Working in Family Support Settings

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THE NORTH DAKOTA STATEWIDE DEVELOPMENTAL DISABILITIES STAFF TRAINING PROGRAM

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# Working in Family Support Settings

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**Introduction**

The purpose of this module is to provide training that will help you provide support to families. These families have a child* diagnosed with a disability living at home. Services are provided in the family home and the support you provide will assist the family as well as the member with a disability. North Dakota defines Family Support Service (FSS) as supporting both the family member with a disability and the rest of their family so they can live as much like other families as possible. The intent is to prevent or delay unwanted out-of-home placement. Your role is to do more than just “sit” with the person who has a disability. You will be an important member of the families’ support team. This module will assist in clarifying roles and responsibilities and help you provide quality services and support in these settings.

*For the purposes of this training module “child” refers to a person with a disability who is living with their parents or caretakers and receives support services from FSS.*
Chapter 1: What is Family Support?

Chapter Objectives

- Describe how the family unit strengthens the global community.
- List supportive programs of Family Support Services.
- Identify needs of families when a member has a disability.
- State the North Dakota Family Support Services’ goals.

Understanding the Importance of Family

Families are a very important institution in the global community. It doesn't matter what culture or ethnic group, the family is the foundation. Governments who ignore the needs of families weaken the foundation of their society. In an article review of the United Nations declaration of the Year of the Family, Nancy Seufert-Barr (1994) defined the family as the most essential of human institutions. She described the family as:

- The oldest and most basic unit of human organizations.
- The most crucial link between generations
- The primary transmitter of culture.
- The sustainer of heritage.
- The major provider of food, shelter and love.
- The smallest democracy.

When the United Nations declared the year of 1994 as the Year of the Family, they recognized that the family is a source of stability in any society. Families are the reflection of the strengths and weaknesses of the community. When governments create this awareness and provide the mechanisms to strengthen families, all segments of society benefit.

History of Services in North Dakota

Social policy that valued support to families led to the enactment of Part H of IDEA (Individuals with Disabilities Education Act) in federal legislation in 1986. One of the goals of Part H was to broaden services to help parents adjust and cope with the stressors and demands associated with raising children with disabilities.

In 1980, community services did not exist for North Dakota children or families who had a member with a disability. Some parents benefited from informal supports such as those provided by a grandmother or another extended family member. Many parents bore the full responsibility themselves. In many cases, a mother had to quit her job to care for the child, as most daycare providers did not feel qualified to serve a child with a disability. If care for the family member became overwhelming, the only option was placement outside the home in a group living situation – which was very difficult for families and the child.
North Dakota established Family Support Services shortly after the ARC lawsuit in 1981. North Dakota's Family Support Services is based on the primary caregiver's need for support in meeting the health, safety, developmental, personal care, and daily activity needs of the family members and the member with a disability. In 2002, North Dakota reported that 94% of children receiving services in the state were living in the family home. Those families received early intervention services, support services, in their homes and help with costs related to their children's disabilities (Olmstead Update, 2002).

Families prevent segregation and isolation. They mentor members in relationships, education, and expectations of society. These roles are best carried out through the unconditional love and support of the family.

**Family Support - State of North Dakota Perspective**

North Dakota Family Support Services (FSS) program has a goal of providing the services needed in order for the family member to remain in an appropriate home environment. These services or supports are:

1) In-Home Supports (IHS) which assist a primary caregiver in meeting the needs of their family member with a disability either when the primary caregiver is present or by providing a respite from the responsibility of being the primary caregiver.

2) Family Care Option (FCO) provides an opportunity for a child to live in a licensed family home when his/her needs cannot be met in the birth family's home either full or part time.

3) Family Care Options III (FCOIII) provides support to older adolescents living in their own apartment or home.

The needs of the family may include training for the family member with a disability as identified in the case plan. It may involve support in carrying out family routines and community integration. These include personal care activities such as eating, bathing, and activities of daily living such as bed making, laundry, or food preparation. For some families, family support services may include support with therapies i.e, PT, OT, speech. Sometimes support workers provide some follow through with academic skills identified in the child’s Individualized Education Plan (IEP). These services contribute to the health, safety, and development of the family and particularly the family member with a disability.
Family Support - Family Perspective

The family is the best and most knowledgeable source for assessing needed supports. The definition of family support from the family perspective would include the definition above but add that the family needs help in creating desirable and productive environments for their child's development. Family members want to be able to:

- Communicate with each other
- Enjoy mealtime
- Enjoy family time
- Visit relatives
- Travel
- Have time to pursue individual interests

They also want to be confident in their decisions regarding the family and the child with a disability. The definition of necessary supports for each family will differ as each family's needs differ.

Families typically ask for informational, emotional, and practical support in raising and educating a child with special needs.

**Informational** support may include facts or data about their child’s disability and what may happen as their child grows.

**Emotional** support may include talking to another family and learning, for example, how to cope with a child’s issues or needs, i.e., perseveration (repeating the same statement 200 times in a day) or where they can purchase an adapted bicycle. This will help families feel less isolated or alone.

**Practical** support can include having a neighbor stay with a child so the rest of the family can go to church together or take a short break. Some children with disabilities require the services of a specialized caregiver. The family members serve in this capacity on a day-to-day basis. When they need a break or respite, it might not be as simple as inviting a neighbor in to stay with a child or help when the family is present. For that reason, ND developed Family Support Services (FSS).

FSS can consist of short-term respite care by a trained caregiver. Respite care is provided when the parents/caregivers are absent. Sometimes the parent may be at home but involved in other activities. Sometimes care is provide while the parents are technically home but involved in other activities, i.e., a landscaping project or painting a room. This service can be delivered in the family home or in another location. In-Home Support refers to a situation where a caregiver works with the parents and the family member with a disability while they are present in the home.

A family may also define support as someone who helps them obtain the support or help they need. This may be a case manager or a social worker that understands the social service systems.
This person could also assist the family in identifying services or resources and contacting people.

In order to qualify for services in Family Support, the family member must meet the definition of developmental disabilities. After eligibility is determined, the Developmental Disabilities Case Managers (DDCM) are responsible for helping the family determine the amount and kinds of supports needed and authorizing services.

**Family Support - Provider Perspective**

The provider is the agency or service that provides the personnel to carry out supports. A provider usually has a system or structure in place for recruitment, hiring, and training the people who will be providing the support to the family. The provider's concern is to supply trained personnel to meet the family’s needs and to make adjustments when those needs change.

In addition to meeting the expectations of the family and the state, service providers also have policy, procedure, schedules, contracts, and guidelines to follow. Providers train, pay, and supervise staff members who provide family support.

**Summary**

The FSS services system exists to strengthen families that have a member with a disability. The support provided is intended to assist the family in avoiding out-of-home placement and to be supported by natural supports - the kind only a loving family can supply. When the family unit is respected and supported, the community at large benefits.
Study Questions Chapter 1

T or F 1. Families with a member that has a disability need support so they can challenge the current system of services.

T or F 2. Creating a desirable and productive environment for their child’s development is one reason that families with a member that has disabilities need support.

T or F 3. It is important to support families with a member that has a disability so that the family can have time with their children without disabilities.

T or F 4. Ensuring that support providing agencies have employees is the most important reason for supporting families who have a member that has a disability.

5. A family is a provider of __________, __________, and __________.

6. The condition of families in a community is a reflection of the __________ and __________ of that community.

7. Families typically ask for __________, __________, and __________ support.

8. List five services that North Dakota offers as part of its Family Support Services Program.
Chapter 2: Disability in the Family

Chapter Objectives

- List five challenges confronting families that have a son or daughter with a disability.
- List five challenges for siblings of children with disabilities.

Having a child with a disability affects all members of a family. Each member reacts differently. Certain family members may be expected to give more support than the amount required of others. Some members may withdraw. At first, some parents may be in shock and feel they have lost control over their own lives and the lives of their new infant and its older siblings. Some theorize that parents go through stages of anger, guilt, denial, and acceptance. These stages are sometimes referred to as the “grieving process”. According to this theory, parents mourn when they are suddenly faced with a child who does not meet their expectations. Parents and siblings face many cycles of love and loss as they grow with their child who has a disability.

As family support providers step into the life of a family, it is important to understand the various challenges faced by families. It is also important to be aware of how each family member perceives his or her role in these situations. Each family, whether they have a member with a disability or not, is unique. The family’s "personality" will impact its response to the new addition. One family may perceive the member with a disability as just another member who has some unique needs. Other parents may see the child with a disability as central to the life of the family and make the comfort, health, safety, and development of the child with a disability the family’s priority. Some parents find themselves unable to move forward until the child has a definite diagnosis. The birth of a child with a disability causes some families to grow closer as they advocate for the needs of their child; while others become overwhelmed by the stress and challenges. Sometimes the family breaks apart. Understanding the family and the challenges each member faces will enable you to provide services that fit the unique needs of each family.

Parents

Parenting is a challenge. It isn’t necessary to have a child with a disability to feel financial pressures, guilt, anger, or uncertainty about the future. Parents of a child with a disability experience these same feelings plus additional challenges. If the child has medical conditions, there can be medical appointments in places that are miles away from home. This means time away from work, communicating with professionals about topics they know little about, hearing discouraging assessment results, and often, huge medical bills. Parents also experience uncertainty about how everything will turn out. They may believe that their child will recover from an illness or get better, but be unsure of what the next stage of development will look like and how to best help their child succeed. It is very common for children with disabilities to be raised by single parents. There are also many situations where grandparents are the primary care providers.
Parents often find it necessary to educate themselves, the extended family, teachers, and friends about their child’s disability. Many parents struggle to keep up with new information and techniques and often seek second (and third) opinions from assorted professionals. They have to sift through the opinions and advice of well-meaning people and make difficult choices. Parents have social workers, early interventionists, and support providers come into their homes with information and recommendations. Teams of professionals, concerned relatives, and caring friends may judge their parenting skills, housekeeping, organization, family dynamics, and communication abilities. Parents may find themselves having to advocate for the right placement or service one day and turn down recommended treatments the next day. They may feel guilty for taking an evening off. Parents of children with disabilities say they often feel isolated, alone, and misunderstood.

While all of this may seem overwhelming and quite negative, parenting a child with a disability can also build strong families. Some parents have gone on to be strong advocates for their child and other families. These parents come to the realization that:

- They have a right to have whatever feelings they have.
- They don't have to follow the stages of grief.
- It is OK to be angry. They channel these feelings into getting services for their child.
- They do have private lives. Some things are simply not the business of anyone else.
- They do not need to accept all the predictions about the development if their child.
- They have limitations and needs and their child is not the center of their lives.
- They can have fun with all family members.
- They can get annoyed with their child.
- They can have a bad day.
- They are the expert-in-charge. They know what works and what doesn't.
- They can have a life.

(Dunlap, 1999)

### Siblings

Siblings play an important part in the functioning of any family. A sibling’s reaction to a child with a disability can affect the overall adjustment and self-esteem of both children. Siblings find that they must adjust to a brother or sister who, because of their condition, may require a large portion of family time, attention, money and psychological support.

Sibling relationships make up a child's first social network and are the basis for his or her interactions with people outside the family. A child with a disability may have limited opportunities to interact with other children. Therefore, the social interaction between siblings often takes on increasing importance. Brothers and sisters are playmates first; as they mature, they take on new roles with each other.
Living with a sister or brother that has a disability can uncover a range of emotions and responses. Siblings may express love, empathy, pride, guilt, anger, and support. The positive and negative nature of the relationship between siblings and family members may be influenced by:

- Family resources
- Family lifestyle
- Childrearing practices
- Type and severity of the disability
- Number of children in the family
- Age differences
- The kinds of coping and interaction patterns that already exist
- Support services available

Siblings can have the same feelings of loss experienced by parents. Brothers and sisters may:

- Think the disability is their fault.
- Have to rearrange family life to meet the needs of the child with a disability.
- Cancel or limit family outings and activities.
- Miss out on time and attention from parents. Feel abandoned.
- Feel guilty if they complain. Cope with that guilt by overreacting to small incidents or becoming hyper-responsible or hyper-vigilant about their sibling.
- Fear that they have “bad genes” or that their future children may have a disability.
- Worry about what their friends think about them. (“If my sister is retarded, what will they say about me?”)
- Be embarrassed when a brother or sister drools, has a sit-down strike or appears clumsy.
- Resent being asked to help with caregiving responsibilities for what seems like the thousandth time instead of just getting to be a typical child or teen.
- Witness parental stress and arguments related to their sibling’s condition. Seeing parents become overwhelmed and not knowing how to help.
- Feel pressure to succeed to make up for their parents’ disappointment.

Each non-disabled sibling’s reaction will vary depending on his or her age and developmental level. The feelings and responses of the child will change over time as the parents and the rest of the family adjusts. Elementary school-aged children may feel embarrassed, protective or supportive and this may trigger conflicts with peers. Young adults may have future-oriented concerns. They may be concerned how their friends will accept their brother or sister with a disability. They may be concerned about planning their own families and be anxious about future responsibilities for their brother or sister.

Siblings need support just like any other family member dealing with a loss or change. Brothers and sisters will share many of the same concerns that parents have. They need one-on-one time with parents and should be encouraged to communicate their feelings. Age-appropriate information about the disability in the form of books, videos, newsletters, or just short conversations with the doctor or parent can be helpful. Siblings may
also benefit from opportunities to meet other siblings of children with special needs. In some areas, Sib Shp provides this valuable resource to siblings of any age. Service providers can support families by providing contact information for local support groups. The important factor is communicating with siblings and giving them the time and opportunity to express what they are feeling and what they need for support. Brothers and sisters can also experience a lot of joy from their relationships with their sibling. They can learn a lot that will help them develop into caring, thoughtful adults.

**Different Perceptions**

Mothers and fathers often react in different ways to the news that their child has a disability or a medical condition. Either parent may look to the other for support at a time when that parent is struggling to adapt and has no support to give.

Fathers of children with disabilities sometimes feel excluded from certain aspects of their child's life. For some, these feelings start at the child’s birth when support systems prove beneficial for their partners but not for them. The following facts emerged as issues for fathers in the studies compiled by Gibson (2004):

- Fathers felt, from the onset, that information about the disability was the first and most important issue.
- Fathers felt their most important need was to be listened to.
- Fathers felt that they were uninformed because their partner saw all the information first and filtered it. This might mean that the mother makes the contacts while the father is at work or doing other tasks.
- Fathers wanted information on finances.
- Fathers felt challenged when dividing time between all family members.
- Fathers felt a sense of stigma associated with having a child with a disability.

Fathers feel that they need to be the supporter of the family and feel an added burden because of the additional finances needed. This leads to a perception that they are not interested or absent from the care of the child when they are on the job. This may be far from the truth. Fathers and mothers may take different perspectives on the family dynamics, but their roles can complement each other and make the family a strong, nurturing unit.

**Summary**

All members of families, parents, and siblings, are affected by the presence of a child with a disability. Each member may perceive the stressors differently. As they deliver supports, in-home support staff and the agency must be aware of how each family member views his or her role.

Families are not all the same. What one family views as a stressor may not be problematic for another. Families change over time, but in general provide stability. In-home support staff do not need to be experts on family theory; but they do need to be aware of the many dynamics that exist in families, particularly those that have a member with a disability.
Study Questions Chapter  2

T or F  1. One of the challenges that parents face as they provide a home for a child with a disability is financial.

T or F  2. Judgmental attitudes of extended family and friends are not a challenge for parents who are raising a son or daughter with disabilities.

T or F  3. Families who have a child with disabilities may encounter fragmented service systems.

T or F  4. Siblings are never embarrassed by their brother or sister who has disabilities.

T or F  5. Siblings may feel cheated if their parents spend a significant amount of time with their brother or sister who has a disability.

T or F  6. For fathers, information about their child’s disability is the most important issue.

T or F  7. Fathers and mothers have the same perspective on the impact a disability in the family may have.

8. When raising a child with disabilities, all families are __________.
   a. the same
   b. dysfunctional
   c. different
   d. doomed to fail

9. When raising a child with disabilities, fathers are more likely to __________ (as compared to mothers):
   a. worry less about finances
   b. feel a sense of stigma
   c. worry less about information
   d. feel that their most important need is patience

10. Family members face many cycles of __________ and __________ as they raise a child who has disabilities.
Chapter 3: Family Centered Approach

Chapter Objectives

- State the goals of family support services.
- List outcomes of family centered services.
- Explain the relationship that schools, support providers, and regional case managers have to families.
- Define family centered services.
- Describe how support professionals should address issues with families.
- Describe a service contract.

In the past, family supports services (FSS) were child-centered. They focused on development of the child with a disability. Parents were expected to do whatever the “experts” planned. These activities rarely considered the family’s needs. Some therapists even viewed families as poor caregivers. It was common to hear that families were “in denial” or “over protective”.

Respect for families is the basis for current services. The goal is to increase the family’s ability to care for their family member. Family-centered services shift the focus from the child’s deficits to increasing support for the family. We now realize the need for positive relationships with families. Services changed because:

- Focusing on deficits had limited success.
- Attitudes about the role of parents changed.
- Family-centered approaches had positive outcomes.

The goal of Family Support Services is to *enhance the development of the person with a disability through action that supports the wellbeing of the whole family*. The family and other team members are all considered experts. All team members are empowered to make decisions. When families reach their goals, members with disabilities benefit as well. When families do well, so do their children. Providers learned the importance of increasing choice, control, and support for families.

Families need time together to enjoy one another’s company. All family members need support for emotional and physical well-being. Parents need their own needs met in order to help their children. Only when these needs are satisfied, can families enjoy the best possible quality of life. People thrive when daily routines match their preferences, values, and ambitions. When these needs are satisfied, family members are better able to support the member who has a disability.

Family-centered agencies partner with families rather than try to fix or judge them. Supported families are better able to deal with service systems and schools. They can better care for their members and make use of resources in the support plan (Dunlap & Fox, 1999).
Providing Family Support Services that respect family preferences means that the family’s sense of well-being is number one. The support plan must identify what the member with a disability needs and the family’s goals for quality life.

Outcomes of Family Supports

The needs of the member who has a disability affects what is important to the family. The outcomes for a family who has three children with the oldest having a diagnosis of autism will be quite different from the outcomes defined by a family that has one child with Cerebral Palsy. The Council on Quality and Leadership has issued Personal Outcome Measures for Families with Young Children (2000). These outcomes focus on the family and provide guidelines on how to respond to the needs of each family. These basic values support the needs of a broad range of families:

1. **Families are informed** – Providers supply families with information for making decisions.

2. **Families choose child development goals** - Providers help children attain skills important to the family.

3. **Families choose their goals** - Goals are what the family wants to achieve. These goals can relate directly or indirectly to the member with a disability. Learning advocacy skills is an example of an indirect goal. Children develop within the context of their family. Supports need to assist families with the challenges of rearing a child with developmental disability.

4. **Families are satisfied with their services** – Responsive FSS providers routinely ask families if they are satisfied. They respond to the needs families express.

5. **Families are satisfied with their life situations** – Service providers help families think about their values and hopes. They use this information to help set realistic outcomes.

6. **Families choose services and supports** - Service providers link families to services. This means partnering with other agencies.

7. **Families have economic resources** - Service providers are sensitive to the family's need for privacy in this area. But, they are ready to link the family to the appropriate services if needed.

8. **Families remain together** – The service provider’s goal is to help families keep their children in the family home.
9. **Children spend time in inclusive environments** - Families reach goals for including their child in school and community. Parents decide where their child will participate.

10. **Children develop relationships** - Relationships help to develop social skills. The service provider works with families on methods to teach social skills and increase opportunities for relationships.

11. **Families are part of the community** - Providers help families that want more community involvement. Some may express this need - others may not.

12. **Families attain their goals** – Supports are coordinated well. Families achieve what they want. The agency empowers families.

13. **Children attain developmental goals** – Support providers assist in family routines that will promote skill development. Skills are taught in places the family frequents. Staff model teaching methods for parents.

14. **Families remain connected to natural supports** - Service providers check to see that families are happy with their natural supports. People become more connected if desired. This can be a very private matter for families.

15. **Families exercise rights** - The service provider listens and families feel heard. Families understand due process and their rights. Privacy is respected. Families feel encouraged to advocate.

16. **Children are safe** - Service providers provide information on safety.

17. **Families are respected** - Families feel supported, reinforced, and not judged. Service providers are responsive. Staff respect the routine and culture of the family. Support workers are positive about their relationship with the family.

18. **Children have the best possible health** - Families may need information or support in medical issues. Supports include medication administration or treatments.

19. **Children are free from abuse and neglect** - The agency defines abuse and neglect and policies for reporting. The provider screens and trains staff.

20. **Families experience continuity and security** - The agency makes every effort to hire staff committed to the needs of families and their members with a disability. The agency minimizes the impact of staff turnover, illness, or absence.

These outcomes establish a value base for responding to the needs of families. Not all outcomes will have equal weight. It is important to respect the choices and privacy of families.
Families indicate that quality services depend upon the relationships that develop. Families want staff with: (Park et al, 2003)

- Knowledge of child development.
- Good communication skills.
- Positive personality traits.
- Positive outlook.
- Casual and "down-to-earth" approach.

They want staff that are:

- Honest and trustworthy.
- Focused on positive aspects of their child.
- Sensitive to family issues.
- Able to listen and respond to all family members.
- Able to build confidence.

One survey of parents' found that parents preferred supports provided by family, friends, and neighbors trained as providers (Knoll & Bedford, 1989). Parents in this survey wanted to be active partners in the planning and implementation of programs and services.

**Family Assessment**

Achieving family-chosen outcomes is the focus of family support. Supports are extended to the child with a disability and the family. The goal of services is to improve the family’s quality of life. In 2003, Park et. al. created a tool to measure family quality of life. Based on the responses, the study identified four general areas important to families. They are:

- Family interaction
- Parenting
- General resources - daily life, finances, emotional, and social well-being
- Support for family members with disabilities

From these areas the *Family Quality of Life Questionnaire* was developed. See Appendices E & F for a copy and a guide to using it. Other forms of assessment include checklists in areas such as motor skills, eating, medical, behavior, or personal care. The service provider and family determine what areas are the most pressing and which can wait until later. See Appendices A and B for a sample question list and service delivery form. Sometimes it’s difficult to identify family goals or set priorities. The *Family Quality of Life Conversation Guide* (Beach Center on Disability, 2003) helps in getting to know the family. Another Beach Center tool is the *Family Quality of Life Survey and Map for Families: Planning and Services* (see Appendix G). This tool measures emotional and physical well-being and disability related supports.
Families often interact with many professionals. Frequent probing, evaluations, and questions can be tiring. Actually, questions of any sort tend to shut down communication. A series of conversations inviting families to share thoughts are less stressful and yield better information.

**Life Plans (Individual Support Plans, Individual Program Plans)**

Organizing family supports requires planning. Plans provide action steps and tell who will do what and when. “Life Plans”, “Individual Support Plans” (ISPs), or “Individual Program Plans” (IPPs) are different terms for support plans. Plans are reviewed periodically to assure they continue to meet the family’s needs.

A service provider may be one of several agencies that develop a support plan. A **regional case manager** supports the family in finding funds and locating an in-home support provider. Case managers complete applications, and generally help families understand their local service system. **Schools** assist the family with early childhood or school programs. Children with disabilities may also have an Individualized Education Plan (IEP) that describe the services that the school will provide to ensure that the child receives an appropriate education. Schools generally address pre-academic, academic, and functional life skills. **Family support agencies** develop plans that complement the school’s plan. Family Support agencies focus on functional skills such as personal care, food preparation, family routines, community participation, and social skills.

It is important for schools, family support agencies, and families to work together. When they do, families and the member with a disability will experience better outcomes. For example, including the school’s communication goals in routines at home will help the child learn the skill faster. In order for this cross-teaching to occur, in-home staff need training in the goals and methods used by the school. The family and case manager also need to understand the school teaching plan.

The family support plan (goals, objectives, and preferences) generally originate with the agency that employs the support workers. The goals are to be carried out while the staff member is in the family's home or accompanying the member with a disability in the community.
The plans developed by each provider (school, case manager, in-home support) have the same purpose - that is to support the family and the member with a disability. Each part of that plan may have a separate focus, but all have an obligation to work with the other.

**Role of In-Home Family Support**

FSS are designed to help families with a member who has a disability to live as much like other families as possible. In-home family supports are designed to prevent or delay out-of-home placement.

Support provided in the family's home is quite different from those provided in a school or residential facility. Family homes are spaces usually reserved for select people. Someone’s home is not just a building. It is a very social and private place. In-home support staff encounter some unique situations. They observe the family culture and daily stresses. They may see financial information or overhear private discussions between parents. Staff may be asked to carry out activities that don’t seem related to serving the member with a disability. For example, they may wonder, “How does preparing a meal for siblings meet the needs of the child with a disability?” The in-home support worker needs to understand the boundaries of the job in relation to the family, agency, and the member with the disability.

FSS are provided in the family home or in the community. These supports may give the family temporary respite from caregiving. When the caregiver is absent, the in-home support staff may be responsible for the siblings of the child with a disability. This type of support is predetermined and described in the support plan. It is only offered if the needs of the child with a disability can be met while giving general supervision to siblings. This type of support is approved because the parent (or other caregiver) is receiving support (respite) that will help the family keep the child with a disability in the family home. The benefit to other siblings in the home is not the focus of the support. Supervision of siblings should not increase the cost of the support. The care given to siblings may include verbal or physical guidance, sharing a meal prepared for the child with a disability, or listening to a story read to the child. These activities help keep the family member with a disability in the family home and provide opportunities for learning with siblings.

Sometimes the benefit to the family member seems far removed. In these cases, a careful review by the in-home support agency, case manager, and the family is necessary. For example:

*A FSS staff was asked to fold and put away laundry for all family members. This chore was not specifically identified in the initial contract nor was learning laundry skills identified as a need for the family member with a disability. This sort of question should be addressed by the case manager, the family, and the service provider.*
Periodic review of the life plans, goals, and objectives will help keep supports and related tasks in line with the life plan.

Respect, Privacy, and Confidentiality

Providing services that respect the family's privacy is a challenge. The family and service provider need to discuss these issues in advance. Don’t wait for problems to surface. Support staff need to know:

- When should they give information to parents? When is it better to keep quiet?
- Who is the primary caregiver, when the parents are home?
- When should they seek parent input?
- What should parents do if they disagree with what the worker tells the child?
- What situations might change the normal routine? These could include occasional late nights, school closures, family emergencies, and vacations.
- Are staff invited or expected to attend IEP meetings?
- How do parents handle discipline? What should staff do if these methods conflict with agency policies?

Ongoing communication helps avoid confusion. When conflicts do surface, address them right away. Everyone needs to understand and agree with decisions made.

Service Contracts

Family Support Services is the name of a program administered by the ND Department of Human Services. FSS are coordinated by case managers at regional human services centers. Support plans are developed around the needs of the family and the member who is disabled. This plan includes a contract for services that specifies the number of support hours a family will need. These hours are usually counted on a monthly basis. The FSS contract defines the types of support the family desires. Some families want periodic respite from the duties of caregiving. Other families require a more intensive support. Assistance can be provided while the parents are present in these cases. Contracts are reviewed as family needs change. The flexibility of the contracts honors family choices and gives them some control.

Who is Your Boss?

Because support staff work in the home, staff may feel as if they have two bosses - the parents and the agency. This can create some questions. Who makes decisions about discipline? Who gives the OK for time off? To what extent can parents change staff duties without agency approval? Will staff schedules be set by staff availability or family needs?

Any job will have some differences between policy and practice. FSS has a lot of these “gray areas.” Flexibility is needed because family’s lives can be unpredictable. Staff need a reasonable
amount of flexibility in their schedules. If personal schedules change for the employee, they need to inform their supervisor. The family needs to be informed of changes or limitations to scheduling. Agencies need to tell families about policies and procedures that affect services. It is important for families to know that agency staff are mandated reporters. The following issues need to be addressed before services begin:

- Child/sibling discipline
- Transportation
- Participation in activities outside the home
- Siblings' friends in the home
- Food preparation
- Involvement of non-custodial parents
- Use of the telephone, Internet, etc.
- Abuse, neglect, and exploitation definitions and reporting requirements.

The service contract can answer questions and provide guidance. In any relationship, it is important to establish trust. Honest and consistent communication builds trust and bridges misunderstanding. When agency policy presents a barrier or conflict, it is important to address it right away. Supervisors should be involved. If the agency needs assistance, the regional case manager should be consulted. For example:

*When staff provided in-home support on Saturdays, the parent used this time as an opportunity to run errands. Siblings of the child with a disability remained in the home so they could watch cartoons. However, the youngest child in the family (who did not have a disability) was frequently the target of teasing by an older sibling (who also did not have a disability). This frequently escalated to physical exchanges that required the staff to break up the fight. The staff member became concerned about whether or not this level of care for the family member’s siblings was appropriate and became uncomfortable with the type of discipline that the parent wanted her to use. The staff member shared her concerns with her supervisor who agreed that the level of intervention and type of discipline were in conflict with agency policies and the contract agreement with the family. After being unable to resolve the situation with the family, the agency asked developmental disabilities case management for recommendations and assistance.*

**Summary**

Delivery of FSS has changed over the years. Families need support to be a family. The goals of FSS are to keep the family member with a disability in the home as long as possible. Support professionals, the employing agency, school, case management, and the family work together to develop and deliver the support plan. As supports are delivered in the home, occasional redefining of roles and services will be necessary. Agencies build trust when they practice clear and frequent communication with families.
Study Questions Chapter 3

T or F  1. Enhancing the services system to serve families who have a child with a disability is the primary goal of Family Support Services.

T or F  2. In family-centered services, the primary focus is on the child’s deficits.

T or F  3. Serving the person with a disability through actions that support the well-being of the whole family is the goal of Family Support Services.

T or F  4. Helping families keep their children in the family home is one outcome of family support.

T or F  5. Providing links to economic resources is not one of the Personal Outcome Measures for families with young children.

T or F  6. One of the outcomes of family supports is supplying families with information that will aid them in making decisions.

T or F  7. Medical professionals should not be involved support plans for families.

T or F  8. Schools should be involved in developing support plans for families who have a child with disabilities.

9. As a Personal Outcome Measure for families with young children, children are free from _________ and _________.

10. One of the outcomes of family supports is that families remain connected to _________ _________.

11. The document that specifies the number of hours a family will need for support is a(n) _________.
   a. 504 plan
   b. individualized education plan
   c. service contract
   d. family assessment

12. An issue that should be discussed with a family before providing support services is _________.
   a. allergies
   b. involvement of non-custodial parents
   c. finances
   d. education
Chapter 4: Developing Supportive Relationships

Chapter Objectives

- List three things parents may have experienced that may cause them to distrust professionals, agencies, or in-home support staff.
- List three things you can do to create a trusting relationship with families.
- List three things agencies can do to create a trusting relationship with families.

Parental Anxieties

Providing in-home family supports can be an intimidating task. The worksite is the family’s home, the subject of the job is the most precious possession of the family, their child, and the hours of work need to remain flexible and individualized to match the family’s needs and routines. The agency that provides family support services must follow agency policies and procedures yet be flexible when circumstances require an innovative response. Each family presents special circumstances that may demand unique interpretations of policy.

With all the flexibility and the fluid parameters inherent to in-home support programs, it is critical that the relationship between support professionals and families be characterized by trust. This trust should be evident to the family, in-home support staff, the service provider, and regional case management. Building that relationship is ongoing. To understand how trust develops, it is important to understand the anxieties families, providers, and others may have.

Many families have been caring for their child for years without help. Their child may have medical or physical involvements that make caregivers reluctant to allow others to provide care. The two most common reasons given by parents for not involving others in the care of their family members are (National Resource Center for Respite and Crisis Care Services, n.d.):

- Concerns about the caregivers’ training.
- Feelings that no one can take care of their child as well as they can.

Families may have had several professionals enter and leave their lives and feel that building another relationship just isn't worth the effort.

Age differences and lack of “experience” with a particular disability may also contribute to lack of trust. An in-home support staff must remember that parents know their children, including the member with a disability, better than anyone. Parents have had years of experience learning the child’s preferences and needs. Even if the staff member has a college degree in special education, he or she must maintain a respectful attitude toward the intimate knowledge the parent has about their child. That does not mean staff cannot share any information they have acquired. However, sharing needs to be done in a collaborative, respectful manner and include
opportunities for the parent(s) to share what they know about their child. (See Appendix D: My Child and Family Self-Assessment.)

Sometimes parents have intense feelings regarding the meaning of their child’s disability. One parent may believe that the disability is a punishment because the parents did not do "all the right things" before, during, or after the pregnancy. Other parents may believe that they must make every effort to compensate for their child’s limitations by giving them the best possible care and training. It is important to recognize how these beliefs are expressed in the family culture. Beliefs may impact the amount of attention that one member of a family gives a child with a disability or the emphasis placed on the quality of caregiving techniques. Responses or attitudes that are judgmental, (for example concluding that a parent is in denial) will only serve to alienate a family. This does not mean that you should never make suggestions. It does require you to become sensitive to family culture and willing to engage in an on-going conversation with parents about their child’s strengths and responses to daily routine.

Respectful professionals provide as much room and time as possible for parents to observe the impact of exemplary techniques that may be demonstrated by the support provider. Parents have limited opportunities to observe a child with disabilities interacting with people outside of the family and often appreciate a chance to see how someone else handles the challenges of setting limits or providing reassurance to their child. Noticing and sharing strengths of the family member with a disability, giving special attention or support to siblings, or showing appreciation for family strengths will go a long way in developing a positive relationship with the family.

People often remember negative experiences much more vividly than positive ones. The long forms, probing questions about private issues, endless waiting for answers from government agencies, or inflexibility on the part of professionals all contribute to mistrust. In-home support providers represent another layer of bureaucracy the family must endure. While it is true that not all families share these sentiments, it is advantageous to be pro-active and make every effort to make a positive impression from the start.

The Agency's Responsibility

In-home support providers can help dispel family mistrust and negative expectations by:

- Scheduling time with the family at the family's convenience.
- Providing flexible support. Provide as many options as possible to meet the needs of the family rather than fitting the family into the service available.
- Involving the family in training of in-home support staff. Include families in agency evaluation and decisions that directly affect family services.
- Maintaining adequate resources to cover family staffing needs.
- Promoting stability for families by hiring committed staff.
- Nurturing employee satisfaction and policies that promote staff "quality of life".
- Providing ongoing staff development.
Staff can develop supportive relationships by:

- Knowing the schedule and planning ahead for any changes. Families depend on staff showing up at the scheduled time.
- Being comfortable with spontaneity. Family life is not always predictable.
- Being fun loving and positive. Be committed to the development of the child with a disability and the family.
- Learning all you can about the disability of the child. The more that is known, the better in-home support the child will receive.
- Respecting the confidential nature of in-home support. Give information to only those people who need to know and only with the consent of the family.
- Addressing problem areas immediately.
- Listening to what families tell you without contradicting or discounting what they have to say by telling them that “all children of a certain age do that.”

**Summary**

Successful programs for in-home support have enthusiastic staff and satisfied families. Developing a supportive and trusting relationship takes time. The satisfaction the family gains from knowing their child has quality care will be worth the effort to both families and support providers.
Study Questions Chapter 4

1. Caregiver’s limited experience with a particular disability is one reason that parents may distrust in-home support staff.

2. In developing trust with families, it is important for in-home support providers to learn all they can about the child’s disability.

3. In order to create trusting relationships with parents, caregivers should wait at least one day before addressing problems that arise with a child so that they don’t upset the parents.

4. If caregivers do not respect the confidential nature of in-home support, it may be difficult for staff to create a trusting relationship with families.

5. Place an X next to reasons why parents may be distrustful of caregivers and hesitant to allow others to care for their child with disability.
   _____ Parents believe that caregivers are inadequately trained.
   _____ Parents believe that caregivers are overqualified.
   _____ Parents believe that it’s too much effort to develop relationships with caregivers who will come and go in their lives.
   _____ Parents believe that others are just as capable of caring for their child as they are.

6. In-home support providers can help dispel family mistrust and negative expectations by _________.
   a. Scheduling time with the family when it’s convenient for the staff.
   b. Canceling appointments with the family at the last minute.
   c. Fitting the family into the available services.
   d. Providing stability for families by hiring committed staff.

7. To create a trusting relationship with families, it is important for in-home support staff to _________.
   a. Respect the confidential nature of in-home support
   b. Offer babysitting services
   c. Provide housekeeping assistance
   d. Stick to the original schedule proposed by the agency
Chapter 5: Abuse, Neglect, and Exploitation

Chapter Objectives

- List 4 challenges staff may face when reporting abuse, neglect, and exploitation.
- Describe the procedure for reporting abuse, neglect, and exploitation.
- Define abuse, neglect, and exploitation.

Almost daily, we hear reports of child abuse and neglect. These experiences can have devastating effects on children. Sometimes the injuries result in permanent disabilities. If the child already has a delay or disability, maltreatment can further compromise the child’s functioning. In-home support professionals are mandated reporters of abuse, neglect, and exploitation. This means that you are required by state law to report suspected cases of abuse or neglect in a timely manner to the protective agency specified in agency policy and state law. Reporting possible incidents of abuse and neglect is essential to protecting children's safety.

In-home support staff members are in a position to be privy to family information that no one else may know. They may observe family practices that might seem foreign or different than what they are accustomed to seeing. The line between family practices and abuse, neglect and exploitation are sometimes vague. The responsibility of reporting suspected incidents makes it harder to establish trust and rapport. These are legitimate concerns. However, the number one priority is to protect and advocate for the child with a disability.

The terms abuse, neglect, and exploitation are freely used by society. Most people, when asked, can define or provide examples of what they believe constitutes abuse, neglect, or exploitation. Unfortunately, in the past, various sources of authority each defined these terms differently, which caused confusion especially among those working in the field of developmental disabilities. Through efforts of the North Dakota legislature, the State of North Dakota now has state statutes which specifically address definitions of abuse, neglect, and exploitation as they relate to people who have developmental disabilities, as well as how to report these alleged violations. The purpose of this law is clear: to provide a uniform set of rules which can be consistently implemented by all involved in the lives of people who have developmental disabilities.

Definitions

Within the statutory definitions of abuse, neglect, and exploitation, the term "caretaker" is frequently used. A "caretaker", as defined by law, means "a person, organization, association or facility who has assumed legal responsibility or a contractual obligation for the care of a person with developmental disabilities or mental illness, or a parent, spouse, sibling, other relative, or person who has voluntarily assumed responsibility for the person's care." For purposes of this section, paid staff members who provide in-home supports are considered to be caretakers.
Below you will find the definitions of abuse, neglect, and exploitation as they appear in the North Dakota Century Code, 25-01.3-01.

"Abuse" means:

a. Willful use of offensive, abusive, or demeaning language by a caretaker that causes mental anguish of any person with developmental disabilities;

b. Knowing, reckless, or intentional acts or failures to act which cause injury or death to a developmentally disabled or mentally ill person or which placed that person at risk of injury or death;

c. Rape or sexual assault of a developmentally disabled or mentally ill person;

d. Corporal punishment or striking of a developmentally disabled or mentally ill person;

e. Unauthorized use or the use of excessive force in the placement of bodily restraints on a developmentally disabled or mentally ill person; and

f. Use of bodily or chemical restraints on a developmentally disabled or mentally ill person which is not in compliance with federal or state laws and administrative regulations.

"Neglect" means:

a. Inability of a person with developmental disabilities or mental illness to provide food, shelter, clothing, health care, or services necessary to maintain the mental and physical health of that person;

b. Failure by any caretaker of a person with DD or mental illness to meet, either by commission or omission, any statutory obligation, court order, administrative rule or regulation, policy, procedure, or minimally accepted standard for care of persons with developmental disabilities or mental illnesses;

c. Negligent act or omission by any caretaker which causes injury or death to a person with developmental disabilities or mental illness or which places that person at risk of injury or death;

d. Failure by any caretaker, who is required by law or administrative rule, to establish or carry out an appropriate individual program or treatment plan for a person with developmental disabilities or mental illness;

e. Failure by any caretaker to provide adequate nutrition, clothing, or health care to a person with developmental disabilities or mental illness;

f. Failure by any caretaker to provide a safe environment for a person with developmental disabilities or mental illness; and
g. Failure by any caretaker to maintain adequate numbers of appropriately trained staff at a facility providing care and services for persons with developmental disabilities or mental illness.

Exploitation, when committed by a caretaker or relative of, or any person in a fiduciary relationship with a person with developmental disabilities or mental illness, means:

a. The taking or misuse of property or resources of a person with developmental disabilities or mental illness by means of undue influence, breach of fiduciary relationship, deception, harassment, criminal coercion, theft, or other unlawful or improper means;

b. The use of the services of a person with developmental disabilities or mental illness without just compensation; or

c. The use of a person with developmental disabilities or mental illness for the entertainment or sexual gratification of others under circumstances that cause degradation, humiliation, or mental anguish to the person with developmental disabilities or mental illness.

State law provides specific definitions of abuse, neglect, and exploitation, yet does not provide for specific examples or situations that constitute such violations. Although additional examples of behaviors which constitute violations would be helpful, it is difficult to do so for the following reasons:

- No one can list every situation or behavior which constitutes a violation; and
- What may constitute abuse, neglect, or exploitation against one person may not necessarily be true for another.

As stated earlier, many people are able to list examples of behaviors which constitute "abuse", such as slapping, pulling hair, or swearing. However, other behaviors, often referred to as "gray areas", are more difficult to define. It is only through in-depth fact finding or investigation procedures that a determination of abuse, neglect, or exploitation can be made.

Requirements for reporting child abuse are intended to protect children with disabilities and any other children. Reporting requirements exist to ensure assistance and resources are available for parent(s) or caregiver(s). Timely reporting can be a catalyst for change in the home environment. In-home support staff that report suspected abuse and neglect are not identified to the alleged perpetrator and should not experience retribution after making a report. By reporting, staff can prevent any further maltreatment in the home. The legal responsibility of reporting abuse and neglect can be overwhelming. It is, however, a responsibility that must be taken very seriously to keep children safe.
Challenges

Professionals face many challenges when reporting abuse, neglect, and exploitation. These challenges are intertwined with the provision of family-centered services. Staff may find themselves faced with the following issues:

- Damage to the trust previously established with the family.
- Parental misinformation about mandated reporting and state definitions of abuse, neglect, and exploitation.
- Guilt over splitting up a family by reporting suspected abuse.
- Lack of understanding of how to stay connected with a family following a report.
- Possibility that the family may discontinue in-home support services.
- Fears of reprisals against staff or the child/siblings.

In-home support agencies inform families of state mandates to report suspected abuse and neglect during the enrollment process. Unfortunately, policies and procedures can’t prevent fears and feelings. Families may regard themselves as being punished and harmed rather than helped, if reported. In-home staff may struggle with the need to report because of their desire to maintain a trusting relationship.

Staff Who Abuse

Staff members are held to the same standard as those considered to be "caretakers". In-home support staff must be careful to recognize signs of stress or burnout that may make them vulnerable to commit abusive acts. Training in recognizing behavioral indicators of stress and burnout, de-escalation techniques, behavior intervention, and crisis intervention should be included in orientation for all staff.

Reporting

Reports may be the only way a child with disabilities can be protected from maltreatment by "caretakers". Staff who work for licensed DD providers must adhere to the definitions and reporting procedures outlined in the Department of Human Services (DHS) policy “DDD-PI – 006”. When staff or parents have determined that an incident or circumstance should be reported, they need to follow the reporting procedures for their agency. Reporting may be the only way a child with disabilities can be protected from maltreatment by "caretakers". Employees of provider agencies are encouraged to report incidents of suspected abuse, neglect, and exploitation internally as described in the DHS policy DDD-PI-006 and the agency's policies and procedures in order to ensure that prompt risk management steps are taken. However, if the employee is not comfortable in reporting internally, or if the employee questions whether the agency will act on the report, then the employee may report directly to the Protection and Advocacy Project.

In every case, the employee must report any alleged incident of abuse, neglect, or exploitation either internally or directly to the Protection and Advocacy Project. Providers must review
incident reports in a timely manner and apply the Reporting Determination Guidelines (Appendix 1 of DDD-PI-006) to determine exploitation. If the incident does meet the criteria, and if the individual is under the age of 18, reporting the incident to the Regional Child Protective Services is necessary. It is also required to report the incident to the Regional Protection and Advocacy Project, Developmental Disabilities Program Administrator or designee and the individual's guardian/parent. If the individual is over the age of 18, action should be initiated with Investigative Action (Section III, DDD-PI-006), or, if applicable with the Protection Services Level System.

An investigation will follow that would include the in-home support staff, employing agency, Child Protective Services, and the Protection and Advocacy Project. When the suspected abuse, neglect, or exploitation involves only the siblings or a child without a disability, only Child Protective Services need to be notified.

In certain circumstances, in-home support staff may not feel comfortable reporting to their supervisor. If the abuse involves a supervisor or an administrator who has a conflict of interest with the family, support staff are still obligated to report to Child Protective Services and/or The Protection and Advocacy Project.

**Failure to Report Abuse and Neglect**

Penalties for individual staff who fail to report abuse, neglect, and exploitation may vary by agency and should be reviewed by the agency with all new employees. Agency failure to report any suspected incidents of abuse, neglect or exploitation may result in a formal investigation by Developmental Disabilities Central Office staff, Regional Developmental Disabilities Case Management and the Protection and Advocacy Project. Applicable corrective action may include, but is not limited to: notification of the Council, licensure sanctions, and/or revocation of the provider's license. The intent is not to assign guilt for an incident but to rectify the conditions that caused it. Failure to report is a violation of state law and will be considered a serious violation of licensure. (Chapter 25-01.3-12(2)).

**Summary**

As caretakers of vulnerable children and adults, it is the obligation of in-home support staff to know the definitions and warning signs of abuse, neglect, and exploitation. Reporting should not be viewed as punishment for the perpetrator but as part of the process to bring change for the family.
Study Questions Chapter 5

T or F 1. Staff may be hesitant to report abuse, neglect, or exploitation because they fear the parents may retaliate against them or the child.

T or F 2. Sometimes the home environment changes when abuse, neglect, or exploitation are reported.

T or F 3. Staff who report abuse, neglect, or exploitation are always identified to the perpetrator.

T or F 4. A police investigation is mandatory when child abuse, neglect, or exploitation is reported.

T or F 5. In-home support professionals are not mandated to report abuse, neglect, or exploitation.

T or F 6. Reporting suspected child abuse, neglect, or exploitation is intended to protect the rights of the parents.

T or F 7. Staff who report alleged abuse, neglect, or exploitation are never required to write a description of the incident.

T or F 8. Sometimes reporting child abuse, neglect, or exploitation prevents further maltreatment from occurring in the home.

T or F 9. If a caregiver does not provide a safe environment for a person with a developmental disability, it is considered exploitation.

T or F 10. Rape or sexual assault of a person with a developmental disability is an example of abuse.

11. __________ is the failure by a caretaker to meet any statutory obligation, court order, administrative rule, regulation, policy, procedure, or minimally accepted standard.

12. An in-home support staff is considered a __________.

13. Neglect is when a caregiver fails to provide adequate __________, __________, or __________ __________ to a person with developmental disabilities.

14. __________ is the use of a person with developmental disabilities for the entertainment or sexual gratification of others.
15. Alleged abuse, neglect, or exploitation must be reported either internally or externally to the __________ __________ __________ __________.

16. __________ __________ or striking a person with a developmental disability is a type of abuse.

17. An example of abuse is a caregiver’s willful use of __________, __________, or __________ language that causes a person with developmental disabilities to have mental anguish.
Chapter 6: Support and Development

Chapter Objectives

- Describe three values support staff should model.
- Name typical actions that you may be asked to teach a child with a disability.
- List one appropriate leisure activity for a child at each age.

The most important task that you will do is assist the family in supporting their child’s growth and development. First, invite the family to tell you what outcomes are important for their child. Next, the team helps the family to list learning steps for the child that will help achieve these goals. Families often choose activities to help a child learn personal care or daily life skills. The whole family benefits when a child takes over some of his or her care. Other important goals are for children to make friends, get along with other people, and take part in community life. Again, the team will help the family decide what steps are needed to achieve social and relationship goals.

You are a teacher as well as a family assistant or helper. These roles will sometimes overlap. During mealtime, you might feed a child part of the meal and teach the child some or all of the steps for feeding herself. At bedtime, you might teach the child how to brush his teeth and help him to bathe or put on pajamas. The plan is your guide for providing support and training. In order to carry out the plan you will need to know important outcomes, goals, and the steps to achieve those goals (objectives).

You can take several steps to learn about the person with a disability. You may read teaching plans, progress logs, and attend planning meetings. Most importantly, the family will teach you how to interact successfully with their child. You will have many conversations with families and learn from watching the child’s response to your teaching. Clear communication will help you learn what you need to know to support families and children. Observe and report any changes so that everyone who carries out the teaching plan is informed and can be consistent. Regular communication provides families with quality services and enhances child growth and development.

Teaching

Parents and support professionals are teachers. We all step in and out of that role daily. You must know how people take in information, process it, remember it, and use it to be an effective teacher. Good teachers are observant and change their approach as needed. You will spend a majority of your time teaching functional skills. These skills usually have an immediate and clear purpose and a direct connection to the goals set by the family. Reading, math or other goals are important; but teaching activities should support and be connected to the family's priority goals. For example:
A family has a child who has been diagnosed with autism. This family has named these priorities:

- Eat a full meal within a reasonable amount of time
- Reduce the length of temper tantrums at home
- Tolerate changes of daily routine at home and school

This child can eat independently (has no physical limitations) but often refuses to eat, and expresses frustration in the form of tantrums. This upsets the peace his family desires.

The team developed a plan to address these challenges. You will need to learn some basic behavior support principles to carry out the plan. The school, in-home support staff, and parents, all need to use a consistent approach. That includes observing responses and taking data on progress. This family needs support workers who understand and can carry out detailed steps when tantrums occur. Use positive steps from the plan to prevent outbursts when possible and know how autism impacts child behavior.

Another family has recently adopted a 10-year-old girl who has significant mobility challenges. Their priorities for their daughter include:

- Learn to feed herself using an adaptive spoon.
- Communicate using a talking device that was recently purchased.
- Use the joy-stick on her wheelchair to move around the house.

This family wants their child to become more independent at daily living tasks. They need to communicate. She needs to become more mobile at home, school, and in the community. The family needs support from someone who understands how to use prompts, cues, fading, and other teaching strategies*. You will need to learn how to operate her communication tool and how to reinforce her responses.

*If you want more information on how to teach, read the following training manuals from the North Dakota Staff Training curriculum:

- Supporting Individuals in the Communities
- Developing Communicative Interactions
- Achieving Personal Outcomes
- Principles of Behavior and Basic Behavior Intervention Procedures

These modules may be obtained in print through the regional staff trainer or at this website: http://ndepd.org/train/
Login: training
Password: isfun
Supporting Development

Children with special needs often take a long time to master skills that other children learn quickly. They may not learn some complex behaviors at all. They may repeat annoying behavior much more often than other children. These differences have a profound impact on family life and relationships. Families get frustrated when children take longer to learn to behave. Children get left behind when communication or mobility skills don’t keep pace with other young people their age. Sometimes they aren’t sought out as a friend or may not have the skills to sustain a friendship. These children often miss important milestones such as playing in sports, driving a car, or being welcomed into typical homes and classrooms. Families can become overwhelmed and discouraged.

These differences can lead to a sense of failure or isolation. Under these circumstances the importance of small changes is magnified. Share any progress you observe no matter how small. This gives families a sense of hope. Families without hope learn that nothing they do makes a difference. Remember that a child can learn important skills besides those listed in the formal plan through their relationship with you. Be someone a child would want to imitate. Interesting activities at home and in the community can provide many opportunities for teaching and learning. For example, a game can teach social skills, communication, numbers, colors, etc.

Do more than keep a watchful eye on children while parents are away. Make your visit an occasion for learning and fun. Young people with disabilities will rely on you to set up and start an activity. They will often need structure to support participation. During these activities, model teaching principles for parents and siblings.

Plan and get approval from parents before starting anything other than routine activities. Some parents may not want their son or daughter to do certain activities or go to particular places. Aim for balance. Not every minute of support time needs to be packed with stimulating activity. Children may need to relax after school and parents need the same after work. TV and video games may take part of the time but should be minimal. See Appendix J for activity suggestions and recommendations regarding age appropriate activities for family member(s).

Values

In all interactions and activities, model and practice behaviors that show respect for the age, choices, and development of the child with a disability. Some of these values include:

**Age Appropriateness:** This means using activities, books, toys, games, or possessions that any other child of the same age would enjoy. Matching what you say and do to the actual age of the child is important for every child. Use conversation topics and a tone of voice that you might use with other children of that age.
Choice: Offer opportunities for making choices during activities with the child and their siblings. Step back and give the child a chance to choose a toy, clothing, or food item or to decide what will happen next. Show other family members the listening and persistence it may take to allow the child to make a decision.

Self Determination: Children need to learn problem solving skills that will help them get what they need now and in the future. Self-determination skills may include learning to negotiate, accepting “No” when told, making healthy choices, cleaning personal items like glasses or hearing aids or asking someone else to do it, or predicting and controlling what others may want to do to or for them. Depending on the age of the family member with a disability, teaching self-determination may be as simple as offering a choice between the red toothbrush and the green one. For another child, self-determination may mean learning to plan their free time instead of just turning on the TV. An older child might need support deciding what classes to take in school. As children grow, look for ways to give children an identity as a person who enjoys certain activities or hobbies and the self-confidence to go after what they need. Believe that anyone can have a voice in their own future and demonstrate this belief through your actions and words. This will encourage families to do the same.

Inclusion: A child with special needs may be more vulnerable than his/her classmates who meet typical developmental milestones. Sometimes parents are reluctant to permit their son or daughter to join other children or take part in community events. Some families want to avoid teasing or rejection. Others may believe that the activities will be too hard for their child. Respect these fears and try to help the family realize the benefits of participation. Propose solutions that will make it possible for a family to take a reasonable risk. Your willingness to take a child to an event and support them as they participate may go a long way to helping a family try something new. Suggest after school activities or summer programs that may offer a positive experience and move in small steps toward more inclusive activities. You may not change attitudes immediately, but small steps will help the child build needed social skills and relationships.

Summary

Supporting the growth of the child with a disability is a shared responsibility. Families can learn from you and you will learn important lessons from families as well. Sometimes developmental gains for the child include functional skills to help the child be more independent and give the family a more normal family life. In other cases, the development occurs in parents or siblings who increase their expectations for the child and begin to take risks and provide new opportunities for a child to enjoy a typical life.
Study Questions Chapter 6

T or F 1. An appropriate recreation activity for a five year old male with developmental disabilities is playing video games that are rated PG-13.

T or F 2. When a child with developmental disabilities plays on a t-ball team with kids who don’t have disabilities, it is an example of inclusion.

T or F 3. Watching Sesame Street is an appropriate free-time activity for a fifteen year old girl with developmental disabilities.

T or F 4. When a child with developmental disabilities selects which outfit to wear to a birthday party, it is an example of making choices.

5. Activities that support staff teach should be based on family __________.

6. Two types of skills that in-home support staff may be expected to teach include __________ and __________.

7. Matching: Match each term with its definition.

_____ Self-determination
a. Offering opportunities to select between options and live with the consequences of that decision.

_____ Choice
b. Using tone of voice, activities, toys, books, and games that match the chronological age of the child or person.

_____ Inclusion
c. Participating in a group, activity, or community event that also includes people without disabilities.

_____ Age-Appropriate
d. Making healthy choices and controlling one’s life; skills that help a person to be assertive and to advocate for what they need.
Chapter 7: Health Issues

Chapter Objectives

- Describe methods of infection control.
- List the symptoms of an allergic reaction.
- Define desired effects.
- List three practices for administering medications.
- Describe three situations that would require emergency intervention regarding seizures.
- Describe three basic principles of positioning.

Infection Control

Basic principles of infection control prevent disease and transmission of illnesses. The infectious process is a continuous cycle:

1. First an organism is present that can cause the illness or disease. These organisms can be viruses, bacteria, fungus, or a parasite.
2. Second, the organism needs a place to live (host) and multiply. These places can be a human, an animal, or a non-human or non-animal such as contaminated dirt.
3. Third, the organism needs a method of escape from the host. This can be accomplished through coughing, sneezing, a body fluid (blood or any body fluid) or just a break in the skin.
4. Fourth, the organism needs an entry into a new host.

The cycle can be broken to prevent or reduce the risk of transmission. These methods include:

- hand washing
- using protective barriers
- preventing accidental cuts or sticks from used needles
- cleaning and disinfecting surfaces
- using correct procedures for contaminated laundry

Note: When appropriate, the individual themselves may perform the cleaning or disinfecting activities if that is what the family prefers.

Hand Washing

Effective hand washing is the most important way to prevent the spread of germs that cause disease and illness. Hand washing needs to be thorough and frequent. The steps in hand washing are:

1. Adjust the water temperature (the temperature of the water used for hand washing isn’t as important as the friction used).
2. Wet the hands and apply soap.
3. Rub hands together to form lather for at least 20 seconds. Be sure to apply friction to all surfaces.
4. Rinse the hands with fresh water.
5. Dry the hands with a single use towel. Turn the faucets off with the towel to avoid recontaminating hands.

Hand washing should occur:

- After using the toilet or assisting someone with bathroom or personal care activities.
- Before and after preparing food
- Before and after administering medications
- Immediately after contact with blood or any body fluids

**Protective Barriers**

Hand washing is necessary even when gloves are used. Disposable gloves are required when the possibility of having contact with a body fluid is likely. Never reuse gloves. Wash hands before and after using gloves. Other barrier devices such as protective eyewear, gowns, or protective clothing should be worn when there is a possibility of blood or body fluid splashes.

**Preventing Accidental Cuts**

Discard needles or sharp objects in a puncture resistant container.

**Cleaning and Disinfecting Surfaces**

Use the following procedures for body fluid and/or blood contaminated surfaces:

1. Wear gloves.
2. Place paper towels or some absorbent material over the spill and wipe it up. Place the towels in a securely closed, leak proof bag.
3. Using the disinfectant the family provides, scrub the surface and then rinse the area clean.
4. Wash your hands.

Surfaces that have been or will be in contact with food should be disinfected using the same procedures. Always wash your hands after cleaning and disinfecting any utensil or surface.

**Laundry Procedures**

Some families will prefer to take care of laundry themselves. Ask what the family prefers and use the products and procedures they recommend. General laundry recommendations for safe handling of laundry contaminated by blood or body fluids include:
- Launder immediately or store in a leak proof bag at the place where it became contaminated. Dispose of any excess body fluid or excrement before bagging.
- Wear gloves when laundering and handle the laundry as little as possible. Wash contaminated laundry separate from any other laundry.
- Presoak or wash any blood stained items in cold water for 10 minutes to avoid setting the stain.
- Wash the clothing according to the manufacturer’s instructions for 20 minutes using one of the following disinfecting procedures based on the family’s preference: (a) hot water setting (140 degrees), (b) veridical laundry detergent effective at a lower water temperature, or (c) chlorine bleach added to the water. **Use caution if the family wants you to use bleach.** It can ruin anything it touches (including your own clothing, furniture, floor coverings) if used improperly. If you get it on your skin, rinse immediately. Avoid contact with your eyes and do not combine with other cleaning products.
- Use a dryer whenever possible.

**Sick Children**

Illness can place heavy stress on parents. Emergency room visits, jobs, unexpected changes in schedules, and ensuing financial burdens can be upsetting. The provider agency and families must agree on the procedure for support when the child is ill and/or when siblings are sick. If the child has a chronic illness, the protocol for care should be part of the initial orientation for staff.

Staff will need to know how to administer prescription and over-the-counter medications and how to use special equipment or special procedures. Whether the child is experiencing a cold or a serious illness, the plan for care should be pre-established. Agencies may ask parents to sign consent forms for transporting children for emergency medical treatment.

Children, especially young children, are susceptible to common illnesses. The ability to observe and communicate symptoms of illness is a skill valued by many families. Note the following:

- Body posture - Is the child in his or her normal posture or slumped?
- General state - Does he or she seem listless or appear to have the normal amount of energy? Is the child happy, depressed, alert, or drowsy?
- Condition of skin – What is the color, texture, and temperature?
- Condition of senses - Does he feel numb, unable to take in or process information as he normally does? Do he respond the way he normally does?
- Speech - Does she/he slur? Is speech faster than normal or slower?
- Mouth, gums, teeth - What is the color of gums? Do they have breath odor?
- Facial expressions.
- Vital signs - Watch the child’s breathing. Take his temperature and pulse.
- Bowel and bladder – Is she regular? What is the appearance of the stool/urine?
- Appetite and eating habits - What has the child eaten? Is it the normal amount?
Some signals may alert staff that there is something different in the child’s appearance or behavior from how a healthy child looks and acts. These changes may occur suddenly or over time. Inform the parents of any health concerns.

**Fever**

A fever is the body's normal reaction to infection. A fever does not necessarily indicate a dangerous infection. Using an approved thermometer is the only accurate way of knowing whether or not a child has a fever. Staff should know how to use the family's thermometer and understand the procedures for care when the child has a fever.

Febrile seizures (convulsions) can occur with high fevers primarily in children (6 months - 4 years of age). If the child does have a seizure, lay him/her on their side and protect them from harm. Call 911 immediately if this is the child’s first seizure.

**Allergic Reaction**

Be alert to the possibility of allergic reactions. When the child begins a new medication or is exposed to a foreign substance, symptoms that may appear include:

- Skin rash
- Diarrhea
- Itching
- Watery eyes
- Discharge from nose
- Nausea
- Irritability
- Difficulty breathing

Symptoms may occur anytime from a few hours to two weeks after exposure. Many allergic reactions can be life threatening. A severe reaction, known as anaphylactic shock usually occurs immediately after the administration of a medication or exposure (i.e., bee sting). Anaphylactic shock can be fatal if immediate assistance is not obtained. Symptoms of anaphylactic shock are: irritability, extreme weakness, nausea, vomiting, acute shortness of breath, and low blood pressure. Call 911 immediately if these symptoms are observed.

Know your agency’s method for alerting staff to known allergies and look for notes regarding allergies whenever you start working with a new child or family.

**Medication Administration**

Although giving medications in the home of the family is quite different than in a medical setting - the responsibility taken by staff is the same. If not given properly, medications can be dangerous. The procedures and formality of medication administration in the family home will depend on the number and types of medications the child takes, existing medical conditions and health
status, the family’s preferences, and the agency’s policies. In some situations, there may be very specific controls on medications and strict documentation procedures. In other situations, the family may “set up” the medication in a pill planner and provide the in-home support staff with a note indicating the times that medication is to be given. If medication is a critical part of your job, it might be a good idea to get specific instruction or information using the Medication Training module that is a part of the Community Staff Training Program curriculum. Some key terms include the following:

**Response time** refers to the amount of time that should pass from taking the medication until the desired effects can be observed. The response time for Tylenol may be 30 minutes, whereas the response time for a psychotropic drug (mood altering drug) may be much longer.

**Desired effects** are what we want the medication to accomplish. The desired effect of a seizure medication may be to reduce the number of seizures or to reduce the length of a seizure. The desired effects of Tylenol is to relieve pain. When the desired effects have not occurred after the appropriate response time has passed, inform the parents.

**Side effects** are effects produced by the medication other than the one for which it was prescribed. Side effects may be predictable or completely unexpected. Some side effects include nausea, a dry mouth, a rash or even a behavioral change. Report changes in behavior or appearance to the family.

**Storage, Directions for Giving, and Documentation**

Some medications must be stored under special conditions so that the chemical composition is not destroyed. It is important to follow storage directions such as refrigeration, keeping in a dry area, or storing away from sunlight.

In our personal lives, we may not take our medication at the exact time the doctor prescribed. We may forget and take it one or two hours later. We may decide to take medication based on what is easier for us. However, when working as in-home support staff, it is important to follow the schedule established by the parents. The correct time means that the medication is given within one hour before or one hour after the time determined by the doctor and/or parent. If the medications are to be given at 6 pm, it can usually be administered safely at 5 pm until 7 pm. When it is obvious that the child will not be home to take their medications on time, the pills should be packed in an envelope, zip lock bag, or pill planner with the name of the medication and time it should be taken written on the outside.

Follow the directions on the label and the advice of the parents regarding the preferences of the child to ensure that medication administration will be successful and a positive experience for the child. Directions that dictate when a medication should be given, such as, before a meal or before bedtime, may influence how well the medication will work. Some medications are time-released so they must be swallowed whole. Other medications can’t be taken with dairy products. Failing to follow these directions may interfere with how well the body will absorb the medicine.
Staff should never administer medications that require special procedures or equipment for which they have not been trained.

Follow the family’s directions for documenting when medications are given. Some families may not require any specific documentation. Emergency numbers, physician, and pharmacy numbers should be accessible.

**Seizures**

If the individual receiving in-home support has a seizure disorder, staff need to be able to recognize the seizure activity and know what to do while the seizure is occurring. Carefully observe the child during and after the seizure. The events immediately prior to the seizure also can provide information important to the physician's diagnosis and treatment of the seizure disorder. For more detailed information on epilepsy see the *Seizures* training manual.

A seizure in someone who has epilepsy is generally not a medical emergency, even though it may look like one. Its best if parents teach staff what to expect during their child’s seizure and what to do during a seizure as a part of the initial orientation for support staff. Included in that information should be the characteristics of their child's seizures, activities or circumstances that may bring on a seizure, and what to do during and after a seizure. Staff should also find out how the parents want seizures documented. They may only want a verbal report. Other families might want the seizure activity recorded in a log or notebook.

The following are some suggestions to help decide whether or not to call an ambulance when someone has a seizure. There is no need to call an ambulance if:

- It is known the child has epilepsy.
- The seizure ends in the amount of time that is typical for the child’s seizure activity.
- If consciousness returns without further incident.
- If there are no signs of injury or physical distress.

An ambulance should be called when:

- The seizure occurs in water.
- The seizure is longer than normal (or 5 minutes if normal length is not known).
- If a second seizure starts shortly after the first has ended.
- If the child injures him/herself as a result of the seizure.
- If the person experiences respiratory and/or cardiac distress.
- If consciousness does not start to return after the seizure has ended.
- If it is the child’s first known seizure.

**Positioning, Turning, and Transferring**

When a person is not able to move around independently, there are physical, mental, emotional, and social effects. Children learn and develop their self-concept based on their ability to impact
and control their environment. Limited mobility has a profound effect on a person's opportunity to develop relationships and participate in activities.

Immobility can cause health problems as well. Being immobile can result in contractures at the joints, unstable joints, weak muscles, and brittle bones. It can interfere with how the digestive system and circulatory system function. Movement is necessary for normal growth and development.

Support staff need to understand basic positioning principles and have training that is specific to each child's needs. This training should be included in orientation before the staff person works independently. Basic principles of positioning include:

- Respect the person's dignity and privacy when positioning, turning, or transferring them. Tell or ask them if they would like to move or assume another position and complete the movement with as much privacy as possible.
- Use slow, smooth movements when moving body parts.
- Provide support to the head, shoulders, and trunk before moving arms and legs.
- Encourage participation and independence during positioning, turning and transferring.
- Give verbal instructions and touch the person to reinforce desired movements.
- Use adaptive equipment for stabilization.
- Promote symmetric alignment in which the head is centered and upright above the body, the spine is straight, and the arms and legs are balanced on either side of the body.
- Reposition a person a minimum of every two hours, unless specifically directed by a physician or therapist.

Another health concern that can develop into serious sores and a lengthy healing process is a pressure ulcer. Pressure ulcers occur when bones closest to the surface of the skin press against the skin and body tissue reducing the flow of blood and oxygen. Backs of heels, shoulders, the tailbone, hips, knees, and buttocks are most susceptible.

If a person complains of pain or if any of the following are noticed, adjust the person's position and notify the parents.

- Areas that remain red for more than 10-15 minutes after pressure is removed.
- Skin that feels warm to the touch
- Swelling

Any break in the skin needs immediate care and attention.

Because each child/person has specific needs, a physical or occupational therapist will provide guidelines for proper positions and specific transferring techniques. Some individuals need exercises on a regular basis to maintain muscle strength and flexibility. Range of motion
exercises usually are done daily. In-home support staff should watch and practice these exercises under the direction of the parent or therapist to make sure they are done properly. See the training manual and videotape on *Positioning, Turning, and Transferring* for more specific information on positioning, lifting, and using mechanical lifts.

**Summary**

Each child that receives support will have unique health needs. Specific procedures for safeguarding health should be provided at orientation and when the contract for services is written. All procedures should be documented and available for review by staff. Communication about health concerns between staff and parents should be consistent and immediate. Maintaining the child's health is a responsibility of both staff and parents.
Study Questions Chapter 7

T  or  F   1. After hand washing, a single use towel should be used to dry hands.

T  or  F   2. Clothing that is contaminated with blood can be washed with other laundry as long as it is washed in hot water.

T  or  F   3. It is not necessary to wear gloves when handling laundry that has been contaminated with excrement.

4. List three times when hand washing should occur.

5. List five symptoms of an allergic reaction.

6. List four ways to break the infectious disease cycle.

7. Name three times when it is not necessary to call an ambulance when someone is having a seizure.

8. List five basic principles of positioning, turning, and transferring.

9. __________ __________ is the most effective way to prevent the transmission of infectious diseases.

10. During hand washing, it is important to rub hands together for at least __________ seconds.
11. To avoid accidental cuts, needles used for insulin shots should be discarded in a __________ __________ __________.

12. A severe allergic reaction that can be life threatening is also known as __________ __________.

13. Giving medications on time means that the medication can be given within __________ __________ before and __________ __________ after the time specified by the doctor.

14. When a child is sick, staff may observe which symptom?
a. Mouth, gum, teeth, and breath odor
b. Changes in breathing, pulse, or temperature
c. Lack of appetite
d. All of the above

15. Basic positioning principles include;
a. using quick movements to make the transfer easy.
b. pulling into position instead of pushing.
c. providing support to the head, shoulders, and trunk before moving arms and legs.
d. using deep pressure when positioning.

16. Matching: Match each term with its definition.

_____Response Time a. Effects produced by the medication other than for which it was prescribed.

_____ Desired Effects b. The amount of time that should pass between taking the medication and the desired effects.

_____Side Effects c. What we want the medication to accomplish.

17. Place an X by each step that should be completed by a person who is disinfecting a contaminated surface.

_____Wear gloves
_____Place a paper towel over the spill and wipe it up
_____Reuse the paper towel for additional spills
_____Throw away contaminated paper towels in the garbage can
_____Scrub the surface with a disinfectant
_____Reuse gloves while scrubbing additional surfaces
_____Wash hands after clean-up is completed
Chapter 8: Positive Behavioral Support

Chapter Objectives

- Define positive behavior support.
- Define the ABC analysis of behavior.
- List three values you should have for supporting behavior change.
- Give one example of the correct way to use consequences to change behavior.
- Define reinforcement.
- List five do's of positive behavioral supports.

Sometimes families prioritize change in their child’s self-defeating behaviors as their highest need. Behaviors that concern families may be disruptive, self-injurious, harmful to others, or interfere with learning and development. You will assist the family to implement a behavior plan that is designed to teach the person with a disability to use appropriate behaviors.

Positive behavior supports assist people to get what they need using ways that are helpful and safe for them and others. The goal is to create environments and patterns of support that help people to view any inappropriate method as a waste of time and energy and work towards a win/win solution.

Tools that will help you support behavior changes include:

- Positive expectations, values and beliefs that guide decisions
- Principles of behavioral support for teaching appropriate behavior
- Effective strategies when the target behavior(s) occur

This chapter looks at all aspects of supporting behavior through planning, assessing, and teaching.

Assessment

People use behavior for specific reasons. Most of the time, the behavior provides a payoff for the person. Because the behavior delivered the desired results in the past, the person continues to use this method to get what he or she needs, even if others think it is inappropriate.

Example:

Rodney frequently disrupted mealtime by getting out of his seat, poking his brother and by making noises. His dad was at his wit's end because, even though he quickly scolded Rodney each time he disrupted the meal, his disruptions were increasing. Rodney’s dads’ scolding became so frequent that it was soon his only contact with him.
In this example, Rodney has found a way to get his dad’s attention. While, the teacher thinks it is an inappropriate way for Rodney to get attention, it gets him what he wants (attention). When the behavior is harmful or reduces the likelihood that others will want to be around the individual, a more in-depth assessment is necessary. The assessment should help determine what circumstances (people or events) cue/signal the child to use the behavior. (In the case of Rodney, mealtime and the presence of his dad triggered the behavior) and what consequence (payoff) the child/individual receives. This type of assessment is called a functional assessment.

You may be involved in determining the "reason" for the behavior. Data will give the team a clear picture of what is happening and will be more effective than a quick guess as to why the behavior occurs. Guesses based on “instinct” or “experience” are usually wrong! An ABC analysis of behavior provides good information to help the team plan. The ABC analysis looks at behavior in three segments:

- **A** = antecedent (what happens before the behavior). A child/individual is more likely to engage in a behavior when certain antecedents are present. These may include an opportunity, certain people, a certain approach someone is using, a familiar event, etc. Think of an antecedent as a signal that tells the individual it is time to engage in this behavior. Usually antecedents happen immediately before a behavior. Sometimes a child/individual can learn to use a negative approach to solving a problem even though a specific antecedent is not apparent to others. The child learns the negative behavior as part of his or her routine.

- **B** = behavior (what the child/individual does that is disruptive, harmful, self injurious, or interferes with learning), defined in observable terms so that all the people involved can agree to what is being targeted for change.

- **C** = consequence (whatever happens after the behavior). Consequences are more powerful than antecedents in maintaining behavior. Consequences increase the likelihood that a behavior will be repeated. Consequences are sometimes (but NOT always) responses that a parent or staff person might apply after a behavior such as a frown, warning, loss of privileges, or some natural negative result (people leaving) that the adult thinks will teach the child to quit exhibiting the “problem” behavior. Consequences ARE the payoffs or results that a behavior produces. **Consequences are about what the child wants (food, attention, avoiding demands, reassurance, etc.) and gets, not about what we think is happening or ought to happen.** Consequences can work together to make the behavior stronger or more likely to continue; that is, a child’s behavior may be maintained for more than one reason.

Example:

*John's aggressive behavior is interfering with his ability to participate in home, school, and family routines. He is unable to sustain any lasting relationships. His aggression*
involves slapping and kicking other people, destroying materials, and then leaving the area. These behaviors may occur up to 10-15 times per day.

The family, school, and support staff all agree on the target behaviors:

- physical aggression (slapping, kicking, and destroying materials)
- escape behavior (leaving the area).

However, it isn’t clear why John exhibits these behaviors. With a more systematic approach to gathering data (descriptions of the A, B, and C), a pattern emerges. The incident reports show that when others ask John to do academic or personal care tasks, he exhibits the aggressive and escape behaviors. John’s team decides to change the circumstances (antecedents) that signal John it is time to use aggression and running away AND the payoffs (consequences) that keep John going back to that behavior.

In this example, the antecedent appears to signal John that a situation that he finds overwhelming (a request he decides is too hard) is about to occur. The family and school believe that if they can offer John reassurance when making a request (new antecedent), the behavior will be less likely to occur. To help John learn new ways to respond to requests, they decided to highlight assistance that will be available (an adult standing nearby for some tasks), offer verbal reassurance (“I’ll help you with this one”) to teach John how to ask for help appropriately, or provide tools that make certain tasks easier.

The school and family also identified the payoff (consequence). Whenever he became physically aggressive, people helped him do the task, or withdrew the request so he avoided having to do it. In most instances, staff did the task for him. With the new behavior support plan in place, the school, parents, and support staff now all deal with the behavior the same way. When John slaps, kicks, destroys materials, or tries to leave the area, they wait until John is calm and then reintroduce the task. This method will teach him that these behaviors no longer work to help him avoid the task. They reinforce John for staying calm (a behavior that is incompatible with aggression) and for tackling tasks (“Wow, that was hard and you did it!”) that are difficult for John even though the same tasks may not be challenging for someone else. The ABC chart helped them understand what was happening.

ABC data assists the team to make accurate reports about behavior and avoid making guesses based on feelings. Objective reports help the assessment process. They help the team members develop common methods for teaching new behaviors and delivering a positive approach.

Using an ABC chart often gives a team enough information to develop an appropriate support plan. However, sometimes the ABC chart does not show a clear picture of what is maintaining the behavior. In these situations, the next step would be to change the consequences that follow the behavior systematically to see which one(s) are maintaining a behavior. This involves creativity on the part of the team and may be necessary at times to see what is really happening.
Values and Principles

The overriding purpose of any behavioral support plan is to increase the quality of life for individuals with disabilities and their families. Specific values that influence support plan development include:

- Behavioral intervention should be proactive rather than reactive. Punishment does not teach new or more appropriate behavior. Behavioral support plans should focus on teaching skills that will help the person meet the need currently being met by their inappropriate behavior.
- Teaching the appropriate behavior may mean redirecting the individual to a different activity. Respecting the person by giving choices and alternatives will help build trust and give dignity.
- You are not hired to control others or teach them a lesson but to support them in their behavior change.
- There is a reason or unmet need behind most difficult behaviors.
- Appropriate behavior does not have to be forced. Behavior will not be controlled or managed with unpleasant events (punishers).

Teaching

You can encourage and teach desirable behavior by establishing helpful routines. Helping a family establish and follow predictable routines around personal care, eating, dressing and transitions are important. Printed or picture schedules are some ways to let a person know what is coming next. If several staff provide support at different times to the same individual and family, it is important that there is a way to communicate information on routines provided by the individual’s parents. Having to repeat the same information to every staff person that comes into the home interferes with quality support provision.

Building success into interactions with the child will give opportunities to celebrate their successes and abilities. It is unrealistic to expect someone who has difficulty understanding verbal directions to follow multi-step instructions. It is also unrealistic to expect someone who has difficulty sitting still for more than five minutes to remain seated during a two hour movie. Expectations need to be based on what is appropriate for the child’s age and disability.

The goal is to teach and reinforce acceptable behaviors to replace the inappropriate behavior. It is unrealistic to expect people to change a behavior that works (meets a need) for them without giving them a new way to meet the need. If John exhibits self-injurious behavior to escape from the noise and all of the people present during meals, he could be taught another, equally effective skill such as asking to leave or asking for quiet time. This could be signing, pointing to a symbol taped to the table, or pressing a button on a communication device. Whenever John attempts the new behavior, his choice should be respected and he should be allowed or assisted to leave or respected by having others tone down the noise.
The goal is to teach skills that are valued and rewarded by others. Inappropriate behavior usually means the person is lacking a skill. The goal of the behavioral plan and staff interactions are to teach the replacement skill.

Sometimes individuals with disabilities attempt to please others by repeating the rules. They may appear to have an awareness of what they should or shouldn’t do or what consequences (punishment) will follow a certain behavior. It is a common mistake to assume from these behaviors that the person could “do it if they really wanted to.” What we say about our own behavior (smoking, over eating, gossiping, or teasing) often has little to do with what we produce under the circumstances.

It is a mistake to assume that once new behaviors are taught, that the person will automatically use the new behaviors. This does not always happen. Everyone in support roles, staff, family members, teachers and therapists, need to consistently reinforce or reward the new behavior. In fact, research shows that persons with intellectual disabilities often need on-going reinforcement to retain behaviors that are difficult for them. They don’t understand or notice social reasons for engaging in certain behaviors. For example, they might not notice the smile on your face when they use a social skill like saying “thank you” or perform a task that you are trying to teach them.

The most natural reward we can provide is to ensure that the person’s need is being met. In the example previously discussed, when John communicates a desire to leave, he will get to leave – every time. If the only time “using a picture to request permission to leave” (the target behavior or skill) works is at the dinner table, teaching him how to communicate that desire will take a long time. It is likely that there are many places and situations where he could use this new skill. Everyone who interacts with John should respond the same way when John asks to leave appropriately (uses the picture).

Reinforcement

Many behaviors are maintained not only by the original payoff but also by the environment or reactions by people in the environment. To maintain or teach a new behavior it may be necessary to identify a reinforcer (something that follows a behavior and strengthens it) to use initially to help the child want to learn the new behavior. As the behavior is learned, the reinforcer is slowly faded. In the previous example, John needed to learn how to ask for help appropriately. In order to teach John the new skill, the family and support staff used a consequence or reinforcer that John was willing to work for to change his behavior. In order for the plan to work:

- John had to find the reinforcer available when he used the new skill, and
- His new strategy for “asking for help” had to be effective and better than his old way (self-injurious behavior- the method his family and others thought was inappropriate).
When John asked to leave appropriately, the family, school and support staff immediately delivered what John wanted so it was obvious to him that the new skill would get him what he wanted (to leave).

Sometimes the behavior or skill the family prioritizes for teaching doesn’t have an immediate reward that is obvious to the learner. For example, when teaching tooth brushing, something extra (artificial reinforcer) might be used to make doing the behavior more attractive to the learner. Reinforcers are not just candy or stickers or whatever the staff person or parent has available and likes themselves. Reinforcers must be meaningful to the individual receiving them. This might be praise, a pat on the back or even a token like a sticker on a calendar. For Sam, the most meaningful reinforcer is praise and attention from people he trusts. When he brushes his teeth correctly, everyone involved in teaching the new skill will praise him and describe what behavior they are praising. The likelihood that Sam will continue to use his new skill is high if the family and support staff are consistent and immediate with their praise. After Sam is consistently using his new skill, the praise can be faded and hopefully the fresh taste in his mouth will be rewarding in itself.

As the new skill or behavior is learned, supports (instructions and reinforcers) provided during the teaching phase are gradually faded. Support workers model this for the family during the teaching phase. A preplanned effort to fade prompts and rewards is necessary so that the learner doesn’t become dependent on the assistance or artificial rewards used during teaching. The goal is for the person to demonstrate the behavior independently, not just when others are there to prompt or reinforce.

**Making decisions**

Staff can prepare themselves for situations when challenging behavior will occur by rehearsing the appropriate reaction before the behavior happens. Knowing what situations may present the biggest challenge will help support the child who may embarrass, hurt, scare or offend staff. Staff should consciously plan how they want to handle the behavior so they are not caught off guard and make mistakes. For example:

**Minimize the power of challenging behavior.** Behaviors may be maintained by reactions of staff, by escaping from demands, or winning a power struggle. Minimizing the power of a challenging behavior can be accomplished by ignoring the behavior, not allowing it to interrupt or change expectations, or minimizing reaction to the behavior. Other times, giving in to the demands of the person is the best course. The goal is to minimize the power of the situation and prevent further inappropriate or volatile behavior. Remember – staff winning a power struggle will not help your teaching and makes someone a loser.

**Disrupting challenging behavior.** If it is necessary to stop a challenging behavior, reduce the disruption by moving to another area. This will prevent any harm to others and may stop the behavior. When interruption is necessary, it should be done gently, safely and calmly.
Using consequences. The best response (consequence) for inappropriate behavior is relevant (fits the behavior and the person) and not done as retaliation (punishment). Whenever possible, the person with a disability and parents should be involved in discussing and deciding on the consequences. Consequences should be relevant to the situation such as cleaning up after having made a mess. Consequences should be respectful and not shame or humiliate the person. They should be reasonable (e.g., cleaning up the mess, not the whole house). Consequences should also provide opportunities to practice the desired behavior. For example: if someone bullies others then a consequence might be supervised practice in helping others (e.g., turn taking, holding the door, compliments). (Positive Behavior Support Program (n.d.))

Guidelines

- Occasionally reinforce appropriate behaviors that occur frequently and/or regularly. This will assist in maintaining that behavior.
- Attend to inappropriate behavior as little as possible. If necessary to interrupt the behavior, do not spend a lot of time talking. At a later time, discuss the expected behavior and its consequences (what will happen).
- Realize that you are shaping and refining behavior. This means that progress will be one step at a time. The individual will need positive feedback following each step.

<table>
<thead>
<tr>
<th>Don’t</th>
<th>Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>State verbal instructions in a negative way: “Do the dishes now!”</td>
<td>State verbal instructions in a positive way: “How fast can you do the dishes, Vicki?”</td>
</tr>
<tr>
<td>“Stop grabbing, Liz!”</td>
<td>“Please wait; now it is Joe’s turn.”</td>
</tr>
<tr>
<td>Use a negative approach: “Gail, that’s not the way to do that!”</td>
<td>Use a positive approach: “Let’s see if we can figure out a better way to do that.”</td>
</tr>
<tr>
<td>Make Demands</td>
<td>Use Requests</td>
</tr>
<tr>
<td>Give general instructions: “Do it!” or “Cut it out!”</td>
<td>Specify exactly what is to be done or not done: “Laurel, please turn off the T.V. so we can set the table.” or “Marilyn, be quiet in church.”</td>
</tr>
<tr>
<td>Let your annoyance or anger show in your voice: “Will you please knock it off and get over here!”</td>
<td>Be matter-of-fact “Sue, stop hitting. Come over here please.”</td>
</tr>
<tr>
<td>Make promises that you can't keep.</td>
<td>Follow through consistently.</td>
</tr>
</tbody>
</table>

Summary

Behavior that makes family life unpleasant can stress relationships. With a functional assessment, the cause of the behavior can be identified and planned teaching can help the person replace behaviors that are not appropriate or functional. Support staff are change agents and role models to parents and siblings. Using effective teaching methods and holding positive values about behavior changes are essential.
Study Questions Chapter 8

T or F 1. Consistent follow through is an effective method for dealing with challenging behaviors.

T or F 2. When shaping or refining behavior, it is not necessary to provide positive feedback after each step.

T or F 3. Challenging behaviors always serve a purpose or have a pay-off for the person who is exhibiting them.

T or F 4. Sometimes it is appropriate to ignore a person’s challenging behaviors.

5. An __________ __________ of behavior provides information to the team on what occurs before and after a specific behavior.

6. __________ __________ supports teach the child to get what he/she needs using ways that are helpful and safe.

7. In a behavior support plan, it is necessary to determine the __________ for the inappropriate behavior.

8. Matching: Match each term with its definition.

_____ Consequence a. What happens before the behavior

_____ Behavior b. Serves to strengthen a behavior

_____ Antecedent c. What happens after the behavior

_____ Reinforcement d. What the person does that is disruptive, harmful, self-injurious, or interferes with learning

9. Place an X by each item that is an antecedent for inappropriate behavior.

_____ Verbal cue “It’s time to go to work.”

_____ A disliked activity

_____ Hitting

_____ A difficult task

_____ Spitting

_____ Timer going off signaling it’s time to clean up

_____ Kicking
10. You are providing in-home supports for a young woman with Autism. When it’s time to prepare dinner, Lesley becomes very agitated. When you ask her to turn off the TV and come to the kitchen, she begins to swear and scream. You continue to prompt her to come to the kitchen to make dinner. Lesley’s swearing and screaming escalates. You try to get Lesley to calm down by ignoring her. She swears and screams even louder. Because she is upsetting the other individuals that you are supporting, you tell Lesley to go back to the family room and to stay there until she calms down. When Lesley goes into the family room, she turns the TV back on and finishes watching her show.

List three potential purposes/pay offs that the challenging behaviors are serving for Lesley in the above scenario.

11. An appropriate method for addressing challenging behaviors is __________.
   a. Stating instructions in a negative way.
   b. Saying “Do it because I said so.”
   c. Making demands
   d. Specifying exactly what is to be done or not done
Chapter 9: Documentation

Chapter Objectives

- Write an objective progress note related to the support activity.
- List four kinds of information that should be documented.
- Identify who should receive confidential information.

Imagine the problems created when important events, statements, directions, or facts are not recorded. Have you ever tried to recall an event and forgotten all or part of the details? With the amount of information we receive in a day, it is easy to remember only things that are important to us personally. When providing support services to people who rely on our expertise and commitment, it is vital to document and to record information that is useful to parents, therapists, and other support workers. Keeping records is important for several reasons. Written information provides:

- A record of events that may be more accurate than individual memories.
- Accountability for funding agencies and surveyors.
- Information that is useful in planning.
- A baseline and data showing progress towards goals and objectives.
- A way to ensure consistency across time.

There must be a balance between the document needed to provide quality supports and what the family considers important and/or confidential. Each family and provider has different priorities. This means that documentation and record keeping requirements will look different across service providers and families.

Types of Documentation

In order for you to provide services that meet company policy, it is necessary that the following records be available:

- Individualized Support Plan (Person-Centered Plan; Essential Lifestyle Plan).
- Directions for behavioral support, medical condition(s) or treatment(s), or reoccurring events (e.g., range of motion exercises, personal care routine).
- Phone numbers (parent's work, school, hospitals, doctors).
- Log notes or progress notes.
- Medications and schedule for administration (according to agency policy).

The Individual Support Plan should provide information on priority supports. The goals, objectives, and preferences should be written in the plan and stored where the staff can refer to them. Staff may be required to record data on objectives or document when a service or activity was provided. Staff should have the opportunity to review objectives, strategies, and activities
that have been tried in the past. New staff members need to read the document to be familiar with the purposes of activities and priorities of the family.

Arrangements, directions, or protocol for handling certain events or circumstances should be easily accessible and reviewed by the family and staff periodically for accuracy. Directions for the following are helpful:

- Personal care routines.
- How and when to give medications (depending on agency policy and family preference).
- Medical treatments.
- What to do when a seizure occurs.
- How to use or apply an orthotic device.
- How a special assistive device (e.g., wheelchair, electronic communication device) is used.
- Family rules for siblings and the member with a disability.
- Any special positioning and transferring techniques.

This is not an inclusive list as families and circumstances will dictate the need for what is written and communicated to support staff.

**Log Notes/Progress Notes**

The extent of documentation of daily events, training, observations, and support provided will vary in support settings depending on the family preferences, the individual receiving services, and agency policies. In some situations, very little written documentation will be required. However, if multiple staff provide extensive in-home support to the family, written communication becomes an important part of ensuring quality and consistent support.

Progress or log notes provide a snapshot of the child's activities and routines. These notes are short, factual descriptions to share information between support staff. They are also written to document any out of the ordinary occurrences. The narratives include the day, time of day, location, and description of actions or events, outcomes, and any follow-up plans. These notes are not intended to exchange opinions or emotional responses to events. Progress notes are considered legal documents. Avoid the use of jargon, abbreviations, or symbols. A note should be written once per visit by staff. Use black ink, neat and legible handwriting or printing, and include the first name of the family member receiving services but only use initials of others that may be included in the log note. Date progress notes with the month, day, year and sign your name. Progress notes can include:

- Comments related to the support plan goals and objectives.
- Documentation of activities at the home or in the community.
- Special healthcare concerns or medication changes.
- Changes in status (family vacations, illnesses, extended family visits).
- Follow-up actions regarding significant events.
- Unusual situations or circumstances.
Because progress notes could be used as legal documents, it is important to be able to see the "who, what, and when" in entries. Corrections must be made with ink and error’s identified with a line drawn through the word or number with "error" written by the mistake with the staff person's name and date (see below). Ink eraser or white out should not be used to correct mistakes. An addendum can be added to an entry by writing "addendum to" with the date of the original entry.

3-5-05

Today John was able to fully dress himself with very little physical help. He chose what he wanted to wear and what he wanted to eat. John was very alert this evening and he only needed one prompt to get up and dressed. A.S. commented that he was good this morning. I noticed a red area on his forearm and wrist. I notified the parent about this.

Richard Seabright 3-5-05
9:15 AM

Communication Between Family and Staff

Families may prefer to verbally relay all information or they may prefer that staff write anything important in a notebook. Effective communication is the key. If information is lost, or safety is compromised because someone forgot to relay information, then communication methods may need to be revised. Things that staff and family should communicate are:

- Changes in schedules (family and support staff).
- Scheduled medical appointments.
- Changes in medications or treatments.
- Visiting family or friends.
- Repair people that may be in the home.
- Activities and reminders about activities.
- Pet issues.
- Sibling issues.
- School issues that affect support staff.
- Transportation arrangements.
- Medical or behavioral concerns.

Confidentiality

Keeping information confidential is a legal and ethical expectation of any service provider. Keeping information confidential contributes to the success and integrity of the services provided. Information in both written and verbal forms should only be shared with those who "need to know". Need to know means that the person has to have the information in order to provide services to the family. Information should never be shared with friends or people who are not giving services to that family. Confidentiality can also be broken when papers with family information are kept in places where others can read it. It is important to keep written information locked or in places not easily accessed by those who do not have permission or a “need to know” the information.

Summary

Written information is a tool to use to provide services to the family. It provides memory, accountability, direction, continuity, and assists in planning. Any documentation and communication with family should be for the purposes of providing quality services. Log notes or progress notes should be written objectively and could be used in legal proceedings. Any information between family and staff is confidential and should only be shared with those people who need to know the information to perform their job or provide support.
Study Questions Chapter 9

T or F 1. When providing in-home support to a child with cerebral palsy who uses a wheelchair, it is not necessary for staff to be familiar with any special positioning and transferring techniques.

T or F 2. The individual support plan provides a list of the families prioritized goals and objectives.

T or F 3. It is not necessary for in-home support staff to have documentation of how to do treatments or use special equipment before beginning to work with a family.

T or F 4. It is appropriate for staff to express their opinions in progress notes to parents.

T or F 5. Before providing in-home support to a child with epilepsy, it would be important to know how and when to administer medications.

T or F 6. When shaping and refining behavior, it is not necessary to provide feedback following each step.

7. Confidential information should only be given to people who “_________ __________ __________” in order to provide services to a family or child.

8. Progress/log notes provide a __________ of the child’s activities and routines.

9. Provide two reasons why it is important to keep written records of information when providing support services to individuals with disabilities.

10. Identify three things that should be communicated between staff members and families.

11. List three components that should be included in the narrative of a progress or log note.

12. Identify two records that should be available in order to provide services that meet company policy.
Study Question Answers

Chapter 1

T or F 1. Families with a member that has a disability need support so they can challenge the current system of services.

T or F 2. Creating a desirable and productive environment for their child’s development is one reason that families with a member that has disabilities need support.

T or F 3. It is important to support families with a member that has a disability so that the family can have time away from their children without disabilities.

T or F 4. Ensuring that support providing agencies have employees is the most important reason for supporting families who have a member that has a disability.

5. A family is a provider of food, shelter, and love.

6. The condition of families in a community is a reflection of the strengths and weaknesses of that community.

7. Families typically ask for informational, practical, and emotional support.

8. List five services that North Dakota offers as part of its Family Support Services Program.

   - Support in caregiving tasks that assist the primary caregiver
   - Respite from the responsibility of being a primary caregiver
   - Support to older adolescents living on their own
   - Instruction to the child with a disabilities to do personal care tasks in their home
   - Opportunity for the child with a disability to live in a licensed family home

Chapter 2

T or F 1. One of the challenges that parents face as they provide a home for a child with a disability is financial.

T or F 2. Judgmental attitudes of extended family and friends are not a challenge for parents who are raising a son or daughter with disabilities.

T or F 3. Families who have a child with disabilities may encounter fragmented service systems.
4. Siblings are never embarrassed by their brother or sister who has disabilities. 

5. Siblings may feel cheated if their parents spend a significant amount of time with their brother or sister who has a disability.

6. For fathers, information about their child’s disability is the most important issue.

7. Fathers and mothers have the same perspective on the impact a disability in the family may have.

8. When raising a child with disabilities, all families are __________.
   a. the same
   b. dysfunctional
   c. different
   d. doomed to fail

9. When raising a child with disabilities, fathers are more likely to __________ (as compared to mothers):
   a. worry less about finances
   b. feel a sense of stigma
   c. worry less about information
   d. feel that their most important need is patience

10. Family members face many cycles of love and loss as they raise a child who has disabilities.

Chapter 3

1. Enhancing the services system to serve families who have a child with a disability is the primary goal of Family Support Services.

2. In family-centered services, the primary focus is on the child’s deficits.

3. Serving the person with a disability through actions that support the well-being of the whole family is the goal of Family Support Services.

4. Helping families keep their children in the family home is one outcome of family support.

5. Providing links to economic resources is not one of the Personal Outcome Measures for families with young children.

6. One of the outcomes of family supports is supplying families with information that will aid them in making decisions.
T or F  7. Medical professionals should not be involved in creating support plans for families.

T or F  8. Schools should be involved in developing support plans for families who have a child with disabilities.

9. As a Personal Outcome Measure for families with young children, children are free from abuse and neglect.

10. One of the outcomes of family supports is that families remain connected to natural supports.

11. The document that specifies the number of hours a family will need for support is a(n) __________.
   a. 504 plan
   b. individualized education plan
   c. service contract
   d. family assessment

12. An issue that should be discussed with a family before providing support services is __________.
   a. Allergies
   b. involvement of non-custodial parents
   c. finances
   d. education

Chapter 4

T or F  1. Caregiver’s limited experience with a particular disability is one reason that parents may distrust in-home support staff.

T or F  2. In developing trust with families, it is important for in-home support providers to learn all they can about the child’s disability.

T or F  3. In order to create trusting relationships with parents, caregivers should wait at least one day before addressing problems that arise with a child so that they don’t upset the parents.

T or F  4. If caregivers do not respect the confidential nature of in-home support, it may be difficult for staff to create a trusting relationship with families.
5. Place an X next to reasons why parents may be distrustful of caregivers and hesitant to allow others to care for their child with disability
   ____X__ Parents believe that caregivers are inadequately trained
   ________ Parents believe that caregivers are overqualified
   ____X__ Parents believe that it’s too much effort to develop relationships with caregivers who will come and go in their lives
   ________ Parents believe that others are just as capable of caring for their child as they are

6. In-home support providers can help dispel family mistrust and negative expectations by __________.
   a. Scheduling time with the family when it’s convenient for the staff
   b. Canceling appointments with the family at the last minute
   c. Fitting the family into the available services
   d. Providing stability for families by hiring committed staff

7. To create a trusting relationship with families, it is important for in-home support staff to __________.
   a. Respect the confidential nature of in-home support
   b. Offer babysitting services
   c. Provide housekeeping assistance
   d. Stick to the original schedule proposed by the agency

Chapter 5

T or F 1. Staff may be hesitant to report abuse, neglect, or exploitation because they fear the parents may retaliate against them or the child.

T or F 2. Sometimes the home environment changes when abuse, neglect, or exploitation are reported.

T or F 3. Staff who report abuse, neglect, or exploitation are always identified to the perpetrator.

T or F 4. A police investigation is mandatory when child abuse, neglect, or exploitation is reported.

T or F 5. In-home support professionals are not mandated to report abuse, neglect, or exploitation.

T or F 6. Reporting suspected child abuse, neglect, or exploitation is intended to protect the rights of the parents.
T or F 7. Staff who report alleged abuse, neglect, or exploitation are never required to write a description of the incident.

T or F 8. Sometimes reporting child abuse, neglect, or exploitation prevents further maltreatment from occurring in the home.

T or F 9. If a caregiver does not provide a safe environment for a person with a developmental disability, it is considered exploitation.

T or F 10. Rape or sexual assault of a person with a developmental disability is an example of abuse.

11. Neglect is the failure by a caretaker to meet any statutory obligation, court order, administrative rule, regulation, policy, procedure, or minimally accepted standard.

12. An in-home support staff is considered a caregiver.

13. Neglect is when a caregiver fails to provide adequate nutrition, clothing, or health care to a person with developmental disabilities.

14. Exploitation is the use of a person with developmental disabilities for the entertainment or sexual gratification of others.

15. Alleged abuse, neglect, or exploitation must be reported either internally or externally to the Protection and Advocacy Project.

16. Corporal punishment or striking a person with a developmental disability is a type of abuse.

17. An example of abuse is a caregiver’s willful use of offensive, abusive, or demeaning language that causes a person with developmental disabilities to have mental anguish.

Chapter 6

T or F 1. An appropriate recreation activity for a five year old male with developmental disabilities is playing video games that are rated PG-13.

T or F 2. When a child with developmental disabilities plays on a t-ball team with kids who don’t have disabilities, it is an example of inclusion.

T or F 3. Watching Sesame Street is an appropriate free-time activity for a fifteen year old girl with developmental disabilities.
4. When a child with developmental disabilities selects which outfit to wear to a birthday party, it is an example of making choices.

5. Activities that support staff teach should be based on family priorities.

6. Two types of skills that in-home support staff may be expected to teach include academic and functional.

7. Matching: Match each term with its definition.

- **d** Self-determination: a. Offering opportunities to select between options and live with the consequences of that decision.
- **a** Choice: b. Using tone of voice, activities, toys, books, and games that match the chronological age of the child or person.
- **e** Inclusion: c. Participating in a group, activity, or community event that also includes people without disabilities.
- **b** Age-Appropriate: d. Making healthy choices and controlling one’s life; skills that help a person to be assertive and to advocate for what they need.

**Chapter 7**

- **T or F** 1. After hand washing, a single use towel should be used to dry hands.
- **T or F** 2. Clothing that is contaminated with blood can be washed with other laundry as long as it is washed in hot water.
- **T or F** 3. It is not necessary to wear gloves when handling laundry that has been contaminated with excrement.

4. List three times when hand washing should occur.
   - After using the toilet or assisting someone with bathroom or personal care activities
   - Before and after preparing food
   - Before and after administering medications
   - Immediately after contacting blood or any bodily fluids

5. List five symptoms of an allergic reaction.
• Skin rash
• Diarrhea
• Itching
• Watery eyes
• Discharge from nose
• Nausea
• Irritability
• Difficulty breathing

6. List four ways to break the infectious disease cycle.
   • Hand washing
   • Using protective barriers
   • Preventing accidental cuts or sticks from used needles
   • Cleaning and disinfecting surfaces
   • Using correct procedures for contaminated laundry

7. Name three times when it is not necessary to call an ambulance when someone is having a seizure.
   • If it is known that the child has epilepsy
   • The seizure ends in the amount of time that is typical for the child’s seizure activity
   • If consciousness returns without further incident
   • If there are no signs of injury or physical distress

8. List five basic principles of positioning, turning, and transferring.
   • Respect the person’s dignity and privacy.  Tell or ask them if they would like to move or be repositioned.  Complete the movement with as much privacy as possible.
   • Use slow, smooth movements when moving body parts
   • Support the head, shoulders, and trunk before moving arms and legs
   • Encourage participation and independence
   • Give verbal instructions and touch the person to reinforce desired movements
   • Use adaptive equipment for stabilization
   • Promote symmetric alignment (in which the head is centered and upright above the body, the spine is straight, and the arms and legs are balanced on either side of the body)
   • Reposition a person a minimum of every two hours (unless otherwise specified by a physician or therapist)

9. Hand washing is the most effective way to prevent the transmission of infectious diseases.

10. During hand washing, it is important to rub hands together for at least 20 seconds.
11. To avoid accidental cuts, needles used for insulin shots should be discarded in a puncture resistant container.

12. A severe allergic reaction that can be life threatening is also known as anaphylactic shock.

13. Giving medications on time means that the medication can be given within one hour before and one hour after the time specified by the doctor.

14. When a child is sick, staff may observe which symptom?
   a. Mouth, gum, teeth, and breath odor
   b. Changes in breathing, pulse, or temperature
   c. Lack of appetite
   d. All of the above

15. Basic positioning principles include;
   a. Using quick movements to make the transfer easy.
   b. Pulling into position instead of pushing.
   c. Providing support to the head, shoulders, and trunk before moving arms and legs.
   d. Using deep pressure when positioning.

16. Matching: Match each term with its definition.
   ____b__ Response Time  a. Effects produced by the medication other than for which it was prescribed.
   ____c__ Desired Effects b. The amount of time that should pass between taking the medication and the desired effects.
   ____a__ Side Effects c. What we want the medication to accomplish.

17. Place an X by each step that should be completed by a person who is disinfecting a contaminated surface.
   ____X__ Wear gloves
   ____X__ Place a paper towel over the spill and wipe it up
   ______ Reuse the paper towel for additional spills
   ____X__ Throw away contaminated paper towels in the garbage can
   ____X__ Scrub the surface with a disinfectant
   ______ Reuse gloves while scrubbing additional surfaces
   ____X__ Wash hands after clean-up is completed
Chapter 8

T or F 1. Consistent follow through is not an effective method for addressing challenging behaviors.

T or F 2. A reinforcer should be meaningful for the person who is receiving it.

T or F 3. Challenging behaviors always serve a purpose or have a pay-off for the person who is exhibiting them.

T or F 4. It is never appropriate to ignore a person’s challenging behavior.

5. An **ABC analysis** of behavior provides information to the team on what occurs before and after a specific behavior.

6. **Positive behavior supports** teach the child to get what he/she needs using ways that are helpful and safe.

7. In a behavior support plan, it is necessary to determine the reason for the inappropriate behavior.

8. **Matching:** Match each term with its definition.

   __c__ Consequence  
   __d__ Behavior  
   __a__ Antecedent  
   __b__ Reinforcement

   a. What happens before the behavior  
   b. Serves to strengthen a behavior  
   c. What happens after the behavior  
   d. What the person does that is disruptive, harmful, self-injurious, or interferes with learning

9. Place an X by each item that is an antecedent for inappropriate behavior.

   X Verbal cue “It’s time to go to work.”  
   X A disliked activity  
   X Hitting  
   X A difficult task  
   X Spitting  
   X Timer going off signaling it’s time to clean up  
   X Kicking
10. You are providing in-home supports for a young woman with Autism. When it’s time to prepare dinner, Lesley becomes very agitated. When you ask her to turn off the TV and come to the kitchen, she begins to swear and scream. You continue to prompt her to come to the kitchen to make dinner. Lesley’s swearing and screaming escalates. You try to get Lesley to calm down by ignoring her. She swears and screams even louder. Because she is upsetting the other individuals that you are supporting, you tell Lesley to go back to the family room and to stay there until she calms down. When Lesley goes into the family room, she turns the TV back on and finishes watching her show.

List three potential purposes/pay offs that the challenging behaviors are serving for Lesley in the above scenario.

- Attention from staff
- Attention from others who are being supported
- Escape from a task that is difficult or unpleasant for Lesley
- Access to the TV show that Lesley was asked to stop watching when it was time to prepare dinner

11. An appropriate method for addressing challenging behaviors is __________.
   a. Stating instructions in a negative way
   b. Saying “Do it because I said so.”
   c. **Making demands**
   d. Specifying exactly what it so be done or not done

**Chapter 9**

**T** or **F** 1. When providing in-home support to a child with cerebral palsy who uses a wheelchair, it is not necessary for staff to be familiar with any special positioning and transferring techniques.

**T** or **F** 2. The individual support plan provides a list of the families prioritized goals and objectives.

**T** or **F** 3. It is not necessary for in-home support staff to have documentation of how to do treatments or use special equipment before beginning to work with a family.

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**T** or **F** 5. Before providing in-home support to a child with epilepsy, it would be important to know how and when to administer medications.

**T** or **F** 6. When shaping and refining behavior, it is not necessary to provide feedback following each step.
7. Confidential information should only be given to people who “need to know” in order to provide services to a family or child.

8. Progress/log notes provide a snapshot of the child’s activities and routines.

9. Provide two reasons why it is important to keep written records of information when providing support services to individuals with disabilities.
   - May be more accurate than individual memories
   - Accountability for funding agencies and surveyors
   - Planning
   - Baseline and data showing progress toward goals and objectives
   - Ensure consistency over time

10. Identify three things that should be communicated between staff members and families.
    - Medical or behavioral concerns
    - Schedule changes
    - Medical appointments
    - Changes in medications or treatments
    - Visiting family or friends
    - Repair people that may be in the home
    - Activities and reminders about activities
    - Pet issues
    - Sibling issues
    - School issues that affect support staff
    - Transportation arrangements

11. List three components that should be included in the narrative of a progress or log note.
    - Date
    - Time of day
    - Location
    - Description of actions or events
    - Outcomes
    - Follow-up plans

12. Identify two records that should be available in order to provide services that meet company policy.
    - Individualized Support Plan (Person-Centered Plan; Essential Lifestyle Plan)
    - Directions for behavioral support, medical condition(s) or treatment(s), or reoccurring events (e.g., range of motion exercises, personal care routine)
    - Phone numbers (parent's work, school, hospitals, doctors)
    - Log notes or progress notes Outcomes
    - Medications and schedule for administration (according to agency policy)
References


The purpose of your IPP is to set goals for you and your child for the next year. The following are some areas that may be of concern for your child. If your child has needs in any of these areas what can CLS staff do to assist you?

1. Does your child have any delays in speech and language?

2. Does your child need assistance in fine motor skills, such as picking up items, coloring/writing, eating etc.?

3. Does your child need assistance in gross motor skills such as walking, sitting, jumping, or range of motion?

4. Does your child need assistance in personal cares such as dressing, bathing, grooming, toileting, or eating?

5. Are there any social skill concerns for your child, such as interacting with others, environment, or participation in activities?

6. Does your child have nutritional concerns? (special diet, allergies, likes or dislikes)

7. Does your child take any medications? Is there any special routine or method in giving the medications?

8. Does your child have a behavior plan? Are there any special things that calm or aggravate your child?

9. Does your child have any special equipment?

10. Does your child have any special interests?

11. Are there any needs that your child has that we have not discussed that CLS staff can assist you with?
Service Delivery Form – Children’s Services
Community Living Services, Fargo, ND

Name____________________________    Parents/Guardian________________________

Address__________________________     Address______________________________

Home Phone:_____________________      Cell_____________work________________

**Personal Information**

Primary Diagnosis___________________  Secondary Diagnosis____________________

Date of Birth_____________  Sex_________  Height_____________________________

Weight_________________  Eye color_____  Hair Color_________________________

Identifying Marks______________________  Special Interests_____________________

Sibling Information________________________________________________________

**Emergency Information**

Emergency contact_____________________  Emergency Contact____________________

Relationship to child____________________  Relationship________________________

Address_______________________________  Address__________________________

Phone________________________________  Phone____________________________

Doctor_______________________________Phone___________Insurance___________

Hospital_____________________________Phone___________MA____________________

Dentist______________________________Phone________________________

Emergency Evacuation Plan (where to go in case of fire or tornado)_________________
Is there anyone restricted from your residence when staff are working?____________________

____________________________________________________________

Allergies___________________________ Medications___________________________

Special instructions________________________________________________________

**Other Services**

School _______________  Speech Therapist_______________________

Teacher_______________  Phone ________________________________

DDCM_______________  Occupational Therapist________________

Phone_______________  Phone ________________________________

Psychologist___________  Psychiatrist_________________________

Phone_______________  Phone ________________________________

Other helping agencies and phone numbers____________________________________

____________________________________________________________
My Child and Family

Completing this page may help you identify some of your strengths, concerns, and priorities. You may choose to share your responses with other members of the team, or use the information as “food for thought.”

1. A description of our family (parents, brothers and sisters, grandparents, special friends and relatives) includes: _______________________________________

2. What we enjoy doing as a family is
   During these times together my child ____________________________

3. My child’s favorite activity is ____________________________
   Because ________________________________________________

4. My child’s least favorite activity is ____________________________
   Because ________________________________________________

5. What I enjoy most about my child is ____________________________

6. What my child and I enjoy doing the most is ____________________________

7. I am most frustrated when caring for my child when ____________________________

8. My child lets me know when he/she needs something by ____________________________

9. I could do more for my child if I had
   (transportation, someone to talk to, time to myself, time for the other children, help with expenses, housing, etc.)

10. Some change or progress I’ve recently noticed in my child is ____________________________

11. Some of my hopes and dreams for my child in the next six months are:
   Independence ____________________________________________
   Movement ____________________________________________
   Social ______________________________________________
   Communication _________________________________________
   Services & supports needed ____________________________

12. How my family, friends or I can help my child do these things:

13. Some of my hopes and dreams for my family are ____________________________
    Things we can do together ____________________________
    What I can do with individual children ____________________________
    Things just for my partner and me ____________________________
    Supports & services needed ____________________________
BEACH CENTER ON DISABILITY

Family-Professional Partnership
Professional Self-Assessment

Based on the Beach Center
Family-Professional Partnership Scale
Family-Professional Partnership Self-Assessment for Professionals

The purpose of this self-assessment is to assist professionals to look at their practice and identify possible barriers and facilitators to their ability to have positive family-professional partnerships.

Below are the individual items based on the Family-Professional Partnership Scale that is used with families to assess their satisfaction with their child’s and family’s services and partnerships with professionals.

For each item, evaluate your current skills and attitudes and give yourself a score between 1 and 10, with 10 being the best. Then, think about and identify what helps you demonstrate the attitude or skill that the item represents. Also identify what hinders (gets in your way) of demonstrating the attitude or skill.

1. I help parents gain the skills or information to be able to get what their child needs (provide training to parents, help parents access information on resources).

<table>
<thead>
<tr>
<th>Score</th>
<th>What Helps</th>
<th>What Hinders</th>
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2. As a professional, I have the skills to help children succeed (have basic competencies, engage in continuous learning to gain new information and skills, hold high expectations for the child’s achievement and provide meaningful opportunities for him or her to succeed).

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3. I provide services that meet the individual needs of each child (know how to individualize instructional or treatment techniques to accommodate the child’s strengths and needs).

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</table>
Family-Professional Partnership Self-Assessment for Professionals

4. I speak up for children’s best interests when working with other service providers (advocate with other programs or professionals on behalf of a child or family).

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<th>Score</th>
<th>What Helps</th>
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5. I let parents know about the good things their children do.

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6. I treat children with dignity at all times (value children as persons, shield children from humiliating or embarrassing situations).

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7. I build on children’s strengths (use a strengths perspective to set objectives or outcomes).

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October 2003
Family-Professional Partnership Self-Assessment for Professionals

8. I am honest with parents, even when I have bad news (honesty both in terms of children’s needs/disabilities, and in terms of program/resource limitations, do not claim to know something when we don’t).

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9. I keep children safe at all times when in our care.

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10. I am available when parents need me (emergency evening or weekend access, dependable availability during posted hours, reliably accessible to families by phone or in person, willing to come to their home).

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11. I value parents’ opinions about children’s needs (ask parents their opinions, incorporate parents’ points of view in outcomes and instructional or service strategies).

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12. I use words that the parent understands (avoid jargon, take time to explain).

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<th>Score</th>
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<th>What Hinders</th>
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13. I protect the family's privacy (maintain confidentiality with other programs, avoid "gossip" about families).

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14. I show respect for the family's values and beliefs.

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15. I listen without judging the child or family.

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<th>What Helps</th>
<th>What Hinders</th>
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Family-Professional Partnership Self-Assessment for Professionals

16. I am dependable (follow through on commitments or promises).

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<th>Score</th>
<th>What Helps</th>
<th>What Hinders</th>
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</table>

17. I pay attention to what parents have to say (listen actively, demonstrate respect for parent's comments, demonstrate belief/respect parent's observations about the child).

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<th>What Helps</th>
<th>What Hinders</th>
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</table>

18. I am friendly to parents (maintain a welcoming and friendly atmosphere).

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<th>What Helps</th>
<th>What Hinders</th>
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DEVELOPING A PARTNERSHIP MODEL
SELF-ASSESSMENT

The Partnership Model is a model for developing parent-professional partnerships. It uses a strength-based approach to building relationships with families and assumes that:
- Programs are designed with a prevention/promotion approach
- Parents want what is best for their children; therefore, families, educators and social service workers share their expertise with each other
- Knowledge is shared and building trust is the foundation of successful planning
- The family is a system whose concerns must be addressed through a comprehensive approach
- The environment around the family must be supportive and empowering
- Family members participate in developing goals and action plans

Partnership groups including representatives from education, human services, families and community members should use this self-assessment form as a springboard for discussion, not as an evaluation of programs. When each question is discussed, partners members can talk about what this would look like in their school or agency. Each member should use his/her own expertise and experience to inform their rating and feel free to add guidelines as they arise.

Directions: Think about the family activities, interactions and physical attributes of your school or agency. Rate your school or agency by writing the number in the rating box next to each statement. Space is included for examples of each statement to support your rating.

<table>
<thead>
<tr>
<th>Rating Scale: 1 = No  2 = Developing  3 = Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Steps in active partnership development. Our organization creates a climate through policy and support that:</strong></td>
</tr>
<tr>
<td>a. Is positive and proactive in communicating with families and demonstrates acceptance, support, and cooperative intentions</td>
</tr>
<tr>
<td>b. Provides staff time to develop rapport with families</td>
</tr>
<tr>
<td>c. Encourages two-way information exchanges between families and staff; is open to sharing of information and ideas</td>
</tr>
<tr>
<td>d. Acknowledges and values the expertise and knowledge of parents</td>
</tr>
<tr>
<td>e. Encourages teachers, services providers and families to support each other in respective roles</td>
</tr>
</tbody>
</table>
2. **Building on family strengths and capacities. Teachers and service providers:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>a.</td>
<td>Recognize and emphasize the positive aspects of the families we work with</td>
</tr>
<tr>
<td>b.</td>
<td>Reframe problems as goals to be addressed with families</td>
</tr>
<tr>
<td>c.</td>
<td>Offer information, resources, and support rather than solutions, causes, or blame</td>
</tr>
<tr>
<td>d.</td>
<td>Model the attitude that “everyone knows something and no one knows everything”</td>
</tr>
<tr>
<td>e.</td>
<td>Are respectful of and knowledgeable about the family’s perspective, including the family’s culture, values and structure</td>
</tr>
<tr>
<td>f.</td>
<td>Help families to see themselves as competent, promote strengths</td>
</tr>
</tbody>
</table>

3. **Collaborative Activities and Atmosphere. Our organization creates an environment and climate in which teachers and service providers:**

<p>| | |</p>
<table>
<thead>
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</thead>
<tbody>
<tr>
<td>a.</td>
<td>Collaborate using the parent’s and professional’s information, and engage in joint information-sharing activities with families—each learning from the other</td>
</tr>
<tr>
<td>b.</td>
<td>Carry out activities and projects together with families</td>
</tr>
<tr>
<td>c.</td>
<td>Support families in identifying their goals, needs and priorities; trust parents to decide what is best for their family</td>
</tr>
<tr>
<td>d.</td>
<td>Empower families to make informed decisions by providing necessary information and guidance</td>
</tr>
<tr>
<td>e.</td>
<td>Work on families’ agendas first, prior to professional concerns</td>
</tr>
<tr>
<td>f.</td>
<td>Engage families in identifying and utilizing community resources and their informal support network (e.g. family, friends, neighbors, church groups, etc.)</td>
</tr>
<tr>
<td>g.</td>
<td>Participate in joint decision-making with family members</td>
</tr>
<tr>
<td>h.</td>
<td>Advocate for/with families</td>
</tr>
</tbody>
</table>

Family Quality of Life
Conversation Guide

Developed by the Beach Center on Disability,
University of Kansas,
in partnership with
families, service providers, and researchers

This conversation guide was developed based on the Beach Center Family Quality of Life Survey. The conversation questions relate to the items on the survey. You can use this guide as a way to generally get to know families, or as a way to identify priorities for supports and services.

You might start with an introduction and tell the family that one of your goals is to support their child and the family as a whole to have a high quality of life. By quality of life we mean:

- the family’s needs are met,
- family members enjoy their life together as a family, and
- family members have the chance to do things that are important to them.

Then, you could use each of the questions below to facilitate a conversation. For each item you could ask them to tell you how important that item is for them and how satisfied they are. You could indicate an L, M, or H for low, medium, or high levels of importance and satisfaction. Then you might ask if there is something they would like support from you in order to make things better. These might be priorities for IEP development, or you could provide specific information pertaining to their needs. Again you can indicate a L, M, or H for the priority for providing information or support. After the parents respond, you might take the opportunity to ask them to tell you more about that item, or why they answered in a specific way. There is a space after each set of items for notes.
### Family Interaction

<table>
<thead>
<tr>
<th>Item</th>
<th>Importance</th>
<th>Satisfaction</th>
<th>Priority for Support</th>
<th>Info</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spending time together as a family</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Talking opening with each other</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Solving problems together</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Supporting each other to accomplish goals</td>
<td></td>
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</tr>
<tr>
<td>Showing that you love and care for each other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Handling life's ups and downs</td>
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</table>

Notes: (dreams, concerns, priorities)
<table>
<thead>
<tr>
<th>Item</th>
<th>Importance</th>
<th>Satisfaction</th>
<th>Priority for Support</th>
<th>Info</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helping your children learn to be independent</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Helping your children with schoolwork and activities</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Teaching your children how to get along with others</td>
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<td></td>
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<tr>
<td>Teaching your children to make good decisions</td>
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<td></td>
<td></td>
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<tr>
<td>Knowing other people in your children’s lives</td>
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<tr>
<td>Having time to take care of the individual needs of every child</td>
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Notes: (dreams, concerns, priorities)
Physical/Material Well-Being

<table>
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<tr>
<th>Item</th>
<th>Importance</th>
<th>Satisfaction</th>
<th>Priority for Support</th>
<th>Info</th>
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</thead>
<tbody>
<tr>
<td>Having transportation</td>
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<tr>
<td>Having a way to take care of your expenses</td>
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<tr>
<td>Feeling safe at home, work, school, and in the community</td>
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<tr>
<td>Getting medical care when needed</td>
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<tr>
<td>Getting dental care when needed</td>
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Notes: (dreams, concerns, priorities)
## Emotional Well-Being

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<th>Item</th>
<th>Importance</th>
<th>Satisfaction</th>
<th>Priority for Support</th>
<th>Info</th>
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<tbody>
<tr>
<td>Having the support needed to relieve stress</td>
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<tr>
<td>Having friends or others who provide support</td>
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<tr>
<td>Having time to pursue personal interests</td>
<td></td>
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<tr>
<td>Having help from outside the family to take care of the individual needs of each family member</td>
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Notes: (dreams, concerns, priorities)
Disability-Related Supports

<table>
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<tr>
<th>Item</th>
<th>Importance</th>
<th>Satisfaction</th>
<th>Priority for Support</th>
<th>Info</th>
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</thead>
<tbody>
<tr>
<td>Having support for your child to make progress at school or workplace</td>
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<td></td>
<td></td>
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<tr>
<td>Having support for your child to make progress at home</td>
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<tr>
<td>Having support for your child to make friends</td>
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<tr>
<td>Having a good relationship with service providers who work with your child</td>
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</table>

Notes: (dreams, concerns, priorities)
Matrix for interpreting the Beach Center Family Quality of Life Conversation Guide

<table>
<thead>
<tr>
<th></th>
<th>Low Importance</th>
<th>Medium Importance</th>
<th>High Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medium Satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low Satisfaction</td>
<td></td>
<td></td>
<td><strong>Shaded</strong></td>
</tr>
</tbody>
</table>

Target the areas of high importance and low satisfaction (shaded area) for intervention or support.
### Example action plan

**Domain:** Emotional Well-Being  
**Indicator:** My family members have friends or others who provide support.

<table>
<thead>
<tr>
<th>Dreams</th>
<th>Concerns</th>
<th>Nightmare</th>
<th>Support Wanted</th>
<th>Key People</th>
<th>Next Steps</th>
</tr>
</thead>
</table>
| - For Jim to have good friends whom he can talk to about his concerns  
- For AJ to have friends he can do activities with  
- For Denise to have more friends to turn to for instrumental support | - Jim has few friends and he often alienates those friends by his behavior  
- At Jim’s age, it is unusual to share intimate concerns with peers  
- Most of AJ’s friendships are from paid supports and are with people older than himself  
- Denise relies almost solely on paid support for AJ. She would like to develop more natural supports | - All of the family members become more isolated.  
- AJ loses paid support and Denise has no natural supports to turn to.  
- AJ’s behavior becomes worse because he doesn’t have friends and is isolated.  
- Jim becomes extremely depressed due to lack of friendships or becomes friends with kids who do not make good choices. | - Jim continues to have support need to build his social skills.  
- Jim stays connected with his friends in KS.  
- Jim makes new friends in TX (join church and acting group).  
- At school to participate in some extracurricular activity where he can build friendships  
- AJ’s PAs facilitate a friendship group for AJ after school.  
- Denise takes the time and effort to nurture her friendships | - Denise (Mom)  
- Dan (Dad)  
- Deb E. (AJ’s teacher)  
- Melinda (AJ’s senior PA)  
- Lynate (Denise’s coach) | - Deb develops plan for AJ to join school clubs. Deb presents plan at next GAP meeting.  
- Melinda and Deb work together to identify kids who might like to get together with AJ after school. Melinda talks to other people who have facilitated circle of friends groups.  
- Denise talks to her counselor about the steps she will take to develop and nurture her friendships.  
- Denise decides to join or start a parent support group.  
- Dan identifies opportunities for Jim to make friends in TX (church, acting, pool).  
- Jim gets contact information of friends in KS so he can stay in touch.  
- Dan contacts counselor at new school to find out what supports are available to new students.  
- Denise arranges friend get-togethers (parties) when Jim comes back to KS to visit. |
FAMILY QUALITY OF LIFE SURVEY AND MAP FOR FAMILIES:
PLANNING SERVICES AND SUPPORTS

Step 1. Family members fill out the FQOL survey. Denise’s Responses:

For my family to have
a good life together...

<table>
<thead>
<tr>
<th>Emotional Well-Being</th>
<th>A little Important</th>
<th>Important</th>
<th>Critically Important</th>
<th>Very Satisfied</th>
<th>Neutral</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family has the support we need to relieve stress.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2. My family has help we need to take care of special needs of all family members.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>3. My family members have friends or others who provide support.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>4. My family members have some time to pursue individual interests.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Jim’s Responses:

For my family to have
a good life together...

<table>
<thead>
<tr>
<th>Emotional Well-Being</th>
<th>A little Important</th>
<th>Important</th>
<th>Critically Important</th>
<th>Very Satisfied</th>
<th>Neutral</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family has the support we need to relieve stress.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2. My family has help we need to take care of special needs of all family members.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>3. My family members have friends or others who provide support.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>4. My family members have some time to pursue individual interests.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
AJ's Responses:

For my family to have a good life together...

<table>
<thead>
<tr>
<th>Emotional Well-Being</th>
<th>How important is it that...</th>
<th>How satisfied am I that...</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A little Important</td>
<td>Important</td>
</tr>
<tr>
<td>1. My family has the support we need to relieve stress.</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>2. My family has help we need to take care of special needs of all family members.</td>
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<tr>
<td>4. My family members have some time to pursue individual interests.</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

Step 2: A Family Service Coordinator and family members complete the MAP (The Council).

<table>
<thead>
<tr>
<th></th>
<th>A Little Important</th>
<th>Important</th>
<th>Critically Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neutral</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Denise – bold; Jim – italics; AJ – script

STEP 3: The coordinator will assist the family in organizing a “family support team”
- The team will reflect on the map to understand family preferences
Resources for age appropriate engaging activities

Young Children (2-6 yrs)

http://www.nncc.org/Curriculum/fc46_cook.kids.html
Cooking with children, kids in the kitchen. Ideas and recipes to make with children 2 - 5 years old.

http://www.extension.iastate.edu/Publications/PM1650.pdf
A printable fact sheet on TV watching for children and some suggestions for parents on how to use the TV to take control of family time.

http://www.nncc.org/Curriculum/art_recip.html
Favorite recipes for play dough, paint, clay, finger paint, paste, and bubbles

http://www.nncc.org/Series/good.time.play.html
Excellent resource on play for ages infant to 9 years. Charts, activities, toys, suggested activities, why play is important, types of play and methods to facilitate play in reluctant children.

Middle School age (9-13)

http://www.search-institute.org/assets/forty.html
40 developmental assets for adolescents. A chart depicting healthy attitudes and use of time. 40 building blocks of healthy development that help young people grow up healthy, caring, and responsible.

http://www.holycsc.org/hccoollinks.html
Internet site of internet sources for kids on all subjects. Good site for the surfer.

http://www.valdosta.edu/~jkttaft/kids.html
Lots of resources and links for every subject possible.

http://www.childdevelopmentinfo.com/development/erickson.shtml
Explanation and examples of social-emotional development of adolescents.

http://www.uwyo.edu/CES/FAMILY/CYFAR/FACT_SHE/Unders~1.htm
Good resource on the social, emotional, physical and cognitive development of adolescents.