Introduction

Parents who have chronic illnesses or developmental disabilities present unique challenges in supervised visitation. Both conditions create parenting stressors that result not just from the parent’s health status but also from related factors such as financial status, access to social services, and access to medical/therapeutic care. The outcomes for parents and children can include financial problems, social isolation, frustration, separation, depression, embarrassment, shame, or resentment.

Chronic illness of a parent, whether HIV/AIDS, multiple sclerosis, cancer, or other condition, can detrimentally affect that parent’s ability to adequately respond to a child’s needs due to fatigue, pain management issues, or the progression of the particular condition. Similarly, a parent’s developmental disability may adversely affect his or her ability to recognize or engage in appropriate family interaction. Research suggests that parents with a developmental disability are at a higher risk for engaging in child neglect or child physical abuse than those without developmental disabilities.

Overview

This chapter provides the visit monitor with information about the impact on children of their parent’s chronic illness or developmental disability. Additionally, the chapter offers strategies for facilitating visits when a parent has a chronic illness or a developmental disability. Information on the Americans with Disabilities Act (ADA) is included, and guidelines for using universal health care precautions are also provided.

Objectives

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

1. Describe common reactions of a child with a parent who is chronically ill or who has a developmental disability;

2. Identify behaviors of a parent with a chronic illness that may impact visitation services;
3. Identify behaviors of a parent with a developmental disability that may impact supervised visitation services;

4. Use effective strategies to facilitate visits between a child and a parent with a chronic illness;

5. Employ effective strategies to facilitate visits between a child and a parent with a developmental disability;

6. Understand how the Americans with Disabilities Act applies to supervised visitation programs;

7. Employ universal precautions for responding to the possibility of exposure to infectious agents; and

8. Identify risk factors which may present the potential for harm during visits.

Snapshots

- Children who have a parent who is HIV-infected tend to be from families who also experience poverty, lack of access to necessary social services, discrimination, or family disruption.

- Parents with a developmental disability are more likely to have children with developmental disabilities.

- Parenting with a developmental disability is becoming more common; this may be due to deinstitutionalization.

- Developmentally disabled parents who come to the attention of child protective services share many of the characteristics of non-developmentally-disabled parents who also have child protective service involvement: inadequate incomes, unemployment, poor vocational skills, and disadvantaged childhoods.

Parents with a Chronic Illness

A parent who has a chronic illness may not be well enough to attend to his/her child, or may allow her/his health concerns to take priority over the needs of the child. Children in this situation may have the following emotional reactions:

- Distress;

- Fear of losing the parent to chronic illness;

- Resentment;

- Anger;

- Embarrassment;

- Disappointment;

- Depression;
• Guilt;
• Feeling ignored; and/or
• Sadness over parent’s inability to attend school or sporting events.

Children are not typically removed from the home of a parent with a chronic illness solely because of the illness; rather, removal occurs because of a constellation of problems resulting from the illness. These problems may include loss of income, the move to residential health care for treatment, loss of transportation, or a lack of another care-giver. Sometimes the parent’s illness results from another problem, such as a diagnosis of HIV related to drug use, and it is the drug use, not the HIV infection, that has resulted in the children’s placement outside the home. In other cases, a parent may have had to be placed in an assisted living facility or hospice and may decide to use a supervised visitation program to visit his/her children as an alternative to having the child see her or him in a hospital or medical setting.

Parents with a chronic illness may also experience a range of reactions to their illness as well as its impact on their parenting roles and responsibilities. These reactions may include:

• Guilt;
• Fear over what may happen to them and their children if their illness progresses or if death is imminent;
• Depression;
• Difficulty establishing limits with children due to fatigue;
• Anxiety; and/or
• Awareness that their level of pain prevents desired parent-child interaction.
Case Example
& Discussion Questions

Read the case example below and then answer the questions about the case.

Louise, age 35, is referred for supervised visits with her ten year-old daughter and six year-old son. She has been HIV infected for over five years because of IV drug use. While she abused drugs, her children were placed in foster care. Louise attended a substance abuse program in the past year and has been drug-free for several months. However, earlier in the year, she was diagnosed with advanced AIDS. During the time she has come to the supervised visitation program, she has lost significant weight so that her clothes are visibly too large. In addition, she is very tired when she arrives and seems to lack the energy to interact with her children. She often has to run to the restroom due to bouts of diarrhea. Her children seem happy to see her but also embarrassed about her appearance. Some program volunteers have told other visiting families that Louise has AIDS. Other children tease and mock Louise's children, saying that they must have AIDS, too. Other parents express concerns over “catching” AIDS from either Louise or from using the same program restroom.

Discussion Questions:

1. How might a visit monitor might prepare Louise's children for their visit with their mother?

2. What suggestions might the program director or visit monitor use to address the reaction of other families to Louise’s HIV status?

3. What are the ethical considerations inherent in this case example?

Strategies for Facilitating Visits in Cases
Involving Parents with Chronic Illnesses

The case example of Louise provides an opportunity to present appropriate strategies for a visit monitor to consider when facilitating visits involving a parent with a chronic illness. These strategies may include:

- Understanding the progression of a parent’s particular illness. 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)?

- Employing universal precautions if the illness presents any risk of transmission to others in the program (See box on universal precautions following this section).

- Obtaining appropriate training and education on common chronic illnesses and avoiding misinformation or myths about certain conditions. For example, believing that touching someone with AIDS will cause you to become infected or that cancer is contagious are both erroneous.
- Being sensitive to the physical needs of parents during visits, such as tiring easily, not being able to physically play with a child, being in pain or appearing sedated because of pain medication.

- Accommodating the needs of parents during visits in compliance with ADA requirements. For example, making sure the facility is accessible to handicapped, that someone is available to sign for the hearing impaired.

- Responding to the child’s reaction to the parent’s health status in a sensitive manner. Children whose parents are receiving radiation or chemotherapy may notice marks from the radiation, loss of their parent’s hair, or catheters placed in chests for drug infusions. Children may notice that their parent is very tired, has to take medications, or is unable to interact with them. These changes can be very frightening for children. Reassurance given by either the visit monitor or the parent can help alleviate the concern. A statement such as “Your mother is sick, and the doctor is doing what she can to make her better” may help the child cope with the emotions of seeing a sick parent.

- Referring the child or caregivers to resources or support groups for children who have parents with chronic illnesses.

Additional information on this topic is included in the Administrative Supplement.

Universal Precautions

Universal precautions refer to a set of guidelines for the handling of body fluids to prevent the possible transmission of bacterial or viral infections. These precautions are based on the premise that the body fluids of all persons should be considered potentially hazardous. Generally, body fluids include blood, drainage from cuts, scabs & skin lesions, urine, feces, vomit, nasal discharge, semen, saliva, vaginal secretions and breast milk.
Guidelines for handling body fluids include:

- Avoiding direct skin contact with body fluids by using gloves;
- Avoiding contact with diapers and soiled clothing;
- Using effective hand-washing;
- Disposing of all soiled contents in plastic bags; and,
- Using freshly mixed household bleach and water solution for cleaning any area exposed to body fluids. This solution consists of one part bleach and ten parts water.

Further guidelines can be obtained from local health care providers or county health departments.

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Case Example & Discussion Questions

Read the case example below and then answer the questions about the case.

Mr. Green was divorced from Mrs. Green several years ago after being diagnosed with Huntington’s Disease, a neuromuscular condition that has progressed rapidly. He now uses a wheelchair, and has little control over his arms and neck. His two children, Amy and Ida, spent every other weekend with him at his home until several months ago, when he became unable to care for them. At visitation, the children are upset with Mr. Green’s deterioration, and are alternately angry and afraid of him. They sometimes refuse to help him pick up toys or turn the pages in a book. They walk away from him and ignore him. The visitation staff observed Mr. Green’s deterioration, and they are saddened by it. Mr. Green is still very upset with Mrs. Green about the divorce, and speaks very angrily about her at visits, especially when he is frustrated by the girls’ actions. Staff feel so sorry for him that they allow him to “vent” and rarely redirect him.

Discussion Questions:

1. What emotions might Mr. Green be experiencing at visits?
2. What emotions might the children be experiencing at visits?
3. How might a visit monitor facilitate the visits in the Green case?
Characteristics of Developmental Disabilities

Individuals with developmental disabilities account for approximately three percent of the population. Developmental disabilities may be caused by genetic factors, including congenital infections, exposure to chemical agents, injury shortly before, during, or after birth, or other factors such as head injuries and accidents. They can also result from factors that occur during pregnancy or in the post-natal period.

Developmental disabilities are characterized by deficits in cognitive or physical abilities that can also cause problems in social development. Cognitive disabilities such as mental retardation are classified based on IQ: profound (IQ=20 or less); severe (IQ=20-35); moderate (IQ=36-51); and, mild (IQ=52-68). Visit monitors will typically encounter parents who are moderately or mildly disabled, since these levels of disability are more common among those who live independently or with supported assistance in the community.

Many individuals with developmental disabilities are cognitively intact, but experience significant challenges in motor coordination, speech, or both. It is important to understand the type of developmental disability presented because it can be extremely insulting to a person whose speech is disturbed if it is assumed he or she is mentally retarded. In these situations, it is helpful for visit monitors to review materials provided in case records that describe the capabilities as well as limitations experienced by the parent.

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**Exercise**

Think about a person you may know or have seen who is developmentally disabled. What did you notice? How did he or she interact with you or others? How did others react to him or her? What was the reaction of your elementary or middle school classmates to children assigned to special education classes?

Now think about someone who not only is developmentally disabled but also is a parent. Do you feel that this person should have had a child? Do you believe that she or he can be a good parent? What do you worry about with respect to his or her ability to parent? Do you view this parent in the same fashion as you view parents who are not developmentally disabled?

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**Challenges Facing Parents with Developmental Disabilities**

Life experiences of parents with developmental disabilities may take their toll over time, especially if others have negatively valued their parenting. Parents with developmental disabilities may report the following:

**Socialization Experiences**

- Learned dependency;
- Rewarded for obedience;
• Not trained for self-sufficiency;
• Loyal to kin;
• Learned not to question authority;
• Learned to fear authority figures;
• Lack normal problem-solving skills;
• Limited social skills;
• Expect social relationships to be unequal;
• Rely on a “benefactor” to make decisions;
• Felt stigmatized and unwanted;
• Learned to use cover-up techniques and compensatory behavior to conceal deficits; and
• Experienced harsh consequences for not meeting reasonable expectations.

Life Experiences
• Deprivation and neglect;
• Abuse and trauma;
• Poverty, unemployment and lack of job skills;
• Mistreatment at the hands of helpers; and/or
• Overwhelming circumstances.

Learning Style Differences (applies to those with cognitive disabilities)
• 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; and/or
• Difficulty applying knowledge from one situation to another.

As a result of these experiences and expectations, parents may display challenges such as low self-esteem, confusion, inability to cope, inability to comply with instructions, or mistrust. These parents may also engage in self-protective measures, which requires a great deal of sensitivity and support on the part of monitors.
Strategies for Facilitating Visits

When facilitating a visit between a developmentally disabled parent and his or her child, a visit monitor must be patient in establishing a positive, trusting relationship. This means taking the time necessary to establish rapport, convey interest, exhibit consistency, and show respect. Visit monitors should understand that there may be a period of “testing” during which time the parent misses scheduled visits, comes late, and/or fails to comply with program rules. To enhance the opportunities for a parent with developmental disabilities to have a positive visit, the visit monitor should make sure that that expectations for the visit are realistic, reasonable, and fair. In a supervised visitation setting this might mean:

- Investigating reliable transportation resources to ensure that the parent can get to the program as scheduled;
- Ensuring that the parent understands the necessity of following program rules;
- Breaking down intake procedures into sequential steps;
- Insuring that program forms can be read at the reading level of a parent or having a visit monitor read forms to parents;
- Not relying on the child to communicate information to the parent;
- Focusing on one task at a time;
- Modeling and demonstrating effective 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 parent will need increased attention from visit monitor during scheduled visits; and,
- Being sensitive to signs of fatigue, inattention or disinterest.
Case Example & Discussion Questions

Read the case example below and then answer the questions about the case.

Because of a dependency court order alleging neglect, a mother with a developmental disability visited her three-year-old daughter at the visitation center. The neglect case continued for two years, during which time the mother visited her daughter once a week. As the child grew older during this period, she became more aware of her mother’s limitations: the mother could not read and had difficulty following the visit monitor’s instructions. Soon the child began to adopt more of a parenting role in order to accommodate the mother’s deficits. For example, the child would tell the mother what to do or “interpret” the visit monitor’s comments to her. If her daughter could not come to a visit, the staff would inform the mother. Nevertheless, she would appear for the visit and cry when told the visit would not occur.

Discussion Questions:

1. How does this case example illustrate the characteristics discussed in the previous section about developmental disabled individuals and their children?

2. How might the visit monitor in this case prepare the mother or the child for the visit?

3. How could the staff better deal with the mother when she comes for a visit, knowing she has been told the visit has been cancelled?

Challenges to Consider

Visit monitors observing visits between a developmentally disabled parent and his or her child need to be alert to the following challenges that might arise when working with a developmentally disabled parent:

- The parent’s ability to follow program rules;
- The parent’s ability to interact in an appropriate manner with the child during the visit;
- The parent’s need for assistance from the monitor; for example, help holding an infant safely, giving an infant a bottle, or changing a diaper;
- The exhaustion of program resources; and
- The parent’s ability to use appropriate discipline with the child.
Role-play the following case example. One visit monitor can play Ms. Browning; one can play Noah, age five; and another can play the visit monitor.

At the end of the role play, discuss how staff might better facilitate visits in this case or in similar cases.

Ms. Browning is a moderately disabled mother of a precocious child, Noah, aged five. During scheduled visits with Noah, Ms. Browning often becomes incontinent, soiling her clothes. Noah lives with his father and grandmother who have appropriately toilet trained him. Although Noah is embarrassed by his mother’s toileting accidents, he giggles as a way of compensating for her behavior. Mrs. Browning is also easily distracted; she often wanders into other visit rooms and tries to engage with both other adults and children. She has developed a particular attraction to one specific visit monitor whom she follows around and insists that only this person can monitor her visit. Her behavior has irritated all the visit monitors, disturbed other families and disrupted staff who have to spend time cleaning up urine and feces from furniture and floor surfaces following her toilet accidents. Staff members who have been with the program for a while and are familiar with the case request that they not be assigned the Browning case. This results in newer, less experienced visit monitors or interns being assigned the case.

QUIZ

1. Identify the typical reactions of a child who has a parent with a chronic health condition.

2. Identify the typical reactions of a child with a developmentally disabled parent.

3. What strategies might a visit monitor employ when a parent with a chronic health problem is visiting his or her child?

4. How does the ADA apply to supervised visitation programs?

5. What is meant by “universal precautions?”

6. What strategies might a visit monitor employ when a developmentally disabled parent is visiting his or her child?