Supporting Families when Parents have Intellectual Disabilities

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Introduction

In the United States, people are free to raise children unless their right to do so is limited by the courts (Montgomery, 1984). The right to keep and raise a child may be restricted only through the use of due process. People with disabilities become legal adults at age 18. Unless the courts appoint a guardian, the person with a disability retains all the rights of any other citizen. The ability of parents, friends and other people to influence choices is limited. Some people with disabilities become sexually active. They may give birth to children whom they love and often decide to raise themselves.

Only a few years ago, most people with intellectual disabilities (or what used to be called mental retardation) were prevented from having children. Many women with disabilities were required to be sterilized. Forcing a woman with an intellectual disability (ID) to become sterilized is no longer legal in the United States. People with disabilities and their advocates changed the laws that allowed families and institutions to forcibly sterilize a woman, just because she had mental retardation. The courts ruled this was a violation of human dignity and freedom guaranteed to all Americans under the Constitution. For that reason, it is unlikely that the use of sterilization will return.

Today, families often tell young people with intellectual disabilities not to have sex, and certainly not to get pregnant or have children. When children are born to parents with ID, families and health providers often suggest that the child be placed for adoption. The parent with a disability does not always agree. It falls to families and communities to support people with intellectual disabilities in parenting their children and to make alternate arrangements for children and families when necessary. The availability of appropriate support is a key component in keeping children and families together. The entire community must live with the pain and cost of withholding that support.

Support for parents with intellectual disabilities involves finding out who the families are, and what kind of support would be most helpful to them. It involves reaching out beyond traditional boundaries and delivering support in a timely, humane and cost effective manner. It requires sensitivity to interactions that are stigmatizing and offensive to people with ID. This manual is designed as a guide for providers who wish to support parents with intellectual disabilities. The intent in writing the manual is to interest family support providers in using their expertise to extend support to parents with intellectual disabilities in new ways. Although specific to North Dakota, the principles and strategies outlined are widely applicable in many communities.

The manual offers practical suggestions and resources that will hopefully make it easier for providers to step out of traditional roles and reach out to parents with pervasive and lifelong learning challenges. It is also hoped that the use of these strategies will lead to the development of integrated service delivery. It is believed that appropriate support will allow families with parents who have intellectual disabilities to thrive and flourish and thus prove the case for continued support. It is also believed that the strategies will benefit many other families, who may not have intellectual disabilities but struggle with parenting.
The Impact of Beliefs and Attitudes

What Communities Believe

Many people today believe that people with intellectual disabilities cannot and should not parent. This belief is so deeply ingrained that it is often not expressed, but simply taken for granted. The belief is based on:

- An awareness of all the things that can and sometimes do go wrong in attempting to raise children.
- Incidents when people with intellectual disabilities used poor judgment or failed to meet responsibilities.
- Limited opportunities to meet people with intellectual disabilities who have successfully parented a child.
- Fears that if people with intellectual disabilities are allowed to reproduce they will pass on the condition to their children.
- Common beliefs that children get in trouble or have emotional or behavior problems as a result of poor/inadequate parenting.
- Beliefs that someone with an intellectual disability cannot do well, that which most people find to be difficult.
- A desire and responsibility to protect vulnerable children and adults.
- Beliefs that typically, developing children born into families in which parents have intellectual disabilities will experience retardation due to a lack of stimulation.
- Anxieties about what are perceived to be limited resources and the need to use assets where they are likely to do the most good.
- And finally, beliefs that providing support will only encourage people with intellectual disabilities to parent, thus increasing the problem.

These beliefs and fears are considered to be “common sense.” They are shared not only by the general public, but also by many professionals who are experienced in working with people who have intellectual disabilities. Administrators and legislators who have decision-making power over tax dollars that fund services also share them.

These beliefs play a role in the systems’ sometimes rapid removal of children from parents with intellectual disabilities. The loss of a child to a parent with an intellectual disability,
even when necessary for the protection of the child, may have a devastating and life long impact on both the child and the parent.

Beliefs about the limited ability of people with intellectual disabilities to handle the complexities of parenting has also been a factor in provider and community decisions to ignore, discount, and decline to coordinate or fund services that might provide families with lifelong support. Both children and parents are forced to get on with the business of living without the support they may need, leading to unnecessary suffering and setbacks which exact a toll on both families and communities.

Facts and Myths

It is critical in preparing to support families with parents who have intellectual disabilities to understand both the reality and myths involved in our common concerns for and about these parents and their children.

1. **Parenting is challenging:** It is true that parenting is risky. There are many things that can and do go wrong. In fact it is so challenging that it is a wonder that young people of any generation decide to parent at all.

2. **People have limitations:** People with intellectual disabilities act impulsively, use poor judgment, become distracted and fail to predict results or meet responsibilities. And so do millions of parents without disabilities. There is no real evidence to suggest that all parents with intellectual disabilities will fail. It is impossible to predict which families will succeed with support. When support is withheld, failure is more likely.

3. **Success is unfamiliar:** Most people have never met a parent who has an intellectual disability or seen such a person succeed in parenting. Child welfare workers may be uncertain of how to support these families. Many family support agencies are equally unsure of how to reach out to families in meaningful ways.

4. **Fear of contamination:** There is a slightly greater risk that a parent with mental retardation will have a child who also has an intellectual disability. Because of many demographic influences, there is no evidence that the gene pool in America is gradually becoming less intelligent.

5. **Blaming the parents:** It is true that children sometimes get into trouble. Inadequate parenting may be one of several factors that contribute to emotional or behavior problems. However, research shows that problems in families cross both intellectual and socio-economic lines. Intelligence alone cannot be used to predict whether parents will be effective. In fact, parents with DD may be less distracted by the array of choices available in communities, which allows them to give their children more time and attention than typical American families.

6. **Worshiping intelligence:** People have all kinds of abilities or gifts.
7. **Being Protectors:** In our sincere desire to protect those we believe are vulnerable, we may make choices that are neither necessary nor welcome. If it is humane to step in and prevent child neglect or abuse, then it is also arrogant or cruel to withhold our support and then wait for people to fail.

8. **Need for stimulation:** Typically developing children may experience social retardation in *any* family that does not provide appropriate stimulation. Since the risk of this is much higher in families where parents have intellectual disabilities, we are confronted with many reasons for offering lifelong support.

9. **Limited resources:** Since wars have been fought over the “haves” and “have-nots”, it would be foolish to underestimate our passion to be safe. There is little evidence that funding services for parents with intellectual disabilities will somehow be the straw that breaks the camel’s back. Research shows that services, which benefit people with learning disabilities, tend to benefit all of society since we are more alike than different. Also, the need for support might be met with existing resources, if those resources were revised and aligned to provide the kind of support needed.

10. **Desire for easy answers:** There is no evidence to suggest that parents with intellectual disabilities, who receive support, have more children than anyone else. Since parents with ID give birth to typically developing children, as well as children with disabilities, we are really not solving a reproductive problem by withholding support or by not getting involved. Failure to offer lifelong support does not impact the ability or desire of couples to reproduce and have children, only the circumstances in which the children may grow up.

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**Parents with Intellectual Disabilities**

No one knows the number of families who have parents with intellectual disabilities. When a count of adults with developmental disabilities in North Dakota was taken in the spring of 2002, the results indicated that just 3.3% (72) of the individuals over 18 years of age who receive case management services were the parents of minor children. Of those 72 parents only 27 families report that their children are living with them. The reasons why their minor children are not in their home are not clear. A more comprehensive study done in 1990 by the Arc (Ingram, 94) suggests that about .013 percent of the population of parents in the United States have intellectual disabilities. If applied to the 2002 North Dakota census figures, about 8,000 residents would have intellectual disabilities.

Actually, both of these numbers are considered to be low, because it is very difficult to identify families whose parents have ID. In reality, communities have no practical way to count the number of families in which parents have intellectual disabilities because:
When a person with a disability leaves school, they may no longer enroll in services that would identify them as having mental retardation. People with intellectual disabilities often choose to live or work on their own, marry and have children without enrolling in any adult service program, preferring to separate themselves from stigma that they may associate with disability services.

A person may receive services without being labeled as having mental retardation. For example: A family enrolls a child in an infant development program. The child is screened and found to have a developmental disability. The program is not designed to identify and label the parent.

Teachers or providers sometimes suspect that a parent may have learning challenges or an intellectual disability. Reasons for this vary and may include:

- The parent does not drive or has difficulty answering the phone.
- The parent is silent or appears confused during meetings.
- The parent seems overwhelmed by routine demands.
- The parent graduated from a special education program.
- The parent is enrolled in an adult education course to learn basic skills.
- The child reports a need to read information to the parent.
- The parent describes him or herself as having lifelong learning challenges.
- The child describes adult struggles with parenting issues.

Of course there are many other reasons why these events occur. Parents may speak English as a second language; have had their own education interrupted by a teen pregnancy, missed out on education due to migrant lifestyle or family illness; or may avoid schools if their past experiences were negative. Also, families sometimes come from a culture in which they are taught to avoid becoming the center of attention by speaking out at meetings.

However, a careful and objective discussion with teachers, early childhood specialists and case managers suggests that a relatively high number of families have one or more parents who report or demonstrate lifelong learning challenges; some of whom may in fact have a developmental or even an intellectual disability.

While teachers or providers have no means or obligation to identify families, they are challenged to provide students with early intervention. Model programs such as Infant Development, Preschool Classrooms and Head Start are also challenged to build family capacity, a requirement linked to special education law. Educators and providers believe that efforts to support the family have a direct, measurable effect on the ability of the child with a disability to benefit from services. The ability of a provider to reach out to parents with intellectual disabilities may also advantageously position the same provider to reach parents who don’t attend meetings, understand brochures, or get involved in their children’s education.
Parenting with Intellectual Disabilities

Parenting Styles

It is important to understand the characteristics of parents with intellectual disabilities and any differences in how they parent. Facts about abilities form a basis for understanding and effectively supporting parents with intellectual disabilities.

Many parents with Intellectual Disabilities:

1. Love and care for children in ways similar to most parents.
2. Respond as individuals to the challenges of parenting.
3. Are most successful when they themselves have been loved and cared for and had opportunities to observe positive parenting practices (Lee, 2002).
4. Want their children to grow and be happy.
5. Desire to be a good parent and to do a good job in parenting.
6. Often learn complex skills and behaviors.
7. May be successful in parenting when provided with the kind of support they need in advance of critical problems.
8. Have needs for support in parenting that change as both child and parent develop or as circumstances change.
9. Want to be consulted in decisions that impact their family and child.
10. Have needs for support that are life long.

Strengths and Limitations

Parents with intellectual disabilities struggle to get information, learn parenting skills, get support and services, and respond to problems or atypical situations. They often begin the job of parenting with less information and confidence than most people. They can easily make decisions that go awry or place their children in harm’s way. At the same time, they have unique strengths.

Strengths:

- Offer tremendous love and affection to their children
- Are liked and valued by others and make good friends
- Make long term commitments to their families
• Learn to manage/keep up a home or apartment
• Manage to hold down a job
• Usually learn to complete basic parenting tasks
• Keep consistent routines
• Contribute to their neighborhood and community

Limitations:
• Sometimes experience limited communication skills
• Often have low self-concept and lack confidence in parenting
• May live in isolation and socialize less than other families
• Have limited income and are less able to buy what they need
• May rely on others to make decisions and obey without question
• May have difficulty remembering what to do and how to do it
• Feel overwhelmed by too much input, demands or a hectic pace
• Can have trouble understanding when and how to set limits
• Often have limited understanding of child development
• Experience problems in controlling feelings and responses
• Have limited awareness of how to keep a child safe
• May try to compensate for or hide learning problems or confusion
• May be protective and less likely to let a child take typical risks
• May distrust people they believe might be likely to take a child away (teachers, social workers, providers) (Green, Cruz, 2002).

Needs and Barriers

Parents with intellectual disabilities are at a specific disadvantage when it comes to getting information and learning parenting skills. Difficulties with memory, grasping abstract concepts, applying knowledge in new situations, over generalizing, communicating and handling complex tasks such as managing money are directly related to the intellectual disability. Often, parents are either ignored by the system until there is a crisis, or viewed as the source of the problem for their children and punished through social disapproval or having their children removed from their home. To succeed, parents with intellectual disabilities need:

1. Contacts and relationships that build up self-confidence and do not put people on the spot through the use of too many questions or directions (“You should, you need to.”). A consultative rather than authoritarian style that leads people with DD to make careful decisions as parents is best.

2. Services that concentrate first on basic survival needs of the family for food, shelter, heat, transportation, employment, benefits, and health care. Beyond this, support may need to concentrate first on the needs of the parent for a sense of acceptance and belonging before focusing on specific parenting skills.
3. **Relationships with support partners/mentors that are sustained over time.**
   Mistakes should be anticipated and viewed as opportunities for growth. The partner or mentor may be “tested” through missed appointments, not answering the door or holding back what the person with a disability really thinks.

4. **More time and demonstration to learn parenting skills such as** being shown several times with a chance to practice rather than being told. Use simple, everyday language and avoid red-flag words that can be misinterpreted. One provider tried to teach a father to select safe pajamas for his son and used the word *flame-retardant.* The father thought she was saying that he was “retarded” and ordered her out of the house.

5. **Just-in-time information about child development and** what it takes to meet the child’s need at each level of development. For example, a two year old who is saying “no”, a four year old who is whining, a ten year old who has homework to do, and a fourteen year old who is rebelling. The information needs to be delivered in a form that shows the person what is meant by a concept. This may involve demonstrating how to play with and set limits for children without making unrealistic demands or without under/over reacting to the child’s behavior.

6. **Object or informational clues to remember and carry out important routines.** One provider used a soft canvass bag to hold all the objects for the baby’s bedtime routine. Calendars or lists are also useful. Routines and adaptations that make life simpler are best. Help to build a lifestyle that centers on parenting and spending time with children and yet allows for continued personal development.

7. **Information about what could happen when/if action is or is not taken.** Parent may need to be shown how it might impact their safety or the safety and wellness of their child. This may include learning “life smart” skills or “safety smart” skills for parenting. Provide feedback that highlights outcomes and options to help make the why of parenting clearer using a supportive rather than a critical approach.

8. **To be shown how to respond to typical and atypical events** and to be given support to learn new routines or responsibilities (i.e. give a child ear drops when they have never done so before). Help parents recognize and plan for emergencies, which could be anticipated and prevented or minimized (locking up cleaning products) is also important.

9. **Strategies that the parent can and will use on their own** or by relying on friends and neighbors for appropriate support rather than remaining dependent on providers. Create opportunities to meet and visit with other parents and exchange information about parenting in a meaningful way.

10. **Support to understand, or bypass the complexities of the Human Service System.** Provide immediate, practical assistance to secure benefits, food stamps, respite care, day care, tutoring, supported employment and other human services.
Even when all of these supports are in place a certain percentage of parents with intellectual disabilities will fail. The goal is to reduce incidence of neglect and abuse and to protect families through appropriate intervention that is early and life long. We do not know all that might happen if we succeed, only what will happen if we don’t try.

What Parents With Intellectual Disabilities Say

Parents with intellectual disabilities become articulate in describing their own needs in response to open ended questions from people they know and trust. Their comments were passed along through personnel from The Arc, Upper Valley and the Minot Infant Development Program who have worked extensively with these families. Their comments reflect some of their experiences and concerns as well as their perspective on what family support really means.

When a person comes to your home to support your family, what do you like, dislike?

“They bring over new toys my son likes.”

“I like it when they play with my kids, and take them places like the park.”

“It’s nice when they help me with house cleaning.”

“They help us with doctor appointments.”

“They help with teaching discipline.”

“I don’t trust people who come with big bags – I wonder if they are stealing.”

“I don’t like it when they throw stuff out from the cupboard or snoop around.”

“I like it when they take me shopping.”

“I like when they help me figure out how much medicine to give my child.”

“They help us make sure our child’s clothes fit properly.”

“They sit down and play with the kids. We just have fun!”

“They help out during the day, give him snacks, and help with feeding him.”

“They take us to Head Start so our child learns things. We learn things too, like about nutrition.”
What do you think when you hear someone say that people with learning challenges should not be parents?

“I feel angry, mad. It’s not right to be called retarded or labeled.”

“We’re like everyone else. I love my kid and have a right to be a parent/love kids.”

“Someone tried to take our baby away because she didn’t think we could handle him. That made me angry.”

“Because of a handicap? I think that is terrible. I think I’ve been a good parent!”

“I don’t think I should have been a parent, but I think I’ve done a good job. I think I’m a good mom now that I have to be. My kids are so gosh darned cute! I care about my kids and I think I am an excellent mom.”

“If a mom with learning problems came to me and asked me if she should have kids, and what to do, I’d tell her to come here (Neighborhood Center). All the help you need is out there, you just have to get it or find it. I sure am happy I’ve had my kids and met all of the people here! They’re great!”

What are the easiest/hardest things you’ve had to learn since you’ve had your baby?

**Easiest:**

“How to be a good parent. To love your child. It’s easy to love.”

“Coming to Neighborhood House and learning and interacting with other people.”

“It’s easy to play with him and get him to take baths.”

“It’s easy to be very loving towards our baby. He will learn through Head Start quicker than he would at home.”

“It’s fun to love him and hug and kiss him.”

“Everything has been easy. I put myself in his position and do what I have to do.”

**Hardest:**

“Lots of doctor’s visits because he got the wrong medication. That was hard.”

“It was hard giving baths and taking care of him at first. I was scared to drop him.”

“It’s hard to keep the kids in the house instead of running all over outside.”

“Getting my child ready for school and having all their supplies.”
“Organizing my home.”
“It’s hard to watch him all of the time.”
“It was hard to get the baby to eat and gain weight.”
“Getting the kids to bed is hard.”
“Keeping the house clean so the kids don’t get hurt.”

“Worrying about one child hurting the other.”
“It was hard to teach the kids to get along with each other.”
“Decision making is hard. I feel like I won’t be able to make decisions when they’re older. I know it’s a part of life and will be hard. It might be a little scary!”

What is the most important thing you’ve learned since you have had your baby?

“How much work it is.”

“Teaching safety, especially of strangers when there are so many people who we work with that come to the house.”

“How sisters and brothers should love one another.”

“Getting them school clothes and stuff.”

“Buying the clothes when they want specific name brands.”

“Setting goals for your kids. Keeping schedules and routines.”

“Keeping him healthy, making sure he eats the right foods and making sure to keep doctors appointments.”

“To make sure he eats a variety of foods.”

“To make sure and watch him all of the time.”

“How to take care of them. It’s a big responsibility!”

“That they love me and I love them.”
What bothers you the most about being a parent?

“When Social Services gets involved and tells you what to do.”

“If you don’t have your kids, it hurts not to see your kids.”

“Seeing other kids do things that your kids can’t because of money or ability.”

“Because Social Services is involved, I can’t even let my kids go outside and play alone. I always have to watch them or they get taken away.”

“I never get any ‘private time’.”

“The biggest problem is finding transportation to anything: jobs, school, activities, or just to visit.” (Many parents echoed this.)

“Too many people try to tell you what to do with your kid. It gives me a headache!”

“To get out of bed with my kid when I want to sleep and he wants to play.”

“Nothing really bothers me!”

“Going out and keeping track of the kids while I am out.”

“Getting the kids to listen. Discipline is hard!”

What do you like most about being a parent?

“Being with my kids.”

“Teaching and working with my kids. It makes me feel wanted.”

“The responsibility.”

“Just taking care of him and teaching him new things.”

“It’s fun to play with him. I like hugs and kisses too.”

“I’m a good dad. I like being a dad. It’s fun to spend time with him, play with him and teach him things.”

“Acting like a kid with him – playing with him and having fun!”

“Being able to read stories to my kids and tuck them into bed.”
Providing Support to Families

What Success Looks Like

Across the United States and Canada, during the 1990’s many providers, for the first time, began to support people with intellectual disabilities who lived in their own homes and were parenting children. Based on their research, the following elements are critical for family and provider success.

- People who come into the home or meet with the family establish a warm, positive, relationship that continues over time.

- The family is provided with intensive, ongoing home visits. In which someone works with the family on whatever they need.

- The family is provided with step-by-step, hands-on instruction, in the home or community by someone they trust.

- The whole family, including siblings and extended family members or partners, is supported as needed.

- Children spend time in as many typical settings as possible (pre-school, after-school programs, learning centers, tutoring, sports, clubs such as 4-H or scouting, etc.). These activities provide the extra stimulation they may need.

- The family experiences both short term and extended reward systems that reinforce learning and effort. Incentives may be needed to attend meetings at the school, follow through at home, or try activities that seem difficult.

- The family is empowered to access the whole array of supports available. Those supports are channeled into services that the family can recognize, accept and welcome. They might include:
  - Going with a mom to a well-baby check up.
  - Helping the family fill out a food stamp form.
  - Encouraging a dad to join a parent support group

- The support hours funded through various programs are merged into one integrated system for service delivery designed to meet the needs of families in which parents have intellectual disabilities. The family deals only with one or two familiar people and receives an array of supports.
When Children Are Removed From The Home

There are essentially three types of families:
1) Families who are effective in parenting from the start.
2) Families who make mistakes but with support, manage to succeed eventually (most of us).
3) Families who abuse or neglect their children. Given that parents who harm children are found in all intellectual and socioeconomic groups, some percentage of parents with intellectual disabilities will abuse or neglect their children.

When children are at significant risk, it may become necessary to remove them from the home to prevent injury or harm. It is usually necessary for an abusive or neglectful family to change its behavior in order for children to return or remain safe. If the family cannot or will not change, removal from the home is inevitable. Social workers and child protection teams make decisions about a family’s ability to change and a child’s risk.

In North Dakota, Child Protective Services (CPS) is a unit within the Children and Family Services Division of the Department of Human Services. CPS is responsible for investigating any allegations of possible abuse or neglect. Decisions made by CPS impact whether a child will continue to live at home with his or her parents. Decisions are based on the safety of the child regardless of whether their parent has a disability.

Although CPS works with families, their primary focus is the safety of the child. Parents with intellectual disabilities may have difficulty understanding the role of CPS or the investigation process. It often appears to families that the social worker is being arbitrary or rushing to remove the child. A parent with intellectual disabilities may be less able to hide or explain their behavior or mistakes thus increasing the likelihood that a neighbor or professional will report them more quickly than other parents. A CPS case worker may not have any specialized training in supporting families in which parents have intellectual disabilities and their understanding of family capability and support may also be limited.

People with intellectual disabilities are vulnerable persons who have rights. A caseworker will recognize this and is challenged to protect the child and respect the rights of the parent. One option sometimes used by social workers is to contact the Protection and Advocacy Project as a potential advocate for the parent. Unfortunately, this is not universally done nor required under existing policy. This would be especially helpful in cases where protective action services are required but may depend on the relationship of the county employees with the regional Protection and Advocacy Project advocate. Similarly if the social worker suspects that a parent has an intellectual disability (or has information to that effect in the file) they may ask if the family is working with a case manager and ask the case manager to step in and support the parent during an investigation. However sometimes families are ashamed and may decline the support they need.

CPS workers must follow state policies and complete a risk assessment when investigating an abuse or neglect complaint. The assessment requires them to consider
twenty-one separate risk factors, one of which is: “Does the caregiver have mental retardation or an emotional or health problem?”

When a CPS investigator suspects that a parent has an intellectual or emotional problem, they will consult with the person’s physician and or a caseworker to determine the person’s ability to parent. While qualified to identify functioning level by virtue of his or her training, a physician who sees a parent in 15 minute blocks of time may not be in the best position to assess parenting skills and may be unaware of the support available. The CPS worker must indicate if specific protection services are required, recommended or unnecessary following an investigation. A CPS caseworker must consider the family situation, must assure the safety of the child, and be fair. They are required to justify their actions in court. The availability of community supports for parents with ID is considered when recommendations are made, but a CPS worker cannot rely on the state in any form (an advocate or case worker) to parent a child for the person with an ID.

A CPS caseworker tries to become familiar with both formal and informal supports that are available to the families in their region. That can take some time. Fortunately, they do not have to make decisions alone. Except in emergency situations (i.e., a four year old child is home alone and the parents cannot be located), the decision is reviewed by a child protection team at the local level. This team is made up of various professionals including social workers, school personnel, juvenile justice workers, public health professionals, etc. Child protection teams are not required to include a professional with a background in supporting persons with intellectual disabilities or anyone who directly serves parents with intellectual disabilities.

Depending on the level of risk and safety, the social worker will take steps to assure that the family has a network of support using available community resources. This process may be informal or formal depending on the decision. If a child does need to be placed out of the home on a temporary basis, the social worker would generally recommend or support placement with another family member such as a grandparent or aunt before considering foster care.

If a child is removed, it must be ordered by juvenile court (the social worker does not have the authority) or a police officer. The social worker can contact the police and ask for an emergency verbal order to remove a child if conditions warrant it (i.e., a parent is intoxicated and passed out on the steps). Removal is initially done for 30 days but a hearing must take place within 96 hours. A second hearing is held at the end of the 30 day process.

There are many factors which can result in either an abuse or neglect complaint investigation or a decision to remove a child from a home. At the time this manual was written, no data was available to determine the primary reason children are removed or services recommended when a parent has an intellectual disability. Statewide, in 1998, 44 cases indicated that the parent had mental retardation as one of the risk factors. Child protection services were required for 17 of the 44 cases (39%), recommended in 18 cases (41%) and unnecessary for nine cases (20%). Overall 4,269 cases were reported.
statewide that year (1998). In other words, only one percent (1%) of cases statewide involved a parent who has an intellectual disability. In the year 2000, about 6,000 cases of potential abuse or neglect were investigated but other statistics for that year were not yet available. The data that is available and the circumstances that surround them raise many questions and provide few answers. For example:

1. What is the primary reason that children are removed from the home when a parent has an intellectual disability? What is the average age of children upon removal? Are the majority of children from single or dual parent homes?

2. Is removal typically due to abuse OR neglect and in what form? Are the children left unsupervised, sexually abused or not provided with adequate stimulation or care? Are the parents addicted or unable to make good decisions about discipline?

3. Is the incidence of removal in cases where parents have intellectual disabilities increasing or decreasing? Is it more or less likely in certain regions of the state? If so, do those differences point to population trends or other factors?

4. When supports are recommended, are they available? What percentage of cases call for repeat investigations? What is the nature of the parenting problems and what can we learn from them? What adjustments (if any) could schools, families or the family support system make when preparing young people for adult life that might address those issues?

5. Should the relationship between Protection and Advocacy and county social services be the determining factor in whether a parent with DD receives advocacy support during an ongoing child protection investigation? What is the best way to support parents without creating undue interference in the investigation process?

6. How familiar are physicians with support available to parents with intellectual disabilities? Are physicians able to communicate with parents who have intellectual disabilities when explaining how to get a child to eat more, heal diaper rash or give ear drops? What happens if those directions are not understood? What other resources do physicians have when communication breaks down?

7. Can we increase or strengthen support to parents with intellectual disabilities? Can we reduce the stigma attached to service delivery systems? Would that have any effect on the rate or outcome of abuse or neglect investigations? Are we brave enough or interested enough to find out and do we have the resources to try?

It is important to keep the circumstances surrounding parents with intellectual disabilities and abuse or neglect investigations in perspective. There is currently no evidence to suggest that parents with intellectual disabilities are not treated fairly by the child protection system. It is also beneficial to look for the best ways to educate and support people with intellectual disabilities when we consider the long-term impact on children and families.
Integrated Service Delivery

Often parents with intellectual disabilities are eligible for support from a wide range of programs. Consider the following list of services that may be available in a North Dakota community for parents and/or children.

- Infant Development
- Independent Living Services
- Job Service or coaching
- In-home family support
- Head Start
- Case management/coordination
- Day care
- Medicaid
- Public and Special Education
- After school programs
- Health care
- Speech, Occupational or Physical Therapy

All of these services must be applied for, managed, coordinated and accessed by the family. This involves filling out forms, going to meetings, making decisions and interacting with a large number of people. But wait! People with intellectual disabilities may not readily trust authority figures (especially those who are mandated reporters). Is it realistic to expect people with limited stamina for meeting multiple demands to hold down a job, keep a home, parent their children AND relate to many different personnel? No!

Consider the current human service system today. We have one set of early intervention services designed to support children and families, one to educate children and another separate set designed to support adults. What does that mean for parents with intellectual disabilities?

Parents may get support from a service provider to make a budget, improve cooking skills, and organize their routine. The same parent may get services from a completely different provider to get to work on time, wear appropriate dress and learn job skills. The child and parent may get support from an infant development program. Once the child turns three, the adult service provider may not view it as their responsibility to work with the parent on basic parenting skills, or if they do, they may refuse to serve the child directly. If the child has a disability the situation can be even more complex as an array of people work with the child but not the family. The school may be involved with the child during the day, but seldom after 5 PM. And on and on it goes. The family is served on a piece meal basis through several systems.

Under this model it is all too easy for the agency focus (adults, kids, resources) to be met rather than the needs of the whole family (parents, children, extended family).
Moving Beyond Traditional Support

Think of families as a system of people who provide one another with mutual affection and support with appropriate boundaries and relationships. The system allows the parents to care for and nurture the children in age appropriate ways while earning an income sufficient to support the family and still have time to be intimate and nourish the individual development of each member.

An integrated service delivery system of case coordination and in-home and community support is critical for success. Under this model, one agency takes the lead and serves the entire family, drawing on dollars from several programs to fund the intensive in-home supports needed. This requires that agencies work in a trans-disciplinary model, with various support agencies passing expertise to one or two people who provide most of the interacting, teaching and support to the family. Because there are not enough hours in the week for the family to meet with each discipline and grasp/absorb what they recommend, the provider must integrate the various recommendations and show the family how to apply them within the daily routine.

This model may require direct service providers to have intensive training and support on integrating recommendations from various disciplines and in supporting parents and children with intellectual disabilities. It also requires that each of the systems accessed by the family understand and use proactive and effective strategies for communicating with the family and their support providers. In many ways, when parents have intellectual disabilities, we are in fact dealing not just with a multi-system child but a multi-system family.

In North Dakota, the most logical partner to take the lead in providing this kind of support, beyond an infant development program, is a provider who currently provides in-home support. The provider must commit to supporting both children and adults and be willing to build a program that is both family-friendly and innovative in addressing needs. The provider must be willing to step beyond traditional roles to meet the needs of the whole family. Planning and training costs, while initially higher than other programs, should be affordable under current funding policies if the provider is given flexibility in accessing the array of program resource dollars possible and funding remains stable.
Getting Started

Planning and Organizing Support

Any community can strengthen its supports for families in which parents have intellectual disabilities. A variety of options for supporting families are available. While comprehensive state/regional planning may be needed to create integrated service delivery, existing family support providers and family support groups can take a leadership role in defining and addressing support needs.

A brief overview of various “best-practice” models is included in this section of the manual. Detailed information about each activity is included in the resource section. Family support agencies might decide to use any of these activities to support parents, train generic community providers about the needs of parents with intellectual disabilities or by serving as a community guide for families in which parents have intellectual.

Conduct A Need Assessment – Find out if there are families in your community in which parents have intellectual disabilities and need/want support. Although agencies cannot give you the names of specific families (confidential information) they can visit with you about the number of families in the region, describe the services and supports that exist and new supports that would be helpful. You might conduct a needs assessment survey with community providers. Contacts can be made by calling the local case management office or serving on local boards such as the Regional Interagency Coordinating Committee or a Family/Educator Enhancement Team (FEET). Start with:

- DD case managers, social services, child protection workers
- Early intervention specialists (infant development, Head Start, preschool)
- Health care professionals (public health nurses, physicians)
- Provider agencies (Independent Living Centers, adult service providers)
- Family support or advocacy agencies
- Public schools or special education units.

Complete A Family Support Assessment – If you will be providing direct support to a parent with intellectual disabilities, avoid assumptions about parent skills. Determine to what extent a parent has the skills needed to care for a family at four levels of competency. Identify starting points for intervention using the Parent Support Project – Parent Skill Hierarchy.

- **Level one:** Completes self-care and independent living tasks
- **Level two:** Communicates thoughts, manages emotion and behavior
- **Level three:** Successfully manages interactions with others
- **Level four:** Meets children’s needs through planning and teaching

Build Social Support for Parents - Eliminate stress and isolation by building appropriate support networks for parents and families in local communities. Different families will have
different needs. Be sure to match families to an activity that appeals to them. During events, model effective parenting and social interaction. Build up the person first.

- **Hanging out** – Pair families to go to garage sales, the library, free concerts, school or sporting events, parades, etc.
- **Family night out** – Bring families together at a park or restaurant for fun
- **Mentoring** – Create friendly and supportive neighbors through a parent to parent project or local church who “adopts” a family.
- **Neighborhood home/center** – Rent an accessible house where families may gather for a meal and play/learning session for young children.
- **Foster grandparents** – Recruit seniors who will drop by, share a meal, help with repairs or “talk things over” with a young family.

**Build Social Supports for Children** – Provide opportunities to make friends and reduce loneliness and isolation for children with/without disabilities.

- **After school activities** – Get involved in scouting, 4-H, sports, study clubs, fitness clubs, church, arts, character or service clubs.
- **Circle of Friends** – Recruit friendship circles for children at school.
- **E-buddies** – Teach children to use email to stay in touch with others.
- **Teens Being Teens** – Recruit teens to serve as peer mentors.

**Strengthen Parenting Skills** – Empower parents with intellectual disabilities to gain confidence and competence in parenting through a variety of informal and formal techniques. Focus on strengths and assume the ability to learn/grow.

- **Home visits** – Hire an in-home support worker to come over and help out.
- **Classes** – Assist a parent with ID to attend a community parenting class.
- **Families and Schools Together** – Teaches family to play together and build on children/family strengths to improve educational performance.
- **Mom’s or family network** – Bring parents together to talk about parenting or special circumstances (i.e., raising a child with a disability).
- **Reminder systems** – Use pictures and objects to help families learn and remember important routines and responsibilities.

**Promote Life Long Learning** – Empower parents to gain confidence and self esteem through life long learning opportunities. Activities may be informational, recreational, or job related. Instruction can be provided by employers, continuing education staff, social clubs for persons with intellectual disabilities, private instructors, church groups, etc.

- **Advocacy** – Learn to lead or speak out through Partners in Policymaking, People First or family support networks.
- **Arts & crafts** – Learn in classes, how-to videos, from family, or in theater.
- **Computer skills** – Learn through adult learning centers or libraries.
- **Fitness**—Take fitness classes or check out Special Olympics.
- **Homemaking**—Learn from parent aides, county extension programs, families.
- **Higher education**—Take classes of interest at the local community college.
- **Literacy**—Learn through tutors, adult learning center staff, providers.
- **On the job training**—Learn new skills at work or take job related classes.
- **Outdoor skills**—Learn fishing, hunting, outdoor skills through the Game and Fish Department, gun clubs, or community service clubs.
- **Repairs/woodworking**—Learn from woodworking, service clubs or families.

### Training Providers

Although providers may have experience in working with people who have intellectual disabilities, they may not be fully prepared to support these individuals as parents or to support their children. Training should include opportunities, activities and resources that will help students achieve the following outcomes:

1. Accurately identify their own beliefs, values and opinions about parents with intellectual disabilities.
2. Meet different parents with intellectual disabilities and listen to their stories.
3. Access data and general information about parents with intellectual disabilities.
4. Access data and information about family systems and child development.
5. Use best practice strategies to teach people with intellectual disabilities to care for the family.
6. Teach families to respond positively to children’s behavior at different stages of the child’s growth and development.
7. Use best practice strategies to enhance personal development/wellness.
8. Demonstrate ability to gain the trust/cooperation of parents and children.
9. Use a variety of strategies for providing intensive in-home support.
10. Accurately answer questions about in-home support policies, child protection services advocacy for vulnerable populations and abuse/neglect reporting.
11. Identify critical elements of successful programs in action.
12. Identify community based resources and supports for parents with intellectual disabilities.
13. Complete an action plan alone and/or with other community partners.
Training components including instructional plans, activity guides and curricular materials that address these outcomes can be found in the resource section of this manual.

**Training Parents with Intellectual Disabilities**

Support involves listening, sharing and obtaining information, observing and appreciating strengths, empathy and recognizing motivation, offering direct instruction on an adult-to-adult basis, modeling and mentoring, supporting feelings and respecting the other person’s agenda. Effective support involves knowing where to begin, how and when to intervene, what to teach and giving support even when the person makes decisions with which you don’t agree. Training involves three key elements all of which are on-going and none of which are intact or complete before intervention begins.

**Establish Relationships**

It is important to establish rapport and begin to build a relationship of mutual trust and respect before attempting to provide any instruction or share information. Training usually implies teaching someone to complete tasks in a certain way, and often involves learning complex skills that will be carried out when no one is present. It also involves deciding what to teach, what to ignore and what to do for someone. Since parents with intellectual disabilities are adults, they have often already learned to follow routines and respond to situations in ways that seem best to them.

Learning and using new skills typically involves unlearning current behaviors and habits. The challenge of generalizing what we learn and changing our lifestyles and responses should not be under-estimated. If change were easy, we might all be healthy and fit, get enough sleep, drink enough water, be rich, have the best social skills and be raising children who were well-behaved and model citizens. It is challenging to behave optimally and change our habits.

Now imagine growing up in a family where the best parenting might not have been modeled and entering adult life with that as your fall-back position. Also, imagine getting information from someone who doesn’t model what they teach, uses words you don’t understand or documents you can’t read; who quizzes you constantly, or demands that you change your behavior or they will take your children away. How much learning would you bring about under those circumstances?

Parents with intellectual disabilities are active learners who can be influenced by someone they trust and respect at times when they are ready to make a change. This means that training may not be accomplished quickly and confirms the need for lifelong support. Trust will be established not only through credible behavior but by sending signals that it is safe for the other person to take a risk in getting to know you and wanting to be like you or try your ideas. It will take patience, humor, and creativity. First, efforts will need to focus on building up the relationship with the parents before an emphasis on housekeeping or child raising is likely to be successful.
If a parent’s skills in caring for his or her family do not grow in direct relationship to their child’s changing development and supports needed to compensate for limited skills are not provided or accepted, conditions leading to neglect or abuse may occur and/or a dysfunctional family situation result. Training parents with an intellectual disability is a high stakes business.
Resources

Assessment

As you work with the family, it will be important to assess the functional skills of the parents related to literacy, work, and independent living. You will also need to find out about their experience and knowledge of child development and parenting, their ability to express themselves, relate to others, manage behavior and emotions and engage in goal directed behavior. On the following page is a tool for evaluating these skills, based on an evaluation process developed by Mark Simpson of New Brighton, MN. It helps to involve parents in self-assessment of their strengths. A tool for self-assessment can be found on the page 28.

Many parents will not be comfortable with or interested in a formal assessment process so much of the assessment must be done through informal methods, primarily observation. Assistance with this assessment can be obtained through a traditional adult service provider. Information about literacy (ability to speak, read, and write) can often be obtained through observation/conversation using common household materials and with help from an adult learning center or psychologist.

Because you will be supporting the whole family, it is important to obtain a clear picture of the child’s development, as well as their academic and functional skills related to future independent living and work on an on-going basis. Assistance with this assessment may be obtained through infant development and/or public schools. Information about the development of young children can be found at the ND web site [http://www.familyn2k.info](http://www.familyn2k.info) Go to “In the Beginning” and then “Child Development.”

Finally, it will be necessary to understand the family’s strengths, motivation for learning and dynamics related to relationships (spouse to spouse, parent to child, sibling to sibling), personal development and mental health. This can be assessed through observation over time. It may also be enhanced by completion of a family/social assessment conducted by a licensed social worker. Specific tools for assessment are included in the next few pages in this section. A pictorial tool to help assess social/sexual functioning for young people with developmental disabilities can be found in the S.T.A.R.S curriculum available through the Pathfinder Family Center at [http://www.ndpass.minot.com/index2.html](http://www.ndpass.minot.com/index2.html) or by calling 1-800-245-5840.
# Parent Skill Hierarchy

<table>
<thead>
<tr>
<th>Level</th>
<th>Thinking Skills</th>
<th>Kinds of skills</th>
<th>Intervention</th>
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<tbody>
<tr>
<td><strong>Level One: Participate</strong>&lt;br&gt;Completes Tasks&lt;br&gt;Carries Out Care Routines</td>
<td>Requires the ability to:&lt;br&gt;1. View items/tasks objectively&lt;br&gt;2. Think of alternatives. Make changes</td>
<td>Observe, report, fix, broken items&lt;br&gt;Complete hygiene tasks&lt;br&gt;Clean and care for clothes&lt;br&gt;Read information, manage money&lt;br&gt;Shop for groceries, buy supplies&lt;br&gt;Prepare/cook nutritious meals&lt;br&gt;Access transportation&lt;br&gt;Access health/dental care</td>
<td>Decide with the family if they&lt;br&gt;1. Don’t understand what to do?&lt;br&gt;2. Need to be shown how to do it?&lt;br&gt;3. Need reinforcement to carry out?&lt;br&gt;Plan to address high-risk areas&lt;br&gt;1. Will parent perform the task?&lt;br&gt;2. What alternatives are available?</td>
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<td><strong>Level Two: Grow &amp; Develop</strong>&lt;br&gt;Understands Life Experiences&lt;br&gt;Manages emotions&lt;br&gt;Manages Stress</td>
<td>Requires the ability to:&lt;br&gt;1. Think about events/needs&lt;br&gt;2. Think about options&lt;br&gt;3. Think about what’s right/wrong&lt;br&gt;4. Set and follow internal limits&lt;br&gt;5. Protect emotional self&lt;br&gt;6. Maintain internal balance</td>
<td>Set/follow budget priorities&lt;br&gt;Identify problems/needs&lt;br&gt;State feelings, opinions, choices&lt;br&gt;Avoid addiction or obsessive behavior&lt;br&gt;Make decisions independently&lt;br&gt;Motivated to solve problems&lt;br&gt;Control temper&lt;br&gt;Use resources to stay healthy-well</td>
<td>Discuss ability to label own behavior&lt;br&gt;Teach ability to regulate their own wants and needs and can teach children to set own limits (discipline)&lt;br&gt;Teach parents to balance their needs with being productive for others.</td>
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<td><strong>Level Three: Relate to Others</strong>&lt;br&gt;Communicates with others&lt;br&gt;Manages interactions&lt;br&gt;Understands relationships</td>
<td>Requires the ability to:&lt;br&gt;1. Clearly state wants/needs&lt;br&gt;2. Read spoken/non spoken cues&lt;br&gt;3. Understand others’ needs/thoughts&lt;br&gt;4. Negotiates for self or child&lt;br&gt;5. Works out a balance gives and takes</td>
<td>Stay connected to parents/family&lt;br&gt;Attachment to children/spouse&lt;br&gt;Cooperate with roommate/partner&lt;br&gt;Find and use community resources&lt;br&gt;Avoid exploitation, high risk behavior&lt;br&gt;Avoid sexual abuse/incest&lt;br&gt;Hold a job, meet boss’ expectations&lt;br&gt;Respond to emergencies</td>
<td>Develop/maintain professional relationships with clear rules&lt;br&gt;Use visual maps to show family relationships/roles/boundaries&lt;br&gt;Teach to objectively interpret the behavior of others. Role play and discuss alternatives</td>
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<tr>
<td><strong>Level Four: Care for Family</strong>&lt;br&gt;Meets children’s needs&lt;br&gt;Works to achieve goals&lt;br&gt;Adjusts to changing needs</td>
<td>Requires the ability to:&lt;br&gt;Perceive a safety threat and act&lt;br&gt;Set priorities (put the child first)&lt;br&gt;Nurture the child (not the reverse)&lt;br&gt;Teach child to set limits/follow directions&lt;br&gt;Think about what will happen if&lt;br&gt;Set goals/imagine how to achieve them</td>
<td>Meets physical needs of child&lt;br&gt;Supervises and protects child&lt;br&gt;Meets emotional needs others&lt;br&gt;Disciplines without injury&lt;br&gt;Responds to child behavior&lt;br&gt;Maintains a consistent daily routine&lt;br&gt;Uses competent child care&lt;br&gt;Provides stimulation</td>
<td>Meet the child’s emotional needs by coaching the parent or modeling&lt;br&gt;Teach the parent to teach the child&lt;br&gt;Help the parent to view his behavior objectively (Use video taping)&lt;br&gt;Help the parent develop a systematic approach for teaching their child competencies needed as an adult</td>
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<tr>
<td>We Need To</td>
<td>Where To Start</td>
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</table>
| Keep Our Family Together                 | • Stay out of jail
                                              • Stay together as a family
                                              • Be safe together
                                              • Stay in touch/talk it over |
| Have a Nice Place to Live                | • Find a place to live
                                              • Have heat/cooling
                                              • Have lights
                                              • Have running water
                                              • Have a telephone
                                              • Make repairs |
| Have a Job/Income                        | • Find a new job
                                              • Get along at work
                                              • Do a good job get a raise
                                              • Get/keep benefits |
| Pay the Bills                            | • Get out of debt
                                              • Pay this month’s bills
                                              • Save money
                                              • Keep records
                                              • Make/stick to a budget |
| Eat Healthy Meals                        | • Feed the children
                                              • Teach healthy eating
                                              • Shop for food
                                              • Cook/Prepare food
                                              • Store food |
| Stay Healthy                             | • Get health check-ups
                                              • Take medicine safely
                                              • Teach health habits
                                              • Give health care
                                              • Have a healthy lifestyle |
| Raise Safe Healthy and Happy Children    | • Kid proof the house
                                              • Have a healthy routine
                                              • Play with/read to the kids
                                              • Discipline without harm
                                              • Help children grow/learn |
| Be Organized                             | • Make plans/calls
                                              • Get the laundry done
                                              • Keep the house clean
                                              • Take care of the yard |
| Get Where We Need To Go                  | • Find a ride
                                              • Learn to drive
                                              • Use public transportation |
Morning Chores

- Fix Breakfast
- Bath Baby
- Play with Baby
- Go Grocery Shopping
In-Home Routines

| Morning Routine          | ✓ Wake up the kids  
|                         | ✓ Make breakfast  
|                         | ✓ Dress the kids for school |
| After School Routine    | ✓ Have a snack  
|                         | ✓ Work on some homework  
|                         | ✓ Read a book or watch TV |
| Supper Routine          | ✓ Prepare supper  
|                         | ✓ Have kids help with dishes  
|                         | ✓ Play in the yard or watch TV TOGETHER |
| Bedtime Routine         | ✓ Give the kids a bath  
|                         | ✓ Read a bedtime story  
|                         | ✓ Bedtime at 8:30pm |
Our Family Routine

Morning - Wake up, shower/bath, toilet/groom, dress/look good, breakfast, get ready for the day, organize.

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<th>Parents</th>
<th>Baby/Young Children</th>
<th>Teens</th>
<th>Pets/Chores</th>
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After School – Run errands, get home safe, do home work, do chores, eat a snack, play, relax, share fix and eat supper.

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After Supper – Finish homework, do chores, play or relax, shop, visit, or work on the yard.

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Bedtime - Put away toys, shower or bath, toilet/groom, undress/PJ's, relax, lock up, lights out, snuggle, sleep.

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Instructional Strategies

Although imbedded in natural conversation and the daily routine, instruction should include these elements:

- **Be multi-sensory** – Use combinations of showing and telling and a variety of aids, audio, visual and hands on activities or objects to teach concepts, routines and problem solving.

- **Promote active learning** – Model and remind people to ask their own questions, rehearse what to do, make and carry out simple plans and evaluate the results, experiment and see what will happen (when safe) role play and work together to complete a task, exaggerate subtle behavior to make it stand out and model appropriate responses, record what works in a meaningful way.

- **Give Feedback** – Provide immediate and sincere feedback, check for understanding, explain consequences, discuss and correct errors, be open and honest in responding, avoid quizzing people. Ask for feedback.

- **Strengthen Learning** – Ask questions, use routines, object cues, calendars, lists, and frequent opportunities to practice. Avoid giving unnecessary help, offer reassurance and guidance. Use meaningful materials based on literacy and problem solving skills. Systematically reduce cues and reminders. Challenge with novelty and humor.

- **Reinforce behavior** – Encourage to try new things and interact with potential friends. Highlight, count and reinforce what works. Encourage to contact Set goals together and celebrate success.

Getting Organized

In home support, instruction and guidance should center around activities involved in establishing positive personal and child care routines, promoting personal development and building a life worth living.

- **Establish a supportive routine** – The routine should focus on meals, sleep, waking, play, work, exercise, service and relaxation within the home and community for children and parents.

- **Promote wellness** – Model and reinforce alternatives to smoking and drinking. Model healthy eating and exercise and help families build it into their routine. Avoid criticism. Encourage participation in family and community outings and gatherings and teach how to participate by sending cards, bringing appropriate food or play items. Avoid sources of stress. Build confidence without excessive demands. Encourage participation in activities that enhance spiritual and moral development by relaxing, sharing, listening and giving to others.
• **Prepare for the future** – Think out loud and visit about what might come up both short term and long term. Keep photo or object records of significant events and milestones. Help to plan for changes at work, transitions in school, moves, disasters and eventual old age and death.

• **Promote Life Long Learning** – Empower parents to gain confidence and self esteem through life long learning opportunities. Activities may be informational, recreational, or job related. Instruction can be provided by employers, continuing education staff, social clubs for persons with DD, private instructors, church groups, etc.

1. **Advocacy** – Learn through partners in policymaking, family support groups
2. **Arts & crafts** – Learn in classes, how-to videos, family, or theater
3. **Computer skills** – Learn through adult learning centers or libraries
4. **Fitness** – Learn through fitness classes or Special Olympics
5. **Homemaking** – Learn from parent aids, county extension programs, families
6. **Higher education** – Take classes of interest at the local community college
7. **Literacy** – Learn through tutors, adult learning center staff, providers
8. **On the job training** – Learn new skills at work or take job related classes
9. **Outdoor skills** - Learn fishing, hunting, outdoor skills through the fish and game department, gun clubs, or community service clubs
10. **Repairs/woodworking** – Learn from woodworking, service clubs or families

**Training Community Partners**

Family support providers are in a unique position to be able to teach generic community work force, recreational, health care and educational personnel about the needs of parents with intellectual disabilities and the benefits and means of providing support to those families. Many of the materials in this curriculum can be used to train partners. Handouts for training can be found in the Resource section of this manual.
Support

Here are some tips for getting started:

- Spend time at the home hanging out with the family and helping as needed. Form an on-going, trust relationship that does not undermine their dignity or independence.

- Model/provide effective parenting for children rather than criticizing families.

- Take the focus off the parent by using observation and word/picture menus or checklists to help families identify their own strengths and needs.

- Support the family in getting organized by suggesting priorities and using object cues to help families organize or set up child-centered routines.

- Assist families with the mechanics of obtaining benefits, transportation, child care, respite care, etc and with knowing that any children are safe, well and happy even if they are not in the home.

- Provide families with needed instruction within natural routines in the home or in neighborhood centers using adult learning models. If support groups or neighborhood centers are used to introduce new skills, assist the family to generalize those skills at home and in the community.

- Empower the family through activities designed to promote self-determination, advocacy and life-long learning. Teach the family how to “get a life.”

- Introduce the concept of balance in the routine, the schedule and life choices.

- Use an effective adult to adult problem solving sequence (Sweet, 90)

  1. What is the whole situation (what is really happening)?
  2. How does this person learn (how does he/she solve problems)?
  3. What is the nature of the difficulty (what is contributing)?
  4. What motivates this person (what have you noticed)?
  5. What are reasonable goals (keep it simple)?
  6. What support (what are the possibilities) can I give the learner
  7. What would be the best match for his or her learning style (what works)?
Contacting Families When Parents Have ID

1. **Offer something that benefits the children.** Remember that most parents will do anything for their children. The best way to reach families when parents have ID is to offer something to the family that might be good or positive for their children. Keep the family coming back for more. Examples of activities:

   - Use power tools to build puzzles or home improvement items.
   - Go fishing together off a bridge or dock at a local river or lake.
   - Bring a brown bag lunch to a local park. Talk while the kids play.
   - Find a field or low traffic cul-de-sac and fly kites for the evening.
   - Invite a nutrition specialist to demonstrate snacks for picky eaters.
   - Ask a local nurse to show parents how to teach children about puberty.
   - Gather at a local neighborhood house and share a meal and play session for mom’s and young children.

2. **Keep it simple.** Typical ND Family Support brochures are written at a 12th grade reading level. That’s too hard! Make written information easy to read and fun to look at.

3. **Check out the neighborhood.** Although families may live in different parts of a city, there may be a location that is central to several family homes and often used. Consider either leaving posters at this location or using it as a gathering place.

4. **Overcome confidentiality barriers.** Although confidentiality is critical, it should not be used as a reason to keep families from getting the support they need. Teachers or providers will be more likely to become involved and obtain a families’ consent for contact if:

   - They are involved in designing supports from the beginning.
   - You have administrative approval for the project
   - Information about the benefits of the project are available in writing and can be easily shared with others
   - Your request is respectful of others’ time
   - The program sounds exciting and beneficial for families who don’t have much education or money.
   - You provide a simple release (agencies often prefer to use their own but having one ready shows your commitment to saving everyone time and paperwork)
   - They believe the group offering the service will refrain from agency bashing and be a positive influence on the family.
• The support is viewed as an extension of something good they are already doing rather than something they should have done but didn’t get to or one more thing to get done.

5. **Send a message or invitation through someone who knows the family well AND has a positive relationship with the parents.** This can be a DD case manager, an adult provider that has served the parents, a classroom teacher, a social worker or an infant development specialist.

6. **Don't just send paper, ask a friend of the family to call.** The family may throw the paper away. Send someone to the home for a visit or chat and try to obtain the families’ commitment. When you find someone who will approach the family, be respectful of his or her time. Consider how they might be reimbursed.

7. **Tap into the family's reminder system.** Parents with ID may intend to get involved or come and then forget. Consider a reminder call the day before AND the day of the meeting. Ask support staff to put the date on the home calendar. Ask the family if they need a ride or a sitter.

8. **Offer a consistent set of activities.** If families cannot come to one event, maybe they will come to the next. Offer a service or support that takes place at the same time and place every week. Give people time to get warmed up and work events into their schedule.

9. **Build in natural incentives for families to participate.** All of us want to know, “What's in it for me?” Remember these are families who don’t have much money or other resources. The kind of experiences that motivate families in which parents have ID include:

   a) Fun for both parents and children.
   b) Meals – one night a week when you don't have to cook.
   c) Time limited – no one wants to go to an event forever.
   d) Child care – provide it on site or build the activities around family interactions so that children may come.
   e) Door prizes – find out what the family could really use. Make an individualized gift or door prize available after a number of sessions.

10. **Provide a ride.** Families in which parents have ID usually need a way to get to the meeting or activity. Unless the event or service will be held in the family home they will need someone to pick them up or tokens to use for the local bus or taxi service.

11. **Use a positive approach and tap into family strengths.** Whatever is planned, be sure to focus events around activities that are easy for a family to understand and try out. Focus on what families are doing right or might do rather than what is wrong. Leave the family with a positive impression of one another.

12. **Leave your jargon at the door.** You may need to re-examine the vocabulary that you use to realize how much jargon you've picked up. For example, you may realize
that it is best to say *other kids* rather than *peers*. But did you also know that it is better to say *other kids* than *other students* because families may not think of their children as students and wonder who you are talking about?

**13. Offer a variety of supports.** Remember families with teens are interested in different topics than families with young children. See the attached list of topics that are often important to families with children at different age levels.

**14. Involve experiences that are non-stigmatizing.** Parents with ID have often worked hard to distance themselves from services that they associate with two words “mental retardation.” If events are held in a provider facility, offered at a school where their child is failing or advertised specifically for parents with ID, families may refuse to attend or participate. This is not always about a specific agency but rather about the need to be seen as a valuable and worthwhile human being, not only by others, but in their own eyes.

**15. Involve mentor families.** Make activities seem normal or typical by inviting parents who do not have disabilities to join the family for fun or learning. Recruit a group of mentor families who will be willing to establish an informal and positive relationship with the family in which parents have ID from the local parent to parent network. Provide them with some training on how to support parents with ID in a non-judgmental manner. Parents who have children with ID may be willing to serve in this capacity. They are often curious about what happens when children with ID grow up and may have the patience and kindness to get to know the family.

**Finding Volunteer or Mentor Families**

A mentor family is someone who is willing to:

- Hang out with the family and have fun together
- Talk things over from time to time informally
- Listen without doing much
- Introduce a parent with DD to a new community experience
- Meet up with a family at a community event
- Show up for important celebrations
- Be a good neighbor, a good friend
- Reinforce self-determination without discouraging the parents
- Offer a ride now and then if it is convenient
- Give frank and positive feedback about behavior
- Watch a child at short notice in an emergency
- Offer encouragement
- Model effective parenting
- Firmly discourage excessive phone calls or contacts
Mentor families:

- Let the parent with DD make their own decisions
- Offer support even when they disagree with choices
- Maintain relationships over a long period of time
- Offer suggestions without criticism or judgment
- Maintain appropriate boundaries
- Do not take advantage of naive behavior or habits

Recruiting someone to serve as a mentor to a parent who has DD is not an easy task but is a worthwhile activity. Recruitment will involve:

- Obtaining a release of information from the parent with DD
- Identifying potential partners who can help recruit potential families
- Providing information for families about how to get involved
- Providing potential mentors with training on how to support another family in which a parent has DD.
- Deciding to research the background of mentor families
- Checking with both parties to make sure each is satisfied with the arrangement over time.
The following partners may be helpful in locating families who could serve as a mentor to a family in which a parent has DD:

<table>
<thead>
<tr>
<th>Agency</th>
<th>Contact Information</th>
<th>Role/Expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>The North Dakota Family to Family Network</td>
<td>Call toll free at 1-888-434-7436</td>
<td>Coordinate a statewide network of parents who have children with disabilities</td>
</tr>
<tr>
<td>ND Head Start Programs</td>
<td>A list of all ND Head Start programs can be found at:</td>
<td>Knowledgeable about the strengths and contributions of parents in their program as well as graduates</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.headstartnd.com/">http://www.headstartnd.com/</a></td>
<td></td>
</tr>
<tr>
<td>Foster Grandparents</td>
<td>Senior Corp</td>
<td>Coordinate a statewide list of senior volunteers</td>
</tr>
<tr>
<td></td>
<td>600 S Second St, Suite 8 Bismarck, ND 58504</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Phone: (701) 223-4517</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fax: (701) 223-5775</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Email: <a href="mailto:ksk@btigate.com">ksk@btigate.com</a></td>
<td></td>
</tr>
<tr>
<td>The Arc</td>
<td>A list of all the Arc chapters in ND can be found at:</td>
<td>May conduct support groups and assist with training mentors as well as recruiting mentor families</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.thearcuppervalley.com">www.thearcuppervalley.com</a></td>
<td></td>
</tr>
<tr>
<td>Centers for Independent Living</td>
<td>A list of all the Centers for Independent Living in ND can be found at:</td>
<td>These centers sometimes support parents with ID directly and are an important partner</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.dakotacil.org">www.dakotacil.org</a></td>
<td></td>
</tr>
<tr>
<td>Infant Development Programs</td>
<td>A list of all the Infant Development Programs in ND can be found at:</td>
<td>Several have experience in supporting parents with ID</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.ndcpd.org/projects/n2k/In_the_Beginning/Infants_and_Toddlers/infantdevelopment.htm">www.ndcpd.org/projects/n2k/In_the_Beginning/Infants_and_Toddlers/infantdevelopment.htm</a></td>
<td></td>
</tr>
<tr>
<td>Community Service Clubs</td>
<td>A list of many ND service clubs and organizations can be found at:</td>
<td>These service clubs may be looking for a project or a way to make a difference.</td>
</tr>
<tr>
<td></td>
<td><a href="http://www.ndpass.minot.com/index2.html">http://www.ndpass.minot.com/index2.html</a></td>
<td></td>
</tr>
</tbody>
</table>
### Experienced Providers Supporting Families with ID in North Dakota

<table>
<thead>
<tr>
<th>Experienced Providers</th>
<th>Types of Service Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Arc, Upper Valley</td>
<td>Offers advocacy, education and family support to children with mental retardation and their families. Coordinates a &quot;Mom’s&quot; group for parents with ID.</td>
</tr>
</tbody>
</table>
| **Contact:** Margaret Fedje, Program Director  
  P.O. Box 12420  
  Grand Forks, ND 58208  
  Phone: (701) 772-6191  
  Toll Free: 877-250-2022 |
| The Minot Infant Development Program | Assists parents in finding information, locating services and working with their children’s specific learning needs. Eligible infants and children must be between birth and three years of age. |
| **Contact:** Kathy Lee, Program Director  
  Minot Infant Development Program,  
  500 University Ave W  
  Minot, ND 58707  
  Phone: 701-858-3054  
  Toll Free: 800-233-1737 |
| Bismarck Early Childhood Education Program | Supports parents as primary educators, offers parent learning opportunities, nutrition and health services and transportation are offered, as well as support for parent career development and training. |
| **Contact:** 400 East Avenue E  
  Bismarck, ND 58501  
  Phone: (701) 221-3490  
  Toll Free: 1-888-879-5313  
  Email: bcep_secretary@educ8.org |
| Community Living Supports | **Contact:** Jim Berglie  
  CLS Inc.  
  111 N University  
  Fargo, ND 58102  
  Phone: 701-232-3133 |
Foster Grandparents

Contact: Kaye Knudson
Dacotah Foundation
600 South Second Street Suite 8
Bismarck ND 58504

Phone: (701) 223-4517
Toll Free: 1-888-603-8376

Foster Grandparents are over 60 years of age, and can volunteer an average of 20 hours per week. They must have limited income and LOVE CHILDREN!!

A foster Grandparent can give children attention they need that can change their lives. They can help kids learn to read, offer counseling to those who need it, or care for children with disabilities. They also help children who have been abused or neglected, mentor troubled young mothers and teens, and care for premature infants and children with physical disabilities.

The name of the program is a little deceiving. The Foster Grandparents DO NOT provide service in an individuals’ home. What they do is provide support and services in school or Head Start, daycares, etc. They might be involved at a neighborhood center, an infant development program, an after school program, a social club, or Independent Living Center, etc. The facility the Foster Grandparents are placed in is responsible for the mentoring and training of these people. A teacher is a mentor to the grandparent as much as the grandparent is a mentor to the child. The type of training is basically “on the job.”

Kaye mentioned that the time with the children is basically one on one, and the parents are not really involved since the program is run out of public facilities. They may provide reading help, learn how to be a volunteer in these situations, and learn about senior related issues, such as health. Kaye’s job as the regional coordinator is to recruit and place these grandparents in areas where they are needed to provide services.

A Family Night Out: How to Manage It!

You and your family may want to choose a night to go out by yourselves or with another family. The hard part about this is deciding where to go, how much it will cost, how to get there and how to keep track of your kids. This can be easier for you than it sounds. Here are a few ideas of how you can manage a night out with your family and/or friends.

1. **Organize a family night at a local pizza parlor.** If you have a group of people that are interested in having a night out, check to see if you can rent the parlor for an evening. If there are a few of you, it may not be that expensive. That way, if your kids are running around, it’s OK! It’s your night out! You and your family and friends can enjoy a meal and socializing in a comfortable environment.
2. **Plan a night with friends to play board games or card games.** You can have it at one of your homes, so it is free! All you have to do is invite some friends, put out some snacks, or ask your friends to each bring a game and some snacks, so it is like a potluck. You and your friends will have a fun evening, and your children can play and interact with each other.

3. **Set up a walking club with friends.** Choose a night that works with some of your friends around your neighborhood. Get your kids together and walk to a local park or around the neighborhood.

4. **Plan to go to local events with friends.** Sometimes families have two big problems that make it hard to get to local events such as a festival, concert or party. Set aside one night a week to go together. If your group is large enough, two parents can volunteer to stay with the children. That way, families are getting out together 2-3 times a month. Rotate this job so everyone gets out. Agree before hand not to charge for the childcare, but for each family to take a turn. It helps to share transportation too. Make sure the parents who stay with the kids know exactly what to do in case of an emergency and know how to give any medication. Bring toys, drinks, diapers or other supplies for your child to the house. Plan to be home by ten o’clock. Ask a good neighbor, support provider or respite care provider to help with the childcare arrangement. Be sure that you have a designated driver if you plan to have an alcoholic drink. Also agree there will be no smoking or drinking in the house when the children stay.

**Free/Low Cost Social Activities**

There are several things that you can do in your neighborhood or community that are free to the public or low cost. Here is a list of things you may enjoy doing:

1. **Visit your Public Library.** There are often children and adult programs available on a daily basis.

2. **Visit a local museum.** There may be art programs available for you or your children.

3. **Go on a picnic in the park.**
4. Join a community organization.

5. **Visit a local church.** They may have activities or programs available for your family to participate in.

6. **Check with a local Head Start Center for programs available for your child.**

7. **Arrange a family night out or fun activity at someone’s house.** This may include simple activities such as a “touch football” game, flying kites, making home-made pizza together, making popcorn and watching a movie, having a sing-along, making holiday decorations, etc.

8. **Local YMCA or YWCA Programs often have recreation and educational opportunities for children and adults.** Check with them for upcoming events.

9. There may be recreation leagues set up in your area. Check for schedules and events. Become a booster.

10. **Special Olympics.** Whether you are a child or adult, there is a sport for you! There is usually summer or winter sports available in most areas.

11. **Check with local Scout troops or other organizations for your child to be involved with.**
Free/Low Cost Social Activities

Visit your Public Library.

Visit a local museum.

Go on a picnic in the park.

Join a community organization.

Visit a local church.
Go Sledding

Help out at a Soup Kitchen

Go Christmas Caroling

Fly Kites

Make Cookies

Hold hands and look at the stars

Ride bikes around the neighborhood
Arrange a family night out or fun activity at someone’s house

Join Special Olympics
How to Find Help

If you need assistance and have a low income, contact your local Community Action Opportunities, Inc. to obtain information on various services such as:

✓ **Money Management:** This program offers budget and money management counseling to assist individuals and families to stabilize and improve their financial situation. The counseling consists of financial analysis, debt management, information and referral.

✓ **Volunteer Income Tax Assistance:** aids low income and individuals who are handicapped to complete their federal and state income tax returns.

✓ **Representative Payee Case Management:** Finances of participating recipients of Social Security and Supplemental Security Income are assisted in making intelligent spending choices on limited incomes.

✓ **Nurturing:** Family based preventative education aimed at preventing child abuse and designed to teach appropriate roles and child development, as well as improve family communication skills.

✓ **Rent & Mortgage Assistance**

  - **Shelter House/Transitional Living:** provides temporary safe housing for women and children who are homeless due to domestic violence, eviction, or lack of money.

  - **Community Housing Development Organizations:** assist with acquisition and rehabilitation of existing rental housing.

✓ **Security Deposit Assistance**

✓ **Weatherization:** Provides energy conservation services to low-income households to make their homes more energy efficient. Services may include insulation, caulking, water heater jackets or replacing windows or doors.

✓ **Energy Share of North Dakota:** Community Action Associations, utility companies and private donors assist eligible households to prevent electrical shut-offs. Assistance is provided when all other resources have been exhausted or in emergency situations.

✓ **Emergency Furnace repair/replacement:** Helps families repair and replace unsafe heating systems. Clients must be eligible for the Fuel Assistance program and may be required to contribute a co-payment.

✓ **Cooling Program:** Window air-conditioning units are provided to households with verified medical need. Clients must be eligible for the Fuel Assistance program and provide verification of medical need.
✓ **Summer Food Service Program:** Provides nutritious noon meals for children ages 7 months to 18 years during summer months.

✓ **Food Pantries:** Provide surplus food commodities to people who qualify.

✓ **Supplemental Commodity Program:** Provides nutritious bi-monthly commodities (peanut butter, juices, cereals, etc.) to eligible individuals. The program targets the elderly and mothers/children.

It is very important to note that these services may not be available in all areas. Be sure to access their website at: [http://www.ndcaa.org/page5.html](http://www.ndcaa.org/page5.html) and choose the area you live in to find out about who to contact and what services are available in your area. You can also contact:

Kristi Pfliger-Keller, Administrator  
NDCAA  
2105 Lee Avenue  
Bismarck, ND 58504  
Phone: (701)-258-2240  
Fax: (701)-258-2245  
Email: ndcaa@tic.bisman.com

You can call in or drop in to fill in the general intake form. The agency will review it and refer you to which services you need and qualify for. All assistance is based on various income levels.
How to Get Books on Tape

The North Dakota Vision Services Vision Resource Center, at the North Dakota School for the Blind, works in conjunction with the North Dakota State Library as well as other educational facilities and agencies serving visually impaired children and adults. The North Dakota Vision Services will loan out a cassette player to an individual, who then can request books on tape from the North Dakota State Library. All books that are requested are sent to the individual free of charge. In order to qualify for services, the individual must have a learning disability, physical disability or visual impairment. The individual must fill out an application and have it signed by a certified person to verify that person indeed has a disability. The certified person only has to be a professional that is NOT a family member.

In order to access what books on tape are available, catalogs are sent to the individual, or they can also access the catalogs online. To request items, all they need to do is fill out the form in the back of the catalog, call it in, or complete an order form online, under the disability services section.

To contact the North Dakota State Library:

Website:  http://www.ndsl.lib.state.nd.us

Toll Free: 1-800-843-9948

To contact the North Dakota State School for the Blind/ND Vision Services:

Website:  http://www.ndsb.k12.nd.us/

500 Stanford Road Suite A
Grand Forks, ND 58203-2799

Toll Free: 1-800-421-1181
**Resources on the Web**

**Videos showing parents with disabilities:** [http://www.intellectualdisability.org/](http://www.intellectualdisability.org/)

This organization sponsored by the social work department at the metropolitan state college of Denver, is a great resource for hand-outs, videos and other curricular resources. They feature two award winning videos including:

"A Fair Chance" hears from six families with parents with intellectual disabilities who talk frankly about their hopes and fears as parents.

"When Parents Can't Fix It" is an up-close and personal look at the day-in-and-day-out lives of five families raising children with disabilities.

**Website for parents with disabilities** [http://www.disabledparents.net/index.html](http://www.disabledparents.net/index.html)

While this website does not feature parents with intellectual disabilities, it does feature many adaptive aids for parenting that may be useful for a parent with limited mobility or sensory input.

**Website for families with children who have delays, disabilities or chronic health care needs:** [http://www.familyn2k.info](http://www.familyn2k.info)

This website is designed for all North Dakota families who have children with developmental delays, disabilities or chronic health care needs. It has many informational resources that explain systems in family-friendly terms and may be useful for parents with ID.
Overview Handouts for Power Point Training Modules
Overview

**Purpose:** The purpose of this tool is to provide family support specialists with information and strategies that will enhance support for families in which parents have intellectual disabilities (ID).

**Intended Audience:**

Family support providers  
DD service providers  
Head start employees  
Infant development specialists  
Administrators  
Direct service professionals

**Contents:** This training package consists of:

**Manual: Supporting Families When Parents Have Intellectual Disabilities**

The manual contains narrative, lists, data, photos, tools, resources and strategies intended for background reading and useful for:

- Examining personal beliefs  
- Understanding parenting styles, strengths and needs  
- Planning integrated service delivery  
- Conducting community needs assessments  
- Completing individual family needs assessments  
- Engaging in collaborative planning  
- Using appropriate assessment strategies  
- Using appropriate intervention strategies  
- Using a collaborative approach for intervention  
- Involving families in planning

**Modules: Power Point Training Modules**

This CD contains four Power Point training modules. Titles and outcomes are:

**Module 1  Beliefs  Learning Outcomes:**

- Identify personal beliefs about parents with ID  
- Review current research about parents with ID  
- Identify a rationale for providing lifelong support  
- Identify service programs for parents with ID  
- Identify barriers to providing family support  
- Identify current family support policies for parents with ID
Module 2  Planning  Learning Outcomes:

Plan community services
- Identify a consumer base in the community
- Identify support partners
- Choose among service delivery methods
- Identify community resources

Plan individual services
- Consider parenting styles
- Restate skill deficits as support needs
- Prioritize needs for support

Module 3  Assessment  Learning Outcomes:

- Begin to understand family systems
- Relate parenting and lifelong learning
- Refine concept of lifelong support
- Identify priority tasks & related thinking skills
- Identify steps of the assessment process
- Identify assessment tools and strategies
- Relate cognitive skills and support strategies

Module 4  Intervention  Learning Outcomes:

- Intervene by addressing important tasks
- Use a consultative style for interaction
- Design a practical intervention plan
- Bring assessment information into the plan
- Identify interventions that match learning style
- Identify intervention strategies

These modules are designed for use in large or small group instruction. The notes for each slide contain suggested activities to assist with comprehension and retention of materials. Activities are based on adult learning principles. It is recommended that potential presenters review all four modules before planning instruction. There is some repetition from slide to slide for instructional purposes but it is recommended that training be given as a whole. The notes also reference specific pages in the manual. Copies of the manual may certainly be made for training purposes.

The following resources accompanying the modules:

1. Quizzes: Ten true/false, multiple choice and short answer questions that test knowledge of module content and concepts.

2. Practica Guidelines: Four 3-item practical assignments that involve interview, writing, thinking and reflecting to utilize module concepts in every day situations.
3. **Handouts:** Several planning resources and handouts that are used during module presentation.

Copies of the handouts may also be made for training purposes.

Questions or Comments:

Questions or comments on these training materials should be addressed to:

Cathy Haarstad, MS  
NDCPD/MSU  
500 University Avenue W.  
Minot, ND 58707

1-800-233-1737  
haarstad@minotstateu.edu

The acknowledgements, cautions, protections and citations listed in the manual extend to the training modules and related materials.
Handouts for Modules 2
Service Delivery Options

**Family support:** This service provides a 1-1 staff person to work with the family in their home or the community, on *whatever tasks or skills are needed*. Intervention may involve assessment, planning, instruction, coaching, modeling and crisis management. Services may focus on meeting the needs of the parents, the children or both.

**Tutoring:** Tutoring may be available to children through an after school program, a boy’s or girls club, a fitness center (i.e. YMCA) or a church program. Tutoring is often available to adults through an adult education program. Tutors must have knowledge of how to teach persons with intellectual disabilities when needed.

**Neighborhood center:** A home or duplex in a neighborhood where families bring children and meet with support mentors or partners to learn new skills. Activities usually center on sharing a meal, playing with the children and may include a demonstration or visit from an experienced parent or a celebration of family achievements. Neighborhood centers need not be staffed on a 24/7 basis. Funding is often provided through multiple programs.

**Money management:** A variety of resources are available to assist families with money management. These include direct deposit of paychecks, an envelope system for managing a cash budget, using limited debit cards and receiving individualized services for managing debt through a community action program.

**Housekeeping or chore services:** Although expensive, these services may be obtained through individuals in the community or private businesses. They are often necessary in a crisis situation. Sometimes people from an area church may be willing to provide this service. Using volunteers for this service may be problematic if the family is unable to keep the house up to a reasonable standard.

**Transportation:** This is the number one concern of many families and is especially difficult for rural families. If dial-a-ride or accessible busses are not available when needed or affordable, voucher systems have been effective in rural communities. Again volunteers from churches or community service organizations may be helpful with this need.

**Community based training:**

**Adult education classes:** Classes may address a variety of needs including getting a GED, gaining a new skill (photography), developing fitness (weight lifting) or learning to read (literacy). Classes are often available through a
local school system or community college. Again instructors may need to get specialized training to support people with ID.

**Parenting classes or support groups:** These classes are often organized by providers to help parents develop a social network and learn new skills in a group. They reduce isolation and many families will need individualized assistance to generalize what is learned in class to home situations. Also group dynamics and anger management skills may play a role in effectiveness. This model works when the presenters have clearly thought through the group dynamics, follow up support and goals and use an approach that addresses individual learning needs.

**Job seeking skills class or instruction:** Classes may be available through Job Service, Adult Education Programs or offered by transition or adult service providers. To be effective, instruction must be practical and offer both teaching and support in job seeking.
Handouts for Module 3
Assessment Strategies

**Home visit:** Home visits are used for multiple purposes including assessment, planning, support, instruction, and exchanging information. Home visits are not welcomed by all families but are an effective tool for service delivery. Assessment strategies that are listed below can be used with a home visit. Observation of parenting styles, relationships, family dynamics, child development and the home environment are available to the team as a direct result of making a home visit. Documentation related to a home visit can become extensive (written notes).

**Self-assessment checklist:** This simple tool uses key words to represent essential tasks or needs that a family may have and draw them into the assessment process. It should be used periodically as needs and perceptions change. (See page 9 in the manual)

**Relationships outline:** (interview) This outline is used to fill in the names of the immediate and extended family and friends. Most people enjoy talking about themselves and their lives and valuable information about resources and family dynamics can be obtained with this tool. (See attached)

**Family story:** A family story tells the history of the family and focus on specific dreams or goals for person-centered planning. Using a photograph album and short paragraphs, essential information about the family can be gathered and displayed. This technique involves families in planning.

**Story – board:** This method is used to SHOW the family an outcome and steps leading to that outcome. Outcomes may be related to a home routine (bedtime) or a personal behavior (hanging out in the living room without bothering others) Family members pose for still life photos that show them successfully carrying out the steps in a routine. The finished story can be used as a reminder to take the family through a routine by placing the finished pictures/captions in page protectors in a small notebook. The story can be lengthy or short, depending on the routines involved and stories replaced with new ones over time. This technique works well with both children and adults.

**Home video of a families’ routine:** Video-taping a family in their home is intrusive but often families enjoy this strategy. The video tape need only be a few minutes in length and may capture a lot of what is going on that is not always apparent to the family until they see their own video. This technique is excellent for helping families understand unspoken expectations and aspects of family dynamics that are hard to describe. Videos can capture life as it is or be used to rehearse life as it could be. A family can pop in the video to prompt them through a new routine.
Relationships Outline (3)
Parenting Skills (3) Child Welfare
Learning Complex Behavior

A parent with ID can often do some of these steps related to a complex task. It is easy for providers to conclude “they could do it if they really wanted to.”

Complex tasks require an understanding of concepts and an ability to string together less complex behaviors to form a new, more complex skill.

**Concept: Awareness of the parts or criterion that make up a whole.** For example: A young child develops a concept for the word chair. A chair is different than a bench, a stool or a couch. All of these concepts have some parts in common, (legs, seat, sometimes padding) but some differences (a chair has legs, a back, and minimal padding and is designed to hold one person). Some concepts have parts, others have criterion. For example, the concept of a stranger is someone whose name you do not know and whose behavior you cannot predict.

Concepts and related behaviors are strung together to create more complex skills. We sit in chairs, rock in chairs, recline in chairs, and may go on to assemble chairs and build chairs. We look at strangers, avoid strangers, and learn how to respond to strangers safely.

Skills related to complex behaviors are not always learned in any particular order but are usually learned incidentally.

**Complex Interpersonal Skill: Negotiate with others to get what we want**

This is a partial list of some related concepts and behaviors that must be learned to negotiate with others to get what we want.

- Identify what I want
- Take what I want
- Refrain from just taking what I want
- Ask for what I want
- Ask someone I trust to get/give me what I want
- Identify behaviors that please another person
- Change the way I ask for what I want to please another person
- Gain experience by helping others
- Gain experience in turn taking and waiting
- Learn to identify conditions when it is safe to talk about what I need
- Learn to wait for a preferred event
- State what another person wants
- Pair asking for what I need with statement of what other person needs
- Offer to do something to please others to get what I want right now
- Offer not to do something to please others to get what I want right now
Offer to do something to please others to get what I want later
• Offer to do something another person wants to gain their trust
• Ask for what I need and suggest an alternative if you say no
• Recognize when you have said yes and when you have said no
• Accept a no without complaining
• Try another request later
• Try another request with another person

Think about the complexities of learning these skills and the typical negotiation skills expected within of adults to understand how difficult it may be for a parent with ID to meet our expectations without support.

Brainstorm a list of concepts and behaviors skills that may be related to these complex skills:

Deciding who will do the chores
Getting a neighbor to watch the children
Finding out what services are available.
RELATIONSHIPS OUTLINE

Background: A relationship outline helps start a discussion about who is in a client's life. The outline blends a genogram and an ecomap onto one page. It expands the focus from documenting facts to relationship patterns. The social worker is able to explore the client's capacity for empathic thought and understanding of reciprocal relationships.

There are two general goals. First, to document basic facts about family and other supports. It is an opportunity to check family names, dates of birth, names of service providers, and phone numbers. The second goal is to discuss links between people and patterns of behavior. Patterns of interactions can be literally drawn out on the page.

Completing the Relationship Chart: Discussion with the parent begins by writing in the child(ren) into the large blank space at the bottom of the page. The eldest child is listed on the left side and the others follow in birth order. Females are drawn inside a circle and males within a square. If there is a pregnancy and the sex of the child is unknown then a triangle is used. The child's full name and date of birth should be included. Disabilities and other unique data can be noted under the child's symbol.

Each child is connected to their parents by drawing a line up to the horizontal line below their parents. The horizontal line has not been completed on this outline. Married biological parents have the line connected and the marriage date added. A divorce is symbolized with a slash drawn through the marriage line and the date of the divorce. Unmarried partners may be symbolized with dashes on the line. A gap is left in the line if there is no formal marriage and the adults have no current relationship.

Members of the extended family can be identified in the top corners. Family information may include the parents’ marital status (see above), someone's death (by drawing a X over the symbol), current residential location (city name), or major health information (physical, mental or chemical dependency). Obviously, this outline has significant space limitations. Clients may have had important relationships with others who do not fit on their chart (e.g. Aunts & Uncles, siblings, or previous marriages). Important data can be added on the back or another page with a reference to this fact.

Discussing relationships: Social worker's can use the outline to discuss relationships by starting with the familiar idea of a family tree. Parents may be interested in having this data recorded for them. It gives the parent the role of the family expert and allows the social worker to be taught about the family details. After writing in demographic information the discussion can expand to questions about family connections. The conversation expands from simple observations about family names ("Was this child named after a relative?") to progressively more abstract question ("How often do you see this person?" or "Who are the people that help you [or take advantage of you]?"). Later, one can introduce more complex issues such as frequency of chemical dependency or physical &/or sexual abuse. The patterns can be highlighted by using different colors.
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<td>A2-Cleanliness/ordeliness-outside maintenance</td>
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<td>1 2 3 4 5</td>
<td>A3-Cleanliness/ordeliness-inside home maintenance</td>
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<td>1 2 3 4 5</td>
<td>A6-Safety-Inside home maintenance</td>
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<td>1 2 3 4 5</td>
<td>B4-Adequate furniture</td>
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<td>1 2 3 4 5</td>
<td>B5-Availability of transportation</td>
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<td>1 2 3 4 5</td>
<td>C4-Available health care</td>
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<td>C5-Provides for basic medical/physical care</td>
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<td>Personal hygiene</td>
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<td>Clothing (choices, care, laundry)</td>
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<td>Math and Reading skills</td>
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<td>Shopping (including counting and correct change)</td>
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<td>Cooking and Nutrition</td>
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<td>B2-Financial management</td>
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<td>Intellectual performance (IQ full scale and written performance scores)</td>
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<td>Recognition of problems</td>
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<td>H11-Meets emotional needs of self/child (balance)</td>
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<td>G4-History of substance abuse</td>
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<td>H3-Current substance abuse</td>
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<td>H4-Passivity/Helplessness/Dependance</td>
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<td>F2-Manner of dealing with conflicts/stress (between caregivers)</td>
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<td>H10-Practical judgment/problem-solving and coping skills</td>
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<td>1 2 3 4 5</td>
<td>H7-Emotional stability (mood swings)</td>
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<td>H8-Depression</td>
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<td>1 2 3 4 5</td>
<td>H11-learning ability/style</td>
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<td>1 2 3 4 5</td>
<td>G5-History of aggressive act as an adult</td>
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<td>1 2 3 4 5</td>
<td>H5-Impulse control</td>
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<td>1 2 3 4 5</td>
<td>H9-Aggression/Anger</td>
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<td>1 2 3 4 5</td>
<td>H12-Self Esteem</td>
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<td>Personal traits or beliefs that increase resiliency (e.g. spirituality, sense of right/wrong, flexibility)</td>
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<td>Leisure skills</td>
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<td>1 2 3 4 5</td>
<td>F1-Conjoint problem solving ability (between all caregivers)</td>
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<td>1 2 3 4 5</td>
<td>F6-Ability to communicate (between caregivers)</td>
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<td>D8-Takes appropriate authority role</td>
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<td>1 2 3 4 5</td>
<td>G1-Stability/Adequacy of caregiver’s childhood (?? Not sure if it goes in L3)</td>
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<td>1 2 3 4 5</td>
<td>C1-Support from friends and neighbors and community involvement</td>
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<td>1 2 3 4 5</td>
<td>Finds and uses community resources</td>
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<td>1 2 3 4 5</td>
<td>G8-Extended family support</td>
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<td>1 2 3 4 5</td>
<td>C6-Ability to maintain long term relationship (friends and significant other)</td>
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<td>F3-Balance of power (healthy independence)</td>
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<td>1 2 3 4 5</td>
<td>F5-Caregivers’ attitude towards each other</td>
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<td>1 2 3 4 5</td>
<td>F4-Supportive –emotional support/ability of CGs to count on each other</td>
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<td>1 2 3 4 5</td>
<td>H6-Cooperation</td>
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<td>1 2 3 4 5</td>
<td>G7-Occupational history</td>
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<td>H2-Paranoia/Ability to trust</td>
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<tr>
<td>1 2 3 4 5</td>
<td>G3-Childhood history of sexual abuse</td>
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<tr>
<td>1 2 3 4 5</td>
<td>G2-Childhood history of physical abuse/corporal punishment</td>
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<td>1 2 3 4 5</td>
<td>History of financial abuse/exploitation</td>
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<tr>
<td>1 2 3 4 5</td>
<td>G6-History of being an adult victim</td>
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<td>1 2 3 4 5</td>
<td>C5-Provides for Medical/Physical care (also listed above in medical)</td>
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<tr>
<td>1 2 3 4 5</td>
<td>C2-Available child care</td>
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<td>1 2 3 4 5</td>
<td>C3-Chooses appropriate substitute caregivers</td>
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<td>1 2 3 4 5</td>
<td>Protects from dangerous others</td>
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<td>1 2 3 4 5</td>
<td>D6-Bonding style with child(ren)</td>
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<td>1 2 3 4 5</td>
<td>D12-Bonding to caregiver (child)</td>
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<td>1 2 3 4 5</td>
<td>D1-Understands child development</td>
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<td>D9-Quality and effectiveness of communication (caregiver to children)</td>
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<tr>
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<td>D10-Quality and effectiveness of communication (children to caregiver)</td>
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<td>1 2 3 4 5</td>
<td>E1-Appropriate play area/things –inside home</td>
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<td>1 2 3 4 5</td>
<td>E2-Provides enriching/learning experiences for children</td>
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<td>E3-Ability and time for children’s play</td>
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<td>1 2 3 4 5</td>
<td>D3-Use of physical discipline</td>
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<tr>
<td>1 2 3 4 5</td>
<td>D4-Appropriateness of disciplinary methods</td>
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<td>1 2 3 4 5</td>
<td>D5-Consistency of discipline</td>
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<td>1 2 3 4 5</td>
<td>D2-Daily routine for child(ren)</td>
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<td>1 2 3 4 5</td>
<td>E4-Deals with siblings interaction</td>
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<tr>
<td>1 2 3 4 5</td>
<td>Clear limit settings</td>
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</tr>
<tr>
<td>1 2 3 4 5</td>
<td>Behavior issues</td>
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</table>

**CWLA – still deciding where this fit**

| 1 2 3 4 5 | D7-Attitude expressed about child(ren)/caregiver role |
| 1 2 3 4 5 | D11-Cooperation/follows rules and directions (this is about the child) |
Handouts
for
Module 4
Scenario 1

Jack and Maria have three children ages 8, 4, and 9 months. Pete the youngest has a serious diaper rash and has not gained as much weight as he should. The pediatrician is concerned that Maria is not following directions. Jack and Maria may have to move because they are 3 months behind in their rent. A home visit showed that the baby is not eating well and there is unwashed laundry in piles everywhere. Jack is gone most of the time at work or hanging with friends. Susan age 8 is often taking care of her younger brothers. Sam is wild and often throws toys and has bitten Maria twice.

1. Jack did well with parenting at first but now he is overwhelmed and it is easier to avoid the chaos of home.

2. Maria is trying to follow directions but she does not like touching the crème prescribed by the doctor for the rash.

3. Also she has tried to introduce solid foods but it is easier to just breast feed Pete. He spits out the new foods.

4. Maria and Jack have no budget and just buy what they want. Jack’s paychecks do not stretch far enough.

5. Susan is becoming a mother to Sam and Pete but does not know how to control Sam’s wild moods.
Scenario 2

Todd and Corey are a family. Todd is 45 years old and grew up in the state Institution. He left in the early 80’s and after spending a few years in housing and work programs run by a local service provider for adults with disabilities he left to live in the community on his own. Todd was married for a few years but he and his wife split up. Todd and Corey (aged 9) live in a small apartment near the grocery store where Todd works to bag groceries. Corey is struggling in school and receives special education services. Todd recently found a new girl friend who Corey does not like – because he says she is too bossy. Todd and his new girl friend like to go out a lot leaving Corey home alone which has resulted in a review by child protection services. Corey’s language development is delayed and Todd is not a guy who chats much himself. The home is relatively clean although not tidy but there is little food in the house. Todd spent some of the food budget on a Valentine’s gift for his girlfriend. Todd takes medication for depression and a month ago when his girlfriend threatened to break up with him he stopped taking his medication for a week.

1. Corey wants to play basketball at school but there is no-one to show him how.

2. Neither Corey nor Todd cook much. Todd just heats up food from cans or buys frozen dinners.

3. Todd’s girlfriend does not have a job and wants to move in with Todd and Corey. Corey has stated he will run away if this happens.

4.
Big Picture Plan For _______________ Family

Crisis Intervention
  1. 
  2. 
  3. 

Typical routines

Atypical routines
Day to Day Plans For ___________ Family

| Outcome: Desired behavior or result | Say: Words to focus attention and build relationships |
| Show: Key skills to demonstrate several times | Organize: Methods used to organize routines |
| Remember: Method used to trigger memory | Self Manage: Important acts of self control for success |
| Feedback: Opportunities to self-assess/plan for next time |

Outcome:

Say:

Show:

Organize:

Remember:

Self Manage:

Feedback:
Support Strategies

- Someone is paid to do the task (housekeeper)
- A family member or friend does task (Wake up call)
- Eliminate the need for a task (direct deposit)
- Simplify task (Put all bills in pouch)

Teaching Strategies

- Demonstration (Show step by step)
- Model (Show what finished product looks like)
- Guided instruction (Hand over hand)
- Story board (Tell a story in pictures)
- Video tape (Tell a story/outcome using film)
- Visual aids (Use objects, pictures or lists to remind the person what or when to do something)
- Reinforcement (Payoff for repeated effort or improvement)
- Rehearse – Plan what to say and do and practice

Coaching strategies

- Point out what is not obvious
- Relate two events – show how they connect
- Show what will happen if or when
- Exaggerate events or responses so they become clearer
- Refrain from quizzing the person
- Express concern for the person
- Role play – Act out the story & consequences
### Scenario One Intervention Plan

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Pay bills, rent</th>
<th>Spend time with Sam</th>
<th>Feed &amp; care for Pete</th>
<th>Laundry</th>
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<tbody>
<tr>
<td>Skill Needs</td>
<td>Abstract Reasoning</td>
<td>Interpersonal Skills</td>
<td>Care giving Skills</td>
<td>Abstract Reasoning</td>
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<td>Skill Level</td>
<td>Concrete Thinker</td>
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<td>Abstract Thinker</td>
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<td>Support</td>
<td>Direct deposit Talk to landlord</td>
<td>Set up a basket ball hoop in yard</td>
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<tr>
<td>Teach</td>
<td>To put possible bills in a save it folder</td>
<td>Parents to do indoor and outdoor games on schedule</td>
<td>Wear glove when applying cream Teach how to wean baby but stay close</td>
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<tr>
<td>Coach</td>
<td>Paying bills = getting nice stuff</td>
<td>Time with Sam = Better behavior</td>
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<tr>
<td>Ignore</td>
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<td>Ignore for now</td>
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Intervention Plan for ________________________________ Family

Start Date: ___________________  End Date: __________________________

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Comments
References


