

Supervising for Successful Transitions for Youth with Complex Needs



Patricia Gilbaugh, Ph.D.

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Introduction:

According to Child Welfare League of America (CWLA), many children in foster care have one or more types of special needs (2007). “Special needs” in this case refers to children “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally,” (McPherson, et al., 1998). The complex needs of many youth in foster care require unique child protection services. The caseworkers’ role in providing these services includes facilitating access to comprehensive care, and facilitating chronic disease management. Chronic disease management is the practice of coordinating the multiple physicians and treatment services, and ensuring providers in all kinds of service settings are current with the youth’s needs (Children’s Health Campaign, 2007). Supervisors have an especially important role in making sure services for youth are accessed and fully implemented in order to help youth transition successfully from youth-oriented services to the adult system of community-based care.

Course Objectives:

Create an awareness of the concerns about youth in foster care who have special needs.

Develop strategies for supervising casework for foster children who have special needs.

Promote an understanding of the supervisors’ role in delivering comprehensive health care services to foster children who have complex needs.

Develop supervisory skills that promote culturally competent practices for youth who have disabilities and other special needs.

Educate supervisors about Community-Based Services Waiver programs.

Educate supervisors about the process of developing a comprehensive health-related case plan.

Supervisor Competencies:

Advocates for/allocates resources that respect the diverse needs of youth.

Uses supervision to assure culturally competent practice with youth.

Ensures that DHS is an effective partner on the transition planning committee.

Develops and sustains collaborative community relationships that support youth in transition.

Recognizes indicators of mental illness and developmental disabilities and provides consultation to workers.

Supervising the Care of Youth with Complex Needs

Different Types of Special Needs

Physical or Medical Health Conditions

Youth who have physical disabilities or chronic medical health conditions face a number of challenges that are unique to their situations. Most often, these youth are at least average in cognitive ability and fully comprehend their differences in ability. They tend to be centered on the master status of their disability or medical condition. For example, a youth who is blind centers most daily life activities around his or her vision impairment. Likewise, a youth who has a weakened immune system has to plan his or her daily activities around other peoples' germs.

These youth are typically challenged by immense loss issues. They may grieve for the loss of their ability, the loss of their family connections, the loss of their participation in meaningful activities, or the loss of their dreams when their conditions limit access to those dreams. These youth are acutely aware of their limitations and most likely experience moments of intense emotional pain, especially when they realize they are being excluded from things other youth are participating in.

In addition to these losses, youth also experience the same losses other foster care children experience. In a conversation with a youth who was confined to a wheelchair, the physical disability is concerning, but it is not always the most profound loss. This youth conveyed his feelings about how his counselor kept telling him that he needed to deal with the loss of his legs, but he clearly was grieving over the bullying and kids making fun of him at school because he had no parents. When the chronic medical conditions and physical disabilities intersect with other foster care losses, these youth may be especially vulnerable to serious emotional disorders, including depression or anxiety-related disorders.

Mental Health Problems

A majority of foster youth have a diagnosed mental health problem. The concern is so great that recent legislative efforts have included strengthening children's mental health services and creating a children's mental health waiver, which we will talk about in depth later in the presentation.

Youth who have mental health problems may or may not have the cognitive ability to understand the extent of their impairment to daily life activities. Youth may wish to discontinue medications that regulate their emotional responses, or they may wish to change medications or increase a dosage of their medication. Some youth may not be informed or may not understand the seriousness of the risks of consuming alcohol, smoking, or combining drugs with their medications. The potential for lethal combinations of their medications with controlled substances is a critical consideration for transition planning discussions and helping youth make decisions about their lives.

Youth who have mental health problems will need supports that can be flexible and altered to meet their fluctuating needs. Resources that will provide families with 24-hour crisis intervention will need to be discussed with workers and the community will need to be explored for where those resources may be found. For example, does the community mental health center provide a 24-hour service, or would youth have to be hospitalized in crisis situations.

Developmental Disabilities

Youth who have developmental disabilities may struggle with cognitive or learning disabilities as well. When youth miss developmental milestones, they may or may not be able to recover from the lost opportunity to develop a critical piece of their well-being in preparation for adulthood. For example, youth who have lost the opportunity to develop secure and attached relationships may not ever be able to form close bonds with other people. Similarly, youth who walk or talk late in their developmental stages may experience challenges unique to their developmental delay. Developmental delays frequently show up during late elementary and early middle school years. Trouble with learning complicated math, advanced language skills, or writing skills become more prevalent as youth are expected to demonstrate mastery over these areas of learning. It is ALWAYS best to intervene as early as possible, but when early intervention did not occur it is critical to get the youth an IEP or other support services as soon as possible.

Youth who do not fit the Traditional Diagnoses for Adult Services

These teens are the youth that workers probably struggle the most with. These youth have mild-moderate special needs, yet they function high enough that they will not be eligible for adult services once they transition out of foster care. Supervisors can benefit these teens the most by monitoring their eligibility for Waiver programs and non-traditional adult support services. The Medicaid Waiver programs cover the youth until age 21. Waiver programs will be discussed in detail during a later section in this course.

Prenatal Drug Exposure & Teen Pregnancy

Teen pregnancy and prenatal drug exposure are strongly correlated to many of the problems that children with special needs have. Mothers who smoke during pregnancy are more likely to have underweight infants and increase their risk of delivering prematurely. Drug affected babies and babies exposed to alcohol in utero are more likely to experience developmental delays, serious chronic medical conditions, and physical disabilities. Moreover, mental health problems may occur and typically show up in symptoms and behaviors similar to hyperactivity, a lack of ability to concentrate, and emotional turmoil (such as strong mood swings or depression).

Effective Case Management Practices and Case Supervision

Importance of public insurance and Waiver programs

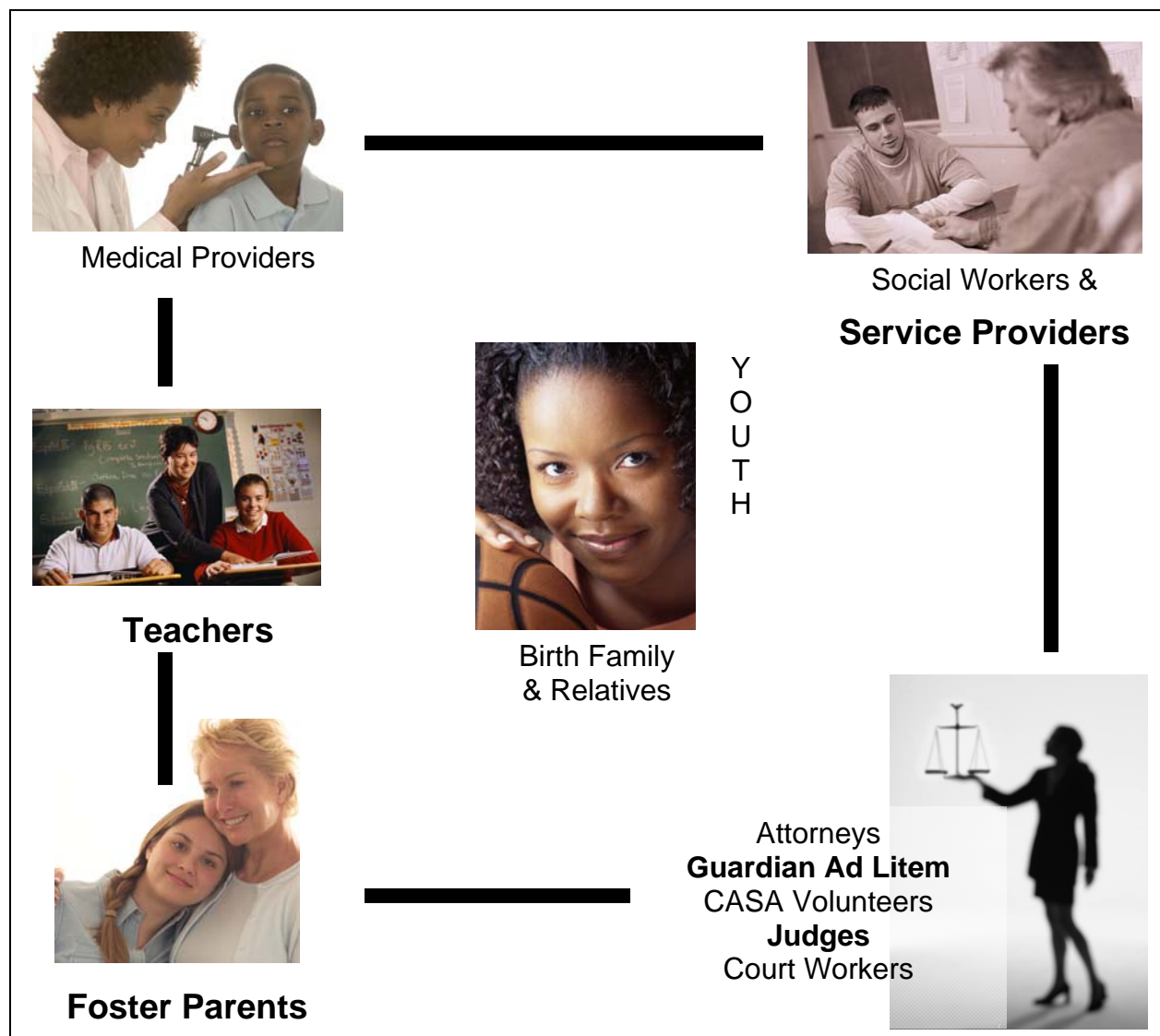
Accessing health care and mental health services is important for children involved with the child welfare system. Medicaid insurance and Waiver (which includes Medicaid insurance for chronically ill children through age 21) programs provide children with complex needs comprehensive health coverage, which helps ensure they have access to critical care and services. Some youth may be covered by parents' or foster parents' private health insurance; however, private insurance typically falls short of covering services such as diagnostic testing, primary care for special needs, specialty care, hospital-based services, prescription drugs, therapies, mental health services, durable medical equipment and supplies, hearing aids and glasses, and other health-related services.¹

Comprehensive health care coverage assists with chronic disease management, which is critical for patients with complex conditions that require services from multiple providers. The primary benefit of chronic disease management is that it lowers health care costs and allows for better coordination of care.

Child welfare supervisors are responsible for ensuring children in child protection services are accessing Medicaid and Waiver programs. The Waiver program is especially critical for the long-term success of chronic disease management. When children are given a slot on a Waiver program, as long as the child meets the level of care he or she can retain their slot in the program regardless of the caregivers' circumstances. For example, should the child be returned home, be adopted, or age out of care the child will remain on the Waiver program (including Medicaid coverage) for as long as the child needs the services, up to the 22nd birthday.

Supervisors who are overseeing child protection services should be:

- Monitoring the symptoms of potential chronic conditions that may qualify children for Waiver services.
- Educating caseworkers about the importance and the processes of linking children to the on-going services of Waiver programs, Early Access for children 0-3, and Iowa's Title V program.
- Reviewing the transition plan to ensure an adult diagnosis is provided where appropriate. The adult diagnosis is an important step for services and Medicaid coverage to continue into adulthood.
- Ensuring children with complex needs are accessing specialty care and have a pediatrician for primary care. Preferably, children with complex needs will have a pediatric Medical Home physician.



Care coordination by caseworkers

Caseworkers have a responsibility to ensure children involved with child protection services are accessing the specialty care they need. “Children in foster care have greater medical and mental health needs than other children in poverty, and far greater needs than children in general.”ⁱⁱⁱ Children in foster care experience enhanced vulnerabilities of childhood, including developmental vulnerability, dependency, and differential morbidity (a mental health condition that limits functioning just because the youth feels so different from the rest of society). Developmentally, children who miss developmental milestones may incur life-long consequences. The functional capacities of foster children and youth are constantly threatened due to the high probability that their development will be interrupted. Foster children are dependent upon a system much in the same way all children are dependent on their parents and caregivers. Foster children generally have higher and more complex needs than other children. They will need comprehensive assessments and all domains of well-being need to be monitored.

The following are typical barriers foster children with complex needs face:ⁱⁱⁱ

- A lack of communication among members of the system.
- Complicated and time-consuming paper work
- Low reimbursement rates for health care services
- Complex health plans and numerous gate-keepers
- Numerous foster placements
- Lack of or incomplete medical records

Comprehensive case plan

All foster children need a comprehensive case plan, and it is especially important for youth in transition to have a case plan that is as comprehensive and complex as their special needs are. A comprehensive case plan includes the following elements:

- Results of a comprehensive assessment that includes multiple dimensions, including physical, developmental, emotional, cognitive/educational, social, sexual and reproductive, and environmental.
- A range of services that meets *all* the needs of youth. (See Figure)
- A continuum of care for youth for when their needs fluctuate. (see Figure)
- Clinical consultation and monitoring of specialty care.
- Age and gender appropriate health supervision.

Culturally Competent Practice

First, workers and supervisors need to develop an understanding of the laws that were designed to protect people with disabilities. These laws include Social Security Act, Individuals with Disabilities Act (IDEA), Americans with Disabilities Act (ADA), and Equal Opportunities Act (EOA). These are just a few of the legislative provisions for protecting people with disabilities. These laws were developed because of the magnitude of concern for discrimination against people who have disabilities in education, employment, and other social activities. All of these acts are designed to provide access to resources and for the inclusion of people with disabilities into all social environments.

The understanding of these laws is important because they regulate the extent to which government agencies and most private agencies serve people with disabilities. Caregivers, caseworkers and their supervisors, and partnering providers all have a responsibility to make sure inclusion is occurring.

Special Considerations that may Require Special Accommodations

- **Growth:** Failure to thrive is a special concern for children and youth who have experienced chronic neglect. Monitoring their growth curves is critical because children who are not receiving enough calories or who have been deprived of enough fat and protein in early childhood can have life-long developmental, cognitive, and health problems.
- **Nutrition:** Youth may have trouble adjusting the food in new homes. Foster parents may serve foods of a different culture, style, or type than what youth is used to. Youth may hoard foods because of prolonged deprivation in previous homes, or because hoarding is a behavior of coping from other types of maltreatment. Hoarding may also be a symptom of a mental illness, such as obsessive-compulsive disorder. Eating disorders are more prevalent in adolescents. Recent studies reveal that anorexia and bulimia are increasing among male adolescents, and that youth who are emotionally and/or sexually abused tend to have a high risk of developing an eating disorder.
- **Dental care:** Dental care tends to be neglected when children experienced higher rates of placement disruption. In addition, children who take certain types of medication may experience advanced tooth decay or enamel deterioration as a result of side effects from the medication. Some youth may enter foster care without ever being taught or not having the ability to learn proper dental care techniques. Youth with complex needs may need to be instructed and supervised by caregivers in their dental care on a daily basis.

- **Respiratory:** A frequent change in environments, development of multiple allergies, and environmental on-set asthma are great concerns to children who have complex needs. In addition, youth with heart conditions frequently catch respiratory viruses with prolonged recovery periods. When youth who have complex needs are placed into farming communities, homes with pets, homes with hardwood floors or plush carpets, environments without an air filtration system, and buildings (includes schools) that are old, their respiratory reactions should be documented and carefully monitored. Frequent respiratory illnesses should prompt a referral to a pediatric pulmonologist for an evaluation.
- **Neurological:** Poor prenatal care, prenatal injury, and postnatal abuse can cause problems in physical development and neurological functioning. “Soft signs” of neurological dysfunction can be transient (fluctuating) or permanent. Neurological dysfunction can be screened for by primary care pediatricians, who can then best determine whether specialty care is needed.
- **Immunizations:** Children in foster care generally have difficulty obtaining documentation of immunizations. Younger children are more apt to have their immunization records posted on a confidential public health website that physicians can access. Older youth, however, may not have their records easy obtainable. Furthermore, youth that were immunized out-of-state may have no records at all. Immunizations are critical for children who have complex needs and are susceptible to major illnesses. However, their special needs may also prohibit them from being able to physically withstand immunizations, or they may have serious reactions to immunizations. Always consult with a pediatrician who has experience with children who have special needs regarding immunizations for a youth, especially when the youth has a suppressed immune system or HIV. Youth in transition will need to have updated immunization records before they can attend college. In some cases, the MMR immunization may be required to be tested for effectiveness, and re-immunized if the test shows the immunization was ineffective.
- **Screening:** Screening for all types of disorders, illnesses, and conditions at each encounter can help monitor for early detection and to prevent chronic conditions from worsening. Screening for lead, anemia, vision, hearing, mental health, behavioral, and maltreatment are just as important for youth as they are for young children. As children age, problems are more likely to manifest themselves, and the need for services or interventions will emerge over time—rather than suddenly appearing.
- **Infectious diseases:** Blood-borne pathogens (HIV/AIDS, Hepatitis B and C, and sexually transmitted diseases) are a higher risk for youth in foster care. Exposure to high-risk parental behaviors and, for some youth, sexual abuse or sexual activity increases their risk to contract a fatal disease. Child with complex needs carry an additional risk factor of contracting childhood diseases, even at older ages, because their immune systems can be suppressed or immature.

Placement of children with complex needs is a critical decision for youth who have hemophilia or bleeding disorders and children who has weak immune systems. Environmental factors and stress can increase the risk of contracting an infectious disease and prolong the illness.

- **Discipline:** Depending on the child's experience and abilities, discipline may need to be very different from how new caregivers discipline other children. Some children with complex needs may have experienced harsh, abusive discipline while other may not have ever been disciplined. Some youth may not understand discipline and, therefore, may not respond to it. Some youth with disabilities identify strongly with the "victim" role, and discipline for them reinforces their framework of being a victim. Often, though, youth with complex needs have survived and coped through many tough situations and developed a strong sense of independence and self-reliance. These character traits are sometimes perceived as "attitude" by caregivers and as such are not appreciated. Youth with disabilities need opportunities and supports to learn self-discipline in order to learn how to control their impulses, balancing their wants from needs.
- **Self-Advocacy:** Positive youth development opportunities include opportunities to advocate for themselves and perform challenging tasks that help them transition into adulthood. Providing youth with these opportunities means caregivers and providers need to be okay with allowing youth to fail in their performance, and supporting them when they want to try it again.
- **Mental health:** The process of disrupting routines, moving youth into new environments, and changing caregivers of youth can exacerbate mental health conditions for some youth. In addition to the high risk of mental health conditions that all children in foster face, children with complex needs are especially vulnerable when their sense of "normalcy" is disrupted. For example, a child with autism can become quite agitated when a parent drives a different route home or serves a new food for dinner. Children with complex needs also carry stigma and experience discrimination in unique ways, mostly due their experiences of exclusion and "being different". These experiences can also contribute to their mental health status.

- **Sleep:** Youth with special needs most likely will experience sleep disorders. Sleeping too much, insomnia, night terrors, night sweats, sleep apnea, or other sleep disorders may be a result of a mental health or chronic health condition, and can also be a result of medication used to treat these conditions. Supervisors and workers need to be aware of age appropriate sleep patterns and account for any developmental differences from the typical adolescent population. Pediatricians are an excellent resource for determining if a sleep disturbance is occurring. Children's hospitals usually include access to a sleep laboratory when experts can observe sleep disturbances and qualified advice can be obtained.
- **Development:** Foster children in general need intervention as soon as a delay is suspected; they should not be asked to wait for intervention services until the delay is confirmed (which can be months later). The assessment of developmental delays can be accomplished quickly by the local Area Education Agency, and they have specially trained, qualified experts who can implement the needed services and Individual Education Plan in a short timeframe. Because developmental delays are most often a result of socio-emotional problems, the assessment must include social and emotional components.

Recommended Readings and Resources:

Green, S. & Powers, L. (2004). Transition planning for Foster Youth with Disabilities: Are we falling short? Fostering Futures Project: An Awareness Document for Parents, Professional, and Youth. Last retrieved on May 22, 2007.

<http://www.aap.org/advocacy/hfca/FosteringFuturesAwareness2.pdf>.

Green, S. & Powers, L. (2003). Are we ignoring foster youth with disabilities? Fostering Futures Project: An Awareness Document for Parents, Professional, and Youth. Last retrieved on May 22, 2007.

www.aap.org/advocacy/hfca/FosteringFuturesAwareness1.pdf.

Halford, N., Kaufman, N., Perez, V., Inkelas, M., Flint, R. (2001). A guide to developing Health Care systems for children in foster care. The UCLA Center for Healthier Children, Families, and Communities.

NYS Office of Children and Family Services (2004). Working Together: Health Services for Children in Foster Care. Last retrieved on May 22, 2007.

http://www.ocfs.state.ny.us/main/sppd/health_services/manual.asp.

Parent Educational Advocacy Training Center. <http://www.peatc.org>.

Williams, B. & Tolbert, J. (2007). Aging out of EPSDT: Issues for young adults with disabilities. Kaiser Commission on Medicaid and the Uninsured: Washington, DC: Kaiser Family Foundation.

ⁱ Campaign for Children's Health Care (2007). Children and Youth with Special Health Care Needs. Retrieved on May 11, 2007. <http://www.childrenshealthcampaign.org>. Washington, DC: Author.

ⁱⁱ Halford, N., Kaufman, N., Perez, V., Inkelas, M., Flint, R. (2001). A guide to developing Health Care systems for children in foster care. The UCLA Center for Healthier Children, Families, and Communities.

ⁱⁱⁱ Parent Educational Advocacy Center. The special role of foster parents. Retrieved on March 16, 2007. <http://www.peatc.org/FosterCare/roleoffosterparents.htm>.

Resources for Children with Complex Needs

Who do I call for.....?

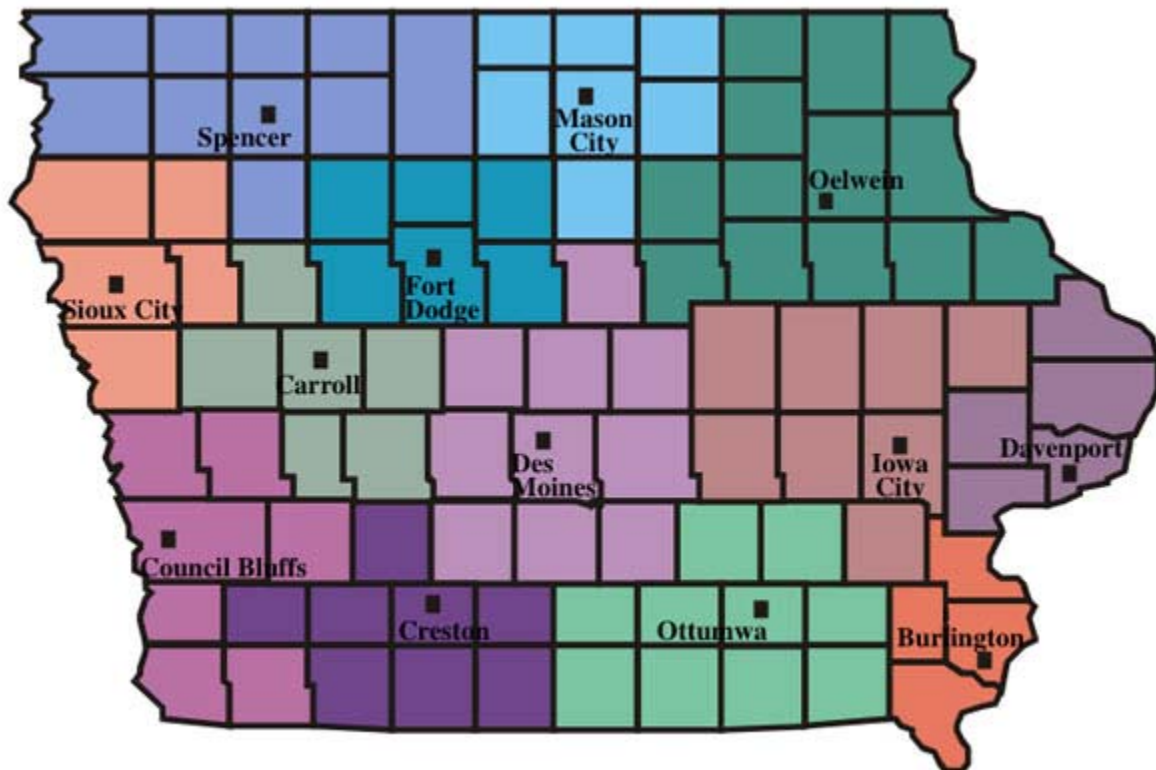
Behavioral Health Evaluation

CENTER FOR DISABILITIES AND DEVELOPMENT

The Center for Disabilities and Development (CDD) is located at the University of Iowa. CDD is Iowa's premier center for people with disabilities or special needs. The first priority is to be a resource people can use to accomplish personal goals. Services provided include: medical care and other services to improve quality of life (at home, school, and work); training; research; and information sharing. For further information, please click on:

<http://www.healthcare.uiowa.edu/cdd/index.asp>

CHILD HEALTH SPECIALTY CLINCS (CHSC)



CHSC Integrated Evaluation and Planning Clinics

Integrated Evaluation and Planning Clinics (IEPC) are designed to provide services for children with health-related developmental and behavioral problems. The clinic physician provides diagnostic and evaluation services. Professional examiners from the community provide consultation in nursing, psychology, and social services. For further information, please contact the nearest [CHSC Regional Center](#)

CHSC Family to Family Support (and Social Worker Support, too)

Child Health Specialty Clinics supports families. Our team of experienced parents provides families one-on-one problem-solving and emotional support as they care for their children with special health care needs. For further information, please contact the nearest [CHSC Regional Center](#)

CHSC Regional Autism Services Program

The mission of the Regional Autism Services Program is to promote excellence in services to lowans with autism (and its spectrum disorders) and their families through leadership and the support of staff development programs, innovative services, and school improvement. We're committed to ensuring that all lowans with autism have regional access to service options and supports that allow them to realize their potential. We provide resource and referral services, technical assistance, statewide library services, and regional screening for toddlers and youth with autism, pervasive developmental disorder, or Asperger's Disorder. For further information, please click on: <http://www.medicine.uiowa.edu/autismservices/>

CHSC Telehealth

Child Health Specialty Clinics uses telehealth to deliver subspecialty physical and behavioral health services to children. Using a television screen and web camera that operates via high-speed internet, telehealth clinics connect the child and family located at a CHSC regional center to a provider located at another site. Special techniques assure confidentiality. Consultation between providers can also occur via the web camera. For further information, please contact the nearest [CHSC Regional Center](#).

CHSC Regional Centers Directory

Burlington

Child Health Specialty Clinics
Eastman Plaza
1223 S Gear Avenue, Suite 012
West Burlington, IA 52655-1690
(319) 752-6313
Fax: (319) 753-0793

Center Hours:
8:00 AM – 4:30 PM Monday thru Friday

Carroll

Child Health Specialty Clinics
726 North Carroll, Suite 1
Carroll, IA 51401-2367
(712) 792-5530
Fax: (712) 792-4825

Center Hours:
8:30 AM – 5:00 PM Monday thru Friday

Council Bluffs

Child Health Specialty Clinics
3501 Harry Langdon Blvd., Suite 150
Council Bluffs, IA 51503-7894
(712) 309-0041
Toll Free Number (866) 652-0041
Fax: (712) 309-0044

Center Hours:
8:30 AM – 5:00 PM Monday thru Friday

Creston

Child Health Specialty Clinics
806 Wyoming Ave.
Creston, IA 50801-3531
(641) 782-9500
Toll Free Number (877) 292-9500
Fax: (641) 782-9519

Center Hours:
8:00 AM – 4:30 PM Monday thru Friday

Davenport

Child Health Specialty Clinics
1230 East Rusholme St., Suite 305
Davenport, IA 52803-2400
(563) 421-3030
Toll Free: (866) 664-3030
Fax: (563) 421-3039

Center Hours:

8:00 AM – 4:30 PM Monday - Friday

Des Moines

Child Health Specialty Clinics
108 3rd Street, Suite 350A
Des Moines, IA 50309-4770
(515) 727-4121
Toll Free Number (866) 208-4088
Fax: (515) 283-2307

Center Hours:

8:00 AM – 4:30 PM Monday thru Friday

Fort Dodge

Child Health Specialty Clinics
Physicians Office Bldg. West
804 Kenyon Road Suite L
Fort Dodge, IA 50501-4901
(515) 955-8326
Fax: (515) 574-5544

Center Hours:

7:30 AM – 4:30 PM Monday thru Friday

Iowa City

Child Health Specialty Clinics
100 Hawkins Drive, Room 247 CDD
Iowa City, IA 52242-1011
(319) 356-1117
Toll Free Number (866) 219-9119
(319) 353-8605 TDD
Fax: (319) 356-3715

Center Hours:

8:00 AM – 4:30 PM Monday thru Friday

Mason City

Child Health Specialty Clinics
910 North Eisenhower Ave.
Mason City, IA 50401-1525
(641) 422-7388
Toll Free Number (800) 433-3883 Ext. 7388
Fax: (641) 422-5755

Center Hours:

8:30 AM – 5:00 PM Monday thru Friday

Oelwein

Child Health Specialty Clinics
212-8th Avenue, SE
Oelwin , IA 50662
(319) 283-4135
Fax: (319) 283-4140
Toll Free Number (866) 279-5023

Center Hours:

8:00 AM – 5:00 PM Monday thru Friday

Ottumwa

Child Health Specialty Clinics
317 Vanness Avenue, Room 114
Ottumwa, IA 52501-1434
(641) 682-8145
Fax: (641) 682-8857

Center Hours:

8:00 AM – 4:30 PM Monday thru Friday

Sioux City

St. Luke's Regional Medical Center
Physician's Center One Building
Child Health Specialty Clinics
2800 Pierce Street, Suite 315
Sioux City, IA 51104-3795
(712) 279-3411
Toll Free Number (800) 352-4660 ext. 3411
Fax: (712) 279-7023

Center Hours:

8:00 AM – 4:30 PM Monday thru Friday

Spencer

Child Health Specialty Clinics
1200 First Avenue East
Spencer, IA 51301-4330
(712) 264-6362 or 6363
Toll Free Number (877) 270-9386
Fax: (712) 262-1526

Center Hours:

8:00 AM – 5:00 PM Monday thru Friday

Respite Care & Crisis Care Services

IOWA RESPITE AND CRISIS CARE COALITION

IRCCC is a STATE-WIDE parent-driven, non-profit organization that provides referral, advocacy, information, and limited funding for respite/crisis care services.

3821 71st Street, Ste A Urbandale 50322 Phone:
1-877-255-3140 or 515/ 309-0858 Fax: 515/ 309-0860
E-mail: ed@irccc.com <http://www.irccc.com/>

The Direct Family Access Program was developed in 2001 to assist families who need respite care, but are not eligible for respite services from any other source. This program is for families/caregivers who know someone that is willing to provide the Respite Care, but who need a way to pay that person. There need not be an agency involved.

This is the first program in Iowa that allows families to choose and train their own respite provider without the involvement of an agency. It is also a very cost-effective way for families to spend the limited respite dollars available as it eliminates the need for administrative fees. Because of the tremendous need, families with substantial other respite funding will not likely be awarded funds. This program, like all respite services funded by IRCCC, is open to people of any age and disability, although funding for some categories may be limited.

Who decides what I pay the Respite Worker?

You do! IRCCC believes the family member or caregiver is the best person to choose and train the individuals who provide the Respite Care. You also are responsible for negotiating their pay rates, hours worked, etc. You may use anyone that does not live in the home.

How large are the awards?

The maximum award for the entire year will be \$250 per individual. Awards made later in the year (that begins October 1) will be less.

How do I receive reimbursement?

- You simply complete a voucher for each individual and mail it to IRCCC. Payment should be received within two weeks. You can print off a voucher form below or call the office and request a voucher.

- Do not complete and send in a voucher unless you have received an award letter from IRCCC. click for a [voucher](#).
- Do not submit a claim for respite expenses before the respite has been provided. We will not pay for camp deposits ahead of the time the individual attends camp.

If I've been turned down by other programs, can this program help?
YES! These programs were developed to provide options for families who don't qualify for Respite Care anywhere else.

What if I don't know anyone to provide the Respite Care?

This program may not be the best one for you at this time. On the application, you will be asked who is providing the Respite Care. IRCCC is not able to recommend specific individuals. Don't send in your application until you have found someone that you are comfortable with providing the care. IRCCC lists resources for families in its website, you may find links by going to [RESOURCES](#) but we do not guarantee the quality of services provided by these resources

<http://www.irccc.com>

Family Supports and Additional Resources

THE ARC OF IOWA

A statewide advocacy organization of parents and others representing people with mental retardation and other disabilities.

715 E. Locust Street, Des Moines, IA 50309

Phone: 1-800-362-2927 or 515/ 283-2358

Other ARC offices exist across the state for local services. Call the Des Moines office for your local phone number.

AUTISM SOCIETY OF IOWA

A statewide advocacy organization of parents and others representing people lowans with autism.

4549 Waterford Drive, West Des Moines, IA 50266

Phone: 1-888-722-4799 515/ 327-9075.

BRAIN INJURY ASSOCIATION OF IOWA

An advocacy organization representing people with brain or head injuries.

2101 Kimball Avenue, Waterloo, IA 50702

Phone: 1-800-475-4442 or 319/ 272-2312

DISABILITY RESOURCE LIBRARY

A lending library of books, videotapes, and other resources on disability issues: free for people with disabilities and family members. Other people, organizations, and agencies may purchase yearly subscriptions or may pay per item. CDD

100 Hawkins Dr. Iowa City 52242 Phone: 800-272-7713

Fax: 319/353-6532 E-mail: disability-library@uiowa.edu

<http://www.medicine.uiowa.edu/uhs/drl/index.cfm>

EMPLOYMENT POLICY GROUP

The Employment Policy Group (EPG) seeks public policy reform to meet Iowa's human resource needs through the employment of people with disabilities. EPG focuses on establishing enduring partnerships among businesses, people with disabilities, educators, and state and federal policy-makers.

108 Third St., Ste. 350 Des Moines 50309-4770

Phone: (515) 283-2310 Fax: (515) 283-2307

E-mail: jack-hillyard@uiowa.edu <http://www.e-epg.info>

IDEAS

A statewide self-advocacy and leadership training program; supports grass-roots, self-advocacy groups and advocates for systemic change. (Not to be confused with the federal education act, IDEA.) CDD 100 Hawkins Dr. Iowa City 52242-1011 Phone: 319/ 353-6448 Fax: 319/ 356-8284

E-mail: michael-hoenig@uiowa.edu

IOWA COMPASS

A free information and referral service for lowans with disabilities and their families. Provides information about services such as health care, child development, education, employment, aging, and others. Also provides information and funding referral about assistive technology, and offers a Used Equipment Referral Service.

CDD 100 Hawkins Dr. Iowa City 52242-1011

Phone: 800-779-200 TTY:877-686-0032 Fax:319/384-5139

E-mail: iowa-compass@uiowa.edu

<http://www.medicine.uiowa.edu/iowacompass/>

IOWA PROGRAM FOR ASSISTIVE TECHNOLOGY (IPAT)

State grants program that works to increase the ability of lowans of all ages to access the assistive technology they need. This is done by conducting training, awareness, advocacy, and policy initiatives.

CDD100 Hawkins Dr. Iowa City 52242

Phone:1-800-331-3027 or 319/356-0550 TTY: 877-686-0032

Fax:319/384-5139 <http://www.uiowa.edu/infotech/>

EARLY ACCESS

Early ACCESS serves infants and toddlers under the age of three that have "a condition or disability that is known to have a high probability of later delays in growth and development if early intervention services are not provided" OR "are currently experiencing a 25% delay in one of more areas of growth and development." Early ACCESS is for families and staff to work together in identifying, coordinating and providing needed services and resources.

Call 1-800-779-2001 for the regional contact in your area.

<http://www.state.ia.us/educate/programs/ecese/cfcs>

EASTER SEALS

Easter Seals is a community-based organization that provides programs, advocacy, education and support to people who have disabilities, their families and communities.

State Offices

P.O. Box 4002 DSM 50333

Phone: 515/ 289-1933 FAX: 515/ 289-1281

TTY: 515/ 289-4069 <http://ia.easter-seals.org/> E-mail: ESSIA@netins.net

FAMILY SUPPORT SUBSIDY

A monthly payment to help defray the costs of keeping a child with special needs at home. Family's taxable net income must be under \$40,000/year. Apply through Marion Kresse.

Phone: 515/ 281-4522

GOVERNOR'S DD COUNCIL

A federally funded state agency committed to the empowerment of persons with developmental disabilities, working to make the system of support and services more responsive to individuals and families. The Council works to build and support other groups, like the Key Coalition, to accomplish this goal.

Voice/TTY: 1-800-452-1936 or 515/ 281-9082

Fax: 515/ 281-9087

E-mail: bharker@dhs.state.ia.us

<http://www.state.ia.us/government/ddcouncil>

INFONET

Newsletter produced by the Governor's DD Council as a resource for information on legislative policy related to people with disabilities.

Phone: 515/ 281-9082 Fax: 515/ 281-9087

E-mail: fmorris@dhs.state.ia.us

IOWA AGRABILITY

Partially funded by the U.S. Dept. of Agriculture to help farm families affected by disabilities adapt their homes and farms.

62 LeBaron Hall Iowa State University

Ames, IA 50011 Phone: 515/ 294-8520 Fax: 515/ 294-2502

E-mail: agrability@exnet.ia.state.edu

<http://www.exnet.iastate.edu/Pages/agrability>

IOWA ASSOCIATION OF COMMUNITY PROVIDERS

An association of agencies providing a variety of services to Iowans with disabilities.

7025 Hickman Rd Urbandale, IA 50322

Phone: 515/ 270-9495 Fax: 515/ 270-1035

IOWA DEPARTMENT OF HUMAN RIGHTS, DIVISION OF PERSONS WITH DISABILITIES

Provides individual assistance to Iowans with disabilities in the areas of employment, education, physical access, housing, transportation, etc.

Lucas State Office Building DSM 50319 Phone:

515/ 242-6172 or 1-888-219-0471 Fax: 515/ 242-6119

<http://www.state.ia.us/government/dhr/pd/>

**IOWA DEPARTMENT OF EDUCATION,
DIVISION OF VOCATIONAL REHABILITATION SERVICES**

Works with individuals with disabilities to achieve their employment and economic goals. Phone: 1-800-532-1486 or 515/ 281-4311 TTY: 1-800-288-7185 Fax: 515/ 281-4703

IOWA STATE EXTENSION OFFICE

www.extension.iastate.edu/answerline/

1-800-3804 Healthy Families-prenatal and women's healthcare questions and information
1-800-639-2229 Iowa Concern-financial questions, legal issues, family transitions

1-800-447-1985 www.extension.iastate.edu/iowaconcern

Teen Line-personal & health-related information and referral

1-800-443-8336

IOWA FAMILY SUPPORT INITIATIVE (IFSI)

A statewide, grassroots organization of parents of children with all types of disabilities who want their children to live at home and be a part of our communities and our everyday lives. IFSI works with policymakers to bring about this change.

321 East Sixth Street DSM 50309

Phone: 515/ 280-6558 E-mail: <mailto:valerie@askresource.org>

IOWA FEDERATION FOR FAMILIES WITH CHILDREN'S MENTAL HEALTH

Iowa Federation of Families for Children's Mental Health is a statewide advocacy organization working independently and collaboratively at all levels towards a seamless system of care.

Iowa Federation of Families for Children's Mental Health is here to assist parents of children who:

- have emotional or behavioral disorders
- are receiving mental health system services
- are receiving special education services
- are in the juvenile justice system

In addition, the IFFCMH website is a consistently updated resources with hundreds of links that provide caregivers and professionals easy-to-find access to all kinds of information about specific mental health conditions, and for resources of all kinds.

106 South Booth ~ Anamosa, Iowa 52205

Ph. (319) 462-2187 Toll Free (888) 400-6302 (Families Only)

Fax (319) 462-6789

<http://www.iffcmh.org> Email: help@iffcmh.org

IOWA LEGAL AID

Provides legal services to low-income Iowans.

1111 Ninth Street, Ste 230 DSM 50314

Phone: 1-800-532-1275 <http://www.iowalegalaid.org>

Legal Hotline for Older Iowans: 800-992-8161

IOWA PROTECTION & ADVOCACY SERVICES INC. (P&A)

Protects the human and legal rights of people with disabilities and mental illness in Iowa.

950 Office Park Rd. Suite 221 West DSM 50265

Phone: 1-800-779-2502 or 515/ 278-2502

TTY: 515/ 278-0571 Fax: 515/ 278-0539

<http://www.ipna.org>

E-mail: info@ipna.org

IOWA STATE ASSOCIATION OF COUNTIES (ISAC)

The association that represents county government, the major funder of services to adults with disabilities.

501 SW 7th Street, Ste Q Des Moines 50309-4540

Phone: 515/ 244-7181

Fax: 515/ 244-6397

<http://www.iowacounties.org/>