

**PERSPECTIVES ON CHILDREN WITH
DISABILITIES IN THE
FOSTER CARE SYSTEM
AND HOW UCP CAN HELP:
FINDINGS FROM A SURVEY OF
UCP AFFILIATES**

December 2006

INTRODUCTION

It is estimated that 30-80% of the roughly 800,000 children who experience the foster care system in a given year have some type of disability.¹ Some research and anecdotal evidence suggests that foster children's disabilities may be unidentified and unaddressed, as these children are thrust into an already over-taxed system that was not designed to meet their special needs.²

Since 2004, United Cerebral Palsy (UCP) and Children's Rights have been collaborating on an initiative to identify the prevalence of children with disabilities in foster care, explore the degree to which their needs are being met in public child welfare systems and develop legal and public policy advocacy approaches to improve the safety, permanency³ and well-being of these children.

A component of this project involved the development of a clearinghouse of information and resources on UCP's website for affiliates and other disability organizations to encourage those not already doing so to get involved in providing services to children in foster care and to provide resources for affiliates/organizations serving this population. In order to create a clearinghouse that would be most useful to affiliates and other organizations, Children's Rights surveyed UCP affiliates to determine their perspectives on the quality of services for and outcomes experienced by children with disabilities in foster care; collect information that would assist in the development of the clearinghouse; and inform future advocacy efforts related to children with disabilities in foster care.

This report was authored by Children's Rights. The primary audience for the report is the UCP national headquarters and UCP affiliates, to assist UCP as it considers increased involvement with child welfare systems across the nation.

This report provides the survey findings, which address the following topics:

¹ AAP, 2002; Berrick, Barth & Needell, 1994; Bilaver, Jaudes, Koepke & Goerge, 1999; Casey Family Programs, 2004; Chernoff, Combs-Orme, Risley-Curtis & Heisler, 1994; Clausen, Landsverk, Ganger, Chadwick & Litronik, 1998; Delfabbro, 2004; Dicker & Gordon, 2000c, 2004b; Dore, 1999; dosReis, Owens, Puccia & Leaf, 2004; dosReis, Zito, Safer & Soeken, 2001; Garland, Hough, Landsverk, McCabe, Yeh, Ganger et al, 2000; Halfon, Zepeda & Inkelas, 2002; Holland & Gorey, 2004; Leslie, Hurlburt, Landsverk, Barth & Slymen, 2004; Hochman, Hochman & Miller, 2004; Hochstadt, Jaudes, Zimo & Schachter, 1987; Kurtz, Gaudin, Wodarski & Howing, 1993; Leslie, Gordon, Ganger & Gist, 2002; Marchenski & Mudry, 2005; McMillen, Auslander, Elze, White & Thompson, 2003; McNaught, 2004; Mech & Fung, 1998; Rubin, Alessandrini, Feudtner, Mandell, Localio & Hadley, 2004; Schor, 1982; Shin, 2005; Silver, DiLorenzo, Zukoski, Ross, Amster & Schlegel, 1999; Simms, Dubowitz & Szilagyi, 2000; Smithgall, Gladden, Yang & Goerge, 2005; Swire & Kavalier, in Dicker, Gordon & Knitzer, 2001; Takayama & Bergman, 1994; Takayama, Bergman & Connell, 1994; Takayama, Wolfe & Coulter, 1998; Urquiza, Wirtz, Peterson & Singer, 1994; US DHHS, 2005; Vig, Chinitz & Shulman, 2005; Weinberg, 1997; Wulczyn, Hislop & Hadren, 2002; Zimmer & Panko, 2006.

² Allen & Bissell, 2004; AAP, 2002; Hochman, Hochman & Miller, 2004; Marchenski & Mudry, 2005; Schor, 1982; Simms, Dubowitz & Szilagyi, 2000; Vig, Chinitz & Shulman, 2005; Wulczyn, Hislop & Hadren, 2002.

³ The term "permanency" refers to the establishment of a lasting, legally secure relationship for a child in foster care with at least one adult, through reunification with biological parents, guardianship with relatives or adoption.

- The types of services and programs currently offered by UCP affiliates for children with disabilities who are in foster care;
- Affiliates' knowledge of and contact and relationship with the foster care system;
- Affiliates' views of the foster care system, and its capacity to provide services for and ensure the safety, permanency and well-being of children with disabilities; and,
- Affiliates' interest in expanding services and supports for children with disabilities in foster care.

In addition to data summarizing the findings from the survey, direct quotes from affiliates are provided throughout the report.

SURVEY METHODOLOGY

This survey was conducted using a structured interview protocol designed by Children's Rights and UCP, and field-tested with 2 affiliates. From August through October of 2006, Children's Rights' staff and interns made outreach to the Executive Directors of all 98 UCP affiliates across the nation to request their participation in the survey. Forty-two affiliates representing 24 states participated in the survey.⁴ Most affiliates completed the survey via a phone interview with Children's Rights' staff and interns. Five affiliates completed the survey in writing and submitted it to Children's Rights via mail. Survey responses were reviewed and analyzed using SPSS (Statistical Package for the Social Services), a commonly used data entry and analysis program.

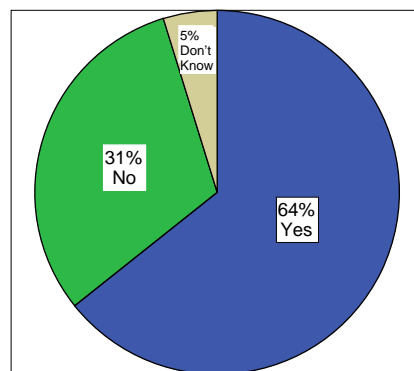
SURVEY FINDINGS

AFFILIATE SERVICES & PROGRAMS

Affiliate interviewees were asked if their affiliate currently served children with disabilities in foster care, and, if so, through what type of programming.

Approximately three-fourths (64%) of interviewees said that they currently serve children and youth with disabilities in foster care through one or more of their programs.

CHART 1: AFFILIATES SERVING CHILDREN WITH DISABILITIES IN FOSTER CARE



In most cases, affiliates were serving this population on an ad-hoc basis, i.e., "If they are somehow referred," or "Only when we get a call from foster parents or caseworkers asking for

⁴ States represented in the survey included Alabama, Arkansas, Arizona, California, Connecticut, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Massachusetts, Maryland, Michigan, Minnesota, Missouri, North Carolina, New York, Oregon, Pennsylvania, Tennessee, Utah, Washington, Wisconsin.

information.” These affiliates reported serving 3-7 children in foster care at a given time. However, a few interviewees said that they were regularly serving 10-50 children in foster care. Two interviewees said that they did not know whether they serviced children with disabilities in foster care with comments such as, “We haven’t done that type of record keeping,” and “We have not thought that far ahead in term of tailoring our work to that population.”

Interviewees who reported that their affiliate works with children with disabilities in foster care (N=27) identified a variety of services and programs through which these children are served. Table 1 below provides the types of programs and services most frequently provided by affiliates to children with disabilities in foster care:

TABLE 1: SERVICES & PROGRAMS FOR CHILDREN IN FOSTER CARE

Service/Program	Percent of Affiliates Who Said Their Affiliate Provided This Service for Children in Foster Care
Assistive Technology	48%
Respite Services	45%
Early Intervention Program	36%
Service Coordination	36%
Social & Recreational Supports	36%
Speech & Language Therapy Services	36%
Physical Therapy Services	36%
Individual Advocacy	36%
Educational Advocacy	33%
Transition Planning	33%
Occupational Therapy	33%
Legislative & Systems Advocacy	31%
Family Services	26%
Providing Information about Rights	26%
Disability Counseling & Consultation	21%
Job Training & Employment Support	19%
Medicaid/Medicare Eligibility	17%
Direct Financial Support	17%
Lobbying	14%
Housing Services	12%
Individual & Family Therapy	5%
Licensed Foster Care Provider	2%

As Table 1 highlights, affiliates report that they are working with this population primarily by providing funding directly and/or helping families to access funding from other sources in order to obtain assistive technologies; organizing respite care and recreational programs to foster families caring for children with disabilities; offering educational and disability-related advocacy to ensure clients receive equitable services and opportunities; and coordinating early intervention services and other specialized supports, including speech and language, physical and occupational therapy.

Services & Programs

- *We have a durable medical and adaptive equipment program that foster care clients have heard of and use, and we build wheelchair ramps for foster families to use with the kids placed in their homes.*
- *Our respite program provides in-home care in two ways. In one, we provide babysitters for foster parents, and in the other, we provide a respite voucher where families can hire their own babysitters.*
- *Children in foster care are in our early intervention program. For therapy services, we refer children in foster care to our service providers. We also do some work with extended day programs and summer camps, which are available to the general disabled child population, but also to foster care clients.*

Although only one affiliate who participated in this survey provides foster care services as a licensed foster care provider, i.e., licenses and supervises foster homes through a treatment/specialized foster care program, a significant number of affiliates are engaging in advocacy and consultation pertaining to children with disabilities in foster care, their foster families and the foster care system in general. As one affiliate explained,

We are not really a direct service provider, but we do work on the advocacy and support services level. We provide special education advocacy training for foster parents on supporting children's educational planning and transitions of school. We also conduct trainings for foster parents and child welfare staff about disabilities because we have a partnership with the foster care system here. We also offer many support services for youth in foster care - benefits counseling; technical support and information; and, referrals on accessing employment opportunities. We do general advocacy and advocacy on accessing youth services benefits and social security benefits. We support accessing assistive technology and physical supports like ramps for foster families caring for children with disabilities.

A few affiliates noted that the array of their services to this population has decreased in recent years, given cutbacks in funding in their county or state. As one affiliate said, "We used to offer an inclusive day care facility, but it never got off the ground due to lack of funding." Other affiliates said that certain state laws and ill-conceived service delivery systems prevented them from fully serving this population. According to one affiliate,

What we can do in this area is very limited. While we may at times be able to serve a few pre-school and school-age kids, in our state, the service delivery system for individuals with disabilities is Mental Retardation and Developmental Disabilities. As a result, we are not allowed to serve people in the foster care system, since they are not able to be served by both this system and the foster care system, as it is seen as double-dipping. So it has limited the ways we can help. For example, although we offer respite services, foster care providers are not allowed to access our respite services because they are involved in a completely different system – child welfare.

AFFILIATES' RELATIONSHIP WITH THE FOSTER CARE SYSTEM

Interviewees were asked how they would characterize their familiarity with the foster care system in their county or state. They were asked about their general knowledge of the foster care system; the degree of contact they have with the system; and the quality of their working relationship with the system.

Knowledge/Familiarity

One-third of survey respondents (36%) said that they had significant familiarity with the foster care system in their jurisdiction; one-fifth (21%) said they had some understanding; and 43% said they had limited or no knowledge of the foster care system.

TABLE 2: AFFILIATES' FAMILIARITY WITH THE FOSTER CARE SYSTEM

Familiarity with the Foster Care System	Percent of Affiliates
Solid Understanding	36%
Some Understanding	21%
Limited Understanding	29%
No Knowledge of the Foster Care System	14%

The affiliates who indicated that they had a good working knowledge of the foster care system said that their familiarity came from their interactions with the caseworkers and foster parents of the children involved in their affiliates' programs. According to one affiliate, "We are pretty tied in through our direct services, since we see the kids all the time and work closely with the foster care workers to know what to look for, what services are needed. We also have some grant programs that we run which connect us to the child welfare system." Another affiliate reported, "We know about the system because we had two grants, one federal and one at the state level, that dealt with children with disabilities and adoptive parents. Even though they ended three years ago, since we provided support for adoptive parents of children with special needs, we gained quite a bit of perspective about the functioning of the foster care system."

Affiliates who reported having limited or no knowledge of the foster care system identified a variety of reasons for this lack of familiarity. As one affiliate stated, "I know child welfare workers I can call, but that is more or less the extent of my knowledge, because there's no regular interface. Another affiliate said, "All program staff are marginally aware of the child welfare system in a general way, but our affiliate does not interact with the system regularly enough for us to be really knowledgeable." Another affiliate explained,

Our knowledge is limited because we are uncertain of exactly what communication channels to use. For example, there's a child in therapy here with us who is in foster care. But we have no idea how much we can/should tell the foster parents about the child's therapy? Between HIPPA, and children's and parental rights laws, it's not always clear how much to disclose and to whom. The second challenge seems to be caseworkers from the child welfare system who are not following up in a timely manner due to working in an overtaxed system. It's not always clear who to call regarding child welfare issues because so many people are so unresponsive.

Nearly three-fourths (61%) of the affiliate interviewees said that they or other staff members had expertise or experience related to the child welfare or foster care system that they had gained apart from their current employment at UCP, typically through prior work experience, being a foster or adoptive parent or volunteering as a Court Appointed Special Advocate (CASA).

Experience in Child Welfare/Foster Care

- *We have over 30 staff members with child welfare or foster care experience, including two regional directors.*
- *We have two licensed social workers who use to be foster care caseworkers, and all service coordinators have worked with kids in foster care before coming to work at our affiliate. I have been directly involved with the child welfare system and community for many years – especially working directly with adoptive families, and participating on various monitoring groups. I have served as the County Quality Assurance chairperson for nearly ten years. I have been directly involved with the child welfare services agency – I did a clinical internship there, and have participated in child death reviews.*
- *I have personal experience as I used to work for a CASA program, and got assigned to all the kids with disabilities, so I saw firsthand these challenging issues.*
- *I worked in child welfare in my prior career to get children back to their birth families. I also started a Child Abuse Prevention Program here and have worked on foster care review boards. I have also had a child in foster care with cerebral palsy placed in my home.*
- *On our staff we have foster parents, foster parents-to-be, MSWs who have worked in the system, adoptive parents, and adoptees.*

Degree of Contact

Approximately one-fourth (28%) of interviewees reported that their affiliate had frequent contact with the foster care system; nearly one-half (45%) said that their affiliates' contact with the foster care system was infrequent or limited; and one-fourth (26%) indicated that their affiliate did not have any contact with the foster care system.

As one affiliate said, "All of our staff interact regularly both with children in foster care and their foster parents, and, when possible, child welfare staff." Another affiliate commented, "When we offer services on a daily basis to a child in foster care, we have much more regular contact. In relation to some of our advocacy activities, however, it could be only five or six times per month."

Affiliates identified several factors contributing to their infrequent contact with the foster care system including lack of accurate information regarding the caseworker assigned to the child's case, often due to high turnover at the foster care agency; lack of outreach by the foster care system to the affiliate serving their state or county; and, in certain instances, children being placed with highly skilled foster families who are in close contact with affiliate staff but do not want or need help from the foster care system.

Reasons for Infrequent Contact with the Foster Care System

- *We try to be really proactive in getting the caseworker involved, but they don't return calls. They don't even know what the problem is, and we often don't get an idea of who the caseworker assigned even is. They typically only get involved because of a problem, but I would characterize the reason for our lack of contact with the foster care system as an overall lack of communication.*
- *There are many reasons for our limited contact, but I think it's mainly because we tend to just get last minute calls for resources. We tend to give out the same information over and over again because there is such high caseworker turnover. So we don't have great contact with the agency.*
- *Our contact is never anything particularly official - it is always that foster or adoptive families are coming in trying to get resources for their kids. We never really hear from the system itself, even though we are always trying to get on their radar.*
- *The one or two foster families a year who have foster children in their homes and use our affiliate's services tend to be fairly stable, so the need for interacting with child welfare services is limited.*

Quality of the Working Relationship

Affiliates were asked to describe the quality of their affiliate's working relationship with the foster care system in their jurisdiction. Almost half (45%) of interviewees reported that their affiliate

had a good relationship with the foster care system, while 14% characterized the relationship as fair.⁵ Only one interviewee noted that their relationship with the foster care system was poor.

Quality of Affiliate Relationship with the Foster Care System

- *Our relationship is very strong, since the child welfare system hires us to conduct trainings on disability related issues all the time.*
- *Well, people at the agency do call me back. And if people call me back, I'm happy.*
- *Our relationship is as good as anyone can have with a system that completely underpays and under supports its workers.*
- *It's strange, really. It depends on the worker, and if they are even aware of UCP.*
- *The affiliate has a good relationship with all the foster families, but because of the overtaxed child welfare system and ongoing challenges with communication and disclosure, at times the difficulty in actually navigating the system limits the effectiveness of the therapy we try to do.*

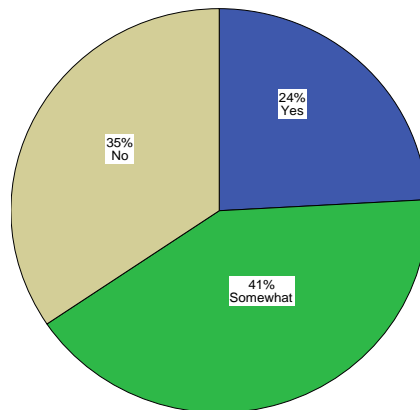
AFFILIATES' VIEWS OF THE FOSTER CARE SYSTEM

Affiliates were asked to provide their perspectives on the foster care system's provision of appropriate services and supports to ensure the safety, permanency and well-being of children with disabilities in their jurisdiction.⁶

Providing Services

Forty-one percent of affiliate interviewees reported that children in foster care in their area are only "partially" receiving appropriate services to address their disabilities and approximately one-third (34%) said that these children were not receiving appropriate services "at all" in their jurisdiction.⁷ Less than one-quarter (24%) reported that child with disabilities in foster care were receiving appropriate services to address their special needs.

CHART 2: RECEIPT OF APPROPRIATE SERVICES TO ADDRESS SPECIAL NEEDS



One affiliate said that children with disabilities are receiving appropriate services, "But only since UCP works hard with all foster care agencies across the state." Another affiliate said,

It is easier for the severely disabled, easily identifiable children between 0-5 to receive services, but much harder for the other less identifiably needy children, since they may slip through the cracks. Profoundly disabled kids are getting services; they

⁵ Excludes 16 interviewees who said that they could not answer this question due to their infrequent or nonexistent contact with the foster care system.

⁶ Affiliates who said that they did not have familiarity with the foster care system were excluded from these analyses.

⁷ Excludes 13 interviewees who said that they did not have enough information to accurately answer this question.

are at our school and generally getting services. The higher functioning kids with learning disabilities or mild Cerebral Palsy, though, may be getting caught and not receiving services.

Another affiliate explained that only “If the foster parents are good, will the children receive services.”

A few interviewees noted that their foster care system offered a model for efforts in this area. According to one affiliate, “Our early intervention system has all foster care children assessed with a thorough evaluation before age three. Every single child.”

Affiliates mentioned a number of barriers to children receiving needed services including lack of specialized disability training for child welfare agency caseworkers and foster families; high caseloads and high staff turnover at the child welfare agency; lack of information regarding the nature of children’s disabilities and needs provided to foster families; lack of communication between the child welfare and disability provider communities; and, lack of timely responsiveness by the child welfare system towards the requests of foster families caring for children with disabilities.

Stories from the Field

We found out about a foster parent who lived in a 2nd floor apartment and wanted equipment for a disabled child placed in her care so that he could get up and down the stairs easier, but there were complications linking her needs to appropriate folks who could get her the resources she needed, so she never got connected with supports, and he never got this equipment.

Reasons for Inadequate or Inappropriate Services

- *The foster care system does not provide foster parents with the information they need on diagnostics and the necessary information needed to do it or specialized education law clinics and doctors.*
- *In the children and family services division, the caseloads are tremendous and caseworkers don’t get enough training. There is a complete lack of training specifically on disabilities.*
- *At the local level in our state, it’s inconsistent. At the state level there are problems because of the bureaucracies and privacy rules involved in the medical system, social service system and child welfare system. The systems are difficult to navigate, particularly if one moves counties because medical cards issued in one county don’t carry over to other counties. Foster parents also struggle because if caseworkers don’t fill out the paperwork correctly, they can’t get any information about their foster children because of HIPPA rules.*
- *There is a big disconnect between state foster care caseworkers and the supports available in communities, and linking these kids with services, such as UCP. There is a breakdown in communication.*
- *It depends on the foster parents – some are supportive and some are not, and most are not prepared when they get a child with disabilities. If families would tap into early intervention systems, that would help. There is no systematic approach though; it’s done haphazardly.*
- *There is huge turnover among workers; training for caseworkers is very poor - many don’t even know that kids with disabilities can attend public schools! The weakest area is the fact that caseworkers actually have access to a ton of resources, but they do not know they exist or they are not using them. The foster care agency is short staffed and so new caseworkers have to hit the ground running without being fully trained first.*
- *I am dubious of all large bureaucracies. The nature of state government is that it takes too long for simple questions to be answered. And this holds true for the foster care system.*
- *In my area, the child welfare system is generally not responsive to foster or adoptive families’ calls until the problem mushrooms into a full crisis.*
- *Foster parents often do not have knowledge of helpful resources, since foster parents do not have all the information about their children’s disability status.*

Ensuring Safety

Affiliates were asked to provide their perspectives on the safety of children with disabilities in foster care.

Nearly three-fourths (73%) of affiliate interviewees said that children with disabilities experiencing further abuse and neglect while in foster care was, to varying degrees, an issue or problem in their jurisdiction.⁸ However, affiliates were in agreement that they did not have enough information to define the scope of the problem. As one interviewee explained, “It’s in the media all the time. But it’s difficult to gauge whether the really bad cases are the norm, since all we hear about are the few different lawsuits addressing this issue [in our state].” As another interviewee said, “Maltreatment is a problem for all children in foster care. In our county, they don’t even keep track of the numbers of children in foster care with disabilities, so it’s unclear what is happening specifically to our kids with disabilities in terms of abuse and neglect in foster care.”

Affiliates identified a number of different factors contributing to the maltreatment of children with disabilities in foster care, including the lack of appropriate preparation of foster families regarding the needs of children with disabilities; shortage of foster homes resulting in the overcrowding of available foster homes; and lack of oversight and support of foster homes due to high caseloads and turnover at the child welfare agency.

Stories from the Field

A young boy with physical disabilities was sent to a group home after his mother abandoned him. He was supposed to only be there temporarily, but instead stayed there for years. He was in this home with other older individuals who had severe behavioral issues, so he was vulnerable to others picking on him and being abused. The system tried to find him a family, but that never happened, as there was a lack of good permanency planning in his case. When he was 18-years old, UCP finally got involved, and we placed him in one of our group homes where he was finally with individuals his same age and with similar disabilities.

Maltreatment of Children with Disabilities in Foster Care

- *Many children with medical issues are being neglected because the foster parents are not properly informed about what the child’s issues are and how best to deal with their disability. They continue to recruit families that are ill-equipped to deal with disability issues.*
- *All children in foster care have some problem with being maltreated. It’s because the caseloads are too high, so oversight is poor, and there are not enough foster families generally and especially not enough who are equipped for kids with disabilities.*
- *Many kids just fall through the cracks. Caseworkers do not always recognize that kids need special services, and the turnover is so high, it’s hard for folks to know what the kids on their caseload need, because the case is always being transferred. So kids end up being hurt.*
- *It is a struggle - there are not a whole lot of families available. But when you have families with 5,6, multiple children, for most foster families it’s a living for them, and I get that. But they don’t understand how to be parents, and they certainly don’t understand basic child development and developmental disabilities.*

Ensuring Well-Being

Affiliates were asked to provide their perspectives regarding the health care and educational opportunities afforded children with disabilities in foster care.

⁸ Excludes 20 interviewees who said that they did not have enough information to accurately answer this question.

Medical and Dental Care

Forty-four percent of affiliate interviewees said that children with disabilities were receiving only minimally adequate health care, and one-fifth (20%) said that they were not receiving adequate health care at all.⁹ According to one affiliate interviewee, “There’s no systematic approach. There are issues with Medicaid, as it’s hard to get providers to take it. Most foster parents are just out on their own, and they don’t get much support in this area.” The majority of these interviewees noted that dental care was virtually nonexistent for children with disabilities in foster care. As one affiliate said, “Basic medical care may be provided, yes, but dental is another issue at all levels in our state, not just for kids in foster care with disabilities, but for everyone.” Another affiliate said, “Generally, the quality of care is good if you can get it, but very few dentists are available and most dental clinics have very long waits and are not equipped to serve kids with disabilities. Fewer and fewer doctors are willing to take Medicaid so access to care is challenging”

Stories from the Field

A foster family was called at 11 PM and told a child had a cold and needed to stay with them since it was an emergency situation. It turned out that the child actually had Cerebral Palsy and the “cold” symptoms were 24/7. Apparently the child’s former foster family didn’t want him because he had some behavior problems. So this 2nd foster family was never even told about the child’s disability, even though it was known to everyone.

Approximately one-third (36%) of affiliate interviewees reported that adequate efforts were being made to ensure health care for children with disabilities in foster care in their area. According to one affiliate, “Failure to receive medical and dental services is really not one of the biggest problems that children with disabilities in foster care face.” Another affiliate noted, “Medical and dental care is something they do very well here, actually.”

Affiliate interviewees highlighted a number of barriers to the provision of health care services to children with disabilities in foster care in their jurisdiction: lack of information and support provided to foster families to ensure their competency in this area; lack of provider willingness to take Medicaid; and, lack of follow-through by foster care caseworkers to ensure paperwork is completed accurately and in a timely fashion.

Challenges to the Provision of Medical and Dental Care

- *The foster parents are usually good, well-intended people, but the foster care agency does not explain what the expectations are when one has a child with disabilities placed in their home.*
- *There’s no systematic approach in this area. There are ongoing issues with using Medicaid, as it’s hard to get providers to take it. Most foster parents are really left on their own, as they don’t get much support.*
- *Fewer and fewer doctors are willing to take Medicaid and also access to care is challenging because if caseworkers don’t fill out the paperwork correctly, foster parents can’t get any information about their foster children because of HIPPA rules.*

⁹ Excludes 17 interviewees who said that they did not have enough information to accurately answer this question.

Educational Services and Supports

Approximately one-half (46%) of affiliate interviewees reported that adequate efforts are made to ensure the provision of educational services and supports for children with disabilities in foster care in their area.¹⁰ As one affiliate explained, “We run an early intervention-to-preschool transition program and in my experience, the school system seems to understand the issues facing children with disabilities in foster care pretty well. Another affiliate noted, “As children in foster care with disabilities are entitled to the same educational opportunities as anybody else, discrimination on the basis of their foster care status is rare.”

Stories from the Field

We adopted our son when he was 14. He'd been in foster care for 6 years, when we adopted him and his brother. He's having trouble in school now, and we're only getting services for him because I am able to advocate and push the system to respond to him. Being persistent and well-educated pays off here, and if you're not a foster or adoptive parent who has those

However, more than one-third (35%) said that educational services and supports were only marginally provided to this population, and one-fifth (19%) stated that services and supports were inadequate. According to one affiliate interviewee, “The school system is pretty poor, and I don't know how much support they are getting in their classrooms. Before they reach school-age, children are supported through the work of UCP, but once they reach school it is like they walk off a ledge and stop receiving any support.” Another interviewee expressed that “many caseworkers don't even know that children with disabilities can attend public schools, and then, the educational system is a crap-shoot, and haphazard at best.”

Affiliates identified several barriers to the provision of educational services and supports: lack of identification of children's disability status and related educational needs; lack of awareness of the rights of children with disabilities by caseworkers and foster parents; foster parents' lack of understanding regarding their roles and responsibilities as educational advocates for the children placed in their care; and discrimination on the part of school districts due to the frequent placement moves of children in foster care.

Challenges to the Provision of Educational Services & Supports

- *Foster care workers don't recognize that the kids have disabilities and no one pushes for the services.*
- *It's hard to get the schools to commit – they say “how long will Johnny really be here anyway?”*
- *There are issues because foster parents and caseworkers do not know what their rights are, or what is available for these kids. There is a lack of knowledge, and so they just accept what the schools tell them, which is not always a great thing, it is not always in the best interest of the child. There is no one doing good advocacy on this issue.*
- *There are a lot challenges and gaps in communication between caseworker, foster parents, school, and other caregivers of the child. The caseworkers are busy and schools don't want to or are not sure they can deal with foster parents because of privacy issues.*
- *Parental rights and termination of those rights are huge issues here. The foster care system is really slow to act and can't trace parents, and hence the children miss out on services that they qualify for.*
- *There are some major gaps in getting supports to foster parents in school, partly because of parental rights issues but also largely because of the lack of service coordination, support, and trainings for foster parents.*
- *Foster parents are put in charge of children's education, like sitting in on IEP hearings, but they are unaware of the child's rights. They need more information, and to know what their rights are at IEP meetings in particular.*
- *Some school districts are good but foster parents do not know about what they need or can ask for. If a kid has an assertive foster parent they get what they need, but most foster parents don't know how to navigate the system.*

¹⁰ Excludes 16 interviewees who said that they did not have enough information to accurately answer this question,

Ensuring Permanency

Affiliates were asked to provide their perspectives regarding children's visitation and connections with their birth families, permanency planning efforts, and transition planning activities for youth aging out of foster care.

Visitation & Connections with Birth Families

Approximately one-third (29%) of affiliate interviewees said that adequate efforts were made to ensure visitation and maintain connections with birth families for children with disabilities while they were placed in foster care.¹¹ According to one affiliate, "Connections with family are beginning to happen more regularly now, as there has been a concerted effort in preserving these relationships at the state level." Yet another affiliate explained, "The state is very realistic on this issue now. Where it is appropriate they do what they can to maintain appropriate contact with the family."

Approximately two-thirds (63%) of affiliate interviewees said that only minimal efforts are made in this area.¹² These affiliates identified a range of issues that affect children with disabilities visiting and retaining ties with their birth families while they are in foster care, namely that siblings are frequently placed in separate foster homes due to foster family shortages, and that foster families are not trained to develop positive relationships with children's birth families.

Challenges to Maintaining Connections with Birth Families

- *Caseworkers maintain notebooks on children for the foster parent and birth parent to share. However, the information often doesn't get filled-in regularly or shared with the birth parent. So even though the foster parent and social worker are up to date, the birth family still is not and therefore they are often shocked by new things that are happening in their child's care.*
- *By policy, siblings are supposed to be placed together, and foster care children are supposed to be in the same area of town as their birth parents. However, this isn't always done because of shortages of foster care homes.*
- *Maintaining connections is a goal, but we've found consistently that foster parents have negative ideas of birth parents – there has never been efforts to ensure foster parents really understand the life situations that kids came from.*

Permanency Planning Efforts

Affiliates were asked whether adequate efforts are made to achieve permanency for children with disabilities in foster care, through timely reunification with birth parents, guardianship with relatives or adoption.

Almost 60% of affiliate interviewees said that efforts to achieve permanency are minimal or nonexistent.¹³ As one affiliate noted, "While there has been some progress in this area for your more 'typical' or non-special needs kids in foster care, those with disabilities are still behind in regards to this efforts aimed at achieving their permanency." Another affiliate explained that, "while permanency planning is something they are supposed to be doing due to the consent decree [in our state], since it's really at the crux of the whole agreement, the whole process really doesn't play out as it should."

¹¹ Excludes 18 interviewees who said that they did not have enough information to accurately answer this question.

¹² Two affiliate interviewees did not feel that adequate efforts were made to maintain children's connections with their birth families at all.

¹³ Excludes 18 interviewees who said that they did not have enough information to accurately answer this question.

However, 42% of affiliate interviewees said that adequate efforts are made to achieve permanency for children with disabilities in foster care. As one affiliate explained, “We have an excellent legal system that pushes to move these kids towards permanency in a good timeframe.” Another affiliate notes that “there has definitely been a shift here - they used to place lots of kids in group homes, but now there is an emphasis on trying to keep those kids at home or with kinship foster families if it is at all possible, and to give those families what they need so they can care for these kids.”

Challenges to Achieving Permanency

- *There are a lot of kids who are bouncing or in limbo because there are not enough programs that give birth and foster families the tools and education to be empowered and successful. There need to more programs, resources and education to support families and more efficient ways to cut strings to allow these children to access and maintain a permanent placement.*
- *The foster care agency really tries to keep kids and their families together, but it is sometimes to the child's detriment. Children with disabilities end up bouncing between homes and not receiving services because the parental rights are not terminated, but no alternative plan is identified.*
- *In trying to address that issue, some local initiatives with local foster care agencies have been developed – for example, there's now a special team designed to work on permanency, so there is a good faith effort occurring in this area. But it's still in its infancy.*
- *DCFS workers are primarily focusing on trying to make relationships with the biological parents work, which oftentimes leads to kids with disabilities remaining for too long in the system without permanency.*
- *All of our clients who are foster children are going for adoption by their foster families – but many of their foster families have been fighting for years to try and adopt them.*

Affiliates highlighted the following challenges to the achievement of permanency for children with disabilities in foster care in their jurisdictions: caseworkers' failure to accurately evaluate the realistic prospect of reunification with birth families and an inadequate array of necessary services available to birth or foster families that would support them in making a permanent commitment to these children.

Stories from the Field

There was one little boy who was in and out foster care and spent a long time in limbo. His birth mom was on heavy drugs when she was pregnant with him, and this little boy had resulting disabilities. Although the agency tried very hard to keep the family intact and offered the mom services, she was unresponsive. Eventually the little boy was placed in foster care, in a therapeutic foster family. He then went back and forth between his birth home and foster home for a while, before his birth mom sort of dropped out of the picture and stopped being involved. Then, this boy started bonding with the foster mom he had for 3-4 years of his life, and his foster mom expressed an interest in adopting him. However, the agency found another potential family to adopt him because they regarded his foster mom as too old for adoption of a special needs child. So the boy started visitation with a pre-adoptive family. His foster mom offered to remain involved in his life as an auntie, but the adoptive family was not interested in having him maintain this relationship. The boy was placed with the potential adoptive family, and not allowed to see his former foster mother who had essentially raised him. Then, his birth mother's rights were never terminated because the agency said they could not locate her, so the adoption never went forward. So now, as the little boy is supposed to start kindergarten, he has spent most of his life in limbo between a number of families who have varying degrees of access to information and rights to intervene in his care. And it looks like things will remain that way.

Transition Planning for Youth Aging Out of Foster Care

Affiliates were asked to assess the adequacy of services and planning for youth with disabilities who are “aging out” of the foster care system, i.e., leaving the system not because they are returning home to their families or being adopted, but rather because they have reached the age of majority.

Two-thirds (67%) of affiliate interviewees reported that adequate efforts are not being made to ensure a successful transition to adulthood, and one-third (33%) said that only minimal efforts are made in this critical area. No affiliates said that transition planning efforts were adequate.¹⁴ As one affiliate explained, “I am not sure any efforts are made once a child turns 18 actually. They are just transferred off to another agency, with no training on life skills. The state just pawns them off onto another agency. They’re pretty much warehoused until 18, and then transferred to adult services.” Another affiliate relayed that “This area needs the most attention – you need to prepare kids who are in foster care for being out on their own. And for kids with disabilities, this is critical, but not happening.” Yet another affiliate expressed that “It’s sink or swim, and bye-bye, for these children. This area of the system is dismal, and part of a convoluted system at best.”

Stories from the Field

This girl was in a foster home, and her foster mother was the primary caregiver of her plus four other kids with disabilities. Then the foster mother died, and the foster father was unable to care for the kids safely. Adult protective services was called, and they found that she had been made to live in the basement with no windows. So she was removed from that foster home by the foster care agency, and they took her to a mental health drop-in center, and told her to say that she was homicidal or suicidal so she could get services and placement. But she was neither, she just had severe disabilities. UCP found out about her, and we met with her and realized that she couldn’t even feed herself! How is she going to hurt herself or others when she can’t even feed herself? But because she wouldn’t say she was homicidal or suicidal, she ended up in a nursing home, because there was nothing available for her.

Affiliates noted several systemic problems impacting youth with disabilities aging out of the foster care system in their respective jurisdictions: lack of a service continuum for this population overall, especially in rural areas; inadequate funding for transition support services; lack of services for youth with disabilities other than mental retardation; failure of the medical community to adequately anticipate issues related to the transition to adulthood for this population; and, lack of ongoing communication between the foster care and disability communities regarding transition planning needs and goals.

Challenges to Transition Planning for Aging Out Youth

- *There are not enough supports for foster kids and definitely not enough for foster kids with disabilities who are entering adulthood on their own.*
- *If you’re in a metro area you can get aging out programs, but not at all in the rural areas.*
- *Lots more needs to be done but there is inadequate funding for this area.*
- *There is no transition from school or foster care into adulthood for these kids. Kids who are declared Department of Mental Retardation-eligible will qualify for a services and a caseworker, but with the other kids with other disabilities, it’s unclear how are they going to survive. There are no services for adults with developmental disabilities in general.*
- *One big problem is that it is mostly pediatricians that treat kids with cerebral palsy, and so when they are older, because doctors don’t know much about adulthood issues, not much gets done in this regard.*
- *They can do a better job – more contact with everyone involved in the child’s life is critical. No one even tells us when the kids transition.*

¹⁴ Excludes 15 interviewees who said that they did not have enough information to accurately answer this question.

Affiliates were also asked about what happens to youth with disabilities when they leave the foster care system without achieving permanency. As one affiliate explained,

If kids are not deemed Department of Mental Retardation-eligible, they are left on their own to fend for themselves. They are just dumped. Some kids get transferred to another agency. Oftentimes, they end up in mental health services because they have learned to fight, which is seen as a mental health issue more than one of survival. For the first couple of years or months, they are okay; maybe they get boyfriends and girlfriends and get jobs and enjoy their new freedom, but then they get fired from a few jobs and are struggling to get by. A large number of foster kids end up homeless. It is clear that many of our youth between 18-25 are homeless, even though they don't think of themselves that way, since they are living with a friend, a friend's parents, or out of their cars.

The box below provides the array of affiliate interviewee perspectives on this issue:

Outcomes for Youth with Disabilities Aging Out of Foster Care

- *They're seen as someone else's problem.*
- *They're just dropped - on the street, into nursing homes....*
- *They are kind of just dumped. Sometimes the schools pick up on this piece, but usually nothing happens.*
- *A lot of families won't keep the kids after 18th birthday. Some apply for services, but a lot are just on their own.*
- *Most kids end up in homeless shelters, in the adult mental health system, and on the streets.*
- *They're left on their own. If the children have made friends or have other ways of getting housing, they do, since there are no systematic supports available at all.*

SYSTEMIC BARRIERS

Affiliates were also asked to provide their perspectives regarding systemic barriers or challenges that existed, which impacted the safety, well-being and permanency of children with disabilities in foster care in their area.

Eighty-eight percent of affiliate interviewees reported the existence of systemic barriers that are negatively impacting the safety, well-being and permanency for children with disabilities in foster care in their jurisdiction.¹⁵ Table 3 provides the range of barriers and challenges cited by affiliates. The most frequently noted were foster family, caseworker and provider shortages; insufficient funding for the foster care system; and lack of disability training for foster parents and caseworkers.

¹⁵ Excludes 10 interviewees who said that they did not have enough information to accurately answer this question.

TABLE 3: SYSTEMIC BARRIERS & CHALLENGES

Barrier/Challenge	Percent of Affiliates
Foster Parent Shortages	64%
Insufficient Funding Levels	55%
Lack of Disability Training for Foster Parents	50%
Staff Shortages in Foster Care	48%
Provider Shortages (i.e., medical, dental, psychological, etc)	45%
Lack of Disability Training for Caseworkers	45%
Service Coordination Issues	41%
Current Political Environment	36%
Children’s Frequent Placement Moves	36%
Lack of Information Provided to Foster Families Regarding Children’s Disability Status	36%
Lack of Providers Willing to Take Medicaid	31%
Foster Care Agency Policies & Procedures	29%
Lack of Evaluation of Children’s Disabilities	29%
Lack of Monitoring of Children’s Health Care Needs	24%

One affiliate interviewee summarized the systemic challenges in the following manner:

Federal disability and foster care policy is a problem. The poor implementation of child welfare policies and procedures is a huge issue, as the system is under-funded and under-staffed. For kids with disabilities, foster parent shortages are a huge problem. Children frequently move because their foster parents are not trained to handle their behaviors. I’d give a huge yes to the lack of disability-related training for foster parents - they just don’t know what they are getting into. And caseworkers and child protective investigators don’t know what options are available or how to tackle the assessment piece.

Another affiliate noted that, “This state has a well-documented poorly running child welfare system. Every week there is something in the paper about the child welfare system. They have changed commissioners three or four times in six years.” As another affiliate explained, “Everything on the list is a problem, especially politics, staffing shortages, and high turnover. There is a lack of information and assessment, which flows from the lack of training for workers, who lack of the ability to identify a possible need.”

One affiliate said that “staff turnover problems, unresponsive staff, and funding issues appear every day in the local paper; there is also a lack of clarity regarding appropriate communication channels and foster parent and child privacy rights.” According to another interviewee, “It’s difficult to access services; kids move all the time; the reimbursement rate from Medicaid is so low. Here, you can’t get everyone to come to one meeting so you can adequately coordinate services, so there’s a huge duplication of services or a lack of services because no one’s talking.”

Stories from the Field

There were two kids, siblings, 13 and 15 years old, both with severe disabilities, and the system could not find anywhere for them to go. They stayed in shelters for a long time. They were finally placed with a family, but with first time foster parents. They barely stayed a month. You just have to wonder if the system is set up to ensure that these foster parents fail. You have to wonder why supports were not even put in place, especially for kids whose disabilities were known to the system, and why certain trainings were not provided to their caregivers. As a result, those kids bounced out of the home almost immediately!

COMMITMENT TO HELPING IMPROVE SERVICES, SUPPORTS AND OUTCOMES

Nearly one-half (45%) of all affiliate interviewees reported that their organization had considered providing additional services or supports for children or youth with disabilities in foster care. An additional one-third (33%) said they were not sure if they could provide additional services or supports to this population, but were open to considering the opportunities.

Many affiliates expressed interest in using their expertise to support the efforts of the child welfare system in their jurisdiction. As one affiliate said, “We’d like to go in and provide a special needs module within the specialized foster care Model Approach to Partnerships in Parenting (MAPP) training already offered to foster and adoptive parents in our area.” Another affiliate interviewee said

We’d love to provide training for prospective foster parents on disability issues. This is something we did many years ago but would love to do again. Right now, I don’t even think ‘disability’ is really mentioned to prospective parents, or if parents are really consulted in terms of their willingness to care for a child with a disability. We would also like to provide training to caseworkers on disability issues. Because there is such a huge turnover of staff, it’s important for us to get this training to all staff in the foster care system, so that the information doesn’t simply lie with one or two seasoned workers who’ve stayed on

As one affiliate explained, “We’d like to work on educating foster parents about birth parents and lifestyle differences, to help them better understand the strengths and weaknesses of these kids’ birth families, especially as they tried to parent a child with disabilities, so that foster families stop focusing on only the bad things birth parents may have done to the child.”

A few affiliates also expressed a desire to develop a therapeutic foster care program in their area. As one affiliate interviewee said, “I’d love to start a foster care program here. It’s near and dear to my heart. I spent 27 years in Child Protective Services.” Another stated, “We would love to start a specialized foster care program here! I was a foster parent for 17 years, and my husband and I have adopted six kids. It’s hard to get services, as the Department of Human Services is overloaded. So it would be great for us to fill that gap somehow.”

Other affiliate interviewees noted their interest in creating special needs pre- and post-adoption programs, or in offering wraparound supports for other therapeutic foster care programs: “Ideally, we’d offer children with disabilities in foster care service coordination, physical therapy, occupational therapy, speech therapy, family support services, and training, although we’re not looking to be a direct service type of agency – we’d want more of a wrap around function, to help support the foster placements monitored by another agency in the state.”

Other affiliates expressed an interest in expanding their respite care programs to more specifically focus on children in foster care. According to one affiliate, “We are considering a weekend overnight respite program where kids would stay at the UCP campsite, and we’d actually like to develop it with a more specific reference to helping foster parents.”

Some affiliates were already in the process of developing these programs or strengthening their ties to the child welfare/foster care system to reach greater numbers of children with disabilities in foster care through existing program offerings. As one affiliate interviewee explained, “A state disability program contacted us recently about providing support for children in foster care with disabilities through a Medicaid waiver program. Essentially, we would then take on the child’s entire case. The child welfare agency would retain legal guardianship, but UCP would manage

the entire case, including placement, case planning and service delivery. We are meeting in the next few weeks to discuss it.”

Other affiliates were interested in helping this vulnerable population, but had not identified the type of programming they might like to develop. As one affiliate interviewee explained, “I am not really sure what we should do – I think the most challenging population are the kids aging out, so maybe focusing on them.”

Finally, while some affiliates were not interested in developing additional services or programs, they were interested in increasing the numbers of children in foster care served through their existing programs. As one affiliate put it, “since these services are available to all children and youth that qualify, we don’t take into consideration the foster care status specifically. But we could do more to make sure they are accessing our programs.” Another affiliate interviewee said that “We could include foster families more in our efforts – family outings, newsletters, information and referral services, parents support group, etc.” One affiliate explained, “We have tried in the past to offer support groups for foster parents, but we haven’t had enough interest in it. Right now there is only one family. But we should find a way to get the word out that foster parents can call us for resources or tools, especially for adaptive toys for their kids.” As another affiliate interviewee said, “The rise in methamphetamine labs and exposure of those drugs to kids is placing a huge percentage of children with disabilities in foster care, especially in rural settings. So we want to explore how to address the needs of the children who come from these settings and what services we could provide to them, their foster parents and their caseworkers, since their exposure often results in specific disabilities and Cerebral Palsy-like symptoms by destroying the brain and negatively impacting their neurological functioning”

Stories from the Field

If you made a bar chart that shows the functional abilities of all people with physical disabilities, the right side of the chart would reflect those individuals with the greatest functional affect. Twenty-four year old Jim would be somewhere near the end of this chart, and, until very recently, he fell into a category of individuals for whom state supports and services, other than health care, are virtually non-existent.

Jim knows this perhaps better than anyone else, because the state has been his sole source of support for most of his life. Jim was a child raised by the state, and as an adult, he is dependent on the state's prevailing "preferred method" of supporting individuals with severe disabilities.

When Jim was twenty-two months old, his birth parents gave him up. His current name is not the one he was born with. He chose to have his name legally changed in 1995 to honor the foster family who cared for him most of his young years.

Jim has a type of cerebral palsy that affects all of his fine and gross motor skills. He cannot control his arms or legs. The rigidity in his torso prevents him from being able to sit or balance properly. Lack of tongue and facial control keeps Jim from being able to speak, and causes difficulty when he eats or drinks. In medical terms, Jim has "pervasive spastic quadriplegia with dysarthria and compound functional deficits."

While Jim accepts these so-called deficits as his own reality, and he is aware of his dependence on others for all functions of daily living, Jim does not define himself in terms of his disability. When you get to know him, you learn that he likes the World Wrestling Federation, Colt 45 Malt Liquor, and a good game of checkers. Don't play checkers with Jim if you don't like being beat. He is quite the strategist.

Perhaps it is this very normalcy through which Jim perceives himself that makes it so difficult for him to understand why he has presented such difficulty to so many bureaucrats for so many years. Jim doesn't like bureaucrats.

When Jim was in school, his foster family was forced to file a lawsuit against the state department of education and the school board for not supplying the educational supports Jim (not his name then) was entitled to under the law. The school board responded by refusing to recognize Jim's foster parents as his guardians. In an unprecedented move, they denied appropriate educational supports and services, and went so far as to appoint someone else to serve as Jim's "educational guardian." It was ultimately determined by the courts that Jim's educational rights had indeed been denied. Jim and his foster family prevailed, but the battle was costly in terms of the family's resources, both financial and emotional.

As a result of the lawsuit, it was determined that the state did not have the resources to meet Jim's educational needs. He was moved out of his foster home and into a specialized residential school program for people with severe disabilities halfway across the country. While the move represented a loss of living arrangements with the foster family he had grown to love, it also represented an opportunity to gain many of the services and supports that he had been without in his home state. The program provided education, health and dental care, occupational and physical therapy, psychological and social support services, recreational therapy, technology assessment, and vocational services and training.

After a brief period of adjustment, Jim began to blossom. He thrived in this program. He developed close bonds with other residents and staff members, and he began to develop communication skills using a plexiglass eyeboard. Jim consistently refers to this as the best time of his life. To Jim, this program was his true home.

Jim's sense of happiness and belonging was not to last, however. When Jim turned twenty-two, he aged out of all services under his home state's child welfare agency and department of education. There was no one to pay the \$90,000 annual bill to his program. Jim was pulled out of the program and returned to his home state, where he was placed in a nursing home.

Continued

Stories from the Field (Continued)

Jim was abused in the first nursing home placement. While the second nursing home was not actively abusive, it was clearly not capable of providing the level of support that Jim needs. Jim became severely depressed. Some days he refused to get out of bed. Other days, staff forgot to dress him. His clothing and personal belongings were stolen. He had no privacy. His specialized feeding needs required more time than the staff had, so his nutritional needs were not being met. Jim was losing weight. Jim lacked everything from age-appropriate companionship to meaningful activities for daily living. He was miserable and to compound matters, he desperately missed his life at his out-of-state program and he wanted more than anything to return there.

UCP first met Jim in this nursing home. When we asked him what we could do to assist him, he was unhesitating in his response. Painstakingly spelling out letters on his eyeboard, Jim said, "Get me out of hell. Give me back my life."

The community based living support services Jim needed were being provided through our state's department of mental health and mental retardation (MHMR). However, Jim needed services for which he did not qualify. Regardless of the Jim's level of functional disability, he had to have a primary diagnosis of mental retardation in order to qualify.

John, a UCP staff member and advocate became Jim's best friend and lifeline to the world outside the nursing home. John made phone calls and wrote letters to legislators and anyone else he thought might help. The entire UCP staff took Jim on as a mission. We visited the MHMR Commissioner. We called the Office of Human Rights. We filed an Emergency Appeal with the state health care board. All to no avail.

Months passed. Jim's condition continued to deteriorate. He had received the necessary mental retardation diagnosis, but this had only moved him to a waiting list, not toward any real services. Jim was becoming angry with UCP for what he saw as our failure to make any difference in his life. Whereas we saw progress in getting Jim certified for services, this was meaningless to Jim as long as he remained in the nursing home.

Truth be known, Jim would probably still be in the nursing home were it not for two things that brought public attention to his plight. First, was the diligence of a newspaper reporter in following up on a story he had written about Jim when he was first returned to his home state. Second, was a profile UCP was producing about Jim for the television program Journeys . . . Redefining Ability. While we were shooting the television feature, Jim received word that he had been moved up on the MHMR waiting list, and that a home in the community had been located for him. On the last day of the television shoot, Jim was moved into his new home. Increasing public attention to Jim's situation had paid off.

Jim started life in his new home in June 2001, two years from the date he was forced out of his beloved out-of-state program. It would be an overstatement to say that everything is all right now, but things are better. Jim is slowly adjusting to his new home. He is gaining weight, and his depression is lifting. His former foster family and UCP friends visit regularly, and he is being introduced to new services and supports.

Jim has had some attachment issues in his new life because of difficulties in maintaining staffing in the home where he now lives. A change in staff means that someone new must learn Jim's routines and how to properly feed him. Jim still misses the community he left behind in his out-of-state placement . . . and it will be a long time before he recovers from the trauma of the past two years. Our state still has a long way to go before it will earn the trust of the young man it raised.

CONCLUSION

Some UCP affiliates are already engaged in working with children with disabilities in the foster care system and there is interest among affiliates in becoming involved or more involved.

Affiliates with experience working with children involved with the child welfare system identified a variety of systemic problems resulting in children with disabilities in foster care not receiving the care and services they require and impacting their opportunities to grow up in a permanent family. Affiliates noted that child welfare caseworkers and foster parents may not receive adequate training to properly serve children with disabilities in foster care; that these children may not receive adequate medical and dental care and educational supports and services; and that efforts to reunify these children with their families, place them for adoption or prepare them to transition into adulthood may be inadequate.

The findings from this survey suggest that there is both the need and the opportunity for UCP affiliates and other disability organizations to become more involved in providing services and advocacy for children with disabilities who are in foster care. Many individuals within the UCP networks have past or current experience with the child welfare system, either professionally or as foster parents. There are some UCP affiliates with substantial current involvement with the child welfare system and these affiliates may be able to provide technical assistance to other affiliates interested in developing this capacity. UCP and its affiliates can utilize the information from this survey and the information provided in the clearinghouse on the UCP website to develop a plan for more robust involvement in the child welfare system to improve outcomes for children and youth with disabilities in foster care.