

FFTA



Foster Family-based Treatment Association

**BEST PRACTICES  
IN TREATMENT  
FOSTER CARE  
FOR CHILDREN  
AND YOUTH WITH  
MEDICALLY FRAGILE  
CONDITIONS**

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## Acknowledgments

This resource guide was created through a collaborative effort between the Foster Family-based Treatment Association and Therapeutic Foster Care at the Kennedy Krieger Institute. It was written and edited by Judith M. Levy, MSW, LCSW-C, MA, with contributions from the following Treatment Foster Care professionals:

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## About the Foster Family-based Treatment Association

Established in 1988, the Foster Family-based Treatment Association (FFTA) is the leading advocate for Treatment Foster Care. Its membership of over 400 agencies provides treatment foster care services across North America to over 50,000 children and youth each year and a larger array of services to over 600,000 children and youth. FFTA provides Program Standards, technical assistance, professional development programs, and other resources to help agencies achieve positive outcomes for vulnerable children and youth. For more information, visit [www.ffta.org](http://www.ffta.org)

## About Therapeutic Foster Care at the Kennedy Krieger Institute

Internationally recognized for improving the lives of children and adolescents with disorders and injuries of the brain and spinal cord, the Kennedy Krieger Institute in Baltimore, MD serves more than 18,000 individuals each year through inpatient and outpatient clinics, home and community services and school-based programs. Its Family Center emphasizes the developmental, emotional and behavioral problems of children and families. The Center offers a range of trauma-informed services, including prevention, treatment, specialized foster care, community outreach, advocacy, research and training through a variety of programs and services. For more information, visit [www.kennedykrieger.org](http://www.kennedykrieger.org).

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## OVERVIEW

In 2011 representatives from several members of the Foster Family-based Treatment Association (FFTA) that have Treatment Foster Care (TFC) programs for children and youth with medically fragile conditions discussed the need for more resources that highlight best practices for working with this population. These individuals decided to form an FFTA Medically Fragile Treatment Foster Care Workgroup to share successful strategies and challenges inherent in serving children and youth with medically fragile conditions in a foster care setting.

The workgroup members, mostly TFC professionals from across the United States who have oversight responsibility for medically fragile foster care programs, agreed to collect and share with other providers the best practices, resources, and strategies they are using in their own programs. Staff from the Therapeutic Foster Care program at Kennedy Krieger Institute agreed to document the information shared within the workgroup, incorporate some of their own experiences, and write this resource guide. The stories of children and youth included in this guide were provided by FFTA workgroup members and depict actual experiences of clients (their names have been changed to protect their identity).

In 2013 the Foster Family-based Treatment Association published a revised edition of its *Program Standards for Treatment Foster Care*. The standards are written for Treatment Foster Care programs that serve a diverse group of children and youth, including those with medical conditions. This guide, which was developed to address some of the unique circumstances of serving children and youth who are medically fragile, is intended to be a supplement to the FFTA standards. Therefore, Treatment Foster Care programs providing service to children and youth with medically fragile conditions should strive to meet all the standards included in the *Program Standards for Treatment Foster Care* as well as the best practices described within this guide.

The following acronyms will be used throughout the guide: TFC (Treatment Foster Care), MF (medically fragile), and MFC (medically fragile conditions).

## Prevalence of Youth with Medically Fragile Conditions in the Foster Care/Child Welfare System

Over 400,000 children are currently in foster care in the United States. Studies on the physical health of children and youth in child welfare vary but generally report that 50% to more than 80% of children and youth in foster care have at least one chronic medical condition. Of the children and teens entering foster care about 50% have chronic physical problems, 10% are medically fragile or complex, and many have a history of prenatal (maternal) substance exposure and/or premature birth (American Academy of Pediatrics).

A report by United Cerebral Palsy and Children's Rights (2006) cites various studies on the prevalence of disability among children in foster care. These studies report that 40% of children and youth in foster care are born with low birth weight or premature; 80% were prenatally exposed to substances; 30-80% have at least one chronic medical condition; 25% have three or more chronic health problems; 30-60% have developmental delays; and 20% are fully handicapped.

Some of the children in foster care who have medical conditions are quite young. In one California study (Leslie, Gordon, Meneken, Premji, Michelmores, Ganger, 2005), of the 1542 children and youth who were between 3 months and 5 years 11 months at the time of placement into the child welfare system, 86.7% of them demonstrated physical, developmental, or mental health needs, with more than half displaying two or more problems.

**James** is a 20-month old male with Cystic Fibrosis (CF). James came into care due to medical neglect and parents' drug use. He was initially placed with relatives but they were not able to keep up with his daily health needs and many healthcare appointments. James requires regular medical appointments with a specialist in CF and many daily medications. He eats a special diet including food supplements. His foster parents have been trained to give him breathing treatments and twice daily percussive therapy. His weight and muscle tone must be closely monitored and he must have daily exercise to strengthen his muscles and lungs. He is very clumsy because of low muscle tone so he must be monitored and protected from falls.

Recently, his CF specialist said he would never guess that James has CF. He has gained muscle tone and loves to run and play; his balance has improved. The rattling sounds that were heard when he breathed are totally gone. James was the first foster child placed with this family. The foster parents met with James' relatives and his CF specialist to learn how to provide the special care that he needs. James' parents relinquished their parental rights and his foster family is in the process of adopting him.

A recent study of foster youth in Minnesota identified about 10% with a developmental disability and another 2% with a physical disability (Lightfoot, Hill, & LaLiberte, 2011).

## **Medically Fragile Conditions and Children with Special Health Care Needs in Treatment Foster Care**

Children who are medically fragile have at least one chronic physical condition that results in prolonged dependency on medical care. However, they can have any number of acute or chronic medical problems and, because of the medical condition, may require assistance with activities of daily living (ADL) such as personal hygiene and grooming, dressing and undressing, self-feeding, bowel and bladder management, and walking with or without an assistive device. These conditions require daily administration of specialized medications and treatments and may be life-threatening or terminal. The children are dependent upon tracheotomies, heart monitors, gastrointestinal tubes, dialysis machines, or ventilators as well as wheelchairs, lifts, adaptive equipment, and communication devices. Their diagnoses include chronic health conditions, such as diabetes, traumatic injuries to the brain and/or spinal cord, sickle cell anemia, AIDS, or kidney failure, and developmental disabilities, such as cerebral palsy, seizure disorder, spina bifida, intellectual impairments, ADHD, autism, and mental health problems. Medically fragile conditions and developmental disabilities frequently coexist. People with developmental disabilities also are at increased risk of having a mental health condition.

### **Placement Considerations**

Today, it is rare for children to remain in a hospital setting for prolonged periods. They are generally sent home with parents who have been trained by hospital staff, generally nurses and other therapists, to provide the care that the child requires in the home. Some children are discharged to foster homes. But not all treatment foster parents feel equipped to care for a child with such serious and complex needs as those described above.

The Treatment Foster Care program staff must determine, through careful assessment of the child's treatment needs as well as the availability of matching treatment family resources, whether the child's care requirements can be met in the program. It is possible that at some times a Treatment Foster Care program will have no foster parents willing or able to care for a child with a medically fragile condition in their home, or even to provide respite care.

The Treatment Foster Care program staff must obtain all information pertaining to the child in question to evaluate the program's ability to meet the needs of the child. Program staff should request information about the birth family as well, including a service agreement between the agency and the biological parents specifying their rights and responsibilities for their child while in care. Information about the interactions between the birth family and agency personnel as well as the reason for the placement will enhance the TFC program's understanding of how to work with the parents.

The identified intake worker reviews the "placement referral packet" provided by the placement agency and determines whether the child's disability and treatment needs can be met in a foster family setting. (This packet may be called by another name depending upon the state's terminology and is the initial information given to the TFC program to assist in determining whether the program can provide optimal care for the child.) This process involves an assessment of the child's level of medical fragility and risk factors associated with the child's medical condition to determine the type of family supports needed for placement. The intake worker may need to consult with the child's health care providers, such as a nurse, physician, mental health practitioner, or physical, occupational, or other therapist, to aid in the overall assessment of the child's needs, including home modifications. Supports include respite care, equipment, in-home nursing (especially overnight), transportation, and day care.

Because TFC programs may be housed in a public department of social services or a private agency contracting to provide services for the state, private agency staff may find it more difficult to obtain records, but they should persist in obtaining all records that state regulations permit them to have. In general, all states have provisions for caring for children with medically fragile conditions in regular or treatment foster homes. Policies and procedures vary from state to state, and the initial steps in developing such a program should be to review the state regulations that apply and to contact the proper state agencies for licensing and guidance.

# PROGRAM

## The Interdisciplinary Team

Because of the complexity of their conditions and impairments, these children require a myriad of specialists to manage the special needs of the total child. For example, team members may include doctors who specialize in working with children with specific medical conditions or children with disabilities (developmental pediatricians); primary care doctors; nurses; social workers; psychologists; occupational, physical, and speech therapists; nutritionists; psychiatrists; and attorneys. With the exception of nurses and social workers, most of the team members will not be employed by the program. For some children this list is incomplete. Program staff members are responsible for making sure that health care services are provided to children in the foster care program by the appropriate providers. Last but not least are the foster parents, who will be expected to participate as team members.

## Staff Roles and Training

### **Social Worker**

Traditionally, social workers have provided clinical foster care services in public and private agencies because their training has prepared them for understanding and working with the foster care system. Additional education and training are necessary in order to translate diagnostic information into the daily care needs of the children and the training of the foster parents. This ability to analyze the relevant information is especially critical when emergency placements are requested by the local child placement agency. As with any organization it is necessary to formulate job descriptions and duties for all agency staff as well as foster parents. Annual reviews should be mandatory.

*The social worker's role includes:*

- Advocating for services and supports to meet the youth's needs in health care, education, and community participation.
- Supervising the placement.
- Providing clinical case management services for the youth and the foster family.
- Providing clinical interventions to the youth and to the foster and birth families.

*The social worker's training includes:*

- General needs and reactions of children living in out-of-home foster care placements.
- General knowledge of human development and the impact of chronic medically fragile conditions and disabilities on physical health and mental health.
- General knowledge about common medical and developmental disorders in children and their respective treatment modalities.
- Child-specific information, gained in a variety of ways, including from the child's health care providers at medical appointments, from the child's evaluations and treatment reports, and from the foster parents, who know the child best.
- Research about medical and developmental disorders with which the social worker is not familiar, using credible online sources such as the National Institutes of Health (NIH) and Mental Health (NIMH) or disorder-specific websites as well as printed materials.
- Skills and techniques for balancing the complex relationship with the foster parents, whom the social worker supervises and who are also members of the child's team, which is an egalitarian group of the child's service providers (a critical element of the job and not easy to do in practice).

## Nurse

The nurse may be on the staff of the TFC agency or contracted to provide nursing services to specific children. Depending on the organization and structure of the Treatment Foster Care program, the nurse provides support to TFC placements in any number of ways with the purpose of providing medical support for the children and their foster parents.

*The nurse's role includes:*

- Providing general training to foster parents or specific training regarding individual care of a particular child in the program.
- Training parents and signing off on their demonstrated ability to understand and perform all needed procedures or any procedure requiring the use of special equipment (e.g., feeding tubes, regular injections, trach care, vent care; requires a registered nurse licensed to provide skilled care).
- Attending training provided by the hospital before the child's discharge and maintaining a record of all such training. If the child has been hospitalized, training will be provided prior to discharge. The TFC nurse may attend this training. A record should be maintained of all such training.
- Reviewing potential placement situations during intake to determine if placement in the community will be safe, what potential risks exist, and what other questions need to be answered to ensure placement stability and safety.
- Attending medical appointments, when possible; providing training in the home regarding other health care issues; providing case management; and reviewing all medical documents provided by the foster parents in order to learn the medical plan for the child (documentation includes hospital discharge summaries, medical visit summaries, medication prescriptions, and/or any documentation provided by the doctors/specialists).

**Ellen** is a 10-year-old girl diagnosed with Cerebral Palsy (CP), Osteoporosis, Cystic Fibrosis (CF), Seizure Disorder (SZ), Hepatic Disease and Reflux. She came into care because, despite training and in-home assistance, her parents were unable to provide the complex care she needed. Melissa uses a wheelchair, needs regular oxygen, uses a feeding tube, and receives manual treatments for her CF. She had numerous hospitalizations and ultimately lived in a nursing home until one of her doctors, familiar with a treatment foster care parent, advocated for her to be placed in the foster parent's home. The foster parents were both trained by hospital staff to implement the necessary care regimens in their home.

*The nurse's training and qualifications include:*

- A license to practice in the state.
- Skill and practical experience in working with children with medically fragile conditions.
- Skill in communicating with diverse populations.
- Willingness to participate on interdisciplinary teams.

## Risk Management

Programs serving children with medically fragile conditions must have specific protocols in place to review and document risk-related issues, including but not limited to the following:

- Medical and peer case consultations.
- Administrative placement review.
- Ongoing supervision of the placement.
- Annual evaluation of the goodness of fit between youth and foster parents.
- Ongoing and annual evaluation of foster parents, using the program's foster parent job description and duties.
- Ongoing and annual evaluation of staff, using the program's social work job description and duties.

Medical professionals may be consulted at time of placement and at medically indicated intervals regarding risk factors and based on the judgment of the program's staff and foster parents. Incidents involving children with medically fragile conditions must be documented and reported to the appropriate licensing, child welfare, health, and other agencies, as well as to the designated risk management personnel in the organization, according to law, regulation, and organizational policy. Contacts with medical and other health care providers must be documented by the foster parents.

Documentation of appointments and treatment should be obtained from the physician and others who provide service to the child. Copies of these documents should be kept by the foster parents, and the foster care agency should maintain these documents in locked, confidential storage.

Documentation about the services provided to children should always include a comprehensive assessment, an admission treatment plan, a quarterly treatment plan, progress notes, and a discharge summary. For children with MFC it is important to document all medical appointments and provider information. Treatment plans should include goals for medical and mental health care, permanency, functional skills and abilities, education, community inclusion, and other documentation required by the program or state regulations. Foster parent records need to include information about the home study, annual reapproval, training to meet the care needs of children in the home, and achievement of required annual training hours. The *Program Standards for Treatment Foster Care* provide additional information about documentation.

## **Program Evaluation**

The *Program Standards for Treatment Foster Care* provide guidance on program evaluation. Foster parents should complete an annual satisfaction survey, which will inform program staff about which supports are most valuable. The survey also allows foster parents to evaluate the quality of the services the program provides. Satisfaction surveys for medically fragile programs should be designed to address the special needs and circumstances of caring for children and youth with medical conditions.

# **TREATMENT PARENTS**

## **Caregiver Characteristics**

Youth with medically fragile conditions require a unique combination of skills from treatment parents. Like all treatment parents, they serve as caregivers of the children and agents of planned change. They need to be able to navigate the child welfare and health care systems, work effectively with the biological family of their foster child, support permanency planning, keep accurate records, and advocate for their foster child in the community. They must also understand their foster child's unique medical and developmental needs and be willing and able to provide direct interventions related to medical care, such as tube feedings, proper positioning, and suctioning. Treatment parents may need to incorporate additional providers into their family routine, including in-home nurses. They must learn to provide behavioral supports for youth with a wide range of intellectual, developmental, and physical functioning. Sometimes it will be necessary to incorporate medical equipment into their home and perhaps even modify the house itself. As a result, programs must accommodate their recruitment and training of foster parents to meet these needs. Foster parents must be willing to commit to raising children with complex needs. This commitment will change their lifestyle, their responsibilities, and sometimes their home. Foster parents must adjust to having a lot of new people in their lives. They must be flexible in their thinking and willing to work and communicate with team members in order to achieve the best possible placement for each child. Potential foster parents must be apprised of these realities in order to make an informed decision about becoming a treatment foster parent.

## **Recruiting Treatment Foster Parents**

Recruitment is about convincing interested people that they have the personal and financial resources to care for a child with a complex set of medical conditions and caregiving requirements. Decisions must be made about what information to give at what point in the process, and each program may have a different protocol for achieving this balance. At a minimum, information about the individual child as well as about financial support, such as room and board payments, stipends for treatment foster parents, and Medicaid funding for the child's health care and for home modifications and furniture, must be provided early on. Although it's clear that people who do this work don't do it because

of money, some programs may be reluctant to provide information about money too early in the process. However, the absence of concrete financial information up-front may make some qualified potential foster parents turn away, fearing that they cannot afford to become treatment foster parents.

One way of informing people is with a brochure, strictly devoted to the recruitment of foster parents, which describes the supports that are provided to them. The brochure should also include the information provided later in this guide under the heading "Support."

The following suggestions provide ideas for advertising the need for foster parents for children with MFC in particular, but they may be helpful in recruiting other foster parents as well.

1. Health care professionals, such as doctors, nurses, paramedics, physical therapists, or staff working at children's hospitals or pediatric nursing homes, can be some of the best foster parents and respite care providers for children with medically fragile conditions. The following are some ways to reach this population:

- Partner with your state nursing, paramedic, or other professional associations to educate nurses and other health care professionals about the urgent need for foster parents and respite care providers for this population.
- Write an article for a nursing or other professional magazine, featuring a child in foster care.
- Advertise in nursing, health care, or hospital magazines. Consider advertising on their websites.
- Target a specific group of nurses (e.g., Hispanic nurses) through organizations such as the National Association of Hispanic Nurses.
- Have an information table at a local farmers' market near a hospital or at a health care fair or health club.
- Request permission to make presentations or set up an information table at local hospitals to educate staff about your medically fragile foster care program. This approach would draw from a larger population than the medical staff alone. Try to disseminate your materials widely to staff.
- If one of your clients is hospitalized, introduce yourself to the hospital staff and give them information about your program.
- Have your agency's RN join a nursing networking site on Facebook or LinkedIn and ask him or her to post information about the need for foster parents for children with special medical needs.

2. Include in your agency's pre-service training a good overview of your medically fragile foster care program. Prospective foster parents who hadn't thought about fostering a child with medically fragile conditions may decide to do so if they are given more information about children in the program or what is involved.

3. Develop a special brochure featuring stories and pictures (stock photos are acceptable if you can't obtain permission to use actual photos) of children and youth with medically fragile conditions and ask children's hospitals, small clinics, camps for children with special needs, and pediatric waiting rooms to display the brochure and other program materials in appropriate areas.

**David** is a nine year old boy who came into treatment foster care as the result of serious neglect while living first with his mother and then with his maternal great grandmother. His mother is thought to have Fetal Alcohol Syndrome (FAS) and his great grandmother is thought to have dementia. David has been in foster care for two years. When he came into treatment foster care he was not enrolled in school, had no language skills, significant tooth decay and after placement he had a massive seizure. He had poor social skills and was not toilet trained. He demonstrated the vigilant and anxious behaviors seen in children who had been abused. He demonstrated tremendous sensitivity to food texture and taste and began a pediatric feeding program.

In school David has an Individualized Education Program and receives speech, occupational and art therapies. He entered mental health treatment with a male therapist and this is going well. He is currently having a work-up for FAS. The foster parents have a long history in treatment foster care and are comfortable with children with medically fragile conditions as well as mental health concerns. The foster mother is a stay at home mom. In addition to David, they have one biological child and one adopted child. He has fit into this family well. David's parents' rights have been terminated. His permanency plan is adoption.

4. Consider housing circumstances in your recruitment efforts. For example, focus your recruitment program on families who live in areas with many ranch-style homes or elevator-equipped apartment buildings.
5. If you do recruit an interested potential foster family whose home isn't accessible, find a local contractor who would be willing to donate time and equipment to make the home wheelchair-accessible.
6. Provide information about your medically fragile foster care program on your agency's automated phone message.
7. Target recruitment to individuals with friends and family members who have children with medically fragile conditions and are already familiar with the rewards and challenges of caring for a child with medical needs.
8. Use advertising to promote the appeal of "rescuing" a child from being placed in a facility when he or she can be safely served in a specially equipped home with a well-trained, loving foster family.
9. If your agency uses Google and Facebook for advertising, include keywords such as "medical disability".
10. Ask existing foster parents to reach out into their communities (e.g., neighborhoods or churches and other organizations) to spread the word about the need for foster parents.

## Training Treatment Foster Parents

Treatment foster parents should participate in an orientation that provides general knowledge about the desired characteristics of foster parents, the reality of life with children who are medically fragile and in foster care, and common medical and developmental disorders and their respective treatment modalities. The training should include an example of a foster parent performing a medical procedure with a foster child. This exposure will give potential foster parents an opportunity to meet and talk with an experienced foster parent as well as to witness a medical procedure that they may have thought was beyond their capabilities, especially if they are not medical professionals. The training should be provided by health care professionals with expertise in this field as well as by clinical social workers in the Treatment Foster Care program who have experience with the population. Child-specific training may be provided in a variety of ways, including by the child's health care providers during the child's medical appointments. Foster parents can also gain useful information from evaluations and treatment reports, which they may obtain with appropriate authorization. Foster parents are required to participate in ongoing in-service training on relevant topics, which can be provided by the program or by another agency or organization.

For children who are hospitalized before or during placement, training will be provided prior to discharge by nurses and therapists who have treated the child. As a condition of discharge and of placement, foster parents will have to demonstrate competence in the use of certain medical equipment as well as their ability to perform certain procedures required for the child's care. Training sessions should be observed, assessed, and documented by the service provider or other staff member working directly with the child and foster family. Treatment foster parents should have annual evaluations of their performance.

It is important that the Treatment Foster Care program develop an annual training program for its foster parents. Training topics can be generated by foster parents, selected from information related to the conditions of the children, or based on the issues and challenges that arise as staff members work with children and foster families.

*The following are examples of topics for foster parent training:*

- Working with birth families to help them understand the medical needs of their child.
- IEP (Individualized Education Program) meetings: How to advocate for your child.
- Vicarious traumatization.
- Developmental tasks.
- Negotiating the health care system.
- The Developmental Disabilities Administration in your state, and other agencies providing services to children with MFC.

## Special Educational Topics for Treatment Foster Parents

### Trauma

Children in foster care have typically experienced some form of trauma in their young lives. The trauma could involve abuse, neglect, the death of someone close, violence in the neighborhood, or a combination of these and other traumatic experiences. Although children with complex health needs may have experienced these types of trauma, they may also have faced the trauma of painful and invasive health care procedures as a result of their medical conditions. The process of being taken from their home and family and entering foster care is, in and of itself, a traumatic experience, as are many medical procedures, especially without parental support. Foster parents should be trained in the impact of trauma on children and approaches to managing it in their home and in health care settings where the child may face re-traumatization by undergoing painful or invasive procedures. This factor becomes a part of the treatment team's plan for the child. Appropriate psychosocial services, such as mental health and behavioral psychology interventions, and other therapeutic modalities must be identified by the team. The social worker supports the child and the foster parents by providing direct clinical services to the child in the foster parents' home. When appropriate, the child's birth family should be involved in the child's treatment. As with any child in foster care, there should be an ongoing assessment of the foster family's ability to meet the child's psychosocial needs.

### IDEA and the IEP Process

The Individuals with Disabilities Education Act (IDEA) ensures that services are provided to children with disabilities throughout the nation. The IDEA governs how states and public agencies provide early intervention, special education, and related services to eligible infants, toddlers, children, and youth with disabilities. These educational services include early intervention for children from birth to 2 years of age and are available to children with disabilities until they are 21 years old.

The IDEA defines transition services as a coordinated set of activities for a student, designed to be within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated competitive employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities must be based on the individual student's needs, taking into account the student's preferences and interests, and shall include needed activities in the following areas: instruction, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation (PL 101-476, 20 U.S.C., 1401[a][19]).

Foster parents play a significant role in the child's education and must understand how to assess and access the special education and related services available to the child or children in their care. The foster parent is frequently the best choice for an educational surrogate for the youth. Treatment Foster Care staff members play a major role in ensuring that the child is receiving necessary services. Sometimes it will be necessary to consult with advocates for children's education, such as attorneys specializing in special education or disability law, or court appointed special advocates (e.g., the Maryland CASA Association).

## Support

### General

Most foster parents agree that the support they appreciate most is the 24/7 availability of clinical social workers should an emergency arise. The value of this support cannot be overemphasized. A staff member providing on-call coverage should be backed up by a supervisor. Staff should be prepared to go to the emergency

**Maria** is a 19-year-old young woman with Cerebral Palsy, severe intellectual disability, quadriplegia and Reflux. Her mother was a single mom who used drugs. At the age of three, a neighbor who had helped to care for Maria since birth took her into her own home until the neighbor died six years ago. The neighbor's adult daughter, who is a teacher's aide, became Maria's new foster parent. Maria uses a wheelchair and needs assistance with all activities of daily living. She is fed through a feeding tube, and needs physical and occupational therapy. Maria and her foster mother are very involved in church activities and church members provide respite care for them. She loves to sing with the church choir and attends the children's services where she becomes engaged in developmentally appropriate activities.

room or the foster parents' home in the middle of the night, if necessary. Given the critical needs of this population of children, and the likelihood that scheduled overnight nursing or other providers will, at some point, call in sick, TFC staff must assist foster parents in developing a backup plan in case of emergency. Other important supports include attendance at doctor's appointments, the child's interdisciplinary team meetings, and IEP and other meetings in the child's school; respite care; and special events designed for foster families and children.

Foster parents appreciate attention being paid to their grief and loss when a foster child or any other family member dies. This response might include providing grief therapy for the family and arranging a formal or semi-formal memorial ceremony for the child. Certainly an agency should try to help defray the burial costs for a child in its Treatment Foster Care program.

*The following general supports are also important to foster parents:*

- A stockpile of clothing, medical supplies, and the like for distribution to children who enter foster care with limited clothing and other supplies.
- Gasoline cards or money for parking to help defray these costs.
- Monetary assistance for needed supplies (Consider writing a grant to obtain funding for supplies. One agency received a grant from a medical supply company and subsequently bought the needed supplies from that company).
- Financial support for a hospitalized child (some states do not pay foster parents when their foster child is in the hospital for an extended period. In such cases try to negotiate to keep payments coming, but if absolutely necessary, negotiate a lower rate).
- Respite care, equipment, transportation, and day care.
- In-home nursing (especially overnight) when medically necessary and prescribed by the physician.

*Special events:* Foster parents enjoy an adult evening out during foster parent month with food, music, and special awards and tokens of appreciation for longevity or other special achievements in the program. Other events might include holiday parties for all family members, or summer picnics. If the program budget permits, foster parents will appreciate receiving holiday gift cards for local stores, and children in foster care should be given a small gift as well. Events and small gifts like these are tremendously important to foster parents.

*Facilitated support groups:* These groups, led by social workers, provide foster parents an opportunity to meet other parents who have foster children with similar needs and to gain insights, strategies, and moral support from others with similar experiences. In addition, TFC programs may develop adoption support groups for foster parents who have adopted their foster child. Many foster parents who adopt continue to have children in foster care. Adoptive parents from the community may be able to attend as well.

*Program involvement:* It is important to engage foster parents in other aspects of a program so that they can feel like part of a team that is making a broader impact. For example, foster parents can become members of the program's foster parent education committee, quality assurance committee, event planning committee, or newsletter committee. They can also be encouraged to become involved in the local or state foster parent association.

## **Financial**

TFC program staff members can help foster parents find the most affordable medical supplies and should make every effort to locate grants and other financial resources for the children in Treatment Foster Care homes. A major source of support for foster children is Medicaid's EPSDT (Early Periodic Screening, Diagnosis, and Treatment) program. EPSDT is the child health component of Medicaid, and all children in foster care have health coverage through Medicaid. EPSDT is required in every state and is designed to improve the health of low-income children by covering appropriate and necessary pediatric services. The connection between EPSDT and Medicaid is basically invisible to the consumer because Medicaid pays for these services.

## Respite Care

Although all foster parents take on a yeoman's job, caring for a child with MFC requires extra time, training, and support due to the complex needs of the child. It is more difficult to find sitters or respite care providers so foster parents can take a break or have a night out. TFC program staff should help foster parents find appropriate individuals to provide respite services. For some children this support may involve in-home nursing.

There are two major challenges to providing respite care for children with medically fragile conditions in Treatment Foster Care. The first is convincing therapeutic foster parents to take a break. Foster parents are no different from biological parents—they worry that no one else will provide the same standard of care that they do. The clinical social worker must help the foster parents take advantage of this support and be prepared for the likelihood that this will happen rarely, especially early in the placement.

The second challenge is finding a qualified person who is willing and able to provide care for a relatively brief time for a child with complex medical needs. Begin by reviewing state regulations for the provision of respite care, and then start to think creatively about locating respite care providers. One strategy is to ask the foster parents to find a “child-specific” respite care provider rather than using a general recruitment approach. In this way you are likely to find some-

one who already has a connection with the foster parents and the child and who will have a particular interest in serving that child. Another approach is to use existing foster parents to provide respite care for one another. The level of trust in the provider is likely to be enhanced by either of these methods because the foster parents have had a part in selecting the respite care provider. The latter approach has great merit, especially if your state requires some kind of certification for respite care providers, because all foster parents are qualified as approved providers. This approach will be easier if foster parents have had occasion to get to know one another during foster parent meetings and social or recreational gatherings. They will likely feel a greater sense of connection with one another. Nursing staff providing in-home care for foster children may be willing to provide respite care as well, either in the foster child's home or in their own.

Therapeutic foster care programs should develop policies and procedures for allocating respite care and locating providers; for example, a program might permit a maximum of 24 days of respite care within a calendar year. Families caring for children

with complex medical needs may require more respite if they are home-bound by the care needs of the child. Foster parents should be allowed to choose their respite times, such as two days a month or a weeklong vacation. Depending on the child's needs, training of the respite care providers can be provided by the treatment foster parents or by one of the child's health care providers.

**Bruce** is a 20-year-old young man with Cerebral Palsy, moderate intellectual disability and Seizure Disorder who was taken from his mother due to severe neglect and abuse at 11 years of age. He needs assistance with bathing, dressing, toileting, and oral hygiene. His foster mother, who is widowed, is a certified nursing assistant, and has three adult daughters. Bruce's foster mother and her daughters have all received training in how to provide care for him. He attends school and is included in all family activities. He participates in the Special Olympics where he walks around the entire track. He likes music, video games and going to the beach in the summer with his family.

## Accessibility

The accessibility of homes is frequently a major issue in placing children with medically fragile conditions in foster care. These children may require several different types of equipment ranging from wheelchairs to machines that support their breathing. These medical supplies and equipment can take up considerable space in a home. Maintaining the equipment requires coordination with durable medical equipment (DME) companies. The DME companies should provide training in the use of the equipment as well. Potential foster parents must decide if they can adapt to having this equipment in their home and be willing, if necessary, to modify a portion of their home to accommodate the child and his or her equipment. Some foster parents have, for example, made a bedroom on the first floor out of a room that previously served another function. Some foster parents have modified bathrooms. The costs of these modifications might not be paid by the local foster care system. Programs should build such costs into their budget proposals and

write letters of justification for these expenses. Social workers and other staff in the foster care program should help foster parents identify sources of funding for these projects.

Foster parents must understand the needs of the child in question and make these decisions before committing themselves to becoming foster parents. Consulting with experts in ADA requirements and local building codes, as well as occupational and physical therapists, will be valuable in helping foster parents make their decisions. Before building additions or redefining interior space, it is important to thoroughly understand state regulations regarding, for example, ingress and egress, rules about children sharing bedroom space, and regulations governing locating the foster parents' bedroom and the children's bedrooms on different floors.

## CHILDREN, YOUTH, AND THEIR FAMILIES

### Assessment, Treatment Planning, and Clinical Case Management

Children with medically fragile conditions need an individualized treatment team that includes Treatment Foster Care staff, staff from the local department of social services, medical and mental health providers, foster parents, legal advocates, and biological parents. This team must understand the broad spectrum of needs of the whole child, including health care, education, legal status, psychosocial issues, medical and mental health status, transition, recreation, and community integration. The team develops a treatment plan for the child that identifies and addresses each child's individual special-care needs, including community integration and visits with the biological parents, when appropriate. Plans are made for treatment team meetings that meet the needs of the child and the requirements of the state regulations.

Assessments are completed by the appropriate providers as needed, and recommendations are incorporated into the treatment plan. Heeding the child's level of intellectual development, the foster parent and the social worker help the child to understand the diagnosis and treatments required. During the child's teen years, the child, the social worker, and the foster parents participate in goal planning and treatment around transition to adulthood. This process will vary from child to child depending upon the child's intellectual capabilities and medical needs. The social worker provides ongoing clinical case management support to ensure that the child's physical and mental health needs are being met, that the foster family understands the child's treatment, that appointments are being scheduled, and that recommendations are being followed. The social worker assists the foster family with the organization of the multitude of appointments and attends appointments as necessary to provide support to the foster parent(s) and to obtain current information about the youth.

### Permanency Planning

It is extremely important that potential foster parents understand the concept of permanency. Foster care is not intended to be permanent, and a permanency plan must be developed for each child. Foster parents have varying reasons for taking children into their care. Sometimes foster parents hope to raise the children until they are adults. This outcome may or may not be possible, depending upon the needs of the individual child. In order to make a fully informed decision about becoming a foster parent, candidates need complete information about the concept and reality of permanency, especially when the plan includes returning the child to a family where abuse or neglect once occurred. Permanency planning should begin on admission to Treatment Foster Care, and both the birth parents and foster parents should play a role in the process.

Staff should determine the child's connections to his or her community (e.g., the nuclear and extended family, teachers, religious affiliations, and the foster family) in order to identify potential permanent families for the child.

Generally speaking, finding a permanent home for a foster child with a medically fragile condition can be challenging. Permanency can be achieved in a variety of ways. Foster parents may adopt a child, or for some reason the court may decide that short of adoption the child may remain with the foster family permanently. The child may be returned to one or both parents or to other relatives, known or not known to the child. Adoptive parents may be found who have had no previous

relationship with the child. However, all prospective permanent families need to have realistic information about the child's condition. What are the child's care needs? Does the child have a normal life expectancy? Will the child continue to grow and develop? Will the child be able to live independently in the future? What kinds of services are available for the child now and in the future when she or he is an adult? Who will cover the medical costs? Will medical costs and coverage be the same when the child becomes an adult? Is there a subsidy for the adoptive parents to cover other expenses? Who will provide support to the family after placement? Who will care for the child if something happens to the parents?

## Birth Families

The Treatment Foster Care program should request a copy of the service agreement between the local department of social services and the biological parents in order to gain an understanding of what is required of the parents in order to regain custody of their child. Additionally, the social worker should request a summary of the agency worker's experience with the birth family since the original case was opened. At a minimum, the social worker should verify the cognitive capacity of the parents, information about other children in the family, and the barriers to returning the child to his or her parents. Assessment of birth parents' readiness and ability to parent their child, as well as their parent-child attachment, will be ongoing from the beginning of placement. The importance of establishing a good working relationship between the foster and biological parents cannot be overemphasized, but in some cases it will be difficult to achieve. Foster parents will be expected to collaborate with staff in fostering this relationship. They can be supported and guided by clinical staff to maximize the potential for positive interactions during visits or conversations when the foster parents are explaining the child's treatment needs.

Supervised visits with the birth family will enable the staff to evaluate the likelihood that the child can return home. A formal supervised visitation plan will include dates, times, and locations, and identify those who will participate in the visits and who will supervise the visits. Birth parents can help the social worker create a genogram, which will help identify other possible family resources. Birth parents should be encouraged to attend all medical appointments and should be given a list of those appointments that are scheduled. At the medical appointments, foster parents and foster care staff should encourage and model active participation for the birth family by giving information about the child, asking questions, and expressing thoughts and opinions about what is being said.

*The following outline of recommended activities with birth families is helpful.*

Using professional judgment, the TFC worker:

- Gathers contact information for the birth family during the intake process.
- Makes contact with the birth family within one week to orient members to the TFC program, begin to establish rapport and team relationship, and gather more information about medical history, condition, and providers, along with other psychosocial needs.
- Arranges a meeting to introduce the birth family and the child to the foster family.
- Invites the birth family to participate in all treatment planning meetings.
- Informs the birth family of all medical appointments and encourages participation.
- Assesses the birth family's understanding of diagnostic information, behaviors, treatment needs, and so on to determine the level of training and support needed for the birth family to safely care for their child.
- Engages the birth family in clinically supervised visitation.
- Assesses the family's participation and capacity and gives feedback to the birth family.

**Peter** is a 13-year-old boy with Type 1 Diabetes and presents some oppositional behaviors. He was placed in the care of the state due to medical neglect. Peter was hospitalized before he came into the treatment foster care program. His foster parent monitors his diet and keeps his daily food log. She also computes Peter's needed humalog dosages, and administers his medication. Peter's foster parent actually has a second foster child in the home, a female teenager with a similar medical diagnosis and medical needs.

- Develops a family- and child-specific training program to help the family learn to meet the specific medical and developmental needs of the child. As with staff and foster family training, medical providers will be used for specific interventions that require medical or other skilled training techniques.
- Continues assessments.
- Provides recommendations to the agency holding guardianship regarding the birth parents' level of readiness to care for the child during the visitation or reunification process.

## Adoption

The adoption process can begin in different ways in a TFC program. Foster parents can choose to adopt a child who has lived with them in foster care. Sometimes children for whom it's difficult to find adoptive parents may participate in statewide adoption programs, hosted by the child placement agency, where people who want to adopt can consider adopting one of a number of children whose permanency plan is adoption. A TFC program can also consider becoming licensed as an adoption agency in its state. Whether a licensed adoption agency or not, a TFC program can offer continuing support to its foster parents who have adopted and to other adoptive parents in the community by developing a facilitated adoption support group.

The social worker assesses the readiness of the foster family and foster child for adoption and provides recommendations to appropriate parties in the child placement agency.

Each state varies with respect to adoption subsidy amounts and the range of post-adoption supports that are provided. Some states, such as Maryland, provide a Medically Fragile Adoption Subsidy for children whose medical condition qualifies them for a higher rate than the routine subsidy amount. The child's prospective parent or adoption worker needs to ask for consideration to receive this special rate when he or she thinks it may apply. It's important for families who are adopting children who have special medical conditions to check with their local department on the availability and range of post-adoption supports offered in their state.

## Transition

Everyone experiences many transitions throughout childhood, beginning in elementary school and moving to middle school, high school, adolescence, and on to adulthood. Children with medically fragile conditions experience these transitions as well, though generally differently than other children because there are more complexities to the transitioning process. White (1997) developed principles of transition services related to health, education, leisure, social-emotional functioning, and independence:

1. The transition process begins on the day of diagnosis.
2. Both the adolescent and his or her family should be involved in the decision process.
3. Providers and parents should prepare to facilitate movement from one developmental phase to another.
4. Coordination of services and providers is essential.

The goal of transition is to move toward greater autonomy, to sustain the highest level of independence possible, or to do both. The transition to adulthood is particularly significant for its ambiguities and barriers to full participation in community life as a person with a medically fragile condition and perhaps other developmental conditions. This transition is further complicated if the individual has limited intellectual capacity or requires assistance with activities of

**Matthew** is a 16-year-old boy with Duchene Muscular Dystrophy who was taken from his mother at 13 years of age due to neglect of his medical condition, poor hygiene and nutrition, and school attendance problems. His mother is a small woman and as Matthew got older and bigger she was unable to provide the care he needed. He is completely dependent on others for all activities of daily living. She is a proud woman and didn't ask for help. He was placed with a family where both parents are nurses. They understood his medical condition and other care needs. Matthew is very bright, does well in school and wants to go to college. He has developed peer relationships at school and is on the chess team. He misses his mother and two siblings but understands that he needed attention that she couldn't provide. His foster parents make sure that he visits his mother on holidays and at other times.

**Rachel** is a 7-year-old girl who was born in the United States after her parents emigrated here from China. She entered treatment foster care at 2 ½ years of age due to abuse by her mother, who threw her into a wall where she hit her head, was unconscious and her mother put her to bed. Her father took her to the hospital where a craniotomy was performed and she subsequently was transferred to a rehabilitation facility. Later, plastic surgery was performed to implant a titanium plate at the site of the original craniotomy. She is diagnosed with traumatic brain injury, moderate intellectual disabilities, seizure disorder, left hemiplegia, visual problems, attention deficit hyperactivity disorder (ADHD) and the persistent craving and compulsive eating of non-food substances (PICA). Her behavior is impulsive and she requires constant supervision. In school she receives therapy to improve her speech, gross and fine motor skills. She is seen at a clinic for children with traumatic brain injury, by a neurologist, ophthalmologist and plastic surgeon. Her foster parents are working on toilet training, hair washing and bathing which she dislikes. They administer medications for ADHD and seizures; they patch her right eye due to amblyopia. She is described as adorable and she loves to hug. Her foster mother keeps the appointments and organizes them. Her foster Dad is described as a “fun dad”. He has a son on the autism spectrum. Together they have adopted two children with special needs. Rachel was adopted by the family at National Adoption Day last year.

daily living because of a severe physical disability, or both. Thanks to improvements in health care, children with chronic health conditions are now living well into adulthood. These individuals and their families are frequently reluctant to leave their pediatric care providers, and, simultaneously, adult care providers may be reluctant to take these patients because of a lack of experience with their specific complex set of diagnoses.

The school system is responsible for developing a transition plan with the parents and student when the student is 14 years old. The transition plan encompasses a coordinated set of activities for a student, designed to be within an outcome-oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated competitive employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. Foster parents and staff should expect to be highly involved in this process as should the student to the extent of her or his capabilities.

For children with medically fragile conditions, the foster care staff and foster parents should take the lead in identifying health care providers who are willing to accept adolescent and newly adult patients into their practice. This shift should be accomplished by the time the child reaches 18 years of age. A resource for this transition is the American Academy of Family Physicians. Current health care providers may be useful in recommending adult resources.

### In closing

Youth in the child welfare system who have developmental disabilities or serious medical conditions pose unique challenges for caretakers and clinicians. The FFTA Medically Fragile Treatment Foster Care Workgroup has developed this guide for foster care programs that want to serve this special population. This resource guide, when used in conjunction with the FFTA Program Standards for Treatment Foster Care, can help programs modify their practice to provide safe, effective care for children and youth with developmental disabilities or medically fragile conditions.

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## Resources

**American Academy of Pediatrics:** This organization provides a wealth of information regarding childhood illness and disability as well as FAQs for parents. <http://www2.aap.org/immunization/>

**Attachment, Self-Regulation and Competency (ARC):** This is a comprehensive framework for intervention with youth exposed to complex trauma. Intervention is tailored to each client's needs and may include individual and group therapy for children, education for caregivers, parent-child sessions, and parent workshops. Staff trained in the model can then train foster parents in applying this philosophy to their work with the foster children in their home. <http://www.traumacenter.org/research/ascot.php>

**Children with Special Health Care Needs (CSHCN):** The federal Title V Maternal and Child Health Program (<http://mchb.hrsa.gov/index.html>) provides a foundation for ensuring the health of mothers, women, children, and youth, including those children and youth with special health care needs and their families. All states receive this block grant.

**Disability-specific organizations have national, state, and local websites.** National sites generally give information about how to contact state and local chapters.

**Fostering Health, Health Care for Children and Adolescents in Foster Care:** This resource manual by the American Academy of Pediatrics is designed for use by medical, mental health, and developmental health care professionals, as well as foster parents, social welfare agencies, and policy makers. It defines the Standards, components of service and care coordination that promote quality health care for children. <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Documents/FosteringHealthBook.pdf>

**Health Care Toolbox:** This resource offers pediatric health care providers with resources and guidance on adopting a trauma-informed perspective on patient care. The site explains the impact of traumatic stress reactions in children coping with illness, injury, and medical procedures; provides tools that can help health care professionals enhance their skills; and includes patient education materials that can be downloaded and shared with clients. This site is developed and maintained by The Children's Hospital of Philadelphia. <http://www.healthcaretoolbox.org/>

**Healthy Foster Care America (HFCA):** HFCA is an initiative of the American Academy of Pediatrics and its partners to improve the health and well-being outcomes of children and teens in foster care. <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america>

**Individuals with Disabilities Education Act (IDEA):** The U.S. Department of Education, Office of Special Education Programs hosts the official website for IDEA at <http://idea.ed.gov/>

**Leadership Education in Neurodevelopmental and Related Disabilities (LEND):** These programs provide long-term, graduate-level interdisciplinary training as well as interdisciplinary services and care. The purpose of the LEND training program is to improve the health of infants, children, and adolescents with disabilities. The program accomplishes this goal by preparing trainees from diverse professional disciplines to assume leadership roles in their respective fields and by ensuring high levels of interdisciplinary clinical competence. LEND programs operate within a university system, usually as part of the University Centers for Excellence in Developmental Disabilities (UCEDD) or other larger entity, and collaborate with local university hospitals or health care centers, or both. Thirty-seven states have LEND programs. Information about UCEDDs and LENDs can also be obtained at <http://aucd.org/>

**National Center for Medical Home Implementation:** This resource is for health professionals, families, and anyone interested in creating a medical home for all children and youth. <http://www.medicalhomeinfo.org/>

**National Dissemination Center for Children with Disabilities:** This organization offers a wealth of information on disabilities and serves as a national, central source of information on disabilities in infants, toddlers, children, and youth. Their state resource sheets provide lists of disability agencies and organizations in states across the country. <http://nichcy.org/>

**Project HEAL:** The project serves as a bridge among advocates, attorneys, doctors, social workers, educators, and health care advocates in Maryland, enabling them to work together for the benefit of children and adolescents needing both legal and medical assistance. <http://www.kennedykrieger.org/community/community-programs/project-heal>

**Recreational resources:** These may be sponsored by disability- or disease-specific organizations such as the Muscular Dystrophy Association or the Cystic Fibrosis Association. Local recreation and parks programs serve children with medically fragile conditions and disabilities.

**State agencies responsible for serving people with developmental disabilities:** Google by name of state and developmental disability; these agencies are generally located within health and mental health administrations.

**State Protection and Advocacy Systems:** Protection and Advocacy Systems (P&As) work at the state level to protect individuals with developmental disabilities by empowering them and advocating on their behalf. There are 57 P&As in the United States and its territories, and each is independent of service-providing agencies within their states. Like the University Centers for Excellence in Developmental Disabilities (UCEDDs), the P&As are primarily funded by the Administration on Intellectual and Developmental Disabilities. <http://www.acf.hhs.gov/programs/aidd/programs/pa>

**University Centers for Excellence in Developmental Disabilities (UCEDDs):** Currently, there is at least one UCEDD in each state in the United States. Funded primarily by the Administration on Intellectual and Developmental Disabilities (AIDD), these Centers work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens. Information can be found at <http://aucd.org/directory/directory.cfm?program=UCEDD>