

Facilitator's Guide

Supervising the Care of Youth with Complex Needs

(75 minutes)

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:

1. Create an awareness of the concerns about youth in foster care who have special needs.
2. Develop strategies for supervising casework for foster children who have special needs.
3. Promote an understanding of the supervisors' role in delivering comprehensive health care services to foster children who have complex needs.
4. Develop supervisory skills that promote culturally competent practices for youth who have disabilities and other special needs.
5. Educate supervisors about Community-Based Services Waiver programs.
6. Educate supervisors about the process of developing a comprehensive health-related case plan.

Supervisor Competencies:

1. Advocates for/allocates resources that respect the diverse needs of youth.
2. Uses supervision to assure culturally competent practice with youth.
3. Ensures that DHS is an effective partner on the transition planning committee.
4. Develops and sustains collaborative community relationships that support youth in transition.
5. Recognizes indicators of mental illness and developmental disabilities and provides consultation to workers.

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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 up to 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.



Medical Providers



Social Workers & Service Providers



Teachers



**Y
O
U
T
H**

Birth Family & Relatives



Foster Parents



**Attorneys
Guardian Ad Litem
CASA Volunteers
Judges
Court Workers**

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.”² 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:³

- 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.



Activity: Have participants think about the different types of needs they see youth struggling with. What are the needs in their communities, for the youth, for the Department? What are the needs in relevance to each of the areas listed above? *Supervisors should be thinking about youth on cases they supervise, past or present, and some of their unique and complex needs youth struggled with. What are the barriers their workers, the youth, or they themselves face to make a comprehensive case plan?*



Cultural competence for youth who are differently-abled or who have other types of special needs: Special Considerations in Supervision of Case Planning

Foster youth who have complex needs tend to have unique situations that caregivers and professionals who do not have a medical background do not typically think about when placing children and monitoring service delivery. Part of practicing social work and case management in a culturally competent manner is being aware of the sensitive nature that comes with being a youth who has complex needs. There are two ways to be develop culturally competent practice with youth who have special needs.

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.

💡 The discrimination of people with disabilities is prevalent, despite the statutory requirements to prevent it from occurring. The language we use is important when we talk about people with disabilities. When identify the person as having a disability or special need, it is important to avoid using the disability or special need as a label that prefaces the person.



Example:

Janie is an autistic child who is having trouble in school

Janie is a child with autism, and she is struggling in school.



The second way to develop cultural competence in social work practice and case supervision for people with disabilities is to educate and monitor the unique situations of health care that are common for people with complex needs. These unique situations include:⁴

- **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. For youth in transition, they will need to have updated records that document their immunizations are current 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. Lead, anemia, visions, hearing, mental health, behavioral, and maltreatment screenings 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 experience 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 more tough situations and developed a strong sense of independence and self-reliance. These character traits are sometimes perceived as "attitude" by caregivers and not appreciated. One of the most important supports youth who have complex needs requires is the opportunity to learn self-discipline, and that when combined with positive youth development 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 o.k. with allowing youth to fail in their performance, yet 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 care, 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, and they should 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.

¹ 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.

² 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.

³ Parent Educational Advocacy Center. The special role of foster parents. Retrieved on March 16, 2007. <http://www.peatc.org/FosterCare/roleoffosterparents.htm>.

⁴ Ibid. Halford

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.
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