker understands the stresses and challenges experienced by primary, foster, kinship, and adoptive families whose children have developmental, emotional, or behavior problems, and the potential impacts on both quality of care and placement stability.
- Caseworker can identify strengths and capacities of families caring for children with special needs, and enter into collaborative partnerships with them to enhance their child management and caregiving capacities, and to facilitate access to needed services.

- Caseworker knows how to help families adapt their parenting and behavior management strategies to be appropriate for a child's special needs and developmental level.
- Caseworker understands the importance of linking families with educational, supportive, and respite services within their neighborhoods, extended families, and communities, to reduce stress and prevent crisis.
- Caseworker understands the challenges and barriers encountered by families in accessing specialized services and resources, and can arrange or engage in personal, legal, and system advocacy on behalf of children and families.
- Caseworker understands the range of placement options available for children with developmental, behavioral, and emotional conditions, and knows the personal and family characteristics associated with successful kinship care, foster care, or adoption of children with special needs.

These competencies form the foundation of standardized training for child welfare workers. As a permanent part of IHS' Universe of Child Welfare Competencies they help ensure that child welfare workers have the knowledge and skills necessary to providing effective child welfare services to children with special needs and their families.

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Identifying Child Needs: Connecticut's Foster Care Multi-Disciplinary Screening Program:

by Cathy Gentile-Doyle

Children in foster care have a disproportionate percentage of health and developmental problems that are often missed or not treated properly. This well-known fact was the impetus for the creation of foster care clinics throughout Connecticut during the early 1990s exclusively dedicated to the health and development of foster children. The State of Connecticut Department of Children and Families (DCF), operating under a court-ordered mandate, requires that all children entering foster care for the first time receive a comprehensive examination completed by a multi-disciplinary team of pediatric professionals within 30 days, pursuant to an order of temporary custody or commitment from the court.

The Foster Care Multi-disciplinary Screening Program at the Connecticut Children's Medical Center (CCMC) is one of the state's oldest and largest contracted providers of the Multi-disciplinary Exam (MDE) through their Foster Care Clinic. Though the program at CCMC ended in August 2005, for the past 15 years it has been very effective in its dedication to promoting healthy development for children in foster care, advocating for each child's individual adjustment and well-being, and supporting and empowering foster families.

Program Description

Children referred to the program, who typically range in age from newborn to 17 years, commonly have one or more of the following health-related problems:

- Lack of health history.
- Incomplete health records missing documentation regarding primary care provider, immunization status and serious allergic reactions.
- Health conditions requiring treatment from specialists in Endocrinology, Cardiology, Orthopedics, Genetics, Gastroenterology, Ophthalmology, ENT, Neurology, Dermatology, Pulmonology, and Gynecology.
- Medical complexities and multiple health problems requiring immediate coordination of services and resources through the hospital's Center for Children with Special Needs.
- Prenatal drug/alcohol exposure, HIV, or sexual abuse requiring follow-up by many of the specialty health programs at CCMC.
- Speech delays and chronic ear infections requiring comprehensive Speech / Language and Audiology assessments and services.
- Hypertonia/hypotonia and motor skills delays requiring Occupational Therapy and Physical Therapy.
- Rampant dental caries requiring pediatric dental treatment.
- Medication assessment and prescriptions.
- Asthma without necessary treatment.
- Fragmented adolescent health care.
- Substance abuse and sexual activity.

The MDE program at CCMC has five goals in relation to these children:

- To identify health, mental health, developmental, and educational needs of children through an MDE at the point of entry into foster care.
- To document the exam outcomes with specific recommendations for further evaluation or interventions and treatment.
- To provide written reports of outcomes and recommendations to DCF and foster care providers, and advocate for emergency intervention and treatment when needed.
- To distribute educational materials and resource information to foster care providers and offer training and

consultation to DCF staff in areas of children's health, mental health, and development.

- To collaborate with community initiatives advocating for and promoting the health and well-being of children in foster care placement.

These goals are carried out by a multi-disciplinary team consisting of the following positions:

- Pediatric nurse practitioner who completes a health assessment for each child, consults with the team and foster care provider regarding identified health problems, documents findings and recommendations for appropriate medical treatment and services.
- Clinical social worker/ team coordinator who coordinates team operation and consultation, obtains case history from DCF, conducts a psychosocial and mental health assessment (including interview with foster care provider) documenting specific findings and recommendations for further interventions or treatment, and incorporates all team findings and recommendations into a summary report for each child that is forwarded to DCF and the foster care provider.
- Dental hygienist who completes a dental assessment for each child to identify any dental problems, consults with team, and documents findings and recommendations for dental treatment.
- Developmental testers who administer a standardized developmental screening tool to identify developmental delays and educational needs, consult with the team, and document findings and recommendations for necessary services.

This team of licensed professionals convenes once a week and examines an aver-

age of 12 children over a 4-hour time span. Last year over 600 referrals were received and processed and approximately 550 children received an MDE.

When a child is referred to the program, their foster care provider is contacted by phone and an appointment for the Foster Care Clinic is immediately scheduled to meet the 30-day deadline. Foster parents are strongly encouraged to accompany their child to the appointment and stay with them as they proceed through each component of the assessment; this is an opportunity for foster parents to discuss concerns and receive feedback from each member of the team. The biological parent is not directly involved with this particular process because the focus of the program is aimed at the needs of the child in the context of their foster care placement.

Upon arriving at the clinic, each child is welcomed by the team coordinator and a representative from the Connecticut Association of Foster /Adoptive Parents (CAFAP) who distributes resource materials and information, and offers support to the foster parents during down-time in between each portion of the MDE. First, the child is weighed and measured and then examined by the dental hygienist who conducts a simple dental assessment in order to minimize the child's anxiety. Foster care providers are offered information regarding dental hygiene and dental treatment resources in the community. Then they move onto the developmental screening test and a tester administers the appropriate test based upon the child's age range. Foster parents are invited to exchange information and concerns regarding their child's development and may receive recommendations and advice from the tester. The health assessment is next and each child and foster parent meet with the nurse practitioner for a health exam and discussion regarding health status. Since the emphasis is upon assessment, no medical interventions or procedures are conducted. Children are referred to a primary care provider to assure continuity of care. Upon completion of all three parts of the MDE, a team consultation

and brief wrap-up take place to identify problems and make recommendations. The team first meets briefly to review their findings and the psychosocial information and then recommendations are presented verbally by the clinical social worker to the foster care provider prior to leaving the clinic. Any foster parent concerns or questions regarding the exam, or follow-up services, or DCF policies can be addressed at this time.

A copy of the summary report is sent to both DCF and to the foster care provider documenting specific recommendations and an action plan for each identified problem. It is the responsibility of DCF to then coordinate with the foster care provider and to pursue the recommended treatment and follow-up services. In cases where immediate action is required, DCF is contacted by phone directly from the clinic to initiate urgent procedures.

Program Effectiveness

Over 80% of the children referred to the program present developmental deficits requiring follow-up through community programs such as Birth to Three or through special education services. Approximately 65% have other types of disabilities or chronic health/mental health needs that must be addressed, and roughly 70% have acute health care needs. The rationale for this child welfare initiative is self-evident: it is in the best interest of this high-risk population to obtain necessary services and treatment as soon as possible. This program has successfully demonstrated a cost-effective approach to achieving positive outcomes and better futures. The foster care clinic minimizes fragmentation of services through a seamless network which allows care coordination and access to desperately needed services that promote healthy child development.

Cathy Gentile-Doyle is former Program Coordinator for the Foster Care Clinic, Connecticut Children's Medical Center, Hartford. She may be reached at 860/214-3480 or 860/529-4977 (fax).

Training Resources for Child Welfare Workers

• Serving Children with Disabilities: Handbooks for Child Welfare Workers.

These free handbooks and companion videos from the Georgetown University Center for Child and Human Development provide child welfare personnel with information about a variety of developmental disabilities and how to work with children with developmental disabilities and their families. The three handbooks and companion videos are titled Developmental Disabilities, Supporting Families with Children with Disabilities, and Accessing Services Through IDEA. In addition, a resource manual is available. The manuals are online in full text for downloading (they're no longer available in print) at http://gucchd.georgetown.edu/topics/special_health_needs/object_view.html?objectID=2597. The free videos are available by contacting Mary Moreland at deaconm@georgetown.edu or calling 202/687-8803.

• College of Direct Support. *This resource provides online, competency-based training to professionals supporting individuals with developmental disabilities. Course topics include Introduction to Developmental Disabilities; Maltreatment of Vulnerable Adults and Children; Individual Rights and Choices; Positive Behavior Support; Supporting Healthy Lives; Supporting Family Connections, Friends, Love and the Pursuit of Happiness; Person-Centered Planning and Supports; and Cultural Competence. The training is a collaborative project of the Research and Training Center on Community Living at the University of Minnesota, and MC Strategies, Knoxville, Tennessee. For information on the training options visit www.collegeofdirectsupport.com or call 865/934-0221.*

Entering a Brave New World: Kennedy Krieger's Therapeutic Family Care Program

by Tania R. Edghill and Elise Babbitt

Now in her second semester as a college freshman at a community college in the Baltimore area, Nicole Jones is still reveling in the new experiences and opportunities. "College is so great...so different," she says. "Everyone wants to be there, wants to learn and wants to sit down and have real conversations." She loves planning her own schedule and enjoys the calm, academic atmosphere.

While Nicole's account may seem like that of any other college freshman's, it isn't. In her 19 years, she has faced much adversity, and has relied on her inner strength, and the support of others, to help her succeed. Removed from her birth family, Nicole was placed in Kennedy Krieger's Therapeutic Family Care program at the age of six. In her younger years, she went through a self-described "rough patch" when she followed the crowd – skipping school and challenging her foster parents. She became a young mother at age 17, but has pushed herself to pursue an education while developing into a wonderful, devoted parent. Looking back, Nicole remembers that each time she went down the wrong path, a Kennedy Krieger social worker was there to encourage and redirect her frustrations.

Over time, Nicole has flourished with the love and support of her foster family and program staff. A part of the foster care program for much of her life, Nicole's college enrollment this past fall is a testament to her will to achieve and to the program's success.

Bringing Stability to Children's Lives

Funded primarily through the Maryland Social Services and Developmental Disabilities Administrations, Kennedy Krieger's Therapeutic Family Care program, which started in 1986, serves more than 100 children each year with developmental disabilities, emotional prob-

lems and medically fragile conditions. The program, which is a part of both the Social Work department and The Family Center at Kennedy Krieger, helps children with special needs find temporary or permanent new homes when they cannot live with their parents and all other family options have been exhausted.

According to Robert Basler, co-director of Therapeutic Family Care, one of the things that makes this program different from other therapeutic foster care programs is the broad range of conditions served. Children in the program have a history of, or are at risk for, institutional or hospital placements for everything from emotional disorders to learning disabilities, severe behavior disorders, pervasive developmental disorders, intellectual disabilities, cerebral palsy, and spina bifida. Through Therapeutic Family Care, they benefit from placements with trained families in the Baltimore region and surrounding counties.

Individuals who open their homes to foster children with such conditions have direct access to an interdisciplinary team of developmental experts at Kennedy Krieger who provide diagnosis, evaluation, treatment and research of a vast range of cognitive, physical, and emotional conditions. In addition, all foster and adoptive families are supported through a continuum of family-based services provided by dedicated team members at Kennedy Krieger. These include respite care, adoption services, and specialized training for parents or foster parents. Training and technical assistance also are available to community agencies. Three years ago, the program's name was changed from Therapeutic Foster Care to Therapeutic Family Care to better reflect the spectrum of family services it offers, as well as its emphasis on building and maintaining families.

Kennedy Krieger believes that children with special needs are entitled to

live in the least restrictive, safest community environments possible. With the right assistance, these youth can participate fully in family, school and community life. "The best part of the work is helping a child reach his full potential in life," says Diane Fiala, a dedicated Kennedy Krieger foster parent.

Growing Up and Out of Foster Care

Working in close partnership with state and local child welfare agencies, Therapeutic Family Care matches children with special needs with families who bring stability, love, and attention to their lives, until they can be returned to their families, adopted or transitioned to independent living. In recent years, the program has found itself in the inevitable position of having to transition many of its children, now young adults, out of its foster care program. "The program has been in existence for 19 years, so we are, as a program, at the point where some of the children have now grown up," Basler says. "And, we're having to face the issue of transitioning them." As these children are now facing emancipation, the question of what is the next step for them has become the primary concern. According to Judy Levy, director of Social Work, when most young adults leave home they maintain their family ties while they learn to take care of themselves. Their families are their safety nets. "For young adults in foster care, the system has traditionally seen them as ready for independence," Levy says. "We know that's not necessarily true. These children may not have their families as safety nets, even if they have a connection with them." In response, a new component was added to the Therapeutic Family Care repertoire of services: the Transition Program. The program is designed to help youth, who have spent their

childhood in foster care, transition into less restrictive environments, to help them gradually become independent. “We’ve helped them to adjust to their disability and understand their trauma,” says Paul Brylske, co-director of Therapeutic Family Care. “They still have a history of trauma and emotional and behavioral issues. They still have developmental disabilities. But, they make it to this point where they’re ready to transition into adulthood, and we’re there to help them be successful.”

Since Therapeutic Family Care serves a wide spectrum of children with varying disabilities and needs, the transition needs vary greatly. Some adolescents require semi-independent living until they reach age 21. These individuals often share an apartment with roommates, and case managers help guide them through daily living activities. Others require more restricted environments, such as assisted living or group homes, because their disabilities prevent them from independently carrying out daily living activities. Still others may remain in the care of their foster parents well into adulthood. Therapeutic Family Care has partnered with several programs outside of Kennedy Krieger to help young people find appropriate living arrangements. “We’re intensively working with a program called New Pathways,” Brylske says. “This allows the young adults to share an apartment and receive wrap-around services, such as independent living groups, job coaching and social work case management.” In addition to clinical case management services, life skills training, and ongoing support, the Transition Program also offers young adults after-care services to ensure that appropriate clinical services are received. Transition coordinators in the Therapeutic Family Care program work closely with the youth after they have transitioned to their new homes, and also when they face other difficult transitions – such as adoption, starting a new job or experiencing the death of a loved one.

In August 2002, Mark Jones, then 18, moved from his foster parents’ home to a New Pathways semi-independent living

program. He had been with Kennedy Krieger for more than eight years. In his new situation, Mark continued to receive social services and counseling, as he had at Therapeutic Family Care, to address any emotional and developmental issues he may have faced. At 21, Mark graduated from the program and now lives in an apartment on his own. Living with his foster family taught Mark vital daily living skills, which helped make his independent situation a success. “I learned how to cook from my foster parents,” he admits. At New Pathways, Mark continued to hone the skills he needed to care for himself and his surroundings. He was responsible for doing household activities, such as washing dishes and cleaning the bathroom. Mark’s hopes for his future are clear: “Someday, I plan to own a home,” he says.

Encouraging Education and Work

An important component to the Transition Program is education and employment, areas in which many children in foster care traditionally do very poorly. But among those in Therapeutic Family Care, 100% graduate from high school and 50% maintain jobs while in school – success rates nearly equal to those of children nationwide. Staff and parents encourage students to pursue higher education, as Nicole has done. Nicole credits her foster parents and Kennedy Krieger for helping her continue her studies. “My foster mother helped me with college and financial aid applications and took me to the open houses,” she says. “I also got support from Therapeutic Family Care’s really great social workers. I always wanted to go to college to make something of myself and they were always there for me and pushed me to do better academically.” With only a handful of classes under her belt, Nicole already has clear ambitions. “I always knew growing up that I wanted to help people,” says Nicole, who plans to transfer to Coppin State University next year to earn a degree in social work. “When I was younger, I never really understood the purpose of the social workers who came

to see me, but now that’s what I want to be. Given my experiences, I think I will have a great instinct for how to help children in difficult situations.”

Kennedy Krieger’s Transition Program encourages students to be proactive decision-makers. Although Mark was steered in the right direction by his social worker, he took the application process into his own hands. “As far as getting into college, my social worker took me to the college to get an application, but I did everything else by myself – setting up my schedule, taking the placement test, meeting with a counselor, going through the enrollment process,” Mark says. He attended a community college in the Baltimore area, where he took general studies courses. Today, he has a steady job at an area restaurant and continues to dream of his future. In a few years, he wants to be a mechanic. “I like to fix cars,” Mark says. Through his experiences with Therapeutic Family Care, Mark learned at an early age the importance of keeping a positive attitude and persevering, no matter how difficult the circumstances. “Stay in school and use Kennedy as a stronghold,” he advises others who may be going through similar situations. “Worry about what you’re going to be doing in the future and not what happened in the past.”

Building Lasting Relationships

One of the goals of Therapeutic Family Care’s Transition Program is to help children maintain healthy, positive connections to their families and the community. According to Brylske, a main component of the program is its focus on community and family. “The Transition Program is unique in that it fosters individual connection and linkages to services,” he says. The Transition Program has formed working relationships with community resources, such as DORS (Department of Rehabilitative Services), to link individuals to community services, with the goal of creating relationships and maintaining them. “These children have been in situations that have led them to have difficulty with

[Edghill, continued on page 36]

Supporting Deaf and Hard of Hearing Children and Parents in Connecticut

by William Rivera and Diane Wixted

The Connecticut Department of Children and Families (DCF) continues to move in the direction of "...working within individual cultures and communities in Connecticut" by incorporating cultural competence as one of its mission statement guiding principles. Until recently, the current cultural competence trend has inadequately addressed the needs of Deaf and hard of hearing children and families. The Federal Rehabilitation Act of 1973 – Section 504, mandates sign language interpreting and communication access as accommodations for persons with disabilities. Connecticut Public Act 97-272 – Section 6, Subsection 17a-3, specifically identifies Deaf and hearing-impaired children in the defined population to be served by DCF. These concerns, along with the goal of removing communication barriers that might prevent any DCF clients from receiving appropriate services, and the commitment and efforts of a collaboration of determined individuals and agencies, led to the establishment of the Connecticut Department of Children and Families Task Force on Deaf and Hard of Hearing Persons in February 2000.

The task force was created to address ongoing concerns related to the lack of services accessible to Deaf and hard of hearing children and/or families known to the DCF. Recurring issues such as the inability of the DCF to count the number children and/or families who were Deaf or hard of hearing, and marginal compliance with federal and state laws related to access to services for this population were identified as clear indicators of the lack of progress the DCF had made in serving this population. Other concerns were the lack of the knowledge regarding the application of culturally competent case practices for protective services investigators and social workers, and strategies for bridging gaps between Deaf culture, DCF, and service providers.

Initiated by a DCF social work supervisor, agencies initially committed to the task force included the Connecticut Commission on Deaf and Hearing Impaired (CDHI), the American School for the Deaf, the Connecticut Association of Foster and Adoptive Parents, Family Services Woodfield (a private provider with a Deaf services program), and Klingberg Family Services. The Task Force identified three priority areas: 1) Recruitment of Deaf foster parents or homes where foster parents are able to sign; 2) identification of resources for Deaf parents, foster parents, and children; and 3) provision of training to DCF staff and service providers regarding Deaf culture, communication, legal access requirements, and strategies and skills for working with this population.

In the first year alone, the task force was responsible for initiating significant system changes within the DCF. Their accomplishments included but were not limited to, two administrative policies that raised social workers' awareness regarding cultural considerations in working with diverse clients, and the delivery of services in native language. The 24-hour emergency hotline installed a TTY machine and staff was trained. A DCF informational foster care meeting for Deaf and hard of hearing families was held at CDHI. The DCF Training Academy, in collaboration with a CDHI community educator, began training on deafness and Deaf culture at each of the regional offices and all pre-service social worker trainings. This same trainer provided training for all hotline staff. Funds were secured to film a sign language interpreted version of the DCF video "Be a Hero, Be a Foster Parent." However, perhaps the most momentous project accomplished by the task force in the first year was a statewide conference for DCF social workers and community providers. With Adoption and Safe Families

Act funding, the committee organized the "Keeping Families Together: Working with Deaf and Hearing Impaired Clients" conference. The conference was attended by over 150 DCF social workers, Deaf or hearing-impaired foster parents, and community service providers. Subsequent conferences in 2003 and 2005 were equally well-attended.

The task force has now expanded to include the director of the Division of Multicultural Affairs, a DCF staff representative from each of the DCF area offices and three facilities, the DCF Training Academy, the DCF Office of the Ombudsman, the Connecticut Office of Protection and Advocacy, foster parents of Deaf and hard of hearing children, children and Deaf adults, Saint Francis Hospital, and social service providers throughout the state. It continues to meet bi-monthly to identify and address emerging issues that affect services to the Deaf children and families in DCF care. In addition to the outcomes of its work listed above, TTY machines are now installed in every office and facility, all workers have been trained and are tested on the procedures for utilizing and working with sign language interpreters, and the Division of Multicultural Affairs maintains resources for workers needing to contact sign language interpreters. Also, the DCF recently approved a contract with a service provider to train and certify an additional 40 sign language interpreters for use with DCF services.

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Serving the Deaf Community in Los Angeles County: The DCFS Deaf Unit

by Veronica Tran

The Los Angeles County Department of Children and Family Services (DCFS) mission is to protect children from being physically and/or emotionally abused by their families, and to provide social service to these children and their families. Due to the large and diverse population that the DCFS serves, the department saw a need to establish 20 Alternative and Specialized Service units. The purpose of these specialized units is to provide services targeting the county's unique populations. The Deaf Unit is one such Alternative and Specialized Service Unit that was created to serve the Deaf community specifically; in addition, American Sign Language (ASL) specialists work with the Deaf Unit.

The need to establish the Deaf Unit came after realizing that Deaf families were not receiving adequate services from the DCFS in relation to their specialized needs. Social workers struggled with Deaf clients during assessments because they were not competent using ASL and lacked cultural awareness of the Deaf community. In addition, providing ongoing and regular services to Deaf clients was difficult and many problems arose. For example, often social workers had to ask other family members or friends to interpret during the initial assessment; this made the family vulnerable and opened the door to errors.

Seeking to solve the communication dilemma, the DCFS assigned ASL interpreters to work with social workers. However, this created a barrier between social workers and Deaf families given that social workers were unfamiliar with Deaf cultural norms. Miscommunication and lack of cultural awareness led social workers to misinterpret a family's situation, which sometimes resulted in unnecessary detention of children. These communication problems were recognized by a group of professionals from county mental health agencies, educational pro-

grams, and judges from the Children's Superior Court. Several of these professionals established the Advocacy Council for Abused Deaf Children (ACADC), which sought to address the communication concerns. After researching the work of the DCFS and its handling of Deaf clients, the council found that not only were Deaf children at higher risk for child abuse and/or neglect, but Deaf children were also being overlooked. The council also found that equal access to services was provided for most children with disabilities, but not for children with deafness as their disability. The DCFS acknowledged inconsistencies in service to clients with Deaf children and after negotiations with ACADC agreed to establish a Deaf Unit. Workers now are required to refer cases involving Deaf family members to the Deaf Unit.

Today after 12 years of working exclusively with Deaf clients the Deaf Unit has made tremendous positive impacts in the lives of Deaf children and families. The Deaf Unit is designed to serve Deaf children and their hearing siblings, Deaf parents with hearing children, hearing parents with Deaf children, and other family configurations consisting of at least one Deaf client. It provides a full range of services from emergency response to permanency planning, and is staffed by eight Deaf social workers and two hearing social workers who are fluent in ASL. These social workers possess the ability to communicate well with Deaf clients and have the cultural awareness needed to work with this specialized population. Over time there has been an increase in the number of cases referred to the Deaf Unit, indicating that hearing workers recognize the importance of cultural and linguistic compatibility in the worker-client relationship. Families have expressed appreciation that the child welfare services they receive are delivered by a social worker that they understand and

with whom they are able to communicate. The workers in the Deaf Unit have been able to successfully connect families to the appropriate resources, workers frequently correct mistakes (such as inappropriate removal of children) which were based on communication errors, and the workers in this unit have worked to develop needed services within the community to better meet the needs of Deaf children and families.

An unintended benefit of the Deaf Unit is that Deaf social workers can be role models for Deaf children and families. Many Deaf clients are positively impacted when they meet and learn from Deaf professionals. Such role modeling provides Deaf clients an important sense of hope, which communicates that Deaf people, like themselves, can be important and successful members of society.

The Deaf Unit maintains a close and ongoing collaboration with outside agencies through meetings with providers, interagency trainings, and quarterly meetings with the ACADC. Agencies the Deaf Unit collaborates with include: Awakening Drug and Alcohol Abuse Program for the Deaf, Catholic Big Brother and Little Sister mentor program for the Deaf, Five Acres mental health services for the Deaf, St. John's Mental Health program for the Deaf, Child Share Foster Home for the Deaf, and so on forth. Through tight collaboration, the Deaf Unit has the ability to ensure that the Deaf families receive equal access and quality services.

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Early Intervention in Minneapolis: PICA Head Start's Supported Parenting Program

by Lee Ann Murphy and Cindy White

Parents In Community Action, Inc. (PICA) provides Head Start and Early Head Start programs throughout our county. Born during the 1960s war on poverty, Head Start and most recently Early Head Start, seek to provide low-income preschoolers, infants, and toddlers a "head start" in development and, later, in school. Woven in the federal Head Start legislation is the principle that parents are the most important educators of their children. The belief in the primacy of parents, together with the federal Head Start mandate to ensure 10% of the enrolled children are children with disabilities, provides the foundation for PICA's Supported Parenting Program. Referrals to the program come from parents, teachers, early childhood special education programs, doctors and public health nurses, rehabilitation centers, and from within the child welfare system.

Children entering the Head Start program who have a diagnosed disability and are in foster care and/or have a child protection worker receive priority slotting. While it is PICA's mission to support and empower all of our families and develop appropriate opportunities for them, it is the work we do with families who have "special needs" children that we have addressed by designing a program that meets their special needs. We offer a place where they can find concrete answers to their questions about the law as it relates to disabilities and education, and where they can find friendship, acceptance, and support.

The journey to provide the best services to children with disabilities and their parents began decades ago and continues today with our long-time partner, Courage, Inc. Courage, Inc. is a non-profit rehabilitation organization that empowers people with physical disabilities to reach their full potential in every aspect of life. But it was our participation in a national Early Head Start initiative

called Special Quest, beginning in 1999, that impelled us to more directly address the needs of parents of Head Start children with disabilities.

Funded by the Hilton Foundation and the National Head Start Bureau, Special Quest brought PICA staff, Minneapolis Public School staff, and a parent whose toddler with a disability was enrolled at PICA together for an intensive week of discussion and goal setting. Core members of this group continued to meet for three years to set additional goals. The objective of Special Quest is to increase the number of infants and toddlers with significant disabilities enrolled in Early Head Start. Lessons learned with infants and toddlers influenced services to PICA preschoolers as well. That heroic parent who joined PICA and Minneapolis Public Schools in the Special Quest effort was the first member of our parenting support group, which started six years ago in partnership with Arc Hennepin-Carver. Arc connects people with community resources and helps them navigate service systems as well as being the voice for people with disabilities in public policy.

Why We Use the Approaches We Use

Because there are many community and school-sponsored support groups specific to parents of children with a particular disability (e.g. parents of children with autism) PICA chose to begin a support group for parents of children requiring enhanced services because of any "special need." The goal of the support group is to "meet parents where they are at." Head Start parent/child advocates are encouraged to promote the group and help to facilitate enrollment. If parents come to group one or two times then the group will keep them coming after that. The group is non-judgmental, nurturing, supportive and a safe place for parents to work out their frustrations with the spe-

cial needs service systems with which they are involved. The Arc co-facilitator of the group is always available to help parents problem-solve and work through frustrating issues around school, medical coverage, respite care, and other issues.

Indicators of Success

The Supported Parenting Program meets every other week and grows in attendance every year. This success is made possible because of three very simple but time-proven practices:

- Treat parents with the utmost respect, which includes greeting them at the door, listening to them and hearing them, and providing them with dinner and a babysitting stipend if babysitting on site is not feasible.
- Have fun. Life is hard. Life with a child with a disability can be even harder. Life in poverty and with a child with a disability can be even harder still.
- Allow parents to set the pace for the group; they know best what they want. Today they may have all the referrals and resources they need. Today they may just want to talk and share.

Through operating this program PICA has repeatedly learned the value of partnering. Partner. Partner. Partner. Partner with parents on an equal footing. Partner with other non-profits who share your mission – they have valuable resources for parents and children with disabilities. And partner with state and local organizations mandated to serve children with disabilities and their families.

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Resources

The following resources may be of interest to readers of this *Impact* issue.

- **National Clearinghouse on Child Abuse and Neglect Information (<http://nccanch.acf.hhs.gov>).**

This clearinghouse offers extensive information in the following areas: preventing child abuse and neglect, overview of child abuse and neglect, reporting child abuse and neglect, and the Child Welfare System. Operated by the Administration for Children and Families, U.S. Department of Health and Human Services.

- **National Adoption Information Clearinghouse (<http://naic.acf.hhs.gov>).**

This clearinghouse offers extensive information for professionals working in adoption, prospective adoptive families, individuals who've been adopted, and birth parents. It includes resources on adoption and children with disabilities. Operated by the Administration for Children and Families, U.S. Department of Health and Human Services.

- ***Child Welfare: Better Data and Evaluations Could Improve Processes and Programs for Adopting Children with Special Needs (GAO Report 05-292)***

This report to Congress published in June 2005 identifies the major challenges to placing and keeping special needs children in adoptive homes, examines what states and the U.S. Department of Health and Human Services have done to facilitate special needs adoptions, and assesses how well the Adoption Assistance Program and the Adoption Incentives Program have worked to facilitate special needs adoptions and what changes might be needed. Available online at www.gao.gov/cgi-bin/getrpt?GAO-05-292.

- **ARCH National Resource Center for Respite and Crisis Care Services (www.archrespite.org).**

This Web site includes information on the National Respite Locator Service, a service to help caregivers and profes-

sionals locate respite services in their community, and the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels. The site also includes extensive online materials, including factsheets related to children with disabilities and their families.

- ***Policy Research Brief: Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities (2000)***

This publication examines permanency planning policies and practices, and their implications for children with disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration, it's available online at <http://ici.umn.edu/products/prb/112/default.html>. Also available in print; for ordering information call 612/624-4512 or e-mail publications@icimail.umn.edu.

- **Child Abuse and Neglect Disability Outreach Project – CAN Do! (<http://disability-abuse.com/cando>).**

A project of Arc Riverside (California) and the Disability and Personal Rights Project. The CAN Do! Project has three key objectives: 1) Enhance interagency collaborations and innovations through statewide Think Tank Meetings, 2) support the development of training on child abuse and disabilities, and 3) support expansion of data-gathering on child abuse and disabilities. Its Web site includes documents and information on training and other resources.

- **The Let's Prevent Abuse Program (LPA).**

This program is available from PACER Center, a national center committed to enhancing the quality of life of children and young adults with disabilities and their families, based on the concept of parents helping parents. The program, which

is available for purchase by groups wishing to present their own child abuse prevention programs, helps children with disabilities and adults gain information about child physical and sexual abuse, as well as helps children to develop personal safety skills. It features four multi-racial, child-size puppets that portray children with and without disabilities. Opportunities exist throughout the program for the children to interact with the puppets through dialogue and role-play. The scripts, geared for children in grades 1-4, address the definitions of physical and sexual abuse, how to get help and whom to tell, the need for children to talk about the abuse if they are in such a situation, and feelings of guilt, isolation and shame associated with abuse. In addition to the puppets, it includes *Let's Prevent Abuse: A Prevention Handbook for People Working with Young Families*, which looks at child maltreatment risks, indicators, laws, prevention approaches, and resources. The handbook includes service issues unique to families of children with disabilities, Hmong families, and Spanish-speaking families. Also available is the *Let's Prevent Abuse Coordinator's Handbook*, a guidebook for organizations that assists in the development of a LPA program. For further information contact PACER at 952/838-9000, 952/838-0190 (TTY), pacer@pacer.org, or visit www.pacer.org.

- **The Child Abuse Prevention Network (child-abuse.com).**

This Web site provides extensive information and resources for professionals in the field of child abuse and neglect as well as families. Child maltreatment, physical abuse, psychological maltreatment, neglect, sexual abuse, and emotional abuse and neglect are topic areas.

[Johnson, continued from page 1]

I always wondered about her. I thought about what she was doing and if she missed me. It really hurt me to be away from her. It did not feel right being with strangers. I was always glad to go back to my mom. Living with my family always felt like the best thing to me.

When I was 14 years old, I had my son. A boy in the neighborhood took advantage of me, and I later found out that I was pregnant. Because I was both a child in the foster care system and an underage parent, I became a part of the child protection system in a new way. As a parent, I felt that a lot of things I ran into with child protection were because I was a young mom with a disability. When child protection looked at me, it seemed to me that they only saw my disability. It felt like they used my disability against me. I was a good mom, and I took care of my son. I even graduated from a parenting skills program. It felt like I was doing all of the right things, but I still felt that they were judging me. Even though I had done everything that I was supposed to do, my son was taken from me. It would have been helpful to have had someone supporting me, someone who knew me and knew how hard I was trying to be a good parent. It seemed that they saw my disability, but did not see all of the ways that I was a good mom.

Some of my experiences in the foster care system were positive. When I was eight years old, I was placed in a wonderful and nurturing foster home. This foster mom showed us love, patience, and kindness – all of the things a child needs. It felt like a real home to me. We each had household chores. I learned about cleaning, cooking, and laundry. She told me when I grew up I would have a family, and that I would be a good mom. It was so important to me that she took the time to listen and explain things in a way that I could understand. She talked to me about my mom, and why she could not take care of us. That was the first time I remember someone explaining the situation to me. She also knew I had a disability, and it felt like she understood. My disability made me feel badly about myself. I could not read, and I was behind all

of the other students. My classmates called me retarded and teased me about being in foster care. My foster mom said that I just learned differently, at a different pace. Because of her support, I started to see my disability in a different way. If I saw her today, I would give her a big hug.

As a teenager, I had a turning point in my life. I made some bad choices and got into trouble. I was sent to a residential setting called the Laura Baker School for persons with disabilities. This experience changed my life. The staff at Laura Baker were wonderful. They believed in me and cared about my future. My opinions were important to them. Sometimes the staff even came to me for advice. It was the first time in my life that anyone seemed interested in my opinion. It helped me to feel confident and to see that I had important things to share. Now I love to communicate and give advice. I give them a lot of credit for my success. I also remember a special education teacher named Mrs. Klinefelter. She understood my needs and abilities. We worked together on my school work, and together we built up my self-esteem.

Looking back at my experiences, there were many things that I wish had been different for me. I learned a lot from my experiences in the foster care system. Yet, it seems wrong that throughout all of the years in the child protection system, I never had a real relationship with any of my social workers. As a child with a disability, it was hard to have so much uncertainty and change. A relationship with my social worker could have provided me with some stability and helped me to feel less afraid.

As a parent in the system, I realized that I needed more support from the child protection system. Losing my son was one of the hardest things in my life. Later on, I had the opportunity to have him come back to live with me. He was so happy where he was living, I did not want to take him away from that. It was hard to let him go, but I thought it was best for him. It is still hurts for me to know that things could have been different for us. I used to have a lot of anger towards my

mom; now I know why she did what she did. It took me a long time to come to this understanding.

I am now the mother of four children, and having my own kids has taught me a lot about life. I used to say that when I have my own kids I do not want them to go through what I have been through in my life. I do not want them to grow up in the foster care system. The best place for them is with me, as a part of a family. They are the most important part of my life, and I want to be the best parent that I can be. That is why I continue to take parenting classes and receive support. Most of all, I know now that even though I have a disability, I am a good mom.

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relationships and connections. They've grown up with us, and we've built connections with them. We want them to maintain some degree of connectedness with us and their foster families," Brylske says. "We hope they go back to their foster families for an evening meal every once in a while. Without these connections, foster children are often at risk of 'falling through the cracks.'"

Nicole feels a strong bond to her foster parents. "It seems like I've always been in this family," she says of their 10-year relationship. "I've learned from them not to judge people and to forgive, because everybody makes mistakes. Without their support, I wouldn't be the person I am today."

This article by Tania Edghill was originally published in Touch, Winter 2002, a publication from Kennedy Krieger Institute and its Atlanta affiliate, Marcus Institute; it was updated for Impact by Elise Babbitt, Communications Manager, Kennedy Krieger Institute, Baltimore. The Therapeutic Family Care program may be reached at 443/923-3800 or www.kennedykrieger.org.

[Baladerian, continued from page 5]

and consultants in each state (for information see www.ada.gov). Begin an ongoing campaign to conduct outreach activities to disability service providers, disability advocates, and families of children with disabilities in your area when you are ready to serve effectively and accessibly.

Teach Disability Awareness

Prior to employment or within six weeks, *all staff* shall have completed disability awareness training. This includes the highest level of administration and the volunteers, clerical and other support staff. A cost-effective method of gaining information, community positive regard, and skill enhancement is to

Through these steps child welfare and disability service agencies can collaborate to ensure excellence in service delivery to children with disabilities.

hold meetings at disability service agencies, and at advocacy and self-advocacy organizations, and to invite them to participate in your regular staff and training meetings at least monthly. For example, you can rotate your meetings between these agencies and organizations during the year: Centers for Independent Living; services for people who are Deaf/hard of hearing, blind/visually impaired, and DeafBlind; services for individuals with developmental disabilities, mental illness, and mobility disabilities; self-advocacy organizations of persons with disabilities; and disability advocacy organizations. By rotating in this way, you will include people with most types of disabilities and their families and establish valuable relationships throughout the disability community.

CREDO

Adopt “CREDO” as your overall working philosophy to interact with children with disabilities and their family members: Treat each child with...

C - Compassion

R - Respect

E - Empathy

D - Dignity

O - Open mindedness to needs of the child

Recognize When You Don't Know, and Ask for Help

Be aware when you run into a situation in which you feel you are in unknown territory. Recognize that it is fine to not to know information and to not have skills yet. However, it is not acceptable to fail to seek guidance, or to generate new “techniques” without regard to how these may affect the client. For example, it is not okay to fail to interview the child with a disability and only interview the adults without disabilities. Seeking guidance from your supervisor, local community experts or specialized service providers is a strength, not a devastating personal failure!

Use the Web and Listservs

Make sure your agency's Web site is “Bobby Approved” – meets proven standards for being accessible for people with disabilities. Utilize existing child abuse and disability resources online, such as Arc Riverside's CAN DO project (<http://disability-abuse.com/cando>), and other listservs for consultation, guidance, support, and advice and to learn about new resources as soon as they are available such as videos, curricula, training programs, and conferences. Participate in online learning experiences, such as the Arc-Riverside First Professional Online Training Program on Abuse and Disability. Make sure to participate in the Arc Riverside National/International Conferences on Abuse and Disability, the only ongoing national conference on abuse and disability.

Meet Monthly with Disability Services

Hosting or attending monthly collaborative meetings with all agencies in your area that provide services to children with disabilities *on a regular* basis will ensure a better response to children with disabilities who've entered the child welfare system, and educate disability and other human service providers to the services provided by child welfare agencies. Conduct cross trainings between child welfare and disability service providers.

Conclusion

Through these steps child welfare and disability service agencies can collaborate to ensure excellence in service delivery to children with disabilities. The work of child welfare system professionals demands awareness and skills in many areas, with recent particular demand for cultural and language diversity expertise. Part of recognizing and responding appropriately to diversity is to assure that the needs of children with disabilities and their families are effectively addressed in child welfare services.

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[Rosenau, continued from page 3]

- Special needs adoption subsidies. Adoption subsidies encourage adoption of children with disabilities and other special needs, and support adoptive families, by providing additional financial resources to meet the child's needs without exhausting family resources.

There are also hopeful trends supporting family life in disability services for children who have challenging needs as a result of a disability:

- Family support. Family-directed services are demonstrating creative and flexible in-home solutions within the realities of limited resources, including the use of cash subsidies.
- Shared parenting. Arrangements exist whereby community families are recruited and matched to support birth families, demonstrating a practical and prudent way to provide family life for a child.
- Life-sharing recruitment. Personal network "mapping" procedures are demonstrating the willingness of community members to make a relational commitment to someone with a disability.

The common thread in these promising practices is that they direct resources to surround an anchoring family – one with the requisite time, means, and personal qualities – with the support and expertise they need. These practices recognize the "special" in specialized treatment is "simply" a configuration of well-supported people with training and access to expertise. These promising practices demonstrate how to redirect people and funds to the secure base of a nurturing family.

Conclusion

The way we've organized services systems has segregated disability knowledge and maltreatment knowledge in different systems. Child protection workers, judges, attorneys, and police investigators have little training in dis-

ability. Disability workers have little training in the behavioral consequences of maltreatment. And in each system, we're too busy with our own problems and can't see how to stretch ourselves any thinner to attend to children who, after all, are the "other guy's" problem. The result is that both systems can respond inappropriately. We need to share knowledge, professionals, families, ideas, training, conferences, and lunchrooms.

The problems are enormous and complex; so too must be the solutions. It takes first looking at ourselves and asking what we don't-yet-but-should-know-better. Relationships, as we know intuitively and scientifically, are at the heart of what children need and that includes children with disabilities. Committed and personal relationships are more than the goal – they're the method.

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family's strengths and challenges as well as their participation in past and present services. If a family case is determined to require ongoing child welfare services, it is vital that the family be asked to involve other key professionals in the service planning process. Professionals, such as disability professionals and advocates, often have a better understanding of the available resources for a person with a disability, as well as funding linkages, than the child welfare professionals may have. A strong working relationship between the family, child welfare professionals, and disability professionals will ensure that a holistic view of problems and solutions.

Conclusion

Child welfare professionals aim to provide effective, appropriate, and fair services to all of the people they serve. That goal is more likely to be achieved when child welfare professionals, disability professionals, and the family work together. The information disability professionals can provide related to appropriate and accessible supports and services not only helps families currently involved in child welfare, but could lead to more families of children with disabilities avoiding abusive and/or neglectful situations in the future. While the nature of the services provided by the two fields can be quite dissimilar, particularly as child welfare is largely an involuntary service while disability services are voluntary, improved collaboration between these two fields is essential.

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including education/training vouchers, independent living programs, SSI, Medicaid, and other health services (Geenen & Powers, in press). At a minimum, transition plans must include employment, education, housing, life skills, personal and community engagement, personal and cultural identity, physical and mental health, and legal information (Sheehy, Ansell, Correia & Copeland, 2000).

- **Appointment and Training of Educational Surrogates.** Although foster parents often act as an educational surrogate, many do not have training in special education and disability issues. Disruptions in foster placement create disruptions in the educational process and leave youth without a consistent, informed, and involved advocate (Geenen & Powers, 2006). A more consistent approach that includes stable, committed adults to ensure youth receive the coordinated, comprehensive services they are entitled to, is imperative.
- **Connections with Caring Adults.** The consistent presence of a single caring adult has been shown to have a significant positive impact on a young person's growth and development (Garmezzy, 1993). Optimal independent living planning should be family-centered and include existing relationships both inside and outside the family of origin. In many cases, youth are the best resource for identifying relationships that can serve as primary, ongoing connections (Sheehy et al., 2000).

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types of Part C services required may change. Specifically, it is likely that children involved with child protection will have social-emotional and behavioral issues more frequently than other children served by Part C. Therefore, Part C may need to enhance its ability to meet early childhood mental health needs.

It is important for states to receive adequate Part C funds to meet the needs of young children and their families, and in particular to ensure that the CAPTA requirements regarding referrals to Part C continue to be implemented effectively. The Association of University Centers on Disabilities (AUCD) is currently working with its partners to increase IDEA Part C funding as well as for all of the programs under CAPTA. Last year appropriators provided level funding for these programs. However, a last minute one percent across-the-board cut was enacted which actually lowered the amount these programs will receive. The President's Fiscal Year 2007 budget proposal also provides level funding. AUCD urges all child welfare advocates to educate member of Congress about the need for more funding for these programs.

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