

New Training Manual for Florida's Supervised Visitation Programs

CHAPTER

THE IMPACT OF DEVELOPMENTAL DISABILITY & CHRONIC ILLNESS ON SUPERVISED VISITATION

Case Scenario

Ms. Johnson has been referred to supervised visits with her three children ages 5, 7, and 8. The children were placed in foster care after a neighbor reported that Ms. Johnson had been using illegal drugs. After recently completing a rehabilitation program and being drug-free for several months, Ms. Johnson has been diagnosed with advanced multiple sclerosis. Ms. Johnson also has a developmental disability and has been having trouble understanding what her diagnosis means. Her children have been noticing her physical deterioration and are very upset by it. Ms. Johnson is confused as to why her children are now acting differently toward her and has been becoming increasingly angry and physically weaker.

After completion of this chapter, you will be able to answer the following questions:

- What might a visitor monitor do to address the emotions of Ms. Johnson and her children?
- What forms of communication between the program and the case manager might be helpful to facilitate this case?
- If the program's efforts to improve visits between the mother and the children were not successful, what steps might the program take?

This chapter is divided into two sections:

Developmental Disabilities

Chronic Illness

Parents and children with chronic illnesses or developmental disabilities present unique challenges in supervised visitation. Each of these conditions can create stressors that may influence parenting as well as other aspects of a family's life. Financial stress, access to social services, and access to medical care are important factors that may arise when families cope with these issues. This chapter will discuss the impact of developmental disabilities and chronic illness on visitation separately. Supervised visitation monitors can use the information in this chapter to better understand how to support families coping with developmental disabilities or chronic illnesses.

Developmental Disabilities

It is reported that 15% of children from 3-17 years of age have one or more developmental disability. Developmental disabilities can be attributed to a mental illness or physical impairment or a combination of both which manifests before the age of twenty-two. Developmental disabilities can affect daily functioning and usually lasts throughout a person's lifetime. There are many different types of developmental disabilities that can affect parenting. A developmental disability can be present in a parent as well as a child, which may affect supervised visitation.

Chronic Illnesses

Chronic illness of a parent or child, whether cancer, diabetes, multiple sclerosis, or other conditions can detrimentally affect the parent or child's physical and mental well-being. These conditions may affect a parent's ability to adequately respond to a child's needs due to fatigue, pain management issues, or the progression of particular conditions. Such issues may affect the parent's ability to meet children's needs as well as cause additional stress. Also such issues with a parent could affect the child and their needs as well. Depression, lack of understanding, and frustration are issues that could be present in a child whose parent has a disability or chronic illness.

What Will I Learn in this Chapter?

Upon completion of this chapter, a visit monitor will be able to:

- Understand the common characteristics of developmental disabilities and chronic illnesses;
- Identify risk factors which may present the potential for harm during visits;
- Identify behaviors parents and children may have that could impact visitation;
- Understand how to respond appropriately when talking with a parent and/or child who has a chronic illness;
- Understand how to respond appropriately when talking with a parent and or child who has a developmental disability;
- Understand the impact that developmental disabilities and chronic illnesses have on parents, children, and supervised visitation;
- Resolve common conflicts that may occur because a developmental disability or chronic illness is present within the family;
- Facilitate activities for parents and children to do during visitation.

As many as one in five people in the United States has a learning disability.



Part 1

Developmental Disabilities

Developmental disability is a term that encompasses a group of conditions that cultivate in the developmental period of a person's life. It is more common for developmental disabilities to be identified before a child enters school, around 6 years old. According to the DSM-V (Diagnostic and Statistical Manual), there is an organized list of neurodevelopmental disorders that can be identified through certain diagnostic criteria. The DSM-V is used to diagnose, define, and categorize mental illnesses, which includes developmental disorders.

This section will address each DSM-V neurodevelopmental disorder and common symptoms. This chapter will also discuss how different developmental disabilities can affect parenting as well as supervised visitation. It is important to consider that all of the developmental disabilities listed could be prevalent in children and adults; they are not limited to a specific age range. This is important to understand because developmental disabilities can emotionally impact and physically limit both children and parents.

DSM-V Neurodevelopmental Disorders

- Intellectual Disabilities
- Communication Disorders
- Autism Spectrum Disorder
- ADHD
- Specific Learning Disorders
- Other Neurodevelopmental Disorders

Did You Know?

- Children with disabilities suffer abuse and neglect 1.7 to 3.4 times more than other children.
- Parents with a developmental disability are more likely to have children with developmental disabilities.
- In some cases, developmental disabilities can be prevented.
- Some health conditions, such as eczema and skin allergies, migraines, asthma, and gastrointestinal symptoms have been reported more common among children with developmental disabilities.

Table 7.1

Categories of Developmental Disabilities

Developmental Disability Categories			
Category	Definition	Symptoms	Disorders
Intellectual Disabilities	When an individual is lacking in general mental abilities. For example, academic learning, problem solving, and perception.	<ul style="list-style-type: none"> • A low intelligence quotient (I.Q.), 75 and below. • Limited functioning in communication, living independently, school, work, or social activities. 	<ul style="list-style-type: none"> - Intellectual Disability (Intellectual Developmental Delay) - Global Developmental Delay - Intellectual Developmental Disorder

<p>Communication Disorders</p>	<p>When an individual experiences a deficit in speech, language, and communication.</p>	<ul style="list-style-type: none"> • Limited vocabulary • Difficulty with forming sounds or speech • Syllable repetitions • Repeating one word in a sentence • Difficulty inferring the meaning of a conversation 	<ul style="list-style-type: none"> - Language Disorder - Speech Sound Disorder - Childhood-Onset Fluency Disorder (Stuttering) - Social (Pragmatic) Communication Disorder - Unspecified Communication Disorder
<p>Autism Spectrum Disorder</p>	<p>A broad term encompassing individuals with observed differences in developmental behaviors.</p>	<ul style="list-style-type: none"> • A baby does not babble or coo by 12 months old • A baby does not point or wave by 12 months • A child does not say words by 16 months • A child is observed with a lack of social skills or language at any age 	<ul style="list-style-type: none"> - Autism Spectrum Disorder
<p>ADHD</p>	<p>When an individual experiences difficulty paying attention or staying organized.</p>	<ul style="list-style-type: none"> • Difficulty listening • Difficulty staying still • Disorganization • Not able to wait 	<ul style="list-style-type: none"> - Attention-Deficit/Hyperactivity Disorder - Other Specified Attention-Deficit/Hyperactivity Disorder - Unspecified Attention-Deficit/Hyperactivity Disorder

Specific Learning Disorders	An individual that experiences learning difficulties and/or has difficulty demonstrating academic skills	<ul style="list-style-type: none"> • Spelling difficulties • Difficulty understanding the meaning of words or what is being read 	<ul style="list-style-type: none"> - Specific Learning Disorder - Specificities: Dyslexia & Dyscalculia
Motor Disorders	When an individual experiences involuntary and abnormal movements.	<ul style="list-style-type: none"> • Difficulty in the performance of motor skills such as throwing a ball, using utensils, riding a bike. 	<ul style="list-style-type: none"> - Developmental Coordination Disorder - Stereotypic Movement Disorder - Tic Disorder - Other specified Tic Disorder - Unspecified Tic Disorder
Other Neurodevelopmental Disorders	An individual experiences limitation in functions, but they do not fall under a specific neurodevelopmental disorder.	<ul style="list-style-type: none"> • A common example is a neurodevelopmental disorder associated with prenatal alcohol syndrome. 	<ul style="list-style-type: none"> - Other neurodevelopmental disorder - Unspecified Neurodevelopmental Disorder

According to the DSM-V, there are other neurodevelopmental disorders that should be considered as developmental disorders. There are certain environmental, medical, or genetic conditions that contribute to developmental disorders. Examples of other specific developmental disorders are Fragile X syndrome, Rett syndrome, epilepsy, low birth weight, fetal alcohol syndrome, tuberous sclerosis, and cerebral palsy.

Impact of Developmental Disabilities on Parents

Developmental disabilities may affect people differently. In some cases, a parent's developmental disability may have played a role in parenting decisions, shared time decisions, or visitation agreements. The presence of a developmental disability does not, in itself, mean that a parent lacks the ability to parent effectively. Parents with developmental disabilities may be faced with many barriers but should be given access to support as needed to perform any parental roles that may prove to be difficult. In addition, it is important for monitors to understand what impact developmental disabilities may have on a parent's ability to parent or participate in supervised visitation.

Parenting with a Developmental Disability

Parenting with a developmental disability often comes with the presumption of incompetence. This may lead to additional presumptions of abuse and neglect of children of such parents. Research shows little evidence to support the claim that parents with a developmental disability are more likely to neglect or abuse their child. In the past, it was common for children to be forcibly taken away from a parent with a developmental disability. Currently, evidence shows that support and training for parents with developmental disabilities can be very beneficial. Monitors should consider how some behaviors in visitation may be a result of a developmental disability and how to address, support, and work with parents that may be dealing with issues that stem from developmental disabilities.

In general, parents with a developmental disability can have differences in socialization experiences, life experiences, and learning styles. This can affect parenting by limiting how a parent behaves with his or her child.

MYTHS

People with developmental disabilities are all the same.

Developmental disabilities encompass a wide range of conditions with many different features. Some examples of developmental disabilities are ADHD, autism spectrum disorder, cerebral palsy, hearing loss, intellectual disability, learning disability, and vision impairment.

Persons with developmental disabilities live very different lives than those without disabilities.

Persons with developmental disabilities are often capable of holding jobs and living in the community with little or no social supports.

Persons with developmental disabilities do not have the same feelings as those without disabilities.

Individuals with intellectual challenges experience the same emotions of happiness, sadness, and desire to be accepted as any other person does.

Socialization Experiences

In this chapter, the term socialization experience is defined by a person's capability to adjust to social norms and cultural practices, and to participate in social activities. Listed below are examples of socialization experiences a parent with a development disability might report.

- Learned dependency
- Rewards for obedience
- Lack of self-sufficiency
- Loyalty to kin
- Learned to not question authority
- Lack of normal problem-solving skills
- Limited social skills
- Expectation of social relationships to be unequal
- Feelings of stigmatization and rejection
- Learned to use cover-up techniques and compensatory behavior to conceal deficits
- Experienced harsh consequences for not meeting reasonable expectations



Life Experiences

Parents with a developmental disability may be at a higher risk for negative life experiences. Research shows that children with an intellectual disability are more likely to experience physical or sexual abuse than children without an intellectual disability. Childhood experiences may lead parents to have additional trauma to work with when parenting their own children. Parents with an identified disability could report the following from their childhood:

- Deprivation and neglect
- Abuse and trauma
- Poverty, unemployment and lack of job skills
- Mistreatment at the hands of helpers
- Overwhelming circumstances

Learning Style Differences

Individuals with a developmental disability can be limited to certain activities. Parents with a developmental disability may have observable learning differences. Listed below are examples of learning style differences for an individual with a developmental disability.

- Learning deficits such as processing and/or memory problems
- Limited functional academics, such as reading and writing
- Limited ability to use problem-solving in complex or unfamiliar situations
- Difficulty keeping track of time
- Difficulty applying knowledge from one situation to another

Emotional Impact

Parenting with a developmental disability can take an emotional toll. It is imperative for supervised visitation monitors to be aware of the emotional impact a developmental disability may have on parents. Awareness of the emotional influence will allow for better communication between the supervised visitation provider and the parent, the monitor and the child, as well as between the parent and the child. Below is a table explaining possible emotions parents with a developmental disability may experience.



Table 7.2
Emotions Parents with a Developmental Disability May Experience

Emotion	Why a parent may feel this way	How to respond
Anger	Anger might be present during certain activities at supervised visitation that the parent is not able to participate in.	Tell the parent how important it is for them to come to supervised visitation, because it shows he/she cares about the child. Discuss certain activities that are available that both the child and the parent will be able to participate in.
Embarrassment	The parent might not feel comfortable around other parents who do not have a developmental disability. The parent does not want to be stereotyped based on their disability.	Explain to the parent that he/she is in a safe place. Tell the parent the focus during a visit is on the child and how important it is that he/she comes to the visits.
Powerless	The parent does not feel in control of their situation or developmental disability. The parent might mention how he/she did not choose this and does not like the developmental disability.	Show empathy by listening to the parent and asking questions about his/her feelings towards the developmental disability.
Sadness	The parent is upset because he/she views his/her developmental disability as a huge obstacle that gets in the way of his/her relationship with the child.	Give the parent time to process his/her sadness. Explain the importance of each visit. If needed, the monitor can talk separately with the parent to thoroughly talk through his/her sadness.

Parenting a Child with a Developmental Disability

Parenting a child with a developmental disability can affect a parent's stress, finances, relationships, and attitude. In this section, supervised visitation monitors will explore the impact that child developmental disabilities may have on parents.

Stress

Research shows that parents with children with a developmental disability reported higher levels of stress than parents with children who did not have a developmental disability. A child with a developmental disability may require more attention, supervision, and energy. Single parents can also experience more stress because they are fully responsible for the child when together. Parents may report the following:

- Exhaustion
- Never having time alone
- Not being able to do things for themselves
- Always feeling busy
- Strict schedule
- Loneliness
- Frustration



Finances

Some children with a developmental disability are encouraged to receive additional services. Some of these services may include behavioral therapists, play therapists, speech language pathologists, physical therapists, and occupational therapists. These services can bring financial burden to parents providing for their child in addition to more expensive child care services. The financial burden of medical and therapeutic services may also cause stress in parents. In some situations, parents may not be able to afford specialized services for their child. For monitors, it is important to know and understand the available resources in the community to assist parents.

REMINDER:

As parents experience stress and seek support, it is crucial for monitors to continually help these parents develop and fine tune the protective factors in their lives. For example, monitors can help parents with creating social and community supports to help with their children with developmental disabilities.

See the Protective Factor E-Books for more information on the development and implementation of protective factors for families in supervised visitation.

Relationships

Studies show the effects of child developmental disabilities on parents and their relationships. Evidence suggests that parents with a child who has a developmental disability participate less in social gatherings than parents whose child does not have a developmental disability. Caring for children with developmental disabilities can be time consuming and emotionally draining for parents. Because parents have less time to participate in social gatherings, they may experience more stress. It is important for parents to have good social supports and community resources. Social supports are resources in the community (friends, groups, organizations, services) that can provide help to another person when they are stressed or in need of assistance.

Some examples of emotional experiences, why a parent may be feeling this way, and how a visitation monitor can respond are listed in the table below. Parents caring for a child with a developmental disability do not exclusively experience the emotional responses listed, so it is imperative for monitors to assess each parent and child relationship individually.

Table 7.3
Emotions Associated with Parenting a Child with a
Developmental Disability

Emotion	Why a parent may be feeling this way	How to respond
Disappointment	The parent is disappointed that his/her child is not living a life without a developmental disability.	Ask the parent about times when he/she witnessed his/her child happy. Remind the parent that the focus needs to stay on the present and how to make life better for the child.
Sadness	A parent is sad because the child may have to experience different challenges in life than children without a developmental disability.	Allow the parent to talk if they express that need. Explain to the parent that it is okay to feel sad, but also go over goals for the parent and child to work on together. Also discuss known strengths of the child with the parent.
Fear	The parent could be afraid that the child will not experience the same things as a child without a developmental disability. For example: fewer socialization experiences, classroom concerns, and independence.	List all of the experiences the child will and could experience more with the help from the parent.
Guilt	Some parents feel guilty, believing that they could have done something different to prevent the developmental disability.	Remind the parents of their strengths and encourage them to focus on the here and now with their child.

Impact of Parents' Developmental Disabilities

Developmental disabilities can affect a parent's ability to recognize or engage in appropriate family interaction. Particularly when parents have a developmental disability, children can be affected, so monitors in visitation may need to work with families in order to create a positive environment to build the parent-child relationship. Children face unique challenges and situations when coping with their parents' developmental disability.

Impact of Parental Developmental Disabilities on Children

Depending upon their age, a child may not understand why the parent has certain functioning limitations. A child whose parent has a developmental disorder may discuss experiences that are different than most. The following list provides examples of experiences from children of parents with developmental disability:

- Cooking dinner for everyone in the family
- Reading to the parent
- Communicating with other people for the parent
- Taking on a part-time job to help financially
- Feeling judged by others

In addition, a child of a parent with a developmental disability may experience different emotional reactions in certain situations. The table below offers examples of how a child may feel when his/her parent has a developmental disability, why the child could be feeling that way, and how to respond.

Table 7.4
Emotions of Children Coping with Parental Disabilities

Emotion	Why a child may be feeling this way	How to respond
Embarrassment	The child may be embarrassed that the parent acts a certain way due to their developmental disability.	The monitor should remind the child that visitation is a safe place and there is no judgment.
Sadness	The child may be sad that the parent is not able to participate in certain activities.	Validate the child's feeling of sadness. "That sounds hard." Ask the child what he/she enjoys doing with his/her parent.

Anger	The child may be angry that the parent is unable to fully take care of themselves, so the child has to act as a parent.	Validate the feelings of anger. "That sounds like a lot of responsibility. What is that like for you?" Tell the child that during visitation the focus is on the relationship with his/her parent. Remind the child that they will not have to act as a parent here if they do not want to.
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Children with Disabilities

Children with disabilities are disproportionately represented in the social services and child welfare community. Children who are abused or neglected are at a higher risk for developing a variety of special needs. Child maltreatment may result in the development of a disability, which in turn can lead to further abuse. Children are also abused and neglected due to a disability because family members do not understand the disability and the



special services and treatment these children require. Sometimes children with disabilities are abused because of the additional stress (e.g., financial, emotional) caring for a disabled child puts on a family. Studies have shown that children with disabilities suffer abuse and neglect 1.7 to 3.4 times more than other children. In 2003, 59,000 children with disabilities experienced abuse or neglect nationally.

Bearing in mind the high likelihood that they will encounter family members who fall into this category, monitors and families need to:

- Understand what having a disability means to each person.
- Know the different types of childhood disabilities.
- Be aware of the barriers to helping this group of children.
- Educate themselves on the services and resources available.

Why are children with disabilities more likely to be abused?

Having a child with a disability can create added stress for the caretaker(s), especially if they are not well educated in positive parenting strategies. This stress creates a strain on the parenting skills of the caretaker(s). A lack of skill in

parenting reinforces the child's negative behaviors and thus creates a cycle that adds stress for the caretaker(s).

There are many barriers that stop children with disabilities from receiving the correct services and treatment. Less than 9% of child protection workers are knowledgeable around the issue of child maltreatment of children with disabilities. Below is a list of barriers to be aware of:

- Family members not realizing their child has a disability.
- Child welfare workers not having training on disabilities; therefore, not recognizing them.
- Not knowing the services and resources available to help these children and families.
- Not knowing what disabilities make children eligible for government services.
- Communication challenges with the child and behaviors associated with the disability.

What can programs do?

- Promote public awareness through public service announcements, posters, brochures and other mediums that promote healthy parenting and child safety and provide instructions for reporting abuse.
- Educate parents regarding positive parenting skills and how to reduce abusive and neglectful behaviors in the home.
- Facilitate parent support groups that allow parents to work together to strengthen their families.
- Provide or locate short-term care for children of parents in crisis situations.

Monitors must be aware of the types of services and resources these children are eligible for, and how to help these families with the added responsibilities. Monitors need to understand what a disability is, the types of disabilities children can have, the barriers to services and resources, and the services and resources available to children and families affected by a disability.

“Parents may respond to the stress of caring for a disabled child with neglect rather than active violence, however when this neglect involves denial of food, medicine, and other life sustaining services, it must be considered a form of violence”
(UNICEF, 2005).

Experiences of Children with Disabilities

Developmental disabilities among children have recently become a more prominent issue. There is more awareness of the need for knowledge of children's development and services available to assess a family's situation when faced with a developmental disability concern. Children with a developmental disability may experience a different childhood than the average child. Research shows children with disabilities are more likely to be discriminated against and have exposure to violence than children without developmental disabilities. A child with a developmental disability can be affected socially, academically, and behaviorally.



Socially

While not every child with a developmental disability will experience fewer social interactions or connections, it is more likely for children with developmental disabilities to have fewer friends, experience bullying, and not engage in social activities. Parents of a child with a developmental disability may desire for their child to have more social interactions. The use

of social supports is crucial for both parents and child when a developmental disability is present. Social supports allow for the parents to understand they are not alone as well as their child is not alone.

Academically

Certain developmental disabilities may call for more focus on academics. Learning disabilities usually require more academic attention than other developmental disabilities. In academic settings there are a variety of resources available for children with disabilities. For example, there are separate classes within schools with teachers who are specialized in teaching children with disabilities. Another alternative for children with developmental disabilities in the school system is to utilize an Individualized Education Plan (IEP). An IEP is a written statement of educational need for an individual. This education plan gives the teachers, parents, child, and any other outside support an opportunity to express thoughts on possible improvements to a child's educational needs.

Behaviorally

With each type of developmental disability there are a variety of behaviors that align with the diagnosis. Behaviors observed from a child are also affected by the child's age. There can be a difference in behavior between a 5-year-old with a learning disorder and a 15-year-old with a learning disorder. Children can be sensitive to their developmental disorder, which is why explaining the effects of a developmental disorder to the child is imperative. Supervised visitation monitors should have an understanding of the limitations a child's developmental disability may have on visitation. Having an understanding of developmental disorders will increase communication between the monitor and the child, as well as the monitor and the parent.

Sibling Relationships

In supervised visitation, monitors may be faced with sibling relationships where one child has a developmental disability. These relationships have special considerations to account for when coping with a disability. Research indicates that age is an important factor when discussing the effects of a sibling relationship when a developmental disability is present. Possible experiences of a child whose sibling has a developmental disability include:



- Feeling that they have less family interaction than their friends
- Leaning more on peer relationships for support
- Feeling responsible for more chores around the home
- Wanting to assist in the caregiving of the sibling
- Feeling isolated from the rest of the family

Monitors can gain an understanding of sibling relationships during intake. Visitation is a time for all family members to focus on the parent-child relationship. Allowing for open and honest conversation during intake with a child whose sibling has a developmental disability gives time for monitors to understand what the child wants from their visit with the parent and can make the sibling feel included.

Monitoring Families Coping with a Developmental Disability

When working with parents who have a developmental disability, supervised visitation monitors encounter difficult situations. Understanding the effects of developmental disorders on parenting and some behaviors associated with each developmental disorder will assist the monitors in handling challenges that may arise. Monitors working with parents who have a developmental disorder can react to situations appropriately through education, facilitating fitting activities, and locating outside additional resources. Listed below are challenges that may arise:

- Inability to follow program rules
- Need to emphasize appropriate interactions during visits
- Need for assistance from the monitor during visits
- Exhaustion of program resources
- A parent's ability to use appropriate discipline with the child

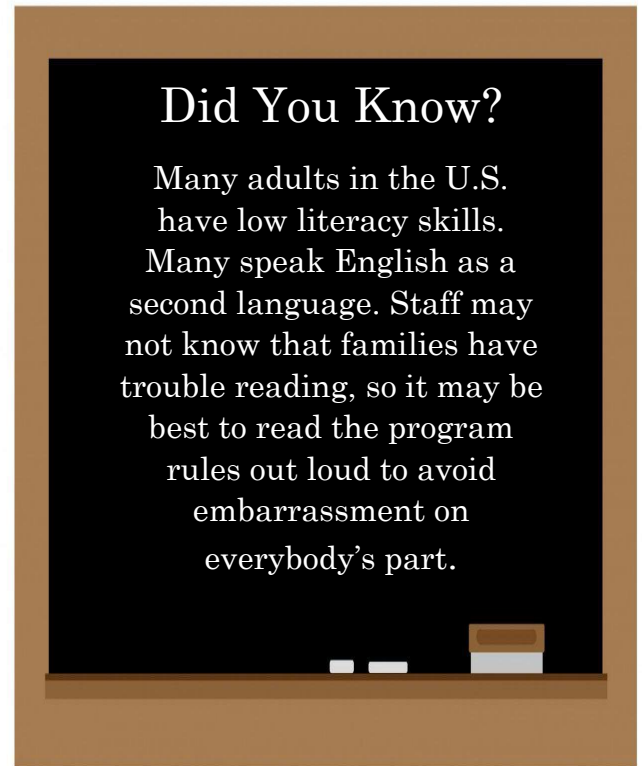
Strategies for Working with Families and Developmental Disabilities

Supervised visitation personnel should be aware of unique issues when working with parents with developmental disabilities. The following are additional strategies that supervised visitation personnel can utilize when assisting parents with developmental disabilities and specific struggles they may encounter.

- Be very clear and direct when talking to parents.
- Avoid jargon or idioms, such as “a stitch in time saves nine” or “reap the benefits of.” Use simple, plain language and avoid phrases that people may not understand.
- Personnel may need to repeat information.
- Assist parents by providing them with referrals to other agencies.
- Assist parents in accessing resources from additional agencies in the community.



- Spend extra time with parents by slowly and carefully going over the policies and procedures associated with your supervised visitation center.
- Encourage parents to ask questions if they become confused or if they are having trouble understanding what is going on.
- Personnel should ask if clarification is needed because parents may be afraid of asking.
- Validate parents' concerns or feelings and encourage them to express themselves.
- Be sensitive about parents' disabilities and do not patronize, belittle, or call them names.
- Do not assume disabilities are the cause of parenting issues. Assess environmental and social factors as well, such as poverty, mental health, and domestic abuse.



Working with Children

Understanding behaviors associated with developmental disabilities will provide monitors with insight on a child's behavior. Monitors must be aware of challenges that may arise during a visit in addition to knowing about a child's developmental disability before visitation. Some challenges that may arise during a visit include:

- Child does not listen to instructions
- Child is upset when he or she is not able to play with certain toys
- Child throws objects at parent or monitor
- Child exhibits hyperactive behavior
- Child is not able to communicate verbally

Preparation for Visit

When facilitating a visit when a parent or child with a developmental disability, a visit monitor must be patient in establishing a positive, trusting relationship. This includes taking the time necessary to establish rapport, convey interest, exhibit consistency, and show respect. To enhance the opportunities for a parent or child with a developmental disability to have a positive visit, the visit monitor should

make sure that the expectations for the visit are realistic, reasonable, and fair. In a supervised visitation setting, preparation can include:

- Investigating reliable transportation resources to ensure that the parent can arrive to visits as scheduled
- Ensuring that the parent understands the importance of following program rules
- Breaking down long intake procedures into a smaller sequence of steps
- Reviewing program forms to ensure that they may be understood at the reading level of the parent (or having the visit monitor read and explain forms to parents)
- Avoiding reliance on children to communicate information to the parent
- Focusing on one task at a time
- Modeling and demonstrating appropriate interactions with a child
- Using corrective behavior and positive reinforcement
- Using concrete examples and avoiding legal terms and jargon
- Allowing extended time for the parent to complete the intake process, and anticipating that the parent and/or child will need increased attention from visit monitors during scheduled visits
- Being sensitive to signs of fatigue, inattention or disinterest

Activities for Visits

When an individual has a developmental disability, he or she may not be able to participate in certain activities. During visitation, monitors have the opportunity to facilitate activities that are achievable by both parties. Supervised visitation monitors should have ideas of what a parent and child can actively do together. Listed below are several examples of activities that could be facilitated by the visitation monitor to a parent and child when a developmental disability is present:

- ❖ **Clapping to Music**
- ❖ **Scavenger hunt**
- ❖ **Marching to Music**
- ❖ **Parachute Play**
- ❖ **Kite Flying**
- ❖ **Arts and Crafts**
- ❖ **Computer Games**
- ❖ **Cloud Watching**



Part 2

Chronic Illness

A chronic illness or medical condition is a health-related problem that lasts for three months or more. It affects a person’s normal activities and requires regular hospitalizations, at home health care, and/or extensive medical care. There is an extensive list of different types of chronic illnesses. In this section, the focus will be on the impact chronic illness on supervised visitation for parents, children, and supervised visitation providers. This section will also provide monitors with resources and possible strategies for how to react when a child or parent is living with a chronic illness.

This section will provide information on several examples of chronic illnesses and symptoms of each illness. It is reported that 50% of the entire world’s population has a chronic illness, which means it is likely that a supervised visitation monitor will encounter a parent or child with a chronic illness. Listed in the table below are examples of common parental chronic illnesses, an explanation of the illness, and symptoms for each.

STOP and Think

Do you know of anyone with a chronic illness?

Table 7.5
Types of Parental Chronic Illness

Chronic Illness	Explanation	Possible symptoms
Alzheimer Disease	A progressive disease that effects an individual’s memory and other brain functions.	<ul style="list-style-type: none"> • Not remembering past events • Not able to recall people’s names • Repeating questions constantly
Arthritis	When an individual’s joints become inflamed in one or more areas.	<ul style="list-style-type: none"> • Experiencing pain in joints • Not able to move as easily as before • Joints feel stiff

Asthma	When an individual's airways are narrowed and swell.	<ul style="list-style-type: none"> • Experience a shortness of breath • Pain in chest • Wheezing attacks
Cancer	Cancer is a term that encompasses a greater number of diseases. Cancer is when abnormal cells have the ability to destroy body tissue at a high rate.	<ul style="list-style-type: none"> • Tiredness • Change in weight • Unexplainable muscle pain • A lump that can be felt under skin
Crohn's Disease	When an individual experiences the inflammation of lining of the digestive system.	<ul style="list-style-type: none"> • Diarrhea • Fatigue • Stomach pain • Weight loss
Diabetes	Diabetes is a collection of diseases that is defined by how an individual's body is affected by blood sugar.	<ul style="list-style-type: none"> • Weight loss • Tiredness • Increased urination • Always feeling thirsty
Heart Disease	Heart disease is a group of conditions that affect an individual's heart. Another term that is used with heart disease is cardiovascular disease.	<ul style="list-style-type: none"> • Pain in chest • Shortness of breath • Pain in legs, arms, or others areas of body • Dizziness
HIV/AIDS	HIV/AIDS is a condition when an individual's immune system is unable to fight viruses that can cause diseases.	<ul style="list-style-type: none"> • Fever • Muscle pain • Swelling
Multiple Sclerosis (MS)	MS is a disease that can damage the spinal cord and brain (central nervous system).	<ul style="list-style-type: none"> • Experiences weakness in limbs • Loss of vision • Slurred speech • Pain in parts of body
Parkinson's Disease	This is a progressive disease that affects an individual's nervous system.	<ul style="list-style-type: none"> • Tremors in hands • Slowness

Did You Know?

- As many as 1 in 4 children in the U.S. have a chronic health problem.
- In the U.S. alone, over 13,000 children are diagnosed with cancer each year.
- Type 1 Diabetes is one of the most common severe chronic childhood illnesses, affecting 1 in every 400 individuals under the age of 20.
- Cancer is the 2nd leading cause of death in the United States.

For children, chronic illness is an umbrella term for conditions that will always exist for the child. Children may be well or ill at any given time but will always live with their condition. Below is a list of chronic illnesses that children may be diagnosed.

Table 7.6
Types of Child Chronic Illness

Chronic Illness	Explanation	Possible Symptoms
Asthma	When an individual's airways are narrowed and swell.	<ul style="list-style-type: none"> • Experience a shortness of breath • Pain in chest • Wheezing attacks
Cancer	Cancer is a term that encompasses a greater number of diseases. Cancer is when abnormal cells have the ability to destroy body tissue at a high rate.	<ul style="list-style-type: none"> • Tiredness • Change in weight • Unexplainable muscle pain • A lump that can be felt under skin
Cerebral Palsy	A disorder that affects muscle tone, movement, and motor skills. Children usually lack the ability to move in a coordinated and purposeful way.	<ul style="list-style-type: none"> • Delay in in normal developmental milestones • Muscle tone that is too tight or too loose • Poorly coordinated movements • Presence of infant reflexes beyond infancy
Diabetes	Diabetes is a collection of diseases that is defined by how an individual's body is affected by blood sugar.	<ul style="list-style-type: none"> • Weight loss • Tiredness • Increased urination • Always feeling thirsty
Sickle Cell Anemia	People with sickle cell disease have red blood cells that are shaped like sickles or crescent moons. This condition can be painful, lead to serious infections, chronic anemia, and damage to body organs.	<ul style="list-style-type: none"> • Some degree of anemia • Painful swelling of hands and feet • Numerous infections • Chest syndrome, difficulty breathing, chest pain, coughing, fever • Painful crises in any part of body
HIV/AIDS	HIV/AIDS is a condition when an individual's immune system is	<ul style="list-style-type: none"> • Fever • Muscle pain • Swelling

	unable to fight viruses that can cause diseases.	
Cystic Fibrosis	A genetic disorder that affects the lungs and digestive system. Disruption in normal functioning of epithelial cells, which line the passageways of the lungs, liver, pancreas, and digestive/reproductive systems.	<ul style="list-style-type: none"> • Lack of weight gain after birth • Failure to thrive on normal diet and good appetite • Skin may appear salty and lose large amounts of salt when sweating • Ability to breathe often decreases
Epilepsy	A disease of the central nervous system in which electrical signals of the brain may misfire. These miscommunications lead to seizures.	<ul style="list-style-type: none"> • Seizures • Staring spells • Confusion spells • Shaking spells • Unexplained deterioration in behavior or school performance
Spina Bifida	Birth defect that happens when a baby's backbone does not form normally. The spinal cord and nerves branch out and may be damaged.	<ul style="list-style-type: none"> • Detected during prenatal care • Abnormal tuft of hair • Collection of fat • Small dimple or birthmark • Often asymptomatic
Congenital Heart Problems	Heart conditions that are present at birth and are often treated with surgery or medication.	<ul style="list-style-type: none"> • Heart murmur • Breathing difficulties from lung congestion • Inability to gain weight adequately

Impact of Chronic Illness on Parents

When working with chronic illnesses, it should be considered that some parents will have a chronic illness and some parents will have children with a chronic illness. Each situation holds new and unique implications for visitation and monitors should be well-prepared to work with parents in either capacity.

Parenting with a Chronic Illness

An individual faces difficult challenges when diagnosed with a chronic illness. A parent with a chronic illness may encounter unique challenges when attempting to balance the responsibilities of being a parent as well as coping with the diagnosed illness. A parent diagnosed with a chronic illness can see effects in family stability, financial strain, and the emotional state of anyone involved. In this section, supervised visitation monitors will be able to understand the impact chronic illness may have on parenting. It is also important to remember that not all parents with a chronic illness will face these challenges. Every family is different and parents may not see as many challenges when they have support from family, friends, and the community.

Family Stability

When a parent is diagnosed with a chronic illness, the entire family is affected. Research shows that in marriages where one partner has a chronic illness, the divorce rate is 75% or more. Chronic illnesses cause most individuals to become tired easily, and those who live with these illnesses spend a lot of time in pain. This level of constant fatigue can cause instability in a household. Below are examples of what a parent with a chronic illness could be experiencing:

- Fatigue causing difficulty in certain tasks, such as making dinner for the children
- Inability to clean the house due to pain
- Needing significant help from friends and family
- Inability to participate in family activities such as playing outside with kids and attending school/sporting events

Financial Strain

Individuals with a chronic illness may likely seek constant medical attention, including doctor's visits and medications. With the added responsibility of providing for children, treatment of a chronic illness can be financially stressful. Financial stresses may include:

STOP and Think

- **What might Ms. Johnson be feeling about her condition of MS?**
- **How can Ms. Johnson's illness be impacting her relationship with her children?**



- Insurance not covering all of the treatment necessary for a particular illness
- Difficulty in keeping employment
- Needing to delay medical care to handle family expenses first

Emotional Impact

Chronic illnesses can place an overwhelming emotional burden on parents. Parents are responsible for their children, finances, family necessities (food, shelter, education), and the added stress of

a chronic illness can magnify this many times over. Studies have revealed that many individuals with chronic illnesses become depressed; up to 1/3 of people with a chronic illness display symptoms of major depression. Depression may even cause the symptoms of a chronic illness to worsen. The emotional impact can include:

- Not wanting to get out of bed almost everyday
- Not enjoying activities as one did in the past
- Isolation, including from children
- Negative attitude about most things

Parenting a Child with a Chronic Illness

With the rate of chronic illness among children at about 25%, it is likely that supervised visitation monitors will come across a child in visitation that is affected by a chronic illness. When a child has a chronic illness, the parents can be affected in multiple ways. The parent of a child with a chronic illness can experience stress, negative feelings towards the illness, and relationship differences. This section will discuss how supervised visitation monitors may understand the impact chronic illnesses can have on parents when the child is diagnosed with a chronic illness.

Parental Stress

When a child has a chronic illness, the parent may have increased responsibilities. Some children with a chronic illness must attend regular doctor's visits and may not be at a developmental stage in which they can take care of themselves. Parenting in itself is often tiring, and with the added worries of a child's special health needs, a parent can become significantly more stressed. Parents may experience the following:

- Needing to prepare unique meals for children
- Monitoring children to ensure medication is being taken properly
- Attending multiple doctor visits
- Monitoring children's general health and well-being

Emotional Impact

Studies show that parents of children with chronic illnesses commonly experience anger, guilt, fear, and sadness, though every parent may react differently when their child is diagnosed with a chronic illness. Listed below are possible emotional responses a parent may be challenged with when his or her child has been diagnosed with a chronic illness:

- Guilt
- Sadness
- Anger
- Fear of fatal condition

Relationships

Parents' relationships are affected when a child is diagnosed with a chronic illness because the time can be easily consumed with the child's needs. When one child of a family has a chronic illness, it is common for the parents to focus more of their attention on that specific child's needs than those of their other children, to socialize less, or to forget to engage in self-care.



Impact of Chronic Illness on Children

In visitation, monitors may encounter children with chronic illnesses or children with parents coping with chronic illnesses. Each situation presents unique challenges in visitation and monitors should be aware of the different dynamics that may exist.

Impact of Parental Chronic Illness on Children

When a child has a parent who has a chronic illness, they are commonly faced with different and difficult experiences. Every situation is different and should be approached differently, but there is research on the common impacts for children who have a parent with a chronic illness. This research shows children with a parent diagnosed with a chronic illness have fewer social interactions and greater negative emotional experiences.

Impact on Relationships

Children coping with a parent's chronic illness may have increased responsibilities at home. With many chronic illnesses the symptoms can include fatigue and aching. Parents may have to lean on children for support and rely on them for help around the house. If a child has added responsibilities around the home, there could be less time for social interactions and building relationships. Some examples of what a child may have to experience when a parent has a chronic illness include:

- Helping to prepare meals
- Looking after younger siblings
- Cleaning in the home
- Taking the bus to school
- Working a part-time job
- Missing school events

Emotional Impact

The age of the child must be considered when trying to understand the emotional impact of having a chronically ill parent. A six-year-old might be impacted



differently than a sixteen-year-old. Research shows that children with a chronically ill parent are more likely to experience lower life satisfaction than children who do not have chronically ill parents. Examples of what a child might be feeling include:

- Constant fear of a rapid decline in parent's health
- Anxiety about balancing family life and school life
- Anger towards the parent has an illness
- Sadness for the parent
- Guilt when not taking care of parent
- Misunderstanding of parent's condition

Children with a Chronic Illness

Every child reacts differently to being diagnosed with a chronic illness. Children living with a chronic illness may not fully understand what their illness means and this understanding may depend on the age of the child. A diagnosed chronic illness may also impact a child's independence and social life. In this section, supervised visitation monitors will understand the impact a chronic illness can have on a diagnosed chronically ill child.

Helping Children Cope with a Diagnosis

For younger children up to 10 years old, understanding the complexity of an illness and how it is managed can be difficult. This can make it hard on parents to explain an illness and help children cope with how it may affect them. Below are common reactions to chronic illnesses by age group, and potential strategies for helping children navigate these experiences as they arise:



Table 7.7
Children's Reactions to Diagnoses

Age Group	Reaction	Response
Infant / Toddler 0 to 3 years	<p>Infants and toddlers generally have very little understanding of their illness. They understand being in pain, not having a full range of motion, and may view separation from their parents for procedures or treatment as threatening the sense of security they are developing at this stage. They may cry, fuss or scream, as they are not at a stage where they can convey their emotional state in any other way.</p>	<p>Encourage parents to be present for any procedures which may be painful for the child, and stay with them (where possible) during other procedures or hospitalizations. They should hold, soothe, and interact with these very young children as much as possible to promote their sense of safety and security.</p>
Preschool Age 3 to 5 years	<p>Preschool age children may understand what it means for them to get sick, but they do not yet understand the nature of their chronic illness. Many believe that their symptoms (i.e. wheezing during an asthma attack) are what causes their illness rather than the other way around (the asthma attack is causing the wheezing). Because they are just beginning to form a sense of independence, this age group may try to gain control of their illness in ineffective ways (such as saying "If I don't wheeze I'll stop having an asthma attack"). Others will try to gain control by challenging parents about treatment; they may fight, cry, or outright refuse to take medication or undergo treatment procedures.</p>	<p>Direct parents to be firm with children about what they cannot give them choices about, but allow them to make choices where possible to help foster the sense of independence their children are learning. For example, parents should not ask "would you like to take your medication now?" This is not optional, as the medication is likely essential to a child's health care plan. Instead, encourage them to ask "which medication would you like to take first today?" or "Would you like me to come with you while you have your blood drawn today? Do you want to sit in my lap or do you want me to sit next to you?"</p>

<p>Early School Age 5 to 9 years</p>	<p>Children in this age group are developing a better understanding of their chronic illness, and noticing how different they are from their classmates and friends. They often try to describe the reason they are ill in ways that are not logical (often referred to as “magical thinking”). For example, the child may believe that they caused their illness by behaving badly (hitting a sibling or telling a lie) or not listening to their parents (not eating their vegetables when asked or refusing to obey the rules).</p>	<p>Instruct parents to reassure their children that the illness is not their fault, and that there is no way that they could have caused it by doing or not doing a particular activity. Encourage them to involve children in managing their illness to help them better understand it (with close supervision by a responsible adult).</p>
<p>Older School Age 9 to 13 years</p>	<p>These children better understand their illness and how it is treated, although they still do not respond the way adults do. They feel left out when they miss school or cannot participate in activities with their peers (such as sports or other extracurricular activities). Children with parents who restrict activities out of concern may begin acting out or making statements such as “I guess I’m not good enough to play soccer” or “I hate going to the doctor, I’d rather hang out with my friends and be normal.”</p>	<p>Monitors should encourage parents to speak to their child's doctor about what activities may be safe for their child's level of ability, and what precautions to take to ensure safe participation. Reassure parents that protectiveness is normal, but gently redirect the parents to be less restrictive of activities with peers and allow their child to cautiously explore new things.</p>
<p>Adolescents 13 to 17 years</p>	<p>At this stage, children are developing their own identity and becoming concerned with self-image. When a chronic illness or its treatment have a negative effect on their appearance (i.e. skin reactions, weight fluctuations, hair loss, etc.), many teens will go through stages where they neglect their</p>	<p>Parents who have thus far been very involved in treatment and care may find it difficult to fulfill this same role with a teenager. Monitors should instruct the parent to encourage their child to maintain their treatment regimen, and to speak to</p>

	<p>treatment or refuse to take medication. If the illness or treatment does have an effect on their appearance or behavior, they may fear bullying or worry about being unpopular with others, or experience being isolated by their peers for being different. They may also stop checking blood sugar regularly if they need to or follow a physician-recommended diet in order to appear more like their peers and fall more in line with what is popular or trendy or participate in social activities where doing so would attract attention.</p>	<p>their child's doctor about how medication may be differently affecting them during the normal changes which occur during adolescence to help with physical side-effects. Parents can also work their child's illness or its treatment into the discussions about independence, puberty, sexuality, alcohol, etc. which parents normally have with their teens in order to normalize them.</p>
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In addition to these helpful responses, it is important for monitors to encourage parents to help their child lead as normal a life as possible. Discuss how they can give their child responsibilities in the home which are manageable with their level of ability, maintain family routines (such as regular bed and meal times or family outings) as much as possible, and remind them not to be afraid to appropriately discipline the child to encourage positive behavior. Be prepared to offer guidance or resources and act as a sounding board for parents as they attempt this very difficult balancing act.

Independence

A child may become limited in his or her independence when coping with a chronic illness. A child’s capability for independence differs from illness to illness and child to child. Independence also generally increases with age. Each child is different and it is imperative for children to know why they might not be able to do certain activities on their own. It is likely that children will begin to learn how to self-manage their illness as a teenager. Examples of differing levels of independence for a chronically ill child include:

- Parents needing to give insulin injections and test blood sugar levels for a younger child with diabetes
- Teenagers knowing to bring an inhaler when they play sports



- Parents needing to manage a younger child's food restrictions
- A 14-year-old learning how to take his or her own insulin injection
- A 16-year-old taking his/her morning medication without being reminded by a parent

Social Life

A child diagnosed with a chronic illness may not be able to participate in all social activities. As a child, not being able to join in certain activities can be frustrating and disappointing. Coping with a chronic illness as a child can also cause children to be emotionally distressed. Children diagnosed with a chronic illness tend to be less socially outgoing than children without a chronic illness. Children may be affected in the following ways:

- A child diagnosed with cancer may have to miss a semester of school for intense treatment
- A child may feel isolated because they do not know anyone with a similar illness
- A child may not be able to participate in a sports team due to a diagnosed illness
- A child may miss school dances, pep rallies, graduation, or other important events

Monitoring Families Coping with Chronic Illness

This chapter has made it clear that families coping with chronic illnesses face many challenges. These challenges may often spill over into the visitation process and monitors should be prepared to help families to the best of their ability. Monitors can help children build confidence and independence or help parents understand their child's illness and strengthen the parent-child relationship. Familiarity with illnesses will play an important role in a monitor's ability to work with families and provide support and referrals. In many cases, it is likely that the monitor can guide families in a positive interaction with regard to the present illness.

Guidelines to Interacting with Individuals Coping with a Chronic Illness

- **Avoid drawing attention to the individual's appearance.** In some cases, a chronic illness may not play a role in how a person appears. It is best to avoid making comments that would diminish the presence of the illness or the validity of the person. Monitors should never tell someone that he or she "looks great" or "doesn't look sick."
- **Acknowledge the person behind the illness.** Like best practices suggest, it is important for monitors to place the person first and the label after. While chronic illnesses may play a major role in a person's life, that person is not their illness alone. Engage in conversation that is not related to the illness. Make clients feel special and recognize them for something other than his or her illness.
- **Avoid implying that you understand his or her experience.** While it is important to be empathetic, it is also important to remember that there is no way that you can understand a person's suffering or pain if you do not have his or her same illness and experience. Relating to the person is not as important as validating his or her own experiences.
- **Offer specific help.** For many people, it can be difficult to ask for help and to even accept such help. It is much more valuable for others to offer sincere help and to ensure that the person knows that they are not a burden in any way.

Consider this...

Rather than saying "I'm always tired too," try using other phrases such as, "this must be so hard for you," or "I can't imagine what you're going through."

Strategies for Facilitating Visits Involving Chronic Illness

There are many appropriate strategies for a visit monitor to consider when facilitating visits involving a parent or child with a chronic illness. Monitors should use the following strategies to help in working with clients to ensure a comfortable and safe environment for all involved.

- **Understand the progression of the individual's particular illness.**

With a large number of illnesses and their ability to progress differently for every person, it is important for monitors to be aware of the role the illness is playing in the individual's life at the moment in time of visitation. Some illnesses may take a long time to cause problems for someone, or the illness can be at a stage that makes visitation very difficult. Consider the following: has the illness recently been diagnosed? Is it in an advanced stage? Is it terminal? Is the illness contagious? If so, under what circumstances (e.g., airborne, bodily fluids)?

- **Employ universal precautions if the illness presents any risk of transmission to others in the program.** While programs employ universal precautions regularly, it is important to be especially cautious when specific precautions should be made. The best practice is to treat all fluids as if they could have an infectious disease. Refer to the Clearinghouse for a training

TRAINING

Visit the Clearinghouse website to gain access to a full PowerPoint training on Universal Precautions.

http://familyvio.csw.fsu.edu/wp-content/uploads/2010/05/PP-Standard-Precautions_Final2.pdf

module on universal precautions.

- **Seek appropriate training and education on common chronic illness and avoid misinformation.** This chapter will serve as a base-level source of knowledge for working with individuals diagnosed with a chronic illness. Although general knowledge is helpful, it is important for monitors to learn as much as they can



about an individual's case and to seek training if necessary. When learning about an illness, monitors will be able to determine if they should be on the lookout for anything specific or if they may need to make any extra accommodations.

- **Be sensitive to the needs of the individual.** Some illnesses may cause someone to tire easily or to be unable to focus or participate fully in visitation. Monitors should be aware of this and be sensitive to the individual's situation. If a parent cannot play, it may not be an attachment issue but rather an effect of his or her illness. If a child faints, it may not be related to heat or food but a symptom of their illness.
- **Make adequate accommodations.** In addition to working in compliance with the ADA requirements, providing a facility and visit that is accommodating will make someone feel comfortable and at ease during the visitation process. Accommodations can include accessibility ramps or providing sign language interpreters for the hearing impaired.

Sensitive Language

“Your mother is sick, and the doctor is doing what she can to make her better.”

This statement may help a child cope with the emotions of seeing a sick parent.

- **Respond appropriately to parent or child's reaction to health status.** Whether the parent or the child is ill, either party can have a difficult time coping with the diagnosis or symptoms. One party may notice bruises or marks from radiation treatment or the constant fatigue that may come with many chronic illnesses. Seeing these symptoms may spark intense feelings and reactions from the other party and it is important for monitors to offer reassurance and comfort.

- **Refer clients to resources or support groups.** As with any client, monitors must seek to fill gaps in services and referring a struggling parent/caregiver or child to a support group can help them build community and social supports as well as coping skills.

Children with Medical Complexities

Some children with chronic medical conditions may be referred to as medically complex. These children require the highest level of services and support from healthcare providers. With the number of medically complex children in the United States expected to reach 5 million in the next decade, it is important for monitors and supervised visitation providers to understand the specific needs of this particular population.

In many cases, medically complex children participating in supervised visitation will have a medical foster parent. Medical foster care placement is available for children (who qualify for Medicaid) to receive specialized medical and therapeutic care to overcome the physical harm and emotional damage they have suffered. In Florida, Children's Medical Services recruits medical foster care parents and provides training for them to care for the medically necessary needs of these children. In supervised visitation, medical foster parents provide an essential role in teaching visiting parents how to care for their children who have medically complex needs. It is important for monitors and visiting parents to understand the importance of using medical foster parents in supervised visitation. While these situations may be uncomfortable for the visiting parent, it is essential for the

REMINDER:

The presence of medical foster parents may cause conflict between staff, foster parent, and visiting parent. In order to avoid conflict, monitors should discuss all medical conditions and the role of the medical foster parent in visitation with all parties before the first visit. Monitors should also provide support and encouragement to visiting parents to learn from the medical foster parent in order to care for their children.



medical foster parent to be present for the best interest of the child.

Common Chronic Illnesses

It is vital for supervised visitation monitors to understand appropriate ways to communicate with clients who have a chronic illness. Understanding possible symptoms associated with common chronic illnesses will provide the monitor insight on different emotional reactions from the individual. Monitors need to be aware of challenges that may arise during a visit, and this includes knowing about common illnesses beforehand.

Asthma

Monitors have a number of responsibilities to prevent asthma attacks during visits.

- Ensure that rooms used for visitation are not cleaned with strong chemicals, including ammonia, bleach or fragrant cleaning products.
- Areas used for visits should be checked to ensure healthy air quality - free from dust, mold, smoke, and other allergens.
- If allowed outside during a visit, monitors should take note of the weather and watch for signs of wheezing and coughing. Avoid going outside when the weather has recently changed, if humidity is high or if it is cold out.
- Playing during visitation is permissible; however, be mindful that exercise is not too

strenuous to avoid an attack.

- If the client is particularly prone to attacks, the monitor should connect the child/parent to resources for healthcare and any medications that may be needed.



Diabetes

Visit monitors should always make sure that the client is carrying his or her care kit at all times. This bag holds important medicines and care tools that can be used in preventing further complications from hypoglycemia and diabetic shock if the individual begins to experience problematic symptoms. Included in the kit may be a glucagon



injection kit, which must be prescribed by doctor and can be very helpful in an emergency situation. Glucagon is a natural hormone that increases blood sugar, and can be injected if a person becomes unconscious from hypoglycemia. If the client does not have an injection kit, it may be a good idea to talk to him or her (or a parent) and explain the necessity of having it, along with informing them of any resources available if they cannot afford it.

For parents, who are just learning about a diagnosis, the adjustment period can be between 9 and 12 months. Diabetes control and general family functioning are difficult during this period and require support from the medical team. This is important for visit monitors to be aware of when supervised visitation takes place.

Good questions to keep in mind are:

- How long ago was the diagnosis made?
- Is there any connection between the client's illness and the reason for the supervised visitation?
- How does the parent/child respond and/or comment on the child/parent's diabetes?

Tips for Visitation

- Be sure to ask about medical conditions of all family members who participate in visitation. Knowledge is the best tool for responding to health problems at visits.
- If a parent or child has diabetes, be sure that he or she has a care kit, or medicine kit, on hand during visits.
- Have some snacks at the center that are set aside for anyone who may have diabetes. Make sure that they are the appropriate type of snacks for children and that the child's parent(s) knows.

- Be empathetic. Diabetes is a medical condition, and those who have it didn't ask for it. Don't be annoyed or tense when someone tells you he or she has the condition as well as his or her limitations.
- Encourage games or activities that keep the child active when they are feeling well.
- Monitors should stay informed about any medical conditions the individual has, both chronic and temporary. If the child has an infection or other sickness, take extra precautions.
- Any allergies should be well documented, in order to avoid exposure during visitation.
- Learn to recognize signs of problems.
- Call emergency services 911 if someone loses consciousness or faints.

Preparation for Visit

Supervised visitation monitors are responsible for providing and preparing a safe place for parents and children to spend time together. The preparation of each visit and it is the responsibility of the monitor to know potential risks and problems that could arise during a visit. During intake, monitors will have the opportunity to learn about each visiting family and when a family is affected by a chronic illness, the monitor is responsible for using effective communication to better understand the situation. A chronic illness may significantly affect an individual's ability to be fully present during a visit. To guarantee positive and realistic visits, visitation monitors should understand the importance of speaking with parents and children about the expectations of the visit. When preparing for a visit monitors should engage in the following practices:

- Investigate reliable transportation resources to ensure that the parent can get to the program as scheduled
- Ensure that the parent's expectations are heard and communicated
- Allow time to talk about chronic illness during intake if the parent expresses a desire to talk about it
- Ensure that the visits do not overlap with any scheduled doctor's appointments
- Be flexible; reschedule a visit if needed
- Assist a child or parent with standing up or opening doors if necessary
- Model and demonstrate appropriate interactions with a child

REMINDER:

Intake is an important time to hear the client's perspective!

- Use encouraging words and embrace the strengths perspective
- Use empathetic practice
- Allow extended time for the parent to complete the intake process
- Be sensitive to signs of fatigue, inattention or disinterest
- Prepare a list of community resources for families affected by a chronic illness

Empathetic Practice

Empathy is the ability to understand and recognize another's feelings as your own. Empathy allows professionals to share feelings and understand the perspective of a client. On the other hand, sympathy is a feeling of compassion but lacks the shared feelings or perspective. When working with families affected by either a chronic illness or a developmental disability, it is important for supervised visitation monitors to practice empathy. Both chronic illnesses and developmental disabilities can be sensitive issues to deal with. Utilizing empathetic practice as a supervised visitation monitor allows for individuals affected by a chronic illness or a developmental disability to feel heard and understood. Empathetic practice will also help monitors avoid offending clients in any manner. A few examples of how a monitor can use empathetic practice when working with individuals with a chronic illness or developmental disability are:



- Carefully listening to the stories of each individual
- Imagining your reactions if you were in the same situation
- Focusing on the feelings behind what a client is saying (e.g., scared, sad, lonely, angry, or overwhelmed).
- Taking out your own personal beliefs and biases and adopting a third person perspective

STOP and Think

- How could a visitation monitor use empathetic practice with a visit with Ms. Johnson?
- How might Ms. Johnson's children be affected by their mother's developmental disability and MS diagnosis?

PRACTICE EXAMPLES

Case Scenario

David, age 15, was removed from his home because his mother was identified as neglecting David's needs. David has a developmental disability and his cognitive and motor levels were assessed to be comparable to a child around the age of 5. David and his mother were referred to supervised visitation. David is having a noticeably difficult time being away from his mother and becomes angry during visits. David's mother also seems frustrated by the situation.

Below are discussion questions to assist in the understanding of how monitors should approach David's situation:

1. What could you say to David's mother to help ease her frustration?
2. What kind of activities could you suggest for David and his mother during visitation?
3. How would you prepare for the visit with David and his mother?
4. What challenges could arise with David during the visits?
5. What are possible reasons as to why David would be angry during visits?

Online Resources

1. National Center on Birth Defects and Developmental Disabilities. <http://www.cdc.gov/ncbddd/sitemap.html>. This source is a full A-Z index on topics of all developmental disabilities.

2. Diseases and Conditions. <http://www.mayoclinic.org/diseases-conditions>. This source is a comprehensive guide on hundreds of health conditions.

3. Normal Stages of Human Development (Birth to 5 years). <http://childdevelopmentinfo.com/child-development/normaldevelopment/>. This source provides an overview to typical behaviors to expect for children aging 0 to 5.

4. Children with Chronic Conditions. <http://www.med.umich.edu/yourchild/topics/chronic.htm>. This is a resource to learn more about how chronic illnesses effect children and families.

MATCH THE TERMS & CONCEPTS

This activity allows you to test your knowledge of relevant terms to this chapter. Draw a line to match the words to their correct definitions.

Word 1:

Sympathy

The ability to understand and share feelings of another individual

Word 2:

Chronic Illness

A developmental disability caused by a brain deformity

Word 3:

Diabetes

A group of conditions due to an impairment in mental or physical capabilities.

Word 4:

Developmental Disability

A condition that is caused by high levels of blood sugar levels.

Word 5:

Empathy

Feeling bad for an individual's situation.

Word 6:

Autism Spectrum Disorder

A long-lasting health condition or disease

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