

Working with Families

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THE NORTH DAKOTA STATEWIDE
DEVELOPMENTAL DISABILITIES
STAFF TRAINING PROGRAM



Working with Families

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Introduction

Before 1980, most North Dakota children with disabilities grew up in state institutions. They lived far away from their families in over-crowded dormitories where conditions were often unpleasant. Unfortunately, families really didn't have any choice but to send their children away because there weren't enough supports for children with disabilities in local communities. Eventually, some families won a lawsuit that put an end to this harmful way of life. Many people with disabilities moved back into the community. This transition was challenging for everyone.

North Dakota families could hardly believe the news that their son or daughter would soon be leaving the institution. A few families resisted. They wanted the institution to stay open. Sometimes families lost track of a son or daughter after the family member entered the institution. But most families were eager to welcome their son, daughter, sibling, grandchild or relative back home. No one knew exactly what to expect.

At first, providers had limited experience in working with families. They were expected to help individuals stay connected to families AND empower people with disabilities to lead their own lives. Families had limited experiences in working closely with providers in the same community. They were expected to be supportive AND let go. It was a confusing time for families and providers. Each partner had to figure out what it took to support people with disabilities in the community. They also had to learn how to get along with each other. Naturally, there were a few bumps in the road.

Some families were content to leave decision-making to the professionals. They visited their son or daughter occasionally but had little interest in planning meetings or the day-to-day details of their lives. Other families questioned every decision. A few families resisted agency attempts to find a job or apartment for their son or daughter. Some parents feared that community experiences would be unsafe or too difficult. Fortunately, most families took a middle route. Sometimes they helped their son or daughter to find jobs or places to live. They talked things over and offered resources or financial help. They tried to make holidays special and encouraged extended family members to visit or get involved. They also learned to ask important questions and challenged providers to individualize services. These families are aging and their relationships with their adult children will change yet again.

Today, most people with disabilities live at home with their families until they graduate. Parents of these children may have different expectations about services and adult life. The idea of an institution is seldom a concern. Siblings, extended family, foster care or even surrogate parents may be very involved. Sometimes families grow tired and look forward to a respite from the day-to-day challenges of care-giving. Other families are fearful, wondering what will happen when the school bus doesn't come any more. A few families face unique situations. Perhaps a son or daughter has been away at a special school, has challenging health care needs or has lived at home for several years after high school. These families may expect expensive or highly individualized services. Most families are eager and willing to become a supportive partner and to help their child succeed as adults. Many are unsure of just what they can do to help.

Service providers have witnessed the changing needs of North Dakota families. They have learned important lessons about how to work together. This module is designed to help direct support and

other professionals work with families to ensure that people with disabilities exceed expectations and lead enviable lives.

Chapter 1: Understand Expectations and Outcomes

Chapter Objectives:

- Describe what families want or expect from providers today
- Identify accreditation standards that guide working with families
- Identify positive steps that welcome and support families
- Describe differences between family and person centered services
- Identify ways to evaluate how well your agency works with families

What Do Families Want?

This question has puzzled providers, schools and human service agencies for years. There are many different kinds of families, all with different experiences and needs. So how can you know exactly what families want? The simple answer to this question is, of course - **Ask them!**



Families do not like to be quizzed or questioned by professionals about their parenting. They do appreciate a sincere invitation to share their stories and visit with others about their hopes and dreams for their children. Listen and you may learn a lot.

What Families Have to Say

Research conducted by the North Dakota Center for Persons with Disabilities shows that six outcomes are common to most families.

- Belonging
- Contact
- Information
- Contributing
- Security
- Working toward success

Today's families expect to be welcomed and supported as partners in helping their son or daughter transition to a successful adult life. Since families differ in what they need and want, it is important for your agency to use a variety of ways to welcome, support, and invite families to work together.

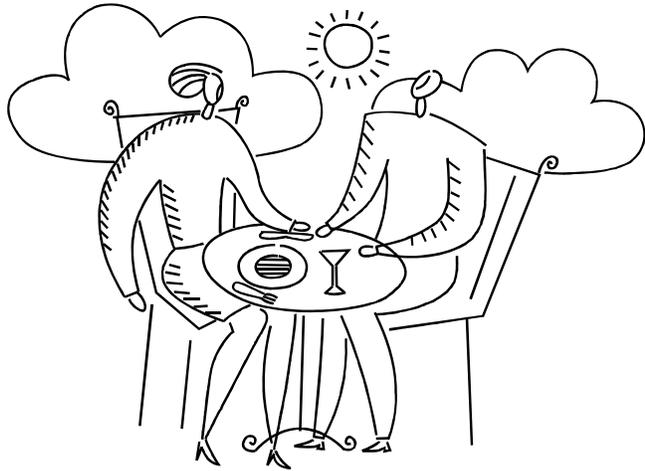
Welcoming and Supporting Families

It takes time to get to know people. Families have long stories. They cannot tell you everything they know in one meeting. You may not have as much time to visit as you would like. Even when families want limited involvement, they will appreciate your efforts to help them feel welcome. The service coordinator or QMRP is responsible for taking the first steps to welcome

and get to know families. Direct support professionals follow up when they meet families in an individual's home, at a work site, or in the community.

Why is it important to welcome and support families?

- If problems occur, the actions taken to welcome and support the family in the past will make it easier for them to approach you with concerns and more likely to accept your suggestions.
- Families are connected and they talk to other families. Making a pro-active effort to welcome one family can enhance your agency's reputation in the community.
- Families who feel welcomed and supported may go out of their way to contribute to the agency's efforts in the community.
- The way your agency welcomes and supports people with disabilities is reflected in the way you welcome and support their families.



What are some of the ways agencies can welcome and support families?

Think about your agency's efforts to welcome and support families. What role can you play in making your agency a "family-friendly" place? Use creativity, kindness, neatness, and thoughtfulness to welcome families.

Invite people over: There are many ways to invite and welcome families. Direct support professionals may offer to help invite a family over for dinner, sponsor a slumber party for teens, put on an information fair, or hold an open house. Greet families by name when you meet them at community events, the grocery store, or church. Encourage the people you serve to call a family member and invite them to come over for a meal or to visit. Get together at a restaurant, ball game, or other community event. *Families want to belong.*



Put out the welcome mat: Help the people you serve decorate the front door. How about sweeping the front steps? Help people practice greeting family members. Brainstorm ideas that would make the building where meetings take place look inviting. Share your ideas with your supervisor. Teach people to make inexpensive decorations for the season. Get a book of ideas at the library. Comb your hair, tuck in your shirt, and smile! Tell people you are glad to see them or glad they stopped to visit. *Families rely on first impressions.*

Be a reliable partner: Follow up on discussions in meetings and do what you promise. If you tell the family that you will help the person sort through old clothes, keep bleach out of the washroom, or try some new tasks on the job; take notes so you don't forget. Reply promptly to calls and emails or route them to the right person. Help the people you serve remember good things to tell their family. Take photographs of fun activities for a person to share with a family member or help someone pick out a card or gift for a family member's birthday. Be easy to talk to and a good listener. *Families are looking for signs that you can be trusted.*



Ask for help: When a new person starts receiving supports, ask the person if you may ask his or her family what works. Invite families in for a cup of coffee. Help individuals receiving services to keep a wish list or give families gift ideas for birthdays or holidays. Some families want to do more. Let families know about opportunities to participate as volunteers, board members, or serve on advisory committees.

Be a good role model: Speak to people with disabilities respectfully and in a normal tone of voice. Be aware of body language and facial expressions during meetings. Be on time! Make healthy choices and be someone that a person with a disability would want to imitate. Go out of your way to share a special interest with the people you support. *Families want their sons and daughters to hang out with people who behave professionally. You have a gift to share that no one else can. Families appreciate the way you do your job and they take their cue from you.*

You get the picture. What families want may change over time. Learning about family needs is an ongoing process. There are many different ways to find out this important information. Some of the most common ways include:

- Informal visits over a cup of coffee
- Annual satisfaction surveys
- Suggestion boxes
- Feedback checklists in a newsletter
- Input during meetings



Make it a point to find out what your agency is doing to welcome and support families. Ask how you can help.

Working Together to Achieve Success

Success looks very different to different people. Sometimes a family's ideas may be different from your own. **Ask families to tell you what success, happiness, and security would look like for their sons and daughters.** This can be done during a tour of the facility, a meeting, or when chatting on the phone. It is a powerful invitation to partnership.

Families know that sometimes what they want for their member with a disability may be different from the person's own dreams. Adults of all abilities need to be free to live their own lives. It may take creativity to support family members to accept the importance of honoring choices made by the person with a disability. *Families need reassurance.* Share how staff will respond if their family member makes an unhealthy choice or decision that may be harmful.



Example – Jack is staying up very late and doesn’t get to work on time. He told his family that his boss was not pleased. They asked staff about the incident. Which of these staff responses would best help build a trust relationship after a self-defeating choice by a family member with a disability?

1. Oh well! Jack is an adult now. He has the right to choose when to go to bed.
2. I’m not sure Jack realized what would happen the next day. I will visit with him about taping that late show to watch later. Do you think that might work?

The second statement honors Jack’s rights but also offers reassurance and invites feedback. Communicating for partnership has three parts.

- State the problem in neutral terms without blaming anyone.
- Tell what action you are prepared to take that might help.
- Invite feedback.

Most of us are not very good at “thinking on our feet.” Why not be prepared? Think about some typical family concerns. Use this three-step method to rehearse what you might say. If you are interested in learning more about how to partner with families around typical issues that challenge people with disabilities, read chapter 4.

Standards for Excellence

Agencies take many steps to make sure people with disabilities get quality services. One is called accreditation. During an accreditation visit, reviewers come to the agency, and meet with individuals to discuss their satisfaction with services. Sometimes they look at records or meet with families and guardians. During this visit, agency staff and reviewers look at a list of quality outcome measures and evaluate how well they are being met. An outcome is a statement that describes the result of quality services.

Example(s):

- Individuals have personal goals
- Families are respected



The Council on Quality and Leadership sets the outcome measures for North Dakota service providers. There are three sets of Outcomes based on the age of the individual receiving support:

- Outcome measures for families with young children
- Outcome measures for children and youth
- Outcome measures for adults (ages 18 and older)

Some standards guide how we communicate and partner with families. Look at how the word “Family” is used in the Outcomes Measures for Children and Youth shown in Figure 1.

Families are informed	Families remain together
Families choose child development goals	Families are part of the community
Families choose their goals	Families attain their goals
Families are satisfied with services	Families remain connected to natural supports
Families are satisfied with their life situations	Families exercise rights
Families choose services and supports	Families are respected
Families have economic resources	Families experience continuity and security

Figure 1: 2005 Outcome measures for children and youth



The focus shifts to the individual when the person reaches adulthood. While many standards do not specifically use the word “family”, the Council reinforces the importance of keeping families connected in the following quality measures for adults:

- The organization promotes communication between and among staff, *families*, and people supported.
- The organization supports employees, volunteers, people served, and their *families* in developing social networks and community connections.
- The organization analyzes the impact of its community involvement in terms of people served, *families*, employees, volunteers, and the community.
- Individuals are connected to natural support networks.

Figure 2: 2005 Quality measures for adults

What are your primary responsibilities to families under the outcome measures?

Your agency is responsible to:

- Assure that individual communication with families is supported
- Assist families to build social networks and make community connections
- Analyze the impact of your agency’s community involvement on families

Person/Family Centered Services

There are two approaches for supporting families and their members with disabilities. Family-centered services are appropriate when families have children with disabilities. Person-centered services are considered best practice for adults with disabilities.



Family-centered services are designed to meet the needs of the whole family (not just the person with a disability). The goal is to increase the family’s ability to care for one another. Family-centered services shift the focus from a person’s deficits to increase support for the family. Families are considered to be the experts in deciding what kind of services they need and how much and how often support will be available. Services are individualized, based on the unique culture and needs of each family member.

Person-centered services are designed to meet the needs of the person with the disability. They may be adult or child-centered. The goal is to increase the individual's ability to meet his or her personal goals or outcomes. The individual and not their family or the agency decides what kind of services and support he or she needs. Families who are court-appointed guardians may act as decision makers in some areas.



Most but not all adults want to stay connected with their families. Some people ask their families to help them solve problems or make decisions. Others prefer to visit their families occasionally but make their own decisions on a day-to-day basis.

The switch from family to person-centered services can be difficult for many parents. Some families feel confident they can meet their own needs and advocate for their son or daughter with disabilities. If they want information or emotional support, they know where to find it or how to ask for it. Other families experience emotional stress during transitions and seek a high level of involvement or support. For some families, shifting the focus away from the family and toward the individual is a welcome relief. For others, it is a source of frustration and resentment. Listen to this comment from one parent.

“One day I was respected and consulted as a partner and the very next day (my son’s 18th birthday) I was out of the loop. He had rights and I had none. How could things change so dramatically in just 24 hours?”

This painful comment shows how important it is to help parents prepare for their changing role. People become anxious when they believe that there aren't any other options. Families will benefit from your reassurance and practical suggestions for how to obtain information and stay connected. If you would like to learn more about roles and responsibilities and how you can support families during transitions see Chapter 3 in this module.

Program Evaluation

Why gather information about family satisfaction with services? Family satisfaction can impact:

- Individual satisfaction
- Agency reputation and referrals
- Continued accreditation
- State licensure

How important are these issues to your agency? Even if a few families contact the agency whenever something is wrong, it is important to understand that that most are happy with agency services. We assume that families will tell us if they have a problem. Unfortunately, that may not always be the case, in fact:

- The number one reason that families do not tell providers when



they become dissatisfied with services may be that no one has asked them to share what they like or dislike.

- Families from both the majority and American Indian cultures may be reluctant to draw attention to themselves (especially women). Many have been taught to avoid direct conflict (Haarstad, 2003).
- Some families hesitate to speak up and risk the loss of a relationship. Agency staff may be the only person they can really talk to about their son or daughter. Sometimes family members have concerns that a staff person might withdraw affection or show disapproval if they complain or ask for things that are important to them. Families have often experienced all kinds of rejection and may not want to risk another loss.

Communication between staff and families can be a lot like a marriage. Each party mentions something in passing and expects the other person to “get it.” However, since we aren’t mind readers, it is important to create lots of opportunities to determine if families are satisfied, connected, and welcomed.

Direct support professionals may have opportunities to connect with families when parents stop by job sites or their family member’s apartment or group living situation. **It’s important to use good communication strategies in these situations.** These skills don’t come naturally to most people. They take time and practice to learn. Sometimes it helps to practice with other staff and rehearse what to say in response to typical questions. Ask a supervisor for feedback on how you come across to families.

The first step is to ask families, “What can I do to help?” Keep notes of suggestions from families and report them to supervisors. Be positive, even when delivering a difficult message. Positive statements give families a sense of hope; negative statements close doors. Here are some examples:

Positive statements	Negative statements
Please feel free to call any time. It would be so frustrating to drive all the way over and find Jack is out and about.	You’d better call first. Jack has a right to privacy.
Let’s see when Mary’s break starts. I know she’d like to visit.	Mary’s working now. This is not a good time.
We haven’t done that before. Tell me more about what would be involved.	Well we don’t have any jobs like that.

If you are a QMRP, program coordinator, or supervisor you may have direct responsibilities for finding out what families think. Here are examples of methods that might help an agency learn what families think about its services and how they want to be welcomed and supported:

- Use a survey to ask important questions:
 - Would you tell another family that this agency has



- been good for your son or daughter?
- What do you like best about the agency's services?
- What do you dislike?
- How could staff be more helpful to your family?
- What actions have made you most welcome?
- How have our services helped your family this year?
- Hold a small focus group
- Put a single item checklist in a newsletter
- Set up a suggestion box
- Interview teachers, case managers, or social worker to find out what families say about your services

Agency supervisors and administrators are responsible for analyzing family input and using the results to improve services.

If you are a direct support professional or QMRP you can:

- Take part in brainstorming sessions to set goals for family satisfaction.
- Volunteer to lead a discussion about how you work with families at a staff meeting.
- Develop a list of common questions and answers about families concerns and share those with new staff.
- Be willing to try a new approach.
- Ask coworkers for feedback after a family visit.

Summary

Families are valuable and powerful partners. Different families want different things but most families prefer to be asked what would be most helpful. You have an important role in learning what kind of services your agency provides to families as well as individuals. Armed with this knowledge, you can begin to build positive partnerships and support people with disabilities in exceeding expectations and leading enviable lives.

Working with Families Feedback Questions – Chapter 1

- 1. One simple way to find out what families want is to _____.**
- 2. Name six outcomes that are important to most families.**
- 3. Choose the best answer: Today's families expect:**
 - a. To be welcomed and supported as partners
 - b. To get any services they need
 - c. To control their child's life as an adult
- 4. Why is it important to welcome and support families? Check the 3 most appropriate reasons.**
 - To build trust
 - To prevent lawsuits
 - To gain community support
 - To benefit the people you serve
 - To increase donations
 - To avoid conflict
- 5. Name at least three ways that you or someone in your agency could welcome families.**
- 6. Name at least two ways for agencies to get feedback from families over time.**
- 7. Communicating for partnership has three parts. Name all three:**
- 8. Name three primary responsibilities agencies have to families under the outcome measures.**
- 9. Match each term with the correct definition.**
 - _____ Family-centered services
 - _____ Person-centered services
 - A. are designed to meet the needs of the person with the disability
 - B. are designed to meet the needs of the whole family
- 10. Name two ways agencies can evaluate family satisfaction with services or the impact of community connections on families.**

Chapter 2: Build Connections

Chapter Objectives:

- Identify a general approach to forming positive relationships with families
- Describe challenges in supporting diverse families
- Describe challenges in supporting siblings and extended family members
- Identify four steps to building connectedness with families

Forming Positive Relationships



What would an effective partnership look like? Researchers agree that effective partnerships among friends and in business have common elements. Good partners try to:

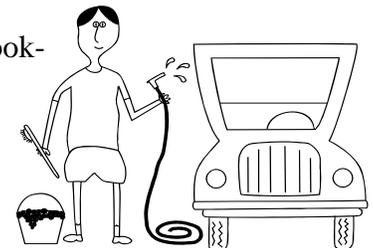
- Build and keep up a positive, long-term relationship
- Take action together to achieve common goals

Building Relationships: You can take some important steps to help partnerships with families flourish and grow. Building a good working relationship with families is everyone's job.

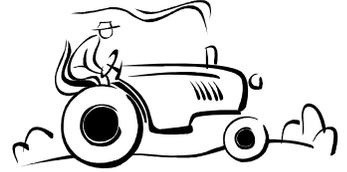
Be Positive	Smile! Show you care. Offer to help. Visit as if you had known the family all your life. Point out what is good, not what went wrong.
Be Hopeful	Suggest lots of options. Be flexible. Take the first step. Reassure.
Be Direct	Talk to, not about each other. Look people in the eye. Show interest.
Be Respectful	Be on time. Be understanding when mistakes happen. Decide together. Be polite.
Be Together	Get to know each other. Work together to complement what each one does to support the person with a disability.
Be in Touch	Stay connected. Take the time to call when everything is going well. If there is a conflict, remember to visit and smile just as frequently as you would have before. Problems come and go. Do what it takes to keep up the relationship over time.

Look for partnering opportunities that fit your situation. Be on the lookout for ways that you can use these approaches to strengthen your relationships with families. Think about the examples below. Would any of these ideas work for you?

- Sue flashes her million dollar smile when families stop to visit.
- When Jenny answers the phone her voice says, "I'm glad you called."

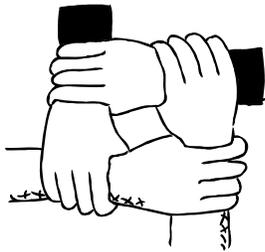


- Mark organized some folks and washed a family's car while they were in a meeting.
- Allen didn't hold Mrs. Martin's angry tone against her. He figured she'd had a tough day.
- Pam and Melissa got together with Diane's mom and took photos of safety hazards. They put together a picture checklist that lots of people who were new to apartment living could use.
- Mary brought photos of tractors, trains, and cars to a discussion about possible jobs. Chris' Dad who runs an auto repair shop really took interest in the discussion.



You can use a thoughtful, open style to build trust and encourage most families. Before your first (or next) meeting with a family, try to think of three steps you could take to build or strengthen the partnership.

Diverse Families



North Dakota communities have families of all shapes, sizes, and colors. Each family has its own unique culture. Different backgrounds shape the way that families think about services. Issues that are very important to some families may not be important to others.

New American and Refugee Families

Many New Americans live in the Red River Valley. Bosnia, Iran, Chad, the Sudan, Haiti and Asia are just a few of the countries whose families have relocated following war or famine. Other families immigrated to the USA for business or career purposes. There are important differences in how families who grew up in other countries view services. Think about it. In many countries and families

- Independence is not valued. Family is. Extended family may live together throughout their lives.
- Governments do not provide services. They are not helpful and are not to be trusted.
- Disability is viewed as punishment for a sin committed in the past.
- Disability is viewed as something taboo and therefore to be hidden.
- Physical affection is shown frequently. Families hug, kiss, smile, and sometimes argue freely in public.
- Only men are allowed to speak in meetings and make decisions.
- Experiences with assistive technology are limited and expectations may be low.
- Low expectations for family members with disabilities are viewed as realistic and a mature understanding of fate.
- English is learned as a third or fourth language.



New American families are often unaware of adult service providers. Special efforts to establish relationships with community leaders and welcome these diverse families are needed to build effective partnerships.

American Indian Families

American Indian families represent about 5% of North Dakota's total population (U.S. Census 2000). The term American Indian is preferred over Native American by most tribes but not all individuals living in reservation communities. If you are not sure about an individual preference, ask the family. Many American Indian families are highly mobile and move into and between reservation communities and the urban communities of Minneapolis, Fargo, Grand Forks, and Bismarck as well as to South Dakota, Minnesota, and Montana.



Each Northern Plains tribe is unique. It is helpful to learn a little bit about the tribal and cultural history of American Indian families if you support an individual from one of North Dakota's five nations. Web-based information about American Indians and people with disabilities is often very general and not always accurate. Read more about the history and culture of American Indians at <http://www.nativeinstitute.org/> or at the website of the North Dakota Indian Affairs Commissioners at <http://www.health.state.nd.us/ndiac/>. You can also read information about supporting American Indian families who are raising children with disabilities at <http://www.ndcpd.org/products>

Cultural Challenges

If your agency does not serve American Indian or New American families you might think that that cultural diversity does not apply to you. However, North Dakota has many other unique cultures. Does your agency have any families with these backgrounds?

- Rural poverty culture
- Deaf culture
- Military culture
- Latino/Hispanic culture
- Depression era parents or grandparents



The background of each family guides how people approach planning and problem solving and the way they view disabilities. Each culture has rules that make sense within the group. You have your own beliefs or rules about the "way it is supposed to be." Agencies usually operate from middle class norms and use the hidden rules of the middle class to solve problems. What happens when a family breaks your personal or the agency's rules? Consider some of the hidden rules of the "poverty" culture in the chart below. Has your agency supported individuals and families from poverty culture?

	POVERTY	MIDDLE CLASS	WEALTH
POSSESSIONS	People	Things	One-of-a-kind objects
MONEY	To be used (spent)	To be managed	To be invested
PERSONALITY	For entertainment – a sense of humor is important.	For getting things. Achievement is important.	For connections. Financial/social connections are important.
SOCIAL	Include only people you like.	Become self sufficient and self discipline.	Exclude people who are not like you.
FOOD	Did you have enough? Quantity is important.	Did you like it? Quality is important.	Was it presented well? Presentation is important.
CLOTHING	Helps express style and personality. Quantity is important.	Shows quality and helps people fit in. The label is important.	Is valued for its artistic sense. The designer is important.
TIME	The present is most important. Decisions are made for the moment.	The future is most important. Decisions are made to secure the future.	Traditions and history are most important. Decisions are based on tradition.
EDUCATION	Valued as a whole but not on a day-to-day basis.	Critical for climbing the ladder of success and making money.	Necessary for making and maintaining connections. Going to the best schools.
DESTINY	Believes in fate. Can't do much to overcome chance.	Believes in choice. Can change the future if you make good choices now.	Destined to lead and care for the unfortunate
LANGUAGE	Casual. Language is about survival.	Formal. Language is about negotiation.	Formal. Language is about networking.
FAMILY STRUCTURE	Mothers tend to be the authority figure.	Fathers tend to be the authority figure.	It depends on who has the money.
WORLD VIEW	Sees the world in terms of the local setting	Sees the world in terms of the national setting	Sees the world in terms of the international view
LOVE	Love/acceptance depend on whether someone is liked.	Love and acceptance are conditional and based largely upon achievement.	Love and acceptance are conditional related to social standing and connections.
MOTIVATION	Survival, relationships and entertainment	Work and achievement	Financial and social connections

Figure 3: From a *Framework for Understanding Poverty* by Ruby K. Payne, PhD.

Many people with disabilities live in poverty. Families may come from poverty, middle class, or even wealthy backgrounds. Staff also can come from different backgrounds. Each group is always sure that their rules are right. These beliefs can cause conflicts in the workplace or make it hard to form effective partnerships with families. It takes time to learn about a culture that is different from your own. What can you do to get to know and relate to people from different backgrounds?

- Plan time before a meeting to enjoy food and visit so



you can get to know families.

- Ask families to share their family stories and traditions. Share your own.
- Build understanding. Think out loud about what decisions may mean for the individual and what strategies may help. These discussions can help establish common ground when people from different backgrounds plan together.
- Make a point to find out about family support networks, food pantries, or counseling resources that may be helpful to families.

Consider the scenario below:

Marilyn's family often drops by unexpectedly. They use her phone to make long distance calls, and eat her groceries. Her younger sister borrows her clothes and doesn't always bring them back. You have overheard Marilyn's family telling her about the cute guys she might meet at the bar. On the weekend they take her around to all the garage sales. Her apartment is filled with boxes of polyester clothes. Marilyn's budget is blown. Marilyn believes whatever her family does is right. They laugh together and have a great time. Marilyn's family is proud of her. She loves her family very much and is happy to share whatever she has. You are trying to help Marilyn to plan for the future. You have grumbled and puzzled about Marilyn's family many times. Don't they know how important it is for her to save her money? Why is Marilyn's family behaving this way? Don't they value her training and job? Maybe they are just no good?

Marilyn's mother is a single parent. She worked part time but a work related disability took her out of the work force several years ago. Going to garage sales and relying on whoever had any food or resources has helped this family survive. When Marilyn moved out they lost her Social Security income. Her mother is having trouble making ends meet. When supplies get short, she comes to Marilyn for help. She helped Marilyn for many years and believes that it is Marilyn's turn to help her. She expects Marilyn will get married and have babies. Your job is to respect and partner with Marilyn's family to help Marilyn achieve her goals. Criticism isn't working. What can you do to help?

Did you think of any of these steps?

- Offer to drive Marilyn and her mother to the food pantry once a week.
- Offer to help Marilyn go through all her new clothes and put some away for later.
- Change the shopping plan so that Marilyn shops more often and buys less.
- Show Marilyn and her family how to get a pre-paid phone card.
- Help Marilyn's family get connected with the Community Action office.
- Outline what would happen to Marilyn if she didn't have groceries or money and suggest a new plan.
- Keep the situation in perspective. Let the family know that you care about their needs as well as Marilyn's.
- Help Marilyn make new friends and make plans to join them for social activities.
- Go with Marilyn and her family to a garage sale. Let the family know when Marilyn



already has an article of clothing.

- Tell Marilyn and her family how lucky they are to be able to spend time together.
- Invite Marilyn's mother or sister to help her make a checklist of what she needs to do to keep her apartment and job.
- Praise Marilyn's family when they help her make good choices and stress how much that helps Marilyn every day.

Sometimes we are challenged to support people from diverse families. We can grumble or criticize when they break the rules; or partner with them. Which approach is more helpful? Which approach is more respectful? Which one matches your agency's policies toward families?



Siblings, Grandparents, and Extended Families

Is there a typical family?

No! The number of traditional, two-parent families is declining and even in the minority in some American cities. Coping with a disability can strain or break up relationships. Many people with disabilities grow up in single parent households or are raised by grandparents.



Sometimes, people with disabilities have large extended families that play an important role in their lives. Some siblings (brothers and sisters) may agree to serve as legal guardians when parents age or die. Others siblings have no legal role but are close to an adult brother or sister with a developmental disability. They visit frequently and may come to meetings and advocate for their family member. Siblings are more likely to be involved as a future primary caregiver (Heller, 2005) if:

- The person with a disability has many independent skills
- The sibling lives closer rather than farther away from the person with a disability
- They have been involved in supporting the person with the disability in the past
- They find satisfaction in providing care for a sibling with disabilities

Some families remember to include siblings or other relatives in planning for the future and others do not. Providing information and support to siblings can be an important service. National studies (Heller, 2005) show siblings appreciate several kinds of support. Find out if your agency provides or refers siblings or parents to any of these services:

- Information support networks, especially for siblings who are at a distance
- Support and psycho-educational groups
- Workshops and information on future planning
- Internet networking groups
- Access to respite care, recreational programs, and a variety of residential living



options

- Financial support
- Legal services/resources
- Transition programs for siblings when they take over guardianship or support duties



Children with disabilities who have been away at a special school or required an out-of-home placement may have foster or surrogate families. There may be a legal relationship (if a child was a ward of the state) or a surrogate family may have been assigned by a public school to provide supports while the child is far away from their natural family. In some situations individuals receiving support are estranged from family members. Custody settlements or court orders may restrict the access of specific family members.

Families come in all shapes and sizes. Most individuals want to stay connected with their families. Some want a high level of family involvement regardless of the legal relationship. Some people want to be close to family members but prefer to make their own decisions and keep private the day-to-day details of their lives.

Sometimes individuals have difficulty with memory or communication. They may not remember to share important information and rely on you to communicate significant details to their families. Other individuals will need support to gradually move from dependence on parents for self-direction to limited or more extensive choice making. In Chapter 3 you will learn more about how to be supportive of both individuals and families during transition.

Taking Action to Build Partnerships

You have read about a general approach to building effective partnerships with families. This approach challenges you to be positive, hopeful, direct, respectful, in touch with, and close to diverse families of all shapes and sizes. An effective partnership helps you work together with families to support individuals in:

- **Getting resources** (clothes, equipment, supplies, furnishings, transportation)
- **Making choices and planning** (moving from simple choices to major decisions)
- **Trying out new experiences** (a job, an apartment, a group living situation)
- **Staying safe** (getting enough sleep, making healthy choices)
- **Learning about relationships** (making friends, dating, being intimate)
- **Participating in community life** (volunteering, seeking entertainment, worship)

A positive approach is only the beginning. Read about important ways that your agency may take action to build effective partnerships.

Provide Informational & Emotional Support

Informational Support: Informational support is a service that gives families important information through web-sites, newsletters, meetings, discussions, posters, checklists, and brochures about agency and community services.



Emotional Support: Emotional support is a service that helps families cope with the isolation and stress that are sometimes experienced as parents or siblings of an adult with disabilities. This service may include talking things over, reassurance, connections with other families, referrals to human service agencies and developing or maintaining an enduring relationship over time.

Informational and emotional supports are often complimentary. Each type of support may lead to the other.

Example 1: Informational support is given. The information provides the answer to many anxious questions. A parent or sibling realizes they have more options than before. Suddenly they feel less alone.

Example 2: A family meets other parents whose adult sons or daughters are going through a similar transition. One of those parents shares a good solution that the family brings back to the team. The emotional support (getting together) leads to a sharing of informational support.

Why is it important to provide informational and emotional support?

- Caseloads are large and no one person or team has as much time to spend with a family as they would like. Linking people up with other families or resources makes sense.
- Supporting the same person from two unique perspectives creates a common bond. We are in this together.
- Printed information is a valuable tool that can help agencies share their mission, values, and approach directly, instead of relying on others to get the message right.
- When information proves to be helpful, trust is established.

Staff provide families with important information. The way you do your job says a lot. The explanation you give to an individual is observed by the family and may be imitated or shared with someone else in the community later. Find out what kind of informational tools your agency has for families. You can offer to help locate, update, or design tools. Here is a list of practical resources that families and the individuals you serve may find helpful:

- The city bus schedule or a description of any available dial-a-ride service.
- A map with the location of affordable housing units marked.
- A list of basic supplies needed before moving into an apartment.
- Photos and brief descriptions of community jobs can help parents



understand the agency's philosophy regarding careers for individuals with disabilities. A list of work opportunities before young people graduate can involve families in supporting transition to adult employment.

- A brochure showing five easy tips to help young people with money management will help families support financial independence for their family member.
- A list of common questions and answers about your services.

Support Connectedness

Effective planning helps to build and strengthen partnerships with families. Your agency probably has a system for welcoming new individuals and providing the person and their family with a general orientation. During this process there are several important steps that you can take to build an effective partnership with the family.



1. **Exchange contact information.** Make sure the family knows who to call after hours. Test to make sure your emergency back up systems really work under typical circumstances AND on weekends, holidays, during vacations, etc. We hope nothing will go wrong, but if it does, everyone will have the assurance of a communication system that works. Be sure that you know how to contact families as well. Have the information accessible after hours and on holidays.



2. **Create a safety plan. Write it down. Follow it!** Don't just gather general information about individuals that you support. Recognize that people may be a little more vulnerable than those who do not have a disability. Ask how the individual handles potential emergencies - like tornadoes, inclement weather, fire, being alone, adjusting the water temperature, coping with pain from a minor injury, a physical exam, etc. Families will appreciate your being prepared for the unexpected.

3. **Stay in Touch.** Talk about how often the family hopes to visit. What will work best for everyone? When will the individual be home? If others live in the same setting, what access will the family have? Can they walk right in, get a key, call first, etc? It is important to balance the need for privacy for people who live in the home and the families' need to visit and see that all is well. Plan how the individual will be supported to make phone calls, write letters, honor and be present at family celebrations, and stay in touch with extended family. These connections are often critical for the person and his/her family. Some people will need significant support to make these connections but it is important to remember that the person's family may be the one constant in their life. To ensure important dates are remembered, direct support professionals can help the person develop a calendar with birthdays, anniversaries, and other important dates. Offer letter writing or phone calls as a leisure activity for weekends or evenings. Families will appreciate individualized plans for support.

Avoid red-flag words. A red-flag word is a phrase or statement that puts people on notice that services will not be individualized or respectful. Examples: Your brochure said that you work with individuals to find jobs that match their interests but during the meeting you announce that the only community-based job you have is a cleaning crew. A family hears you use people first language “Marty has a hearing-loss,” but they also hear two staff people in the hall call one another an “idiot”. Unfortunately, red-flag words can un-do all someone else’s positive work. Be on the look-out for and work to eliminate these types of problems. Families will appreciate your thoughtfulness.



Keep Confidentiality

Confidentiality is more than just an agency policy about communicating on a “need-to-know” basis. It is also the cornerstone of effective family partnerships. Think of North Dakota as one small community with a lot of distance between houses. The families you support are connected. In small towns especially, information shared outside of the agency has a way of getting around. Even if you have not spoken about a specific individual or family, they may hear what you say about service recipients, through friends or relatives.

Using only a first name may not be as confidential as you think. If a family overhears staff talking about someone who is not present using a first name, they may know more than you realized from the details. Be careful.

Sometimes a family knows another family whose son or daughter receives services. They may ask about those individuals during a tour in a “friendly way.” “So and so is here isn’t he?” “Is this where such and such lives?” You will want to appear friendly but maintain confidentiality. Ignoring the question won’t work. You might say: “If your son decides to choose our agency for services, I will be happy to help him look up any old friends.” Families appreciate staff members who are discrete.

Be aware of standards on confidentiality that you are required to meet. The Health Information Privacy and Portability Act or HIPPA guarantees the rights of individuals to privacy concerning health and medical records. The Council of Quality and Leadership also has outcome measures that stress confidentiality, “Individuals decide when to share personal information.” This means that people supported decide what information staff may share with their family. The QMRP or service coordinator will review rights to privacy with individuals. Details about what information you can share with others should be documented and on file.

Summary



In this chapter, you have learned about a general approach to building effective partnerships with families. Good partnerships begin by establishing positive relationships and working together to support young people with disabilities in meeting goals. The people you serve come from diverse families. You are responsible for learning about ways to support families who may have a cultural background that is different from your own. People that you support may want brothers and sisters (siblings) as well as extended family members to be involved in their lives. The person you serve will decide how much information you can share with their family. You play a vital role in helping your agency provide informational and emotional support, plan effectively, and keep confidentiality.

Working with Families Feedback Questions – Chapter 2

1. Circle the two best answers. Good partners try to:

- a. Build/keep up a positive, long-term relationship
- b. Achieve outcomes no matter what it takes
- c. Take action together to achieve common goals
- d. Guess what the other partner may want or need
- e. Avoid contact to prevent conflicts

2. Match these terms to the examples:

- | | | |
|------------------|-------|--|
| a. Be positive | _____ | Look people in the eye. Talk to not about others. |
| b. Be hopeful | _____ | Suggest lots of options. Be flexible. |
| c. Be respectful | _____ | Take the time to call when everything is going well. |
| d. Be direct | _____ | Be on time. Be polite. |
| e. Be together | _____ | Smile! Show you care. Offer to help. |
| f. Be in touch | _____ | Get to know each other. Work together. |

3. True or False: In many new American or refugee families who have children with disabilities:

- _____ English is learned as a second, third or fourth language.
- _____ Only men are allowed to speak in meetings and make decisions.
- _____ Independence is highly valued.
- _____ Physical affection may be shown frequently.
- _____ Low expectations may be viewed as realistic.

4. North Dakota's largest minority population is _____.

5. Name two other unique cultures in North Dakota.

6. People raised in generational poverty are motivated by:

- a. Survival
- b. Achievement
- c. Status
- d. Partnership

7. A sibling is:

- a. An extended family member
- b. A foster family
- c. A surrogate family
- d. A brother or sister

8. Name three types of support that siblings may find helpful.

9. Why is it important to provide informational and emotional support?

10. Name four steps you can take to build connectedness with families.

Chapter 3: Understand Roles & Responsibilities

Chapter Objectives:

- Identify family roles in supporting adults with disabilities
- Indicate how family roles change over time
- Identify how disabilities impact family expectations
- Describe good communication practices

Understanding Family Roles

Most people who grow up in America leave home sometime after high school. They usually get a job and find a good place to live. Some people go on to college or get advanced training. Others join the military, visit family and friends, or see far-off places. The majority date, marry, or form long-term relationships with someone they care about. Many contribute to their workplace or community.

Employment, housekeeping, military service, volunteering, advanced training, and marriage are all adult roles. Families play an important role in helping all young people grow up. When you were younger your parents might have:

- Let you know when to be home
- Given you an allowance
- Told you when to get a haircut
- Told you to clean your room
- Taken care of you when you were sick
- Grounded you if you broke the rules
- Made you stop fighting with a brother
- Taught you how to, fish, use the phone & cook



Families continue to play important roles in helping young people move into adult life. Did your family help you with any of these activities?

Money	Networks	Problem Solving	Support	Time
<ul style="list-style-type: none"> • Co-sign a loan • Make a down payment • Buy supplies • Pay for school 	<ul style="list-style-type: none"> • Told you who was hiring • Suggest a doctor or car dealer • Help you find a good school? 	<ul style="list-style-type: none"> • Figure out a way to cut costs • Plan a party or wedding • Solve a health concern 	<ul style="list-style-type: none"> • Listen when a relationship ended • Welcome you back on holidays • Congratulate you on something 	<ul style="list-style-type: none"> • Loan you a tool • Help you hunt for an apartment • Help you study • Baby-sit for you • Shop with you • Take you out to eat

Figure 1: Ways families help out when young people leave home

Changing Relationships

Sometime shortly before you left high school your relationship with your parents probably began to change from an adult-child relationship to an adult-adult relationship.

Adult-child relationship: In this relationship . .

<p>The parent:</p> <ul style="list-style-type: none"> • Acts as a primary care-giver • Sets and enforces limits • Provides guidance and support • Provides opportunities for growth 	<p>The child:</p> <p>Depends on parents for physical/emotional support</p> <p>Learns life skills</p> <p>Learns how to get along with others</p>
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Adult-adult relationship: In this relationship . . .

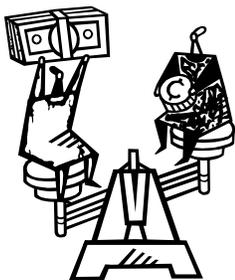
<p>The parent:</p> <ul style="list-style-type: none"> • Gives primary care during emergencies • Sets limits only in their own home • Provides guidance/support when welcomed • Provides opportunities for growth • Serves as a successful role model 	<p>The adult child:</p> <ul style="list-style-type: none"> • Establishes his/her own space • Makes choices and takes risks • Tries out new lifestyles • Carries on family traditions • Takes on adult responsibilities
--	--

Notice how parental role change from care-giver/enforcer to guide/mentor. This change is gradual and can take several years. And of course some things never change. My friend Mary is 54 years old but her 80 year old mother still reserves the right to tell her she drinks too much diet soda.

Impact of Disability

How does having a developmental disability impact changing roles in families?

1. Many youth with disabilities take longer to learn basic skills. In fact, some skills may never be learned. Some young people may handle their own personal care but are easily exploited, have difficulty solving problems, and are more vulnerable than other people of the same age. Some young people with disabilities will continue to depend on others for assistance with personal care as adults. *It is natural for parents to want to fill this role as they finish the job of parenting.*



“I used to wonder why more families didn’t teach young people with developmental disabilities how to use the phone, manage money, or finish self-care tasks, etc. Then I had a child of my own. I learned just how long it can take to teach even simple steps. I realized that the reason many families do not teach all those skills I named before is because it takes all the time they have to teach what they do

before their child leaves home. It was at that point that I stopped judging families and started thinking about how to support them.”

2. Most parents back off and change their relationships when young people send important signals: “I can do it myself,” “You can’t make me,” or “Everyone else gets to.” Children show parents they are ready for more responsibility by taking on new projects or jobs. Some may not have the words to express what it is they long for. Others avoid risk or failure and are content with the security that comes with dependence. Young people with disabilities may not send the same signals or do so at the same time as typically developing youth. *It is natural for parents to continue a role until they get a signal that needs have changed.*

3. Most parents learn how to help a young person grow up by visiting with friends and relatives, watching TV, reading books or newspapers, or observing young people in the community. Although murky at times, roadmaps for the future abound. Parents whose children have disabilities have fewer role models. The sons and daughters of their families and friends may have options or skills that seem very different. They may be the first member of their family or network to raise a child with special needs. *It is natural for relationships to change more slowly when information about what to expect and how to help is more difficult to obtain.*



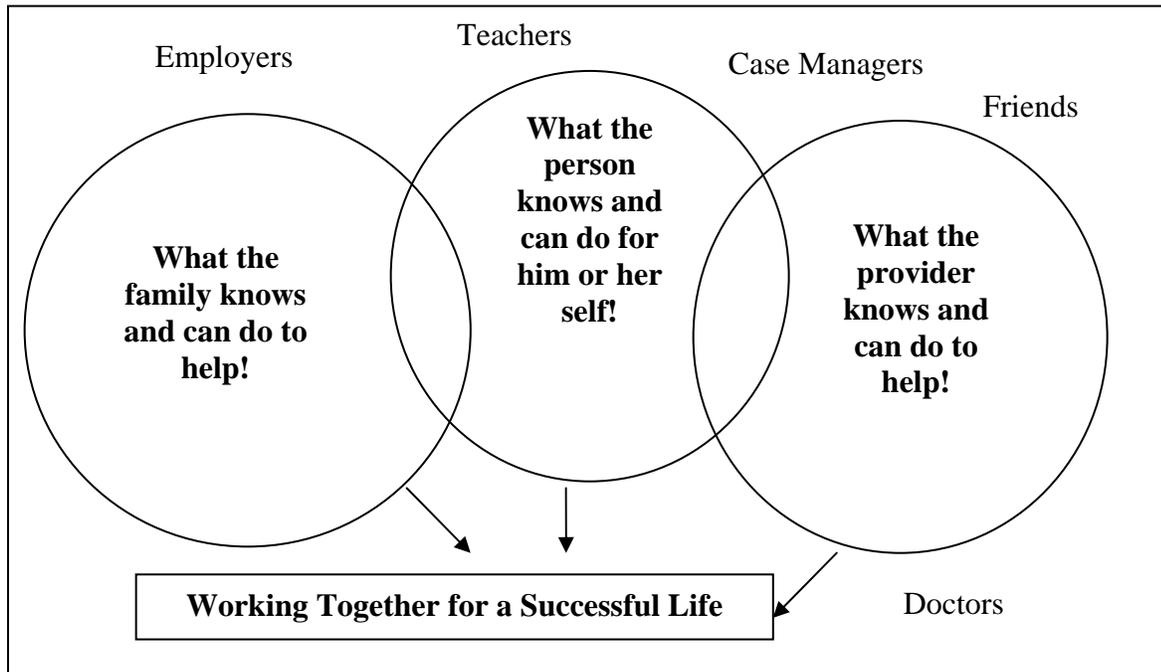
4. Many communities or providers are not able to provide all the supports that a young person with a disability may need to succeed. A few individuals will need very unique or specialized environments that are new to agencies. Some families continue to provide accessible transportation or take their adult son or daughter to community events when staff members are not available. Some families know more about management of complex behavior than the 20 year-old staff person who just met her first person with a disability two weeks ago. *It is natural for families to fill a void until they have the assurance that needed supports are dependable.*

What have we learned? We support families in changing to an adult-adult relationship when we:



- Provide tools and routines that individuals can manage with less help
- Gradually support young people in taking on reasonable risks and challenges
- Support young people in communicating their need to “do it myself”
- Give families lots of information about what to expect and how to help
- Provide a stable, secure environment and minimize the impact of turnover
- Recognize and build on family expertise

Figure 1 shows how expertise come together to create successful experiences.



The truth is that no one knows exactly what the future holds for the person with a disability.

Families know what worked in the past at home and at school. They may not know what will work in an apartment or assisted living situation, or on the job. They cannot duplicate what a provider can offer. Families may not know what they can do to help and what will make things harder for everyone. *In the absence of good information they will do what seems natural or best.*

Providers know what has happened with other young people in similar circumstances. They may not know how this young person will respond or what has been tried before that is not likely to work in new situations. Providers do not know the stories of the family or individual and cannot duplicate everything that a family may offer. *In the absence of good information they will use what has worked with other people.*

The person with a disability knows what has happened in the past but not what will happen next. They may not know what will happen if they try something. They need family for support and ties to the past. They need providers for support and ties to the future. *In the absence of good information and appropriate support they will resort to trial and error or give up and quit trying at all.*

Families, providers and people with disabilities need one another. Only by working together will they be able to individualize services and build on each other's expertise and unique perspective. Partnerships with families are critical for success.

Good Communication Practices

Good communication practices are important tools that can help you work with families. Chapters 1 and 2 already outline a general approach that can be used to help you get to know families, honor differences, and show respect. Your agency may use some other special techniques to communicate effectively with families.

1. **Single-point-of-contact.** A single point of contact is a person (usually a QMRP or service coordinator) who serves as the primary contact person for families. Their role is to explain policy, answer questions, discuss needs, and lead planning. The advantage to using this method is that it tends to keep everyone on the same page. Families know who to call about concerns and problems of sending mixed messages from multiple staff are avoided. However, many families prefer informality and want to know what the direct support professional thinks. Some agencies are very formal about the use of this approach. Staff are expected to refer all questions from families to the single-point-of-contact. Other agencies are flexible, using this approach generally but going along with what seems to work best for each family. **Check to see if your agency has policies about using a single-point-of-contact and do your best to follow them.** If families question the policy, refer them to your supervisor or the appropriate person.



2. **Exchange of information.** When individuals first begin receiving services from an organization, families and providers have an opportunity to **exchange important information.** At first everyone will share general information about the agency or family. Example: “We have been operating for ten years.” “We have seven different work placements in the community.” “We have four people in our family and two dogs.” “Jack’s favorite hobby is soccer.” Be careful not to take up too much time with this kind of chat. As quickly as you can, move on to exchange information that will tell one another what to expect, what works, and what might help. One way to do this is to “Think out loud.” Here are some examples:



- “What would a typical morning be like for Mary?”
- “I was thinking that assisted living means sharing a bathroom or group cooking. Tell me about the times that Mary has stayed overnight away from home.”
- “Getting enough sleep, being on time for work, and staying healthy are the top three challenges that most people have when they move into an apartment. I wonder if Mary will struggle with any of those.”

3. **Give each other feedback.** Create opportunities to give each other feedback. Invite families to tell you how you are doing. Be willing to accept constructive suggestions. Listen carefully when families tell you about their son or daughter. Don’t discount what they have to say, “Oh all young people do that,” when they express a concern. Take comments seriously and respond in a positive manner. Be careful to not ask too many questions because that can shut down communication. In the following example, the staff person invites the family to give

feedback about what they think might be going on without asking a lot of questions: “That is a concern. I am wondering if this is a letdown just before the holidays or if John is really planning to quit his job. It’s hard to tell. I wonder what might work best.”

- 4. Document important information.** Be sure to write down informal exchanges with families and share any information with your agency’s single point of contact and/or a supervisor. Examples may include questions and how you answered them, concerns shared by the family (spoken or unspoken), ways that they offered to help, and information they might be able to use. Use your agency’s policies to forward the information through the chain of command.

Summary

You have learned how family roles change as youth with disabilities leave home and enter adult life. Disabilities can impact family expectations. Individuals with disabilities often enter adult life with less information than typically developing peers and may be more vulnerable. Families need your support in learning how they can successfully help their son or daughter to enjoy a meaningful life. Good communication practices are important tools that help providers to assist families in realizing new roles and responsibilities.

Working with Families Feedback Questions – Chapter 3

- 1. List three ways that families help young people grow up.**

- 2. True or False**
 - _____ Parents in an adult-to-adult relationship may act as primary caregivers during emergencies.
 - _____ Asking too many questions may shut down the lines of communication with some families.
 - _____ Providers seldom know what has happened with other young people in similar circumstances.
 - _____ Families, providers, and people with disabilities need one another.

- 3. When children leave home the parental role changes from care-giver/enforcer to _____.**

- 4. Name two ways your agency can support families in changing to an adult-adult relationship.**

- 5. Name four communication practices that can help providers work with families.**

- 6. A policy that directs one person to serve as the primary contact person for a family is called _____.**

Chapter 4: Tackle Typical Challenges Together

Chapter Objectives:

- Identify ways to manage risk and opportunities
- Identify ways to control the pace of change
- Identify ways to share information

Manage Risks and Opportunities

Families, providers, and individuals can work together to identify opportunities and manage risks. People with disabilities have many choices. Choice involves:

- Identifying opportunities that match preferences
- Taking action to select something or participate
- Evaluating the results
- Using that information to live a meaningful life



Reasonable risks: Choice also involves some risk. Families and providers are important partners in helping individuals manage risk. Together you can look at opportunities that may interest an individual, consider the choices that person may make, weigh any risks that are involved, and decide how to work together to provide supports that enhance opportunities and minimize risks.

Managing opportunities and risk is a challenge present in almost every decision or plan. There is no way to eliminate all risks. People sometimes disagree on what meets the definition of an “acceptable” risk. Agencies are responsible to promote health and safety AND to honor individual rights and choices. Families and providers cannot be present on every occasion that places an individual at risk.

Risk Management Strategies: Teams use many different approaches to respect the rights of individuals and minimize risk. Families appreciate the following strategies:

- **Minimize overtime.** Keep the number of over-time hours you work at a minimum. Overtime can contribute to stressful working conditions. Stressful working conditions can increase the likelihood that abuse or neglect will occur (Mercer, 2004). Families need to know their sons or daughters are safe.
- **Individualize services.** Look for ways to support emerging interests. Don’t squelch an idea just because something bad could happen or because you’ve never done it before. Invite families and individuals to consider new ways of doing things. Talk about the risks involved and how to manage these risks.
- **Set up ground rules.** Encourage discussions about risk during meetings with families. Use ground rules to help everyone feel comfortable. See the examples in



Figure 1.

Discussion Ground Rules	
<ul style="list-style-type: none"> • This is a safe room • There is no rank in this room • All ideas are valid • Each person gets a chance to speak • Each person gets a chance to listen • We are here to focus on the future • Our purpose is improvement, not blame • Speak up and tell us what you can live with 	

Figure 1. Examples of ground rules for group discussions

- **Use Graphs and Charts:** Graphs and charts can clarify what is important. The graphs in figures 2 and 3 were used by teams to show participants how to consider both risks and benefits while making choices. This tool helps people work together rather than take sides.

Now that Mary has her own apartment she plans to have a party and invite all her friends. She has triumphantly informed her family that there is nothing they can do about it. Mary’s family is concerned that a party might get out of hand. They think Mary should focus on her new job and drop the idea of a party. Mary refuses to budge. You are caught in the middle.

Opportunity/Choices: Having a party in your apartment		
<p style="text-align: center;">Benefits: Why is This Good?</p> <p>1. 2. 3.</p>	<p style="text-align: center;">Risks: What Can Go Wrong?</p> <p>1. 2. 3.</p>	
<p style="text-align: center;">What We Decided Together:</p>	<p>Mary will . . .</p> <hr/> <p>Staff will . . .</p> <hr/> <p>Mary’s family will . . .</p>	

Figure 2. Benefit/Risk Analysis

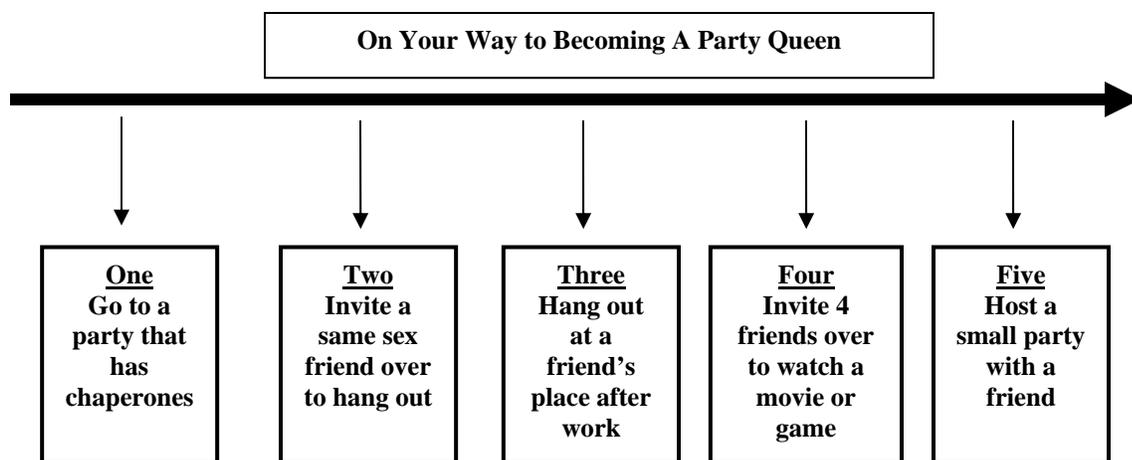


Figure 3. Example of steps leading to a goal

Using graphs and charts can help team members take a step back from the emotion they bring to the conflict and work together to support choices and minimize risks. Think of a situation in your program. Can you draw a simple chart to outline choices? Be creative.

Control the Pace of Change

Taking Small Steps

Your agency is committed to helping people achieve individual outcomes and learn new skills. You may not always be able to reach this goal immediately. Sometimes, it works best for families and individuals to move towards this outcome in small steps. Think about the story below:

Jack lived in a residential program and attended a specialized private school in another town for many years. He has multiple physical, cognitive, and sensory disabilities and requires support from professionals who are trained in life-saving procedures. Jack requires complete assistance with dressing, meals, and personal care.



Jack recently transferred to a supported living setting in his hometown. The staff members plan to promote choice making, community inclusion, and a lifestyle that is typical of other young men his age as quickly as possible. They consider his previous setting to be highly restrictive and are preparing to serve as the primary caregiver. They believe Jack can do much more than previously expected and he will thrive with new opportunities.

Jack's family is looking for a program that will ensure his health and safety and recognize his significant limitations in communication and self-direction. As Jack's full legal guardian, they plan to monitor the staff closely to assure that Jack receives the best possible care. They hope to provide Jack with some aspects of care that they could not offer when he lived in another community. They also expect his new residence to be as clean as the hospital setting he recently left. They consider his previous setting to be

therapeutic and trusted the school staff who helped Jack survive several life threatening infections.

Jack makes simple choices and responds with pleasure to people he knows and trusts. The current living arrangement is new to him and he has responded in a passive manner to attempts to involve him in many new activities.



Jack's family and support staff appear to value different outcomes. Jack's family places a high value on medical techniques and therapeutic care. Jack's support staff places a high value on choice and community inclusion. Jack is unable to express his own values. He can only respond to what is familiar.

Often, the most challenging problems occur when both parties are right! Without medical care and life saving techniques, Jack could die. A community setting can offer Jack a chance at a new and meaningful life. Unfortunately, the family and staff haven't had time to form a trusting relationship. **What is likely to happen if both parties attempt to push their values on the other?** Conflict will continue and may result in stress and hostility that will probably not benefit Jack or his family.

The agency brought in a mediator to help everyone work through the conflict and find common ground. After lengthy and thoughtful discussion, the team decided to support Jack and his family in making a successful transition one step at a time. After talking things over with Jack's family, they decided:

1. Keeping Jack alive is **everyone's** top priority. Staff will work closely with the family and school to gain experience in this vital area.
2. Staff will introduce community activities slowly. They will begin with massage and swimming, two activities that Jack's family believes will be therapeutic. Everyone will observe Jack's response to these activities and try to determine from his behavior if he enjoys each one.
3. The agency will provide assistance with housekeeping for six months until Jack is used to his new home. The team will then agree on three tasks that he can do on a partial participation basis.
4. Jack's family will be invited to stop by frequently and observe the daily care routine so that they are reassured that care is optimal and trust can be established. Staff will use privacy screens and bedding to assure his privacy.
5. Staff will encourage Jack's family to gradually relax their vigilance and enjoy social events that Jack chooses. Together they will think about how Jack might get involved.
6. School personnel will show everyone how they involved Jack in making choices that his family may not have observed when he lived at their residential center in another town.
7. Staff will gradually involve Jack in making those same kinds of choices in his new home.



Communication and Problem Solving

You can work *with families* to support individuals through these common challenges:

- Managing Relationships
- Keeping up a Household
- Achieving Employment
- Assuring Health and Safety
- Enjoying a Meaningful Lifestyle
- Planning for the Future
- Understanding Death & Dying

Families need to know what to expect, how to prepare, what ideas work best, who will do what and how they can help. Without this information, families, providers, and individuals can only react to events as they come up and resort to trial and error. Learn from the people in your agency who have already successfully met these challenges. Share this information with families.

Share Information

Look at the following examples of ways to share information. Which of these might work best in your agency?

Share Developmental Information. Practical information on development helps families understand what to expect in the immediate future. Families wonder what the future will bring. It is helpful to get a glimpse of how interests and challenges change over time. Young people often try out different jobs, gain weight, learn how to manage an apartment, make new friends, and may become sexually active. They need to learn how to balance their nightlife, diet, and sleep. As people reach middle age, life becomes more stable. Individuals may experience some new health challenges or changes in their own family. As people become senior citizens, they may need to find more accessible place to live or need more support with daily living tasks. Understanding death and dying becomes critical. Here are some examples:



1. A nurse and social worker prepare a brief one-page description of the life changes and challenges typically experienced by:
 - Young Adults with Developmental Disabilities (ages 18 – 30)
 - Middle Aged Adults with Developmental Disabilities (ages 31 to 50)
 - Seniors with Developmental Disabilities (ages 51 to 80+)

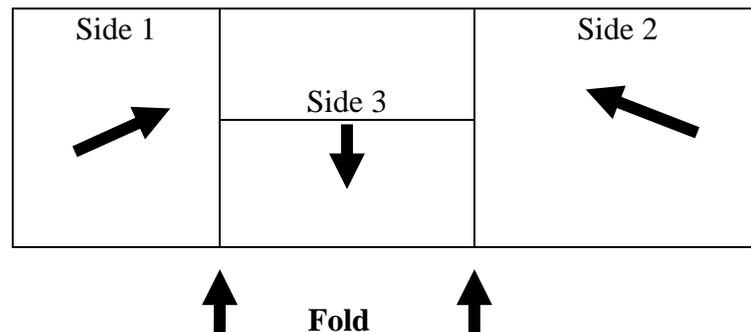
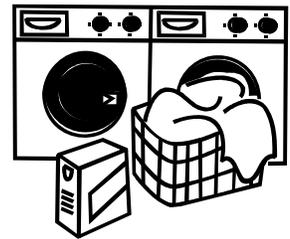
The handout is offered to families as their sons or daughters reach important age milestones to help them plan for the future. This information helps families form important questions.

2. A QMRP researches information on health challenges faced by adults with Cerebral Palsy, Down Syndrome, and Fragile X Syndrome. She used the information to make fact sheets on each challenge and treatment options. The agency shares these materials with families who need them.

3. Direct support professionals and psychologists put together a picture/word guide to teach students with cognitive disabilities how to make friends after high school. This is designed so that families can read through the guide with a son or daughter and help them think about choices and challenges.

Tips and Tools. Families benefit from practical tools that they can use at home when a son or daughter visits or stays for a holiday. They also appreciate learning about these tools while their son or daughter is still in high school. Think about these examples that were shared with families by an agency that worked closely with special education staff at the high school.

1. A step-by step guide on how to use a debit card or cash envelopes to manage a budget.
2. A picture checklist of what to look for in a safe apartment.
3. A plastic flip-flop device to use while folding laundry. Hang matching outfits together. Use a zip lock bag with undergarments or accessories.



Remember that **families have tips and tools to share also**. Why not highlight some of these in your agency newsletter or orientation information. Identify the person who shared each tip.

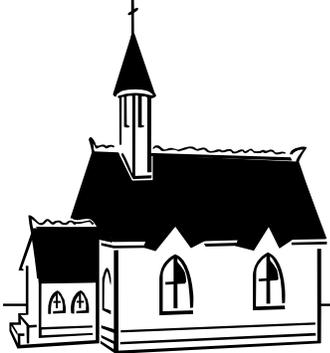
Link Families to Support Networks. A support network links families with other families so they can learn from one another. There are many different ways to help families connect. Think about these ideas:

1. The Community Action program offers individualized financial planning to families. A provider helped them design classes for parents with intellectual disabilities.
2. The ND Family-to-Family Network connects families with other families whose sons and daughters have reached transition age. The QMRP provides new families with a release of information form for this project.
3. An agency offers a training course on *Understanding Death and Dying* to people with



disabilities. They decide to open the class up to families. Ten family members are invited. A meal is held in conjunction with the class to encourage parent involvement. Four family members decide to take the class. They have never met before. Through the class they form an informal support network and begin to get together at other times.

Draw on Community Connections. Your knowledge of the community gives you important social capital that can benefit individuals and families. You can help families link up with important services in their communities. Look at these examples of ways that direct support professionals have bridged connections for families:



1. Contacted a pastor and found a volunteer to offer an aging parent a ride to church.
2. Called a family and let them know about a community car wash.
3. Helped a person with a disability call a sibling so she could invite her sister to a play that was put on by the local community theater.
4. Passed out flyers as families arrived to pick up their sons or daughters for the Memorial Day holiday. The flyers told families about an upcoming fishing derby sponsored by the Game and Fish Department.
5. Gave a family the phone number of the North Dakota Association for the Disabled after they commented on struggles to pay for diabetic supplies for an aging parent.
6. Told a family about a local scrap-booking group, after learning about the parent's hobby the last time they visited.
7. Showed a family a new way to help their son tie his shoes using elastic laces and where to buy some for a younger brother.
8. Offered to serve as a fitness partner for a person with a disability. Met the family at the park and walked with their daughter.
9. Told a mom about a weight loss program sponsored by the community college after learning that she wanted to lose some extra pounds.



Share Resources for Adult Learning. Families benefit from access to videos, books, and curricula that help them read about adult challenges and understand how providers work to support people with disabilities. These can be made available to families by:

- Sharing them with special education teachers
- Setting up links to an agency web page
- Sending home a resource list before the holidays
- Encouraging the public library or video store to offer the resource



- Encouraging families to “borrow” materials from an agency or program resource library
- Sending a mass email with a tip for the day or link to a resource.

Create Social Opportunities. Create social events and invite families and people that you may support. These activities help to create informal contacts and conversations that support families in community life and create a sense of belonging. Here are some examples:

- A holiday party
- A hay ride
- A medieval feast
- A corn feed
- A scrap booking party
- A health fair
- A skit on people first language
- A jobs fair
- A tail gate party and touch football game



During these social gatherings, you will have an opportunity to get to know families. You can help the people you serve look good in front of their families and help families gain perspective by observing how other people with disabilities and families interact. Families are much more likely, especially in small towns, to turn out for this kind of event. And you can gain support from the community by inviting area business to advertise the event or help to underwrite the cost.

Summary

People with disabilities face many challenges. You can partner with families on many levels to help support their sons and daughters. This involves working together to manage risk, learning to talk about challenges and choices, creating a climate where people feel free to speak about their real concerns, sharing information about what works, and helping families connect. Families are often anxious to have individualized services. A comprehensive effort to come together as partners in supporting their sons and daughters may be the best way to a family’s heart.

Working with Families Feedback Questions – Chapter 4

1. Choice also involves some degree of _____.
2. List three types of risk management strategies.
3. To control the pace of change, providers may need to _____ and _____.
4. List at least two examples of ways to share information:
5. Name at least two examples of social opportunities.
6. Social opportunities create _____ that support families in community life and create a sense of _____.
7. Access to _____ help families read/learn about adult challenges and understand how providers work to support people with disabilities.
8. One effective way to minimize or manage risk is to:
 - a. Limit all contact with strangers
 - b. Limit the amount of overtime you work
 - c. Provide a structured program
 - d. Provide continuous supervision
9. Using graphs and charts helps clarify what is _____ to all team members and can _____ conflict.

Chapter 5: Collaborate to Solve Problems

Chapter Objectives:

- **Recognize common fears and the need for mutual support**
- **Identify strategies for problem solving**
- **Identify types of conflicts**
- **Identify strategies for managing conflicts**

Supporting Each Other

Families and providers both deserve respect and support. Each party has fears about the unknown. Look at the list of concerns below. Do you have any of these?



Family fears

- Son/daughter is injured or abused
- Son/daughter is neglected or exploited
- Son/daughter is lonely or anxious
- Restrictive and isolated programs
- Limited choices, not what most people do
- Boredom, no challenges
- Someone who encourages bad habits
- Sickness, poor health
- Criticism of parenting
- Providers who just don't "get it."
- People who make you fight for what you need

Staff or agency fears

- Person is injured or abused on my shift
- Person is neglected/exploited on my shift
- A person I support is lonesome/anxious
- Programs are restrictive and isolated
- Limited choices and options for people
- People who micro-manage my work
- People who oppose or undo efforts
- Individuals who are sick or unhappy
- Criticism of programs and services
- Families who just don't "get it."
- People who fight instead of listening

Did you notice that we have many fears in common? Two groups with this many challenges and opportunities to misunderstand each other need to pull together to make services work.

Remember to:

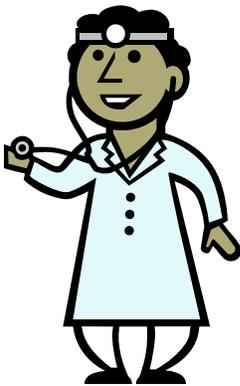
- Welcome and support families
- Let families know how they can help and support you
- Collaborate to solve problems

Collaborating to Solve Problems

Earlier in this module we described strategies for welcoming and supporting families. Families often show support for providers by telling others about their satisfaction with services. They will give staff a second and third chance and, in some cases, settle for less than they want, if their relationship with the agency is positive and helpful to their child. What are some of the ways that families show you their support?

Even when providers and families support one another, problems may still occur. Collaborating with families to solve small problems builds trusting relationships. These experiences prepare both parties to respond to or resolve significant crisis or problems in the future. Here are some strategies for collaborative problem solving:

Solve problems *when they appear*. It is human nature to hope problems will go away. Unfortunately, they seldom do! Sometimes, if you ignore a problem it DOES go away (at least for a while) and so we all get reinforced for believing that this is a good idea. Here is a story that shows how ignoring a problem can make things worse.



Mrs. Frank mentioned one Sunday when she brought Joe back from a visit that she found a slight bit of blood in his pajamas. Staff listened but Joe was pretty independent in self-care and the idea of checking this out was “gross.” So, the problem was ignored. Two weeks later, Joe came down with a high fever and chills. After a quick trip to the clinic, doctors discovered that Joe had a serious health problem. It seems that a sore developed near his anus, went untreated and became infected. Joe had never had this type of problem before and was too embarrassed to talk to staff about it. Mrs. Frank remembered quite clearly telling staff about the problem. She became irate!

Not only did someone drop the ball, but it seemed to her that the supervisors did not really believe that she had reported the problem in the first place.

- *What do you think happened to the relationship with Joe’s family?*
- *Did ignoring this problem work?*

The solution: Solve problems *when they occur*.

- Report problems immediately, using the correct channels.
- Identify the problem without blaming others. (Remember, it is *usually* no one's fault – just different people who see things differently).
- Report the problem calmly. People tend to discount or dismiss problems when excess emotion is attached.
- Talk to *all* the people who need to know about the problem.
- Write down the facts in full sentences. Sign and date the information.
- Do NOT talk to people who don't need to know about the problem.
- Work together to come up with possible solutions.
- Pick the best solution together.
- Follow through with your part.
- Check back to see if the problem reoccurs (many do), gets better or worse.



Act to maintain positive relationships. Relationships can become strained when conflicts occur. Try not to take sides even though you may believe one course of action is best or that someone's approach or behavior is less than helpful. Keep the lines of communication open.

Remember:

- Even if you don't talk about it, the people you serve will be sensitive to any negative feelings between providers and families.
- You may not have all the information that would help you understand the family's position or motives.
- A calm explanation may help the family reconsider their position.
- Families don't want relationships to become strained or unpleasant.
- When people are hostile, it is usually because they feel as if they have no other options.
- Sometimes it is best to just overlook negative behavior that isn't harmful. Focus on maintaining a warm relationship.
- If harm does occur, families may be justified in their feelings. In these cases, it is critical to take the time to listen to families. We cannot skip that step even if we would rather not hear what an angry parent needs to say.
- MOST interactions with families are positive. Everything else is a learning experience.

Maintain a positive relationship in a difficult situation. What can you do to maintain a positive relationship in a difficult situation?

- Keep your head up during visits or meetings and remember to exchange eye contact.
- Monitor your facial expressions and body language.
- Call and visit with the family just as much as you did before.
- Remember to state that you feel badly about what happened and what you will do to avoid repeating the same mistake.



Kathy participated in a vocational program but lived at home with her mother and sister. Kathy had significant health problems related to obesity. This affected her motivation at work and her energy levels. Staff often wished that Kathy would move in the residential program where they could control her apparently unlimited access to food and assure that she started making healthy choices. Her mother, a single parent, showed no sign of wanting her daughter to move into a residential program and neither did Kathy. Staff believed that Kathy's mother was clearly part of the problem and felt she needed to be confronted.

After complaining bitterly to Lisa, the agency's social worker, the staff thought they had enlisted her help in confronting Kathy's mother with the truth about her "enabling" of Kathy's over eating. A meeting was scheduled and the social worker agreed to attend. Staff were amazed when Lisa placed her chair right next to Kathy's mother and in the friendliest way possible, chatted as if she had known her forever. It looked like they were best friends. Kathy's mother clearly enjoyed the meeting and responded well to the social worker. The problem of Kathy's weight was not mentioned and staff were disappointed that Lisa appeared to be ignoring a serious problem.

About three months later, Kathy's younger sister moved out after graduation and Kathy began to ask her mom if she could move away from home also. Kathy's mother contacted the agency with the news that Kathy was now ready to tackle residential living.

- Who do you think Kathy's mother called?
- Why do you think she called this agency when so many people obviously disapproved of her choices in letting Kathy eat what she wanted?
- Do you believe that disapproval changes behavior?
- Does it help you change?

Kathy's mom called the social worker who was so nice at that last meeting. Getting ready to move away from home is a process. Kathy's mother was wise enough to know this decision had to come in its own time. Staff soon learned that changing someone else's unhealthy choices is not as easy as it seems. When Kathy moved into the residential facility, staff had the same challenges as Kathy's mother had over her daughter's appetite. Today staff members have a great relationship with Kathy and her mother. It has taken all of them, Kathy, her mom, and staff to put together the supports Kathy needed to change her lifestyle. They are glad the social worker didn't burn any bridges and they are a lot less quick to judge.

Understanding Conflict

Because conflicts are a part of life, it is important to learn how to manage conflicts well if we want to work effectively with families. Conflicts develop because of:

Different Perspectives

- Viewpoints on why we're here

- Understanding of what is most important

Differing Belief Systems

- Feelings or ideas that will not change
- Teachings that cannot be challenged

Differing Interests

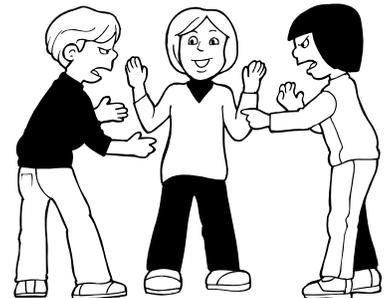
- These are hidden, not always obvious
- People share their position, interests are harder to discover

In meetings you have attended, did participants ever have problems because:

- There was not enough time
- There were not enough paid work options
- People disagreed about what was best
- Someone dominated the meeting and intimidated others
- People did not speak up
- The data was misleading or open to interpretation
- People had strong emotions about a situation
- Someone took a rigid position and would not bend

Managing Conflict

People will disagree. Both families and providers can own behaviors, positions, and circumstances that create conflicts. Human behavior and problem solving are complex issues. Conflict management is an advanced skill that requires special training. You are not expected to be an expert in these areas. However, some simple strategies can help keep the team on track and avoid competition over ideas or options. Effectively resolving conflict requires teams to sort issues into one of three categories:



- Wars not worth fighting (minor issues)
- Negotiable issues (important things with a variety of solutions that are acceptable- open to discussion)
- Bottom line postures (positions on issues that aren't flexible, i.e., health and safety issues, state regulations, issues central to the agency mission and values)

Prepare for meetings by personally sorting out any issues into the three categories listed above. This will help you avoid unnecessary power struggles or win/lose arguments. Developing an effective problem solving approach means perfecting your ability to:

- Define the problem (make sure you know what the real problems and issues are)
- Separate people from the problem (use rules/procedures to control emotions, reduce conflict)
- Focus on interests not position (focus on parent interest in safety, not her position on a specific trip)

- Suggest options or choices that benefit all parties (win-win solution)
- Be sure you are using effective communication skills (get feedback from a neutral party)

Seek help to resolve or mediate concerns. Confronting someone at a meeting seldom works. Most people become defensive and hostile when confronted, accused, or humiliated. Don't you? The solution to these types of conflicts is to find common ground. Then move forward with a positive plan that supports all the players. This takes considerable skill in situations in which all the parties have a lot to lose. In these types of circumstances it is important to:

- Recognize the warning signs that relationships are at risk.
- Seek help from senior staff, before a problem gets worse.
- Know when to ask a professional mediator to help teams resolve conflict.

Warning signs: What are the signs that a simple problem has escalated and needs attention?

- People accuse instead of talk to one another
- Complaints escalate
- Teams seem confused or disagree about what is best to do
- No one takes action to resolve a problem shared by several parties
- People get hurt
- People are feeling overwhelmed and avoid one another

What other warning signs have you observed?

De-brief after a crisis. In many agencies, staff get together to de-brief after a crisis or a significant behavioral incident. De-briefing involves gathering together those who were involved in a traumatic incident, talking over what happened, and deciding together what worked and what didn't. Staff members are often hardest on themselves. They need and appreciate reassurance and praise for how they handled a situation (even when things didn't go according to plan).

De-briefing helps alleviate tension, gets people laughing and feeling better about the situation and can serve as a "teachable" moment as everyone shares what they learned and what they might do differently next time. After a crisis, families often need de-briefing just as much as staff do. However, families seldom receive this opportunity. In some agencies the QMRP or service coordinator may call the family to explain, listen, or discuss an incident. But this seldom has the full power that a face-to-face de-briefing session offers.



When families live nearby it is helpful to obtain permission from the individual to meet with their family to work through any remaining tension or frustrations after a crisis or problem situation. This should be presented as an opportunity or invitation, not a demand. Some families may be fearful or uncertain about the process and will need reassurance. Involving families in a de-briefing meeting leaves the family with a final impression of a team, pulling together to make things right. Otherwise, their final impression may be a time when things did not go so well.

Summary

Welcoming and supporting families helps to build positive relationships. A positive start is important because conflict at some level may happen over time. While conflicts are not bad in and of themselves, people can become frustrated and relationships can break down. Worrying or hoping things will get better probably will not help. Successful facilitators use the strategies in this section to help families and providers work together. You can learn to do many of these steps in your work with families. Learn to manage conflict instead of just reacting. Families are important partners who are worth the time it takes to work through issues and find common ground.

Working with Families Feedback Questions – Chapter 5

1. Name at least two fears that families and providers have in common.

2. Because we have so many common challenges providers and families need to _____.

3. True or False:

____ When providers and families support one another, problems never occur.
____ Families are more likely to tolerate mistakes when relationships are positive.

4. List three ways that providers and families can collaborate to solve problems.

5. Conflict occurs because of different _____, _____, and _____.

6. In a meeting, people often share their _____, interests are harder to discover.

7. Sorting out problems into categories of importance before a meeting will help avoid _____ between families and agency staff.

8. Steps for effective problem solving include:
 - Define the _____
 - Separate _____ from the problem
 - Focus on _____ not positions
 - Suggest options or choices that benefit _____ (win-win solutions)

9. List at least two warning signs that a simple problem has escalated and needs attention.

10. What are the benefits of debriefing after a crisis?

11. _____ are positions that are valued but could be open to discussion.
 - a. Wars not worth fighting
 - b. Negotiable
 - c. Bottom line postures
 - d. None of the above

Working with Families

Feedback Question Key – Chapter 1

1. One simple way to find out what families want is to _____.

Ask them

2. Name six outcomes that are important to most families.

Belonging

Contact

Information

Contributing

Security

Working toward success

3. Choose the best answer: Today's families expect:

- a. *To be welcomed and supported as partners*
- C. *To get any services they need*
- D. *To control their child's life as an adult*

4. Why is it important to welcome and support families? Check the 3 most appropriate reasons.

- To build trust*
- To prevent lawsuits*
- To gain community support*
- To benefit the people you serve*
- To increase donations*
- To avoid conflict*

5. Name at least three ways that you or someone in your agency could welcome families. (*Any of the following suggestions would be correct*)

- *Invite a family over for dinner*
- *Meet families for coffee*
- *Hold a sleep over for teens*
- *Decorate the house*
- *Make a good first impression*
- *Follow through with promises*
- *Help people call home, share news, send photos*
- *Invite families to serve on a committee*
- *Ask families what works*
- *Be respectful*

6. Name at least two ways for agencies to get feedback from families over time.

- *Informal visits over a cup of coffee*
- *Annual satisfaction surveys*
- *Suggestion boxes*
- *Feedback checklists in a newsletter*
- *Input during meetings*

7. Communicating for partnership has three parts. Name all three.

- *State the problem in neutral terms without blaming anyone.*
- *Tell what action you are prepared to take that might help.*
- *Invite feedback.*

8. Name three primary responsibilities agencies have to families under the outcome measures.

- *Assure that individual communication with families is supported*
- *Assist families to build social networks and make community connections*
- *Analyze the impact of your agency's community involvement on families*

9. Match each term with the correct definition.

 b Family-centered services

 a Person-centered services

- a. are designed to meet the needs of the person with the disability
- b. are designed to meet the needs of the whole family

10. Name two ways agencies can evaluate family satisfaction with services or the impact of community connections on families.

- *Use an annual survey*
- *Hold a small focus group*
- *Put a single item checklist in a newsletter*
- *Set up a suggestion box*
- *Interview teachers, case managers, or social workers*

Feedback Questions Key – Chapter 2

1. Circle the two best answers. Good partners try to:

- a. *Build and keep up a positive, long-term relationship*
- b. *Achieve outcomes no matter what it takes*
- c. *Take action together to achieve common goals*
- d. *Guess what the other partner may want or need*
- e. *Avoid contact to prevent conflicts*

2. Match these terms to the examples:

- a. Be positive d Look people in the eye. Talk to, not about others.
- b. Be hopeful b Suggest lots of options. Be flexible.
- c. Be respectful f Take the time to call when everything is going well.

- Printed information is a valuable tool that can help agencies share their mission, values and approach directly, instead of relying on others to get the message right.
- When information proves to be helpful, trust is established.

10. Name four steps you can take to build connectedness with families.

- *Know how to reach one another in case of problems.*
- *Create a safety plan. Write it down. Follow it!*
- *Stay in touch.*
- *Avoid red-flag words.*

Feedback Questions Key – Chapter 3

4. List three ways that families help young people grow up. (Any of these answers)

- *Co-sign a loan*
- *Make a down payment*
- *Buy supplies*
- *Pay for school*
- *Told you who was hiring*
- *Suggest a car dealer*
- *Help you find a good school*
- *Figure ways to cut costs*
- *Plan a party or wedding*
- *Solve a health concern*
- *Listen when a friendship ended*
- *Entertain you on holidays*
- *Offer congratulations*
- *Loan you a tool*
- *Help you hunt for an apartment*
- *Help you study*
- *Baby-sit for you*
- *Shop with you*
- *Take you out to eat*

5. True or False

- T Parents in adult-to-adult relationships may act as primary caregivers during emergencies
- T Asking questions is a technique that shuts down communication
- F Providers seldom know what has happened with other young people in similar circumstances.
- T Families, providers and people with disabilities need one another.

3. When children leave home the parental role changes from caregiver/enforcer to guide/mentor.

4. Name two ways your agency can support families in changing to an adult-adult relationship.

- *Provide tools and routines that individuals can manage with less help*
- *Gradually support young people in taking on reasonable risks and challenges*
- *Support young people in communicating their need to “do it myself”*
- *Give families lots of information about what to expect and how to help*
- *Provide a stable, secure environment and minimize the impact of turnover*
- *Recognize and build on family expertise*

6. Name 4 communication practices that can help providers work with families.

- *Single point of contact*
- *Exchange of information*
- *Giving feedback*
- *Documenting important information*

6. A policy that directs one person to serve as the primary contact person for a family is called: single-point-of-contact.

Feedback Questions Key – Chapter 4

1. Choice also involves some degree of risk.
2. List three types of risk management strategies.
 - *Minimize overtime*
 - *Individualize services*
 - *Setting up ground rules*
 - *Using charts & graphs*
3. To control the pace of change, providers may need to find common ground and take small steps.
4. List at least two examples of ways to share information.
 - a. *Share developmental information about typical life stages and challenges*
 - b. *Share tips and tools about what works*
 - c. *Link families to support networks*
 - d. *Build community connections*
 - e. *Share resources for adult learning*
 - f. *Create social opportunities*
5. Name at least two examples of social opportunities.
 - *A holiday party*
 - *A hay ride*
 - *A medieval feast*
 - *A corn feed*
 - *A tail gate party*
 - *A scrap booking party*
 - *A health fair*
 - *A skit on people first language*
 - *A jobs fair*
6. Social opportunities create informal contacts and conversations that support families in community life and create a sense of belonging.
7. Access to videos, books and curricula help families read/learn about adult challenges and understand how providers work to support people with disabilities.
8. One effective way to minimize or manage risk is to:
 - a. Limit all contact with strangers
 - b. *Limit the amount of overtime you work*
 - c. Provide a structured program

- d. Provide continuous supervision
9. Using graphs and charts helps clarify what is *important* to all team members and can *reduce conflict*.

Feedback Questions Key – Chapter 5

1. Name at least two fears that families and providers have in common.

- *Son/daughter is injured or abused*
- *Son/daughter is neglected or exploited*
- *Son/daughter is lonely or anxious*
- *Restrictive and isolated programs*
- *Limited choices, not what most people do*
- *Boredom, no challenges*
- *Someone who encourages bad habits*
- *Sickness, poor health*
- *Criticism of parenting*
- *Providers who just don't "get it."*
- *People who make you fight for what you need*
- *Person is injured or abused on my shift*
- *Person is neglected/exploited on my shift*
- *A person I support is lonesome/anxious*
- *Programs are restrictive and isolated*
- *Limited choices and options for people*
- *People who micro-manage my work*
- *People who oppose or undo efforts*
- *Individuals who are sick or unhappy*
- *Criticism of programs and services*
- *Families who just don't "get it."*
- *People who fight instead of listening*

2. Because we have so many common challenges, providers and families need to *work together and/or support one another*.

3. True or False:

- F When providers and families support one another, problems never occur.
- T Families are more likely to tolerate mistakes when relationships are positive.

4. List ways that providers and families can collaborate to solve problems.

- a. *Solve problems when they appear*
- b. *Act to maintain positive relationships*
- c. *Maintain positive relationships even in difficult situations*

5. Conflict occurs because of different *perspectives, belief systems, and interests*.

6. In a meeting, people often share their *position*, interests are harder to discover.

7. Sorting out problems into categories of importance before a meeting will help avoid *power struggles* between families and agency staff.

8. Steps for effective problem solving include:

- Define the *problem*
- Separate *people* from the problem
- Focus on *interests* not positions
- Suggest options or choices that benefit *everyone* (win-win solutions)

9. List at least two warning signs that a simple problem has escalated and needs attention.

- *People accuse one another*
- *Complaints escalate*
- *Teams seem confused or disagree*
- *No one takes action*
- *People get hurt*
- *People feel overwhelmed/avoid one another*

10. What are the benefits of debriefing after a crisis?

Debriefing helps alleviate tension, gets people laughing and feeling better about the situation and can serve as a “teachable” moment as everyone shares what they learned and what they might do differently next time. Involving families in a de-briefing meeting leaves the family with a final impression of a team, pulling together to make things right.

11. _____ are positions that are valued but could be open to discussion.

- a. Wars not worth fighting
- b. Negotiable
- c. Bottom line postures
- d. None of the above

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