Assessment and Setting Goals

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THE NORTH DAKOTA STATEWIDE DEVELOPMENTAL DISABILITIES STAFF TRAINING PROGRAM

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Assessment and Setting Goals

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# Table of Contents

Lesson I: The Purpose of Assessment and Planning ................................................. 4  
Feedback Exercise I.................................................................................. 14

Lesson II: Criteria for Selecting and Evaluating Goals............................................. 16  
Feedback Exercise II.................................................................................. 28

Lesson III: Tools and Techniques ........................................................................... 30  
Feedback Exercise III.................................................................................. 39

Lesson IV: Person-Centered Planning ..................................................................... 41  
Feedback Exercise IV.................................................................................. 47

Lesson V: Using Technology to Support Personal Outcomes and Goals  
Attainment ......................................................................................................... 49  
Feedback Exercise V.................................................................................. 58

Lesson VI Developing a Summary for the Team ...................................................... 59  
Feedback Exercise VI.................................................................................. 63

Answer Keys ........................................................................................................ 64

References ............................................................................................................. 72
LESSON I: THE PURPOSE OF ASSESSMENT AND PLANNING

OBJECTIVES:

After completing this lesson, staff members will be able to:

- Explain the purpose of assessment
- Describe how to engage the person supported in the assessment process.
- Describe basic information that must be gathered by the team
- Describe and differentiate between the different models.
- Define global goals
- Explain why global goals need to be established before assessments are performed.
- Explain what a person-centered functional assessment means.

INTRODUCTION

Assessment is a problem-solving process that involves collecting and interpreting the information needed to plan individualized supports. Your agency is required to design person-centered plans based on "comprehensive assessments." The team then designs each person’s supports based on data it collects and interprets. Many people may need to participate in the assessment processes in order to build a comprehensive picture of what each person knows and can do. Agencies typically use specific assessment tools to get the information they need.

This module DOES NOT describe how to use specific assessment tools. This module DOES describe the basic skills needed to plan assessments and set appropriate goals.

PURPOSE OF ASSESSMENT – DEVELOPING A SHARED UNDERSTANDING

The major reason for performing assessments is to developed a shared understanding of what each person needs, knows and can do. Information about the person’s preferences, dreams and capacity is what helps to make our plans person-centered. Information about the person’s deficits or challenges helps us plan how to support the person to overcome barriers to goal achievement. The primary goal in obtaining both kinds of information is discovery. The two most important assessment questions we need to answer are “Who is this person and why do they matter.”

We can’t really “get to know” the person through formal assessments alone. We can discover a person’s dreams by spending time together or by asking people who have significant experience with the person. The support team must try to understand the essence of who the person is. They learn about his/her personality, character, and preferences. The planning
focuses on discovering capacities and capabilities, on what the person can do and his/her gifts as well as what it will take to support that person in being successful in being actively and meaningfully engaged in their own life. develop

**Develop a Personal Profile.** Building a personal profile is the crucial starting point of any assessment plan. No matter what process is used to create the profile, the goal is the same: to help the person tell what is important to him/her in his day-to-day life and the future he/she desires. This information helps teams to **create opportunities and alternatives that enable individuals to learn, grow, and realize personal outcomes and to be actively engaged in meaningful activities throughout the day.**

Consider Future Environments. We need to do more than assess the person’s skills, strengths, and support needs. We also need to "assess" the environments in which the person will be supported. We need to ask: “What resources, services, and supports are present or need to be present in the person’s current and future work, living, and recreation environments for that person to be actively, and meaningfully engaged?”

**View the Trailer for the Video: The Key of G.** What were some of the resources, services and supports needed by the person with disabilities in this video? How were natural support networks used to provide those supports?

https://www.youtube.com/watch?v=BJDxhpcXgr8

**Plan How Personal Outcomes Might Be Obtained.** How will your organization, service system, and community support the attainment of personal outcomes and individual quality of life? The Council on Quality and Leadership (CQL) assesses these organizational processes through its “Responsive Services” indicators (CQL, 2005). Responsive agencies provide “organizational supports and processes that contribute to the attainment of personal outcomes…”

**Engage People in the Assessment Process.** The person and their dreams are the central focus of the assessment process. Each person needs to be engaged in the assessment process in a meaningful way. Meaningful engagement in assessment happens when people first enroll for services and whenever assessment activities are planned. To engage the person in the assessment the team may ask you to:

- Explain the assessment process and how it helps people to reach their personal goals.
- Ask people what they want to learn during the process.
- Ask individuals what they want other people to know and do to support them.
- Look at videos or photos of current or future environments together
- Take tours or try out new activities to see how the person responds
BASIC INFORMATION TO GATHER

Assessment information helps us to identify potential goals. Make certain that whatever tools your agency uses, the team has obtained the following information when they meet.

What is important to the individual? An underlying value statement is, "If it's important to the individual, then, it's important."

What is this person’s day like now? Look to see if the person is engaged throughout the day or has long periods of time waiting for the next activity to happen. How meaningful is this person’s typical routine?

What new skills and competencies would enhance the quality of life? Rather than focusing on a generic list of skills that everyone needs, identify the skills needed for this person to be fully involved in the life they want. The team asks, "In what areas does the person want to grow, develop, and become more independent?" and, "How will developing skills and capacity improve his or her quality of life and help the individual achieve a meaningful level of engagement?"

How can relationships of all kinds be fostered? Relationships are basic for inclusion into society and quality of life.

What would enhance the person’s choice and control? If people cannot articulate a goal or outcome that has meaning, look for opportunities to give the person skills that would offer them more choice and control in a variety of environments and situations.

HISTORY TEACHES US AWARENESS

Agencies have been on a journey in learning about how to conduct assessments. We can learn from these experiences and avoid repeating past mistakes. Each transition has impacted how we offer supports, set goals and conduct assessments today.

1960's & 70's - Developmental Model: Teams expected that people would learn and grow. The individual’s skills in specific domains (i.e., gross motor, cognitive, and affective) were assessed. The person’s current ability was compared to the skills of people of the same age without disabilities. Goal setting involved moving toward the next set of skills in the sequence. Goals didn’t always have anything to do with improving the person's quality of life. People were often denied new learning opportunities until they mastered all the earlier skills in the sequence.

1980's and 90's - Habilitation Model: Teams began to teach skills not only because the person needed to learn them but because they held meaning or importance for the person. But the Habilitation Model was also based upon readiness. Entry criteria were set for various residential and work options. The person couldn’t move to the next level until they had the required skills. Assessment focused on identifying "needs." Access to more integrated settings
(i.e., from the institution to a group home to an apartment) was limited until the person demonstrated all the skills on the list. Habilitation itself was the GOAL.

2000 – Present - Inclusionary Model: Learning is not considered to be the goal of services, but the RESULT. Options for living, working, and recreating are NOT limited to what the person can do, but by the type and amount of support needed. The Inclusionary Model has five basic elements:

1. **Community Integration**: All people live in their communities among family and friends; have access and choice in health care, employment, and leisure pursuits; and have opportunities for increasing self-direction.

2. **Opportunities for Participation**: Community integration occurs when people have opportunities for meaningful participation. At the heart of this model is the belief that all people, regardless of the extent of disability, are capable of participating and contributing when appropriate supports are provided.

3. **Developing Meaningful Relationships**: Quality of life is found in the varied relationships one develops. Social capital, natural support networks, and close friends promote growth and opportunities. Strong social capital leads to healthier and happier lives and increases opportunities to exercise choice and self-determination. People need connections that range from casual "on-the-street" types of interactions to deep, close, enduring relationships with loved ones.

4. **Personal Outcomes**: The definition of quality in services is responsiveness – a continuous system of learning about, listening to, and responding to people. Choice, personal preferences, and self-determination are recognized as the foundation of quality of life. Since the definition of personal outcomes varies from person-to-person, supports and services must be individualized.

5. **Active Support**: The individual consistently receives the support needed within planned and unplanned opportunities to be actively, and meaningfully engaged in their own lives. The person has opportunities for growth that help him or her to gain new skills and enhance their presence and contributions to the community.

**GLOBAL GOALS (My Dreams)**

Begin by thinking in general terms of the person’s desired outcomes. Goals are statements of desired outcomes and a required part of all person-centered plans. Clearly defining the general direction and desired outcomes will help the team individualize supports.

Major goals describe, in general terms, the desired final outcomes. They describe the individual's dreams in terms of overall life aims. Global goals
should be broad, long range, and futuristic. They should set the direction for all future learning and support activities. They should be consistent with the inclusionary model, providing supports which are as typical and positively valued as possible.

Global goals describe what the person wants to accomplish. Train yourself to think in terms of outcomes so that the goals you write can be measurable. Consider some typical kinds of goals that many people set. See the different kinds of outcomes that are part of each goal in the list below.

- **Something to have or to own** that you must prepare for in advance or that positions you to contribute on the job or in the community in a unique way. “Todd’s goal is to own and operate an expresso machine to bring to a job at the coffee bar.”
- **A special place to visit** that you must prepare for in advance that helps you to learn more about a new culture or location. “Lucy’s goal is to compete at the United Tribes Pow-Wow in Bismarck wearing traditional ceremonial garb.”
- **Something to learn about or explore** that will help to broaden your experiences and enhance self-determination. “Sara’s goal is to take an art class at the local college to expand her passion for 3-dimmensional art.”
- **Something to join or be part of** that leads to a new social role within the workplace or community. “Dennis’ goal is to become a certified volunteer with the local fire department.”
- **A milestone to achieve** that allows you to access greater opportunities and resources. “Martin’s goal is to learn to drive a car.” “Tom’s goal is to start dating a person he likes.”
- **Some way to contribute or give back** that helps you to build up your family or community. “Franks goal is to raise $200 for his mom’s cancer fund.” “Dorothy’s goal is to become a reader for her local church service.”

**Put Personal Goals Ahead of Current Conditions.** Goals should NOT be limited to what the team thinks can be accomplished based on current conditions. When plans are developed by only considering available resources, the person has to fit or meet the needs of the system and may never achieve a life worth living.

**What Happens When We Focus Only On Current Conditions:** Eric wants to own a home one day. If the team were to **focus on current skills and service conditions**, you might hear comments like these:

“The bank won’t loan Eric the money without a hefty down payment.”
“Eric doesn’t earn enough to make a mortgage payment.”
“Eric doesn’t know how to take care of a yard or maintain a home.”
“We have never done that before.”
“The state will never approve the level of support Eric needs to live on his own.”
“If Eric buys his own home, we have an open bed in the group home.”
As a result, the team basically talks themselves out of helping Eric reach his goal.

**What Happens When We Focus on the Goals of the Person First:** When plans are developed from a value base that puts the goals of the person first, the plan will focus on how to modify our supports to meet the needs of the person. If the team were to focus on Eric’s goal, you might hear comments like these:

“What kind of a home do you want, Eric?”

“Would you (Eric) like to look at some homes that are for sale? I’ll help you make a list of the things you like and want.”

“We need to figure how much money you would need for the down payment and mortgage.”

“We need to determine how much money you would need monthly to live in the home.”

“Do you want to have a roommate who could share in the costs and work of owning a home?”

“Eric, would you like to work more hours at your current job to save for a house?”

“Would you rather look for a job that pays more?”

“Who should be invited to be on the planning team to help make Eric’s goal a reality?”

“Are there ways assistive technology or remote monitoring could reduce the level of on-site staff support that Eric might need?”

“What are some funding sources that could make it possible for Eric to fulfill his dream to buy a house?”

“What are the pros and cons of home ownership for Eric? How can we help him understand what this will mean?” “How can we insure he is making an informed decision?”

What would Eric like to do while he is checking out home ownership that would support him in learning to live on his own in the near future?

**We Are More Alike Than Different.** We all want to live and work in typical community settings. In planning for people who have no disabilities, that goal is simply assumed. Each person figures out what he/she needs to reach his/her goal (assessment process) and creates a plan for how to get there. It’s not appropriate to tell a high school senior that, because he doesn’t know calculus, he cannot become a physicist. Also, an art student would not be assigned to take a calculus course simply because a test indicated a deficit in that area. Planning for everyone should begin by setting global goals.

**Natural Support Networks.** Many people talk to family and friends, business people, or community experts the first time they tackle complicated decisions. We call these resources “natural support networks.” We all have people in our lives who know more about some things than we do. No one, no matter how talented or intelligent, knows everything. We have to rely on people who have more experience or information than we do for many decisions.

**Example:** Tammy and Derek have been renting apartments for five years. They want to get a dog, which isn’t allowed in their apartment building. Now that they are no longer college students they are tired of paying rent and having nothing to show for it. They want to buy a home but they don’t feel they have
the experience needed to make such a big investment. They also aren’t sure if they can afford to buy a home. Tammy’s mother is a realtor and Derek’s uncle is a loan officer in a bank. Both Tammy and Derek’s families have owned their own homes for many years. Derek’s best friend, Alan, owns a construction company. Tammy and Derek visited with each of these people before they made any plans. Based on advice they received from their “team” of experts they decided:

- Tammy and Derek will develop a plan to cut back on their current expenses or increase their income (assess and revise monthly spending and/or income).
- Tammy and Derek will make an appointment to visit a home mortgage banker to find out if they prequalify for a home mortgage (assess financial situation).
- While Tammy and Derek look for options to save enough money for a down payment on a house and increase their monthly income so they can pay a monthly mortgage, they will start going to open houses to figure out features they want in a home (assess personal preferences related to living environment).
- Alan will go with Tammy and Derek to the open houses to help them learn how to check the quality of construction of the homes (assess knowledge of building practices).
- Tammy and Derek will take a class through Community Action on managing finances. By doing that, they will be given $1.00 for every dollar they save. They can use these funds toward a down payment.

Global life goals should be developed so that every person can live, work and play in the community and participate in the main stream of community life. After global goals are set, assessments are used to determine what supports are needed in order to achieve the goals.

What Happens if a Person Doesn’t Appear to Have Goals? Some people with significant intellectual disabilities may not be able to sit down and express a specific goal. They may not even be aware of what a goal is. Does the process of setting global goals change for that person? Not really. We still have the community value that every person can live, work and play in the community and participate in the main stream of community life. So we need to pay especially close attention to what this person is showing us through their behavior, strengths and preferences and consider to what extent they are being supported to experience the same outcomes and quality of life that anyone else may enjoy. We also need to consult with those people who know this person best and to make sure they are not urged to accept some form of status-quo based on the person’s significant need for support.

A PERSON-CENTERED APPROACH TO ASSESSMENT

Rather than using the same assessment tools and activities for everyone, the team considers the best way to gather the necessary information for each person and individualizes the assessment process.

Individual dreams and goals do not always relate to services that are available.
In the past, teams assumed that individuals would continue to live in agency settings, work at jobs created by the agency, and participate in leisure activities developed by staff. Traditional programs provide many opportunities for community participation but sometimes an existing location or program limits individual choices. Person-Centered assessment challenges teams to envision a new future and to go beyond what is immediately available to what is needed to help each person achieve his or her personal outcomes.

**Assessment Through Real-world Experiences.** People can’t make informed decisions about where to live, work or play if the only known options with the support they need requires the individual to live in a group home, work in a day habilitation program and participate in recreation activities with other people who have similar disabilities.

Active support focuses on getting people involved in every aspect of their day and in building meaningful lives regardless of the intensity of the person’s support needs. Teams recognize the dignity of partial participation where people are involved to the extent possible for them in whatever aspect of a typical life appeals to each person. Achieving this goal and planning a related person-centered assessment requires careful planning.

Opportunities to gain real-world experiences with varied work, social, leisure and living arrangements assist people to make informed choices and set goals. Team members assist the person to have these kinds of opportunities and to think about what they liked or didn’t like about each of these experiences. The team then uses the information to help the person identify goals important to him or her. This process is part of assisting the person to prepare for the individual program plan meeting. Direct support professionals who know the person well ask questions like, "Where would you like to live (work or spend free time) if you had your choice?" After we know the person’s dreams and hopes, the person and his or her team will identify the skills and supports the person needs to accomplish his or her dreams.

If the person is not able to express their preferences with words, much can be learned by careful observations in natural settings. Team members share their observations of the person in living, working and leisure settings with the rest of the team. Augmentative communication and assistive technology are tools that assist people who don’t use words to express their dreams and goals and to develop pictures of the future they desire.

**WHAT ABOUT “UNREALISTIC” GOALS?**

Individuals with disabilities may express “unrealistic” goals (dreams), such as, "I want to be a brain surgeon," or “I want to be a veterinary.” This often happens because the person does not have enough information about the goal that looks desirable to them. Or the person may not have information or experience to make more realistic goals. Assist the individual to find and understand
information that will help them define their ideal life. As people try things their preferences change. After their first flying lesson, many people change their minds about becoming a pilot. An organization that offers real choice is continuously supporting people to identify and express their preferences.

Sometimes the goals (dreams) people identify seem unattainable because of barriers that seem impossible to overcome. It can be tempting to try to talk the person out of their desired future by showing or telling them why it’s not possible. Remember barriers are sometimes just challenges waiting to be overcome. If we bring the right people together to try to eliminate the barriers and find solutions, we are much more likely to be successful than any team member could do alone. Positive thinking and sincere efforts, even if they are ultimately not successful, are more respectful than dismissing ideas as unimportant or undoable.

Sometimes what people ask for is not what they want. If direct support professionals keep asking and listening to what lies beneath the surface, it is likely the person will help us understand what is really important to them. Here is one example from the Council on Quality and Leadership (2000):

Jay said to his team that he wanted to be a Ninja. The team didn’t know what to do at first. Jay couldn’t tell them any more verbally. The immediate thought by the team was that Jay would want the Ninja costume and want to wear it wherever he went. They feared it would undo the efforts and successes Jay and they had made for community acceptance. After some thought, the team decided to explore this more with Jay and looked into classes where Jay could learn Ninja-like moves. They found a kick-boxing class, and Jay loved it and called it his Ninja class. He has never asked for the Ninja costume and continues going to the class, as well as the other activities he enjoys.

Michael Smull (1995) reminded us that most of what people want is modest. Smull acknowledges that a few people do want frequent trips to the tropics, fancy cars, expensive homes, and all the entrapments of the rich and famous. Without the means to support these desires, they will be disappointed. **The fact that someone wants something does not mean that it has to be delivered. However, the team does have a responsibility to respond to sincere requests.**

Sometimes the team worries that the person will get hurt (physically or emotionally) if they fail while pursuing a goal they view as risky or unsafe. A brief from the National Center on Secondary Education and Transition (2004) reminds teams: “A person with a disability who is protected from failure is also protected from potential success.” Teams have the responsibility to balance both perspectives by helping the person dream and achieve a goal while working to manage not eliminate risk.”

Sometimes what people want may put them at serious risk to their health and safety. There are lots of things that we all like to do where there are some risks - often the very best things! Think about some of the risks you have taken, falling in love, applying for a new job, buying a house,
learning to drive, taking your first airplane ride. Helping people stay safe AND happy is a balancing act. Most of us would be pretty miserable if people kept telling us we could not do things because something might go wrong. So how does the team support the person in being “responsible” but also living a fulfilled life? The Marshfield “Balancing Safety and Happiness Risk Assessment” is one way to review these decisions.

Safety

- Only use these strategies if the person, or others, is in real danger
- These goals present little risk and high satisfaction.

Happiness

- Never select these goals.
- Only select these goals if the person, and everyone else, agrees that the risk is worth taking and it does not leave the person, or others, in real danger

When a choice seems unrealistic because of the real or perceived risk involved, the person and his or her team need to:

- Become clear about what the issue/risk is
- Become clear about when, and maybe why an unsafe outcome might occur
- Carefully consider the potential opportunity lost and why it is important to the person
- Devise strategies to reduce, or manage, the risk
- Consider the strategies and the balance between safety and the person’s happiness
- Decide on which strategies to adopt
Feedback Exercise I

1. Define assessment.

2. What is the purpose of assessment in person-centered approaches?

3. What basic information need to be gathered through assessments?
   a. 
   b. 
   c. 
   d. 
   e. 

4. Briefly describe the Developmental Model.

5. What is the focus of the Habilitation Model?

6. Describe the Inclusionary Model and its five major components.
   a. 
   b. 
   c. 
   d. 

7. Describe why program planning should begin with the establishment of global life goals.

8. What two important questions should the assessment process answer.

9. Global goals (My Dreams) should be:
   a. __________ statements of desired outcomes rather than individualized and specific.
   b. Broad, long range and ____________.
   c. Describe the ____________ overall life aims.
   d. Set ____________ comprehensive assessments are completed.
   e. Set the __________ for all future goals.
   f. Established as the ____________ step in program planning.
g. Based on the dreams and aspirations rather than ________.

11. When plans are developed that puts the goals of the person first, the plan will focus on how to modify our _______________ to meet the needs of the person.

12. List a goal you have set for yourself or a complicated decision you are facing. Who would be included in the “natural support network” that will assist you in this decision?

13. If a person has expressed a choice that the team believes is unsafe, team members need to consider the potential _______________ lost and devise strategies to reduce, or manage, the _________. Select strategies that balance ________ and the person’s happiness.

14. If a person with a significant cognitive disability and cerebral palsy expressed a desire to be a police officer or fireman what would you recommend to the team?

15. If a person wanted to explore science and be involved in research, how would you provide active support for that person to get information?

16. If a person did not use words to communicate and had no way to express a specific goal and seemed unaware of what a goal is; how would you support that person to have meaningful goals?
LESSON II: LEGAL AND ETHICAL CRITERIA FOR SELECTING AND EVALUATING GOALS

OBJECTIVES

After completing this lesson staff member will be able to:

Describe the importance of legal rights in shaping services for people with disabilities.
Discuss the influence of Section 504 of the 1973 Rehabilitation Act and the Americans with Disabilities Act (ADA) on setting goals for people with disabilities.
Apply the following concepts as a member of a team setting goals for people they support:
   a. Age Appropriate
   b. Physical Enhancement
   c. Competence Enhancement
   d. Status Enhancement

INTRODUCTION

In the past, goal setting attempted to fit people into programs. Needs were often defined in terms of deficits and disabilities. We thought that people sharing the same label needed the same types of supports and options. Programs specialized in providing services for certain groups of people with the same label. A fundamental principle, “Most learning is incidental, taking place in natural environments, among other people”, was frequently ignored. Michael Smull reminds us of the negative results of these practices, in his paper on Supporting People with Severe Reputations in the Community.

LEGAL RIGHTS AND GOAL SETTING

There are important legal guidelines which impact goal setting. People with disabilities, like everyone else, have legal rights guaranteed by the U.S. Constitution. All persons have the right to or must not be denied the right to:

- Freedom of speech
- Association
- Marry, procreate and raise children (can be restricted after due process has occurred).
- Vote
- Contract and the right to own and dispose of property
- Equal protection and due process of law
- Equal employment opportunity
- Services provided in the least restrictive setting
Section 504

Section 504 of the 1973 Rehabilitation Act guarantees equal opportunity for an appropriate education, for employment, health care, and so forth. The law protects people who:

a. have any physical or mental impairment which substantially limits one or more major life activities
b. have a past record of such impairments but are not presently handicapped;
c. are not handicapped but are regarded by others as having a handicap(s).

Your agency and its programs must comply if the agency:

- Receive federal funds either directly or from the state (Medicaid)
- Uses federal equipment or properties.

Americans with Disabilities Act 1990 (ADA)

The ADA gives civil rights protection to individuals with disabilities in private sector employment, all public services, public accommodations, transportation, and telecommunications. When you help people to seek employment, housing, and independent life styles, inform individuals of their rights and protection under the ADA.

- Employers may not refuse to hire or promote a person with a disability because of the person’s disability, if he or she is qualified to perform the job. Employers’ must make reasonable accommodations. Reasonable accommodation means that if there is some modification in a job's requirements or structure that will allow the employee with the disability to do the job, it must be made, unless it would impose an undue hardship on the employer.
- ADA requires that new vehicles bought by public and private transit entities be accessible to people with disabilities. No modifications to current vehicles are required. Para-transit services for people with disabilities who cannot use the mainline system are required unless providing such service would result in an undue financial burden.
- Under ADA, it is illegal for public accommodations to exclude or refuse a person with disabilities. Public accommodations are the business and services that are used every day by all people such as hotels, restaurants, dry cleaners, grocery stores, schools, and parks. New buildings must be accessible to people with disabilities and existing facilities must remove barriers if the removal is "readily achievable" (i.e., easily accomplished without much difficulty or expense).
- Public accommodations are required to provide auxiliary aids and services to enable a person with a disability to use and enjoy the goods and services available at a facility unless doing so would be too burdensome or disruptive to the business. Auxiliary aids and services refer to such things as large print materials, tape recordings, and captioning. Practicality and effectiveness can be considered in choosing among alternative aids. For example, a restaurant would not be required to provide menus in Braille if waiters read the menu to a person who is visually impaired.
State or local governments may not discriminate against qualified individuals with disabilities. ADA further states that all government facilities, services, and communications must be accessible consistent with the requirements of Sections 504 of the Rehabilitation Act of 1973.

**How do legal rights issues directly affect the goal setting process?**

The basic assumption of goal setting is that each individual will ultimately live and work in typical community settings. Any major goal which involves an outcome to be carried out in a segregated setting would be acceptable only if the team shows that it is the least restrictive alternative for meeting the service needs of the person. The most inclusive and least restrictive goals should be developed and selected in order to respect the individual's legal rights.

**BALANCE GOALS THAT ARE IMPORTANT “TO” AND IMPORTANT “FOR”**

People show us what is important TO them with their words and their actions. Our behaviors reflect passions, dreams, interests, personal goals, and quality of life issues for each person.

Teams must also address what is important FOR a person to be successful. This may include assuring health or safety; complying with applicable laws, meeting job expectations, other important skills that help the person be engaged and live a meaningful life. The chart below shows some items that fall into each category.

<table>
<thead>
<tr>
<th>TO What the person needs TO experience a life worth living</th>
<th>FOR What the person needs to do FOR themselves to be successful</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Go to a Twins Game</td>
<td>• Get dressed</td>
</tr>
<tr>
<td>• Go camping</td>
<td>• Fix breakfast</td>
</tr>
<tr>
<td>• Redecorate their room</td>
<td>• Ride the bus</td>
</tr>
<tr>
<td>• Enjoy music throughout the day</td>
<td>• Turn on the radio</td>
</tr>
<tr>
<td>• Volunteer at a non profit</td>
<td>• Choose what to wear</td>
</tr>
</tbody>
</table>

**LIFE SKILLS**

While assessment and goal setting are individualized processes that focus on the person’s preferences, several skills are considered basic because of their direct impact on one’s ability to live a meaningful life. The list below is an adaptation of the College of Direct Support’s list of core skills to be considered during assessment and goal setting.

- **Self-Determination Skills**: Choice and decision-making ability, independence, risk-taking and risk management, self management/self-regulation, self-advocacy.
- **Health and Safety**: Sexuality, self-care (dressing, bathing, toileting, etc.), nutrition, privacy, self-medication, first aid, crime prevention.
• **Relationships and Community Participation:**
  Communication, contribution and initiation, recreation and leisure skills, social skills, relationship skills, use of public facilities including transportation, recognition of common community signs.

• **Vocational and Functional Skills:** Money management and budgeting, functional time concepts, shopping, home care, and employment skills.

For persons with more significant support needs related to cognitive disabilities, opportunities to be aware of, act on, communicate about, control and gain experience must be identified.

**THE "WHY QUESTION"**

Agencies that regulate services for people with developmental disabilities (i.e., The Council on Quality and Leadership (CQL) and Title XIX) require individualized goals and objectives for each person receiving supports. We know that people with cognitive disabilities learn more slowly than the general population and, therefore, may acquire fewer skills and competencies than others have time to learn over their lifetime. **It is critical that the person be given opportunities to learn the goals and objectives that are most important to him or her.**

It is the ethical responsibility of the person’s team to ask why certain goals are selected over others when planning (Brown, et. al., 1986). Acceptable answers to the "why question" include:

1. It is something the person and/or guardian wants.
2. The number of places and people in the person’s life will increase.
3. It will help to improve the person’s quality of life.
4. It is chronologically age appropriate.
5. It enhances physical condition.
6. It helps individuals gain new experience and skills.
7. It yields status enhancement.
8. It is attainable for the person, given appropriate supports.
9. It will help the person be actively and meaningfully engaged in their own life.

1. **Address Individual and Guardian Preference**

The assessments and the resulting plan will be built around what is important to the person and his or her guardian (if appropriate). Remember the goal is for the person to participate in meaningful activities. Learning what is important to each person will help the team understand what is meaningful. Participation in decisions that affect a person is a basic right that should be extended to all.

*We also need to consider the person’s cultural background.* The family may insist on a more modest choice of clothing than is
considered fashionable by other team members. The team and the person may agree that he or she needs support learning to cook, but their family may have very different ideas and information about traditional foods and family favorites. It is important to understand the influence that culture has on the person and how it can be recognized, respected, and supported in the assessment and setting goals processes.

Some people are unclear about expressing preferences. Often they need opportunities to try out a specific activity so that it becomes familiar before they are asked if that is something they want to do.

Legal guardians are authorized by the court to give informed consent to the plans. Their decisions should be based on what the person would choose if that person had all of the needed information to make an informed decision.

2. Increase Places and People in the Person’s Life

Consider Access to Natural Environments. Historically people with disabilities participated in fewer environments (places) than people of the same age who were not disabled (Van Deventer et al., 1981). For many adults with intellectual disabilities, a special vehicle picked them up in the morning and transported them to an activity center or sheltered workshop. The same van returned them to their home in the evening, where they stayed until the vehicle came again the next day (Brown et. al., 1986). Unfortunately, many people with developmental disabilities still live restricted lives.

Increase Access to Multiple Environments. Increasing the number of environments refers to expanding the number of different places a person goes each day, week and year. The person and his or her team identify places and activities that will enhance the person’s opportunities for growth and quality of life. The goal is to increase opportunities to connect with people who do not have disabilities and to be engaged in meaningful activities.

Support Success in Natural Environments: Support the person to learn skills needed to be successful within these settings. Teaching takes place in the actual environments whenever possible. Learning to order food in a neighborhood cafe will both expand the number of places in a person’s life and opportunities for social interaction with other customers.

Build Social Networks and Capital. We also need to acknowledge and strengthen the person’s existing relationships. What supports does the person need to nurture relationships that are forming and maintain long-standing connections with family and friends? The focus of planning should be to shift from agency services to a personal network of supports.
The term “social capital” is used to describe the impact of social ties and trust. Research has demonstrated how our lives are enhanced by ties with family, friends, neighbors, social groups, churches, and co-workers. Increases in social contacts have been associated with improved mental and physical health and greater access to economic security. Social capital increases community ties and opportunities for choice and self-determination. CQL (2005) research on Personal Outcomes shows “a strong relationship between safety and freedom from abuse and neglect, and continued connections to natural support systems and to close, intimate friendships ...”

3. **Engage People in Functional and Meaningful Activity.**

**Identify Functional Activities:** Consider whether or not the skill will be needed in the places and activities the person selected during goal setting. **If the person themselves cannot do the task, would someone else need to do it for them?** Can they participate on a partial basis if support is available? Is it a required task for their desired lifestyle? If so, it is functional and may justify teaching the skill. Also ensure that the person will have opportunities to practice this skill. For example, when an individual who likes to eat toast is taught how to make toast, he/she will continue to have frequent opportunities to make toast. Is this functional? Yes. Learning to brush one’s teeth is functional. Is there opportunity for continued practice? Yes. Learning to put beads onto a string is not functional. If the person didn’t put the beads on a string, we wouldn’t need to find someone else to do it.

Wasting time on objectives that do not teach and activities that do not involve functional skills is unacceptable. We are not here to “keep people busy.” Utilize the person’s and staff "time" to teach what is important to the person's quality of life. Remember there are many “functional” activities that provide meaning within the daily routine. Not every activity will be targeted in a specific goal but it is still important to assess what each person needs to be actively, and consistently engaged in meaningful activities throughout their day.

**Function vs Meaning:** An activity like brushing teeth may be functional but not particularly meaningful to a person. The team may need to look at every day experiences and think about what would make that experience more meaningful. What would give the person a better way to be engaged in the activity. For example: Does this person prefer to listen to music while brushing his or her teeth? What choice of toothpaste or a toothbrush do they have? If the person needs physical assistance to brush, are they able to signal when they would like to begin or stop?

“Learned helplessness,” is often observed among people with disabilities and can quickly lead to a lack of initiative or even depression. In observing if people are actively and
meaningfully engaged in their own lives, we need to take a look at what is being done to or for a person and how that person could be meaningfully engaged instead. For example: If a person takes nourishment through a tube feeding is that a passive experience? Can they assist to open the cans or pour the formula into the tube – even with hand-over-hand support? If getting the nourishment is a functional activity, how can the person be meaningfully engaged.

One way to assure that people receive active support is to create or examine their individual daily routine from the time they wake until they go to bed for the night. The team discovers just how much of the person’s day is spent engaged in meaningful and functional activities and works with the person or their guardian to replace non-functional or meaningless tasks with new opportunities for growth and engagement.

Think of a person you serve and you review their 24hr/daily schedule. What is on there? Where are the learning opportunities? Where/how can you help them to be more actively involved?

4. **Chronological Age Appropriateness**

Social expectations change as we grow older. Think of how your recreational interests have changed over the years. Young children like to spend time with dolls and play cars. Later they spend more time with books, bikes, skateboards and video games. As people mature, their interests shift. They may choose to spend their free time playing cards, gardening, or bowling.

People with disabilities do not always change their behavior as they get older. To some degree this is true for everyone. However, reluctance to change can impact how people are accepted by others. If we find out that our neighbor collects dolls, we might think that was interesting. It wouldn’t occur to us that she is more childlike than adult. We wouldn’t limit the amount of time we spent with her because of her hobby.

However, if Jane, a woman with a Down Syndrome "plays with dolls," we are likely to perceive her as childlike and immature. Jane’s behavior serves to reinforce the stereotype that adults with cognitive disabilities are intellectually and emotionally more like children than adults.

Viewing people with cognitive disabilities as “childlike” is a barrier to their participation in the community. “Why talk to Jane? She plays with dolls. She couldn’t be interested in the same things I am.” Also, when interactions do occur, this perception often results in others treating the person with cognitive disabilities as if he/she were a child. Therefore, it’s very important that the goals we select be as age-appropriate as possible. Factors to consider when judging age-appropriateness are:
a) **Space and settings** - If the goal involves a specific setting, is it age-appropriate? Are adults attending the adult education classes available to all community members or a segregated program in a school built and designed for children? Is the residence decorated in a typical adult manner, or are there childlike cartoons, posters, furniture, etc.?

b) **Scheduling** - If the goal is for the person to participate in a recreational activity, does it take place at an age inappropriate time? Adult bowling leagues are usually scheduled at night or on weekends. However, it is not unusual to find that a bowling activity for adults with disabilities scheduled for one afternoon a week. This schedule decreases the likelihood bowlers in the segregated group will have an opportunity to interact with same-age peers who do not have disabilities since most adults are at work in the afternoon!

b) **Performance standard** – When setting the standards for learning a skill or changing a behavior, the team should set age-appropriate standards whenever possible. For example, if the person is learning how to get dressed, in addition to teaching the mechanics of getting dressed, it may be appropriate to help the person learn skills in selecting clothes for the weather and occasion, matching colors, etc. – skills which are expected to some degree, of all adults.

Clearly, it’s not possible for everyone to always value age-appropriate activities or behavior. It IS often true that a person performs at a child-like level simply because the team did not consider adult standards when developing the person’s goal statements.

c) **Getting Information** – Sometimes the idea of developmentally appropriate activities is too abstract. It may be difficult for each person to get information about expectations that are hidden such as what other people think about you when you do certain things. Also, it is not very helpful to be told that something is “for small children,” if that is what you really enjoy. Sometimes people may benefit from learning an age-appropriate way to enjoy what they have learned to like. A person who is in their 30’s and still likes ‘Pokemon’, might benefit from playing “Pokemon Go” which will help them be active and participate with other adults in the community.

5. **Physical Enhancement**

When planning goals and objectives, consider objectives that will enhance the person’s physical well being as well as those that will help the person learn skills. Recreational activities which increase range of motion, assist with weight loss, or improve hand-eye coordination can enhance a person’s physical condition. With some creative planning, the team can select objectives that would both provide skill development and improve physical condition.
<table>
<thead>
<tr>
<th>Skill Training</th>
<th>Physical Enhancement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vacuuming</td>
<td>Arm strengthening</td>
</tr>
<tr>
<td>Putting dishes into a cupboard</td>
<td>Stretching and range of motion</td>
</tr>
<tr>
<td>Walking to a specific location</td>
<td>Exercise and weight loss</td>
</tr>
<tr>
<td>Board games</td>
<td>Hand-eye coordination</td>
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6. Competence Enhancement

Marc Gold described **competence as "a skill or attribute that someone has, that not everyone has, that is wanted and needed by others."** Competence, then, is directly tied to social values and social perceptions.

Simply doing something well is not always viewed as competent by others. For example, brushing your teeth is a skill, not a competence. Almost everyone can brush their teeth. Being able to brush your teeth is no big deal. Singing, wood carving, photography are both skills and competencies. Not everyone can do the skills well and many people wish they had that ability. Whether or not a skill is seen as a competence depends on whether or not other people want and need that ability and how common that skill is.

The more competence a person has, the more likely he or she is to be welcomed and valued by the community. Goals that help to build competence, help people gain social acceptance. All people have differences. The more competence a person has, the more likely the community is to tolerate any differences they may also have. This idea was first proposed by Marc Gold and is also called the "competence/deviance hypothesis." He asserted, **"The more competence a person has, the more deviance will be tolerated in that person by others."**

**Remember: Competence is socially defined.** What might be a competence in a large city (elements of being "street wise", for example) could well be seen as a deviance in a small, conservative town and vice versa. There is no universal list of competencies that are true for every situation.

**Important Point:** It’s very common to find individual plans that focus solely on life skills such as bathing, hair care, etc. These may all be legitimate goals which will result in improvement in that person's life. However, they are NOT examples of competencies. They are not examples of skills that other people want and not everyone has. Basically,
they are goals which focus on decreasing deviance or differences. **If the person learns these "typical" tasks they are perceived to be less different but not more competent.**

For example: Susan finally learned to dress herself independently at age 18. This accomplishment may be an occasion for celebration. A major activity of daily living has finally been learned. But how long does this celebration last? Even those persons involved in the teaching program eventually "forget" that, not long ago, Susan could not dress herself. Look at it from the point of view of the "typical community member." Susan’s neighbor won’t be impressed because Susan can dress herself. Dressing is simply typical or average, an expected performance. If the neighbor knew that Susan couldn’t dress herself until recently, the fact that she does dress herself now is still not a big deal - almost everyone can. But what if her neighbor found out that Susan is a good gardener, baker, or singer? These are competencies which will probably influence the way the neighbor perceives Susan.

Person-Centered Plans need goals that balance increasing competence with acquiring functional life skills. Persons with significant support needs due to cognitive disabilities will always show some differences. Their opportunities for community integration will be enhanced if these deviancies are balanced by powerful competencies.

Some people with developmental disabilities will need support to move from a situational goal (get dressed by myself) to a community outcome such as “get a professional picture taken of myself (which would include dressing)” something most adults do at some point in their lives or dressing for a specific community activity. Susan’s neighbor may not be impressed that Susan can dress herself but she might be happy to introduce Susan to her gardening club. Susan’s getting dressed is a necessary step in getting ready.

In summary:

- Competence is socially defined.
- Competence requires more than merely doing something well.
- Unless we break a law, the more competence one has, the more that person will be allowed to differ from typical expectations for adults.
- A person with few or no competencies is more likely to be excluded from valued community settings.
- The definition of competence and deviance varies from community to community and from time to time.
- Individual planning must systematically encourage attention to the development of an individual’s competence to insure continued inclusion in communities.
7. Status Enhancement

- Did you go to college? Where?
- What do you do in your leisure time?
- What part of town do you live in?
- Who are your friends?
- Are you married?
- What do you do for a living? (i.e., "how do you make your money?")
- What clubs or organizations are you a member of?

The answers to questions like these determine one's relative status among members of a community. We believe that "all people are created equal." That does not mean that all people in the community have equal status or value. The issue of status is neither good nor bad; it's a fact of life. With regard to individual planning, it really isn't helpful to grumble, "Well, it shouldn't be that way; people ought to be respected for who they are and not for how they look or what kind of money they make." Imagine that your answers to the questions above were:

"I never went to college. I was always in a special education classroom and got a certificate from school when I was 21 because I was 21 and couldn't stay there any longer. My only leisure activity is watching television. I'm 32 years old and healthy, but I live in a group home where others cook my meals, clean my house, do my laundry, and pay my bills. Almost all my friends have disabilities or are paid to spend time with me. Married? I'm not even allowed to be alone with a person who's not 'staff.' I get some disability benefits, and I average 34 cents an hour at the work activity center down the road from the home. What do I do to earn that money? I sit at a table with a lot of other people with disabilities and put plastic forks and spoons in plastic bags. It's real boring, but we get to quit work after lunch on Friday and everyone goes bowling. I'm not a member of anything, not even a church. They have a guy come out to the home every Tuesday night to teach us about the Bible - otherwise, like I said, I watch television."

Now answer the same question about your own life, with the same degree of objectivity. Compare your answers with those above. Which would you prefer to be a description of your life? Which would be most interesting or inviting to other community members?

An essential function of a person-centered plan is to enhance the status of the person. Not all elements of the plan will necessarily elevate the person's status, but each element of the plan (both the "what" and "how") should be evaluated according to whether it does, or could, affect the person's status. Here are just a few examples of how status can be enhanced:

- Acquiring a new competence, especially one that is widely valued. Baking a great chocolate cake, knitting a scarf, fixing a car, building a birdhouse or growing a beautiful rose.
• Moving from a devalued living situation, such as a state institution to a more typical living arrangement like an apartment or purchasing a home.
• Obtaining better pay or more responsibility at work. Getting a good performance appraisal.
• Being treated respectfully, as an adult instead of as a child.
• Taking a class as a part of the adult education classes at the local high school
• Being actively engaged in the everyday activities of the household and not excluded because it’s faster or easier for someone else to do it for you.

There are many ways to enhance a person’s status. Some improvements will require new or better skill performance on the part of the person, but not all. Often status-enhancing ideas require no additional money. Creativity and rethinking about how to use money and staff currently available will make the difference.

8. Acquisition Probability

Acquisition probability refers to the relative likelihood that a skill will be learned. There are many choices a team could consider. It isn’t good enough to choose skills that are easy to attain, if they have no meaningful value for the person’s life. Choose goals that are meaningful skills that can be learned over time. Some goals may take considerable time to learn but will make a vast difference in the person’s quality of life.

For example: Learning to operate an electric scooter safely may take a relatively long period of time for a person with a significant disability. However, the long range benefits of this investment of time are well worth the efforts.

SUMMARY AND CONCLUSIONS

Planning teams should keep their focus on the individual when selecting goals and objectives. A goal must never be selected simply because:

1. It is where the person is developmentally
2. It is a recommendation from a standardized program
3. It is what you have been trained to do with people who have a significant cognitive disability or autism or who are self-injurious, etc.

Instead, focus on the person, ensure the person's rights are respected, and ask the "why question." Prioritize how to use the time available (the person's lifetime) to help the person reach his/her full potential.
Feedback Exercise II

1. List at least five of the legal rights every U.S. citizen has.
   a. 
   b. 
   c. 
   d. 
   e. 

   What is the major protection provided by Section 504?

3. What are the major protections of the American with Disabilities Act (ADA)?

4. What are the employment provisions under ADA?

5. What are the provisions of ADA regarding transportation?

6. What does ADA require concerning state and local government?

7. In what situations would a major goal which involves a segregated setting be acceptable?

8. List and explain the eight criteria the person’s team should use when selecting one goal over others during the team process. (The "why question.")
   a. 
   b. 
   c. 
   d. 
   e. 
   f. 
   g. 
   h. 
9. Mark the following skills that are examples of competencies.
   _____ a. shaving  _____ e. embroidering
   _____ b. singing in the choir  _____ f. gardening
   _____ c. dressing  _____ g. bathing
   _____ d. making the bed

10. Which of the following are true for status enhancement?
    _____ a. Always requires the individual to learn new skills.
    _____ b. Requires a lot of money from the agency.
    _____ c. Increases the range of opportunities for individuals.
    _____ d. Should be evaluated in all aspects of planning.
    _____ e. Occurs when a person is treated respectfully in an age-appropriate manner, instead of as a child.

11. What is the difference between what is important TO a Person and what is important FOR a person? Why must teams attend to both issues?

12. Life skills are considered basic because of their direct impact on one’s ability to ____________________________.

13. According to Marc Gold, the more ______________ one has, the more that person will be allowed to deviate.

14. Competence is socially defined. What might be a competence in a large city could well be seen as a __________ in a small, conservative town.

15. List four examples of functional life skills:
   a.
   b.
   c.
   d.

16. Think about the people you support on a daily basis. Give four specific examples of how their status has been or could be improved?
LESSON III: TOOLS AND TECHNIQUES

OBJECTIVES

After completing this lesson, staff members will be able to:

- Differentiate between formal and informal assessments.
- List and define some formal assessments.
- List and define informal assessments.
- Define validity and reliability.

INTRODUCTION

In the previous lessons we discussed the reasons for doing assessments. In this lesson we will discuss two related issues:

1. How do we collect information and complete the needed assessments?
2. How do we turn the information into a meaningful plan to help the person reach his/her goals?

Specific assessments or screening tools are selected based on the individual’s desired future and current status. Typically, the following assessments or screenings are required for all recipients of services funded through state contracts:

- Health (including the presence of seizure disorder, seizure type, dental assessment and assessments of oral hygiene practices; nutritional screening, vision screening)
- Speech and language screening
- Social evaluation (including social and developmental history)
- Psychological evaluation
- Adaptive behavior (including independent living skills)
- Vocational assessment
- Hearing screening
- Discovery
- Environmental analysis

Additional assessments will be conducted based on results from the initial assessments or screenings and what the team has discovered about the person’s preferences and desired futures. These may include but will not be limited to:

- Medical consultation
  Physical therapy assessment
- Occupational therapy assessment
- Medication review (for individuals receiving two or more drugs for behavior management) recreation and leisure
• Functional Behavior Analysis.

These assessments are conducted by a variety of professionals such as nurses, speech pathologists, doctors, dentists, psychologists, and occupational therapists who contribute in their areas of expertise. Others, such as family, friends, and direct support professionals who know the person, contribute valuable information about the person's daily life. They know about the person's behavior, skills and preferences on a day to day basis.

ACCREDITATION

All disability organizations must meet basic requirements in the areas of health, safety and human security as a part of the services and supports it provides. Organizations accredited by CQL have specific assessment considerations as a part of meeting CQL’s Performance Measures. The following list of indicators of comprehensive assessments is based on CQL’s Basic Assurances (2005). It is not meant to be all inclusive, but to give a general idea about the direct link between assessment and attainment of personal outcomes.

Rights Protection and Promotion: A system is used to ensure that the team understands what rights are important to each person. The team assesses the person’s abilities to exercise his or her rights, especially those rights that are most important to him or her. The assessment addresses civil and legal rights and personal freedoms. The need for advocacy, guardianship, and alternatives to guardianship are assessed. Each person’s specific range of decision-making abilities is assessed so that guardianship does not extend beyond the areas needed. Supports needed to protect and promote the person’s rights are identified. Rights assessments are ongoing and reviewed at least annually.

Dignity and Respect: The team routinely uses a personal preference assessment to learn about people’s opinions, preferences, likes, wants, and personal needs. Supports are adjusted based on what is learned in the preference assessment. Personal preference assessments identify the kinds of work and recreational activities people want.

Natural Support Networks: Existing and potential natural supports are identified. Natural supports are those that are available to everyone. The tellers at the bank, librarians, and pharmacists help all of their patrons/customers when they have questions. The person’s satisfaction with extent and frequency of social contacts is assessed.

Protection from Abuse, Neglect, Mistreatment and Exploitation: The person defines actions, circumstances, and environments that he or she considers abusive and neglectful. The person’s ability to report abuse, neglect, and exploitation is assessed and supported appropriately. Current needs related to past incidents of abuse, neglect, mistreatment or exploitation are assessed and supported.
**Best Possible Health:** Results from health care screenings and evaluations are documented. The person’s preferences and ability to self-administer medications and treatments is assessed at least annually. The person’s understanding of his or her health status, medical conditions, and health care preferences including health care providers and treatments is assessed and supported. Effectiveness of health care services and supports, progress toward health care goals, and the person’s satisfaction with their health care are recorded. Person-centered plans, including health care supports are modified in a timely manner based upon acute health changes.

**Safe Environments:** Assessment of people’s abilities to be safe in their environments are ongoing and reviewed at least annually and documented in the person’s plan. Safety assessments include but are not limited to: safety in the kitchen; ability to adjust hot water, evacuate in the event of fire or severe weather; call for help; use cleaning supplies; and safety concerns specific to the individual or environment. The person’s feelings about safety at home, work and in his or her neighborhood are measured and steps are taken to resolve concerns.

**Positive Services and Supports:** Plans incorporate the results of assessments, evaluations and screenings required by the agency and those that relate to the individual’s strengths and needs. Assessments, evaluations, and screenings focus on the person’s skills and supports presently in place, those preferred and desired by the person, and those needed to realize the person’s goals. Implementation of the person centered plan is systematically monitored and necessary revisions are made in a timely manner. Behavior support plans are based on functional assessment including assessment of the communicative intent. People are monitored for adverse effects from all intrusive/restrictive procedures, including drug side effects, using a standardized tool or other accepted standard of care. Effectiveness of psychoactive medication is reviewed by licensed health care provider at regular intervals.

**Continuity and Personal Security:** People have sufficient resources to meet their daily needs and personal goals or plans are in place to assist the person to attain needed resources.

**TYPES OF ASSESSMENT**

Assessments are commonly classified into two broad types: formal and informal. Traditionally, formal instruments, procedures and strategies have received the most attention, but informal techniques must be included to make assessments person-centered.

**Formal** assessments are conducted by professionals who have received special training in giving specific tests and in interpreting the results. Instruments such as these may be used:

- Tests of intellectual ability (learning aptitude)
- Achievement tests
• Measures of specific abilities (such as motor abilities, auditory discrimination, color discrimination, adaptive behavior, language abilities, and others)
• Social adjustment or behavior rating scales/checklists

Standardized tests such as I.Q. tests scores tell how a person compares to other people of similar characteristics, such as age in their ability to reason, solve problems and tackle learning various types of academic tasks. To be considered reliable and valid, these tests need to be given in exactly the same way and interpreted consistently. I.Q. tests have often been misused and misinterpreted. In some cases, I.Q. tests were used to decide where a person could live or work, or to "predict" how well the person could learn. In some cases, I.Q. test results were used to limit the person from even trying to succeed at goals the tests indicated would be too challenging. It is important to remember that these tests give limited information about the person, telling very little about exactly what options and supports would be appropriate and beneficial.

The terms evaluation and examination are used quite interchangeably. These refer to the part of the evaluation process carried out by professionals, often using standardized procedures. A screening is that part of the assessment process that is more limited in scope and intensity. It is intended to determine whether or not a more in depth assessment is needed. Examples of screening include nutritional, vision, auditory (hearing), and speech/language. The following are examples of evaluations/examinations:

**Physical and Health:** This is performed by licensed physician, a specially trained physician's assistant, or a nurse practitioner who is supervised by a physician. It includes a medical history, physical examination of all body systems, and appropriate laboratory findings. Special health concerns, such as seizure disorders, should be identified and monitored closely.

**Dental:** A licensed dentist must perform the examination. It should include an evaluation of the individual's oral hygiene practices, dental health, and recommendations for treatment.

**Social:** A social and developmental history includes a description of the type and frequency of social interactions, and make-up of the individual's social support network, including family members, friends, co-workers, and neighbors.

**Psychological:** An evaluation by a qualified examiner includes an assessment of the individual's emotional and intellectual status. Information can be gained from direct observation, non-standardized screening measures, as well as standardized evaluation tools. Challenging behaviors may be addressed.

**Adaptive Behavior or Independent Living Skills:** Areas such as mobility and personal health care are included. Functional skills that the individual does use, will use, or will have to use in his or her daily life to reach personal goals are
assessed. It is important to note whether or not the person will perform the skill when direct support professionals are not present. If not, what level of support is needed (reminder, gesture, physical assist, etc.)?

**Developmental, Educational, or Employment:** Typically, the recommended type of evaluation is based upon age: a developmental assessment giving information about infants and young children; an educational assessment done for school-age children; an employment assessment carried out with adolescents and adults.

**Occupational and Physical Therapy:** This evaluation gives information regarding the person’s ability to move around in everyday settings, gross and fine motor movements, strength, coordination, and independence. This would include but not be limited to: walking, sitting, standing, negotiating stairs and curbs, opening doors, entering and exiting vehicles, opening/closing containers, and manipulating objects. It describes gross and fine motor movements, strength, eye-hand coordination, and strategies for independence, the need for adaptive or special equipment, and eye-hand coordination. The assessment should include recommendations regarding the modifications needed in the environment and equipment to enhance mobility and independence.

**Communication:** This assessment describes the individual’s current communication. It includes evaluation of vocabulary and receptive/expressive strengths and needs.

**Audiological:** The audiological assessment/screening addresses issues regarding the person's hearing and possible need for amplification (hearing aids) and other modifications to the environment to enable the person to obtain optimal use of hearing.

**Functional Vision:** The vision assessment describes how the person uses vision to perform tasks within the daily routine, orientation and mobility. Does he or she need glasses, special lighting, or special print/other adaptive equipment? Can he see in all quadrants or should materials be presented in a certain way, size or color?

**Functional Hearing:** The hearing assessment describes how the person uses what hearing they do have to perform tasks, make sense of the environment and be motivated. Does he or she need to have background noise kept at a minimum? Do they need to have group instructions repeated individually? What kinds of every-day tones, alarms and signals can they detect?

**Nutritional:** This assessment will address nutrition, diet, weight range; recommend foods and textures, the effects of medication on diet habits, the effects of certain foods on medications and methods to enhance chewing and swallowing. Individual food preferences and preferred dining times are included.
It is important to note that areas may overlap. Different specialists and staff may be involved in the assessment. For example, a nutritional assessment may include:

- Physical exam to evaluate the need for special diets (reduced calorie, low fat, low sodium, etc.)
- An occupational therapist or speech pathologist to evaluate oral motor development and the possible need for special diets (related to the texture or consistency of the food) or feeding techniques
- The dietician to recommend how to follow the diet prescribed by the doctor
- Functional behavior analyzed by a psychologist and direct support professionals, working together (rate of eating, lack of appetite, etc.)

**Informal** techniques and strategies are needed for a comprehensive, person-centered assessment. Examples of informal strategies include:

**Interviews** are flexible and adaptable to many situations. The interview has been described as a "conversation with a purpose". The interview is not one-sided. Both parties receive information and provide responses. When interviewing:

- Use paraphrasing, a restatement of what the person said
- Use perception-checking, a description of the other person's feelings as perceived (or understood) by the interviewer.
- Ask open-ended questions. Avoid questions that can be answered with a "yes" or "no" response.
- Ask for clarification when general statements are made, such as "pretty good", "without difficulty," or "terrible".

**Questionnaires**: Unlike interviews, which can be expanded to take new paths and directions, questionnaires are structured to limited topics. These are simple, quite effective ways of obtaining information. They provide a permanent record that can be reviewed and included with other information about the person. However, the results can be misinterpreted (which is a problem with many types of assessments). Questionnaires’ fixed format limits options for responses.

**Inventories**: These are usually thought of as comprehensive listings of some sort. They can be quite individualized, constructed to relate to particular settings and subject matter. Self-concept inventories and ecological inventories are two examples.

**Observations**: Especially when combined with previous strategies, these can give much information about the person's choices and responses to daily life. There are a variety of ways to organize an observation and to record the information obtained. An observation
checklist, a running narrative or ABC (antecedent, behavior, consequence) record can be used.

An observation checklist is a record of behaviors that have been observed in the individual.

**Example:**

<table>
<thead>
<tr>
<th>Greeting</th>
<th>Yes</th>
<th>No</th>
<th>Type of assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Initiates greeting</td>
<td></td>
<td>x</td>
<td>verbal prompt</td>
</tr>
<tr>
<td>(b) Responds to greeting</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(c) Makes eye contact</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d) Shakes hands</td>
<td></td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

Observation checklists can be used to answer specific or general questions. Examples of specific questions include: "What method does the individual use to communicate?" or "Can the person feed themselves?" If the individual is not independent in an item on the checklist, the person completing the checklist should indicate the level of support that is needed. General questions might include, "What does the person like to do in their spare time?" or "What learning techniques are the most effective with this person?"

A running narrative (anecdotal record) describes what a person is doing minute-to-minute during the observation period. This can be done in written form or video or audio tape and transcribed later. It contains detailed information about the setting, the actions of the individual and the actions of other people. It is a running description of the person and their surroundings. It should include only objective, observable information. These include descriptions of specific significant events in an individual's life.

**Example:** Jim came home from work at 5:30 p.m. He hung up his coat, said “Hello” to Sue and Allen and went to his room and closed the door. Twenty minutes later he went to the kitchen and made coffee for the evening meal. When Susan asked if he had a good day at work, he looked the other way and didn’t reply. He went into the living room and sat and looked out the window until dinner time. During the evening meal, he only ate three bites of his supper and didn’t participate in the mealtime conversations. Susan asked if he wanted to go to the movies and he said he was tired and wanted to stay home. After helping with the dishes, Jim said that his stomach hurt and he wanted to go to bed. Allen asked how long his stomach had been hurting and for more information about the type of pain. Jim said it started hurting at work and that he felt like he might have to throw up.

An ABC record is a systematic, objective observation of a behavior, its antecedents and the consequences.

- “Antecedents” are events that happen before the target behavior that increase the likelihood that a behavior might follow. Antecedents may include factors within the setting. An antecedent might be as subtle as the noise level or temperature of the room.
Any other variables (people present, activities, statements, etc.) that might explain the behavior are included in the record. Direct support professionals keeping data on antecedents to behavior should track: when, where, with whom, and under what circumstances the behavior occurs. This may include recording people present, when the behavior takes place, what the person was doing just prior to the time the behavior occurs, and any verbal or nonverbal communication preceding the behavior.

- “Behaviors” refer to the actions of the individual. While behaviors may be considered to be appropriate or inappropriate by others, almost all behavior serves a specific function (gets a desired outcome) for the person. Not everyone can connect a consequence with what they did immediately prior. They influence the behavior and determine whether it will be repeated.

**Example:**
Antecedent: Jim was eating popcorn while he watched T.V. with Jean and Sam. Jean switched the TV channel from the WWF Wrestling to the home and garden channel.
Behavior: Jim threw popcorn at Jean.
Consequence: Staff members asked Jim to stop and told him that WWF Wrestling was too violent. Jim became aware that when he threw popcorn, people paid attention.

Ecological Assessment: The setting where the person needs to succeed is examined to determine what kind of demands the person will need to respond to in that setting. Demands can include, but is not limited to: the kind of tasks needed to be done, the kinds of communication the person will be expected to respond to, materials that could prove to be a distraction, the social expectations in that setting and the physical requirements needed to navigate the setting. This information helps the team to identify specific supports and teaching activities that will be needed to help a person succeed.

**VALIDITY AND RELIABILITY**

Validity and reliability are important factors in any assessment process. **Validity** refers to the extent the assessment measures what it claims to measure. Validity looks at the content of an assessment tool. This is important to prevent making decisions based on irrelevant information. For example, if we ask an individual with a learning disability to respond to verbal questions about choice of recreation activities and don’t provide the time he requires to process our questions, the results are not valid. This would not be an assessment of choice of recreation activity, but instead a test of language processing. It also would not be a valid assessment if we did not provide a broad enough range of choices that included all the activities the person enjoys. In other words, does the assessment tool/strategy answer the question that we are asking or does it tell us something else?

**Reliability:** Refers to the extent to which the assessment tool or strategy is consistent in what it is measuring. Would we obtain basically the same result if the assessment was repeated at a
different time or with a different valuator? In other words, we need to get basically the same answer to the question each time.

One of the factors that contributes to the validity and reliability of an assessment is the "conduct" of the person doing the assessment. If assessments are going to be valid and reliable the person conducting the assessment must:

- Follow the directions - conduct the assessment according to the directions provided.
- Be objective evaluators - record what is observed, not what you believe to be true.
- Be accurate - evaluators must record the results of observations correctly.
Feedback Exercise III

1. What are some examples of assessments required by Accreditation bodies such as CQL?
   a.
   b.
   c.
   d.
   e.

2. What are formal assessments? What kinds of instruments can be used? (List three).

3. Explain the term "screening" and describe its purpose.

4. List and describe three types of evaluations/examinations.

5. List and explain the four different types of informal testing.
   a.
   b.
   c.
   d.

6. Use _____________ questions during interview assessments.

7. Give a brief description of each of the following:
   a. observation checklist
   b. a running narrative
   c. ABC record

8. What is validity?

9. What is reliability?
10. Standardized tests ___.
   a. give a great deal of information about a person
   b. suggest options that would be appropriate and beneficial
   c. have very general administration guidelines and can be adapted by the person giving the test
   d. indicate how a person compares to other people
   e. are used correctly when used to predict future performance

11. In valid and reliable assessments, the person conducting the assessment must:
   a. Follow the ____________ - conduct the assessment according to the directions provided.
   b. Be _______________ evaluators - record what is observed, not what you believe to be true.
   c. Be ____________ - evaluators must record the results of observations correctly.

Matching

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Events that happen before the target behavior. May include factors within the setting (i.e., noise level or temperature, people present, activities, statements, etc.), communication that occurred prior to the behavior, or what the person was doing prior to the behavior.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The actions of the individual. May be considered appropriate, or inappropriate. Some may be desirable to increase, while some may be decreased.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Events that happen after the target behavior occurs. They influence the behavior and determine whether it will be repeated.</td>
<td></td>
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</table>
LESSON IV: PERSON - CENTERED PLANNING

OBJECTIVES
After completing this lesson staff members will be able to:

- Identify personal goals for individuals served.
- Use assessment data to generate a plan for achieving personal goals
- Describe function and form by giving examples.

INTRODUCTION

A person - centered approach to planning considers issues that are important to the individual. It is functional, meaning the person’s goals are the focus of assessment and planning. Since learning takes more time for individuals with developmental disabilities, everything taught should be justified. Planning is specific to the person's dreams and abilities. Supports are designed to increase the person’s independence and decision making skills. Planning sets the direction for the near and long-range future.

Developing a person-centered plan begins with learning how the person defines his or her priority outcomes. CQL’s Personal Outcome Measures provide a guide to person-directed planning. Information gathered about outcomes in the factors My Self, My World, and My Dreams help the team learn the person’s priorities or focus. In Personal Outcome Measures – Measuring Personal Quality of Life (2005), CQL explains “My Focus” in this way:

My quality of life is about me. It is about My Self, My World, and My Dreams. I define each area based on what is important to me. My Focus is what I am paying attention to now. It is what is most important to me today. It might be about several things, from my relationship with my best friend to my dream to own my own home. The circles interconnect and may not always look the same. My Focus is the basis from which all planning and personal goals:
Since personal definitions of outcomes will vary, supports must be individualized. The supports that facilitate a particular outcome for one person may not do so for another.

The team uses a variety of tools to discover the individual’s personal outcomes. These outcomes are prioritized through the person-centered planning process. The team then organizes resources to provide services and supports that will help the person attain the outcomes most important to him or her.

IDENTIFYING PERSONAL GOALS

In Lesson III you learned about tools and techniques used for assessment. If the person has limited communication with words it may be hard for us to be sure we know what the person wants. Here is a list of ways to help identify personal goals. It is often useful to combine these strategies to get the clearest “picture.”

1. **Interview the person and significant others in their lives.** Individuals with good communication skills and a range of experience can tell you about their personal goals. Family members and those who know the person well often have insights into the person’s goals, as well. During the planning process, it is important to encourage these people to share their information.

2. **Discovery.** Sometimes the individual may not have enough information to make informed, realistic choices. It may be helpful for the person to try out some activities to get the information needed to make optimistic, but realistic, choices.

3. **Observe the person.** Much can be learned about personal preferences by observing an individual participate in activities he or she selects. Some excellent personal preference checklists are available to help identify preferences for people who do not use language to communicate. These checklists can be helpful in thinking broadly about preferences.

4. **Observe or sample with inference.** When an individual does not communicate readily, clearly indicate preferences, or try activities without support, we may need to infer general preferences from our observation. This information is used to match similar characteristics in other settings and activities. For example, an individual may show preferences for active, large motor, outdoor leisure activities. Some matches for work settings could be inferred and sample jobs that have the same characteristics (yard work, zoo attendant, farm hand) could be explored. Observation or sampling with inference can also be used, if appropriate, for providing ideas for living and recreational/leisure options.
5. Match to a person of the same age with no disability. Although every person, regardless of disability or age, is different, and the strategy of matching to age needs to be used cautiously, a consideration for choice-making is, "What would a person of the same age without a disability want?" Young adults, in general, may choose to live near friends, have easy access to recreational sites, public transportation, etc. People at different stages of life tend to have changing wants and needs. While one doesn’t want to compare, looking at what is "typical" can foster inclusion into society. (Olson & Rast, Assessment, pp.14-15)

WHAT IS NEEDED TO BE INDEPENDENT AND SUCCESSFUL?

After a global picture of the individual's future has been created, the person and his or her team need to figure out how these dreams can become realities. The first step is to figure out what the individual needs to be successful in the settings where his or her goals will be realized.

The team develops a list of the skills people need to be as independent as possible in a certain setting or activity (ecological inventory). The setting is observed while activities are going on and a list of all the skills needed is developed. These are listed as skills or steps that would be useful in developing plans of action. These lists can also be made in work, living, and recreation settings.

COMPARING ACTUAL SKILLS WITH WHAT IS NEEDED

The next step is to compare the requirements needed in a specific setting or activity and the person’s current skills (discrepancy analysis). A list of skills, strengths and competencies is developed for areas where the person is already independent. The remaining skills become the action steps in the person’s plan. The team decides which skills will be supported and which skills are prioritized for teaching and learning. When behavioral and service objectives are developed, task analysis can be used for a detailed breakdown of steps.

How does this work? Let’s use an example to show how this works. Before children start preschool there is usually an orientation for parents who want to send their children to school. The teacher meets with parents and tells them about what he or she expects of children who attend the preschool. The list may vary from one school to the next but often consists of a few basics, using the toilet independently, putting on their own jacket (zipping or buttoning), and putting on their own shoes or boots. Usually preschoolers are required to bring supplies from home and bring snacks at least once during the term. When parents hear the list, they either breathe a sign of relief that their child has all these skills or they figure out how to fill in the gaps so that their child will be ready to go when school starts. No one says, “Little Frank can’t tie his shoes, so I guess he won’t go to pre-school.” His parents think about ways to meet this requirement and pick the one that makes the most sense for their child and family.
FUNCTION and FORM

The function of behavior refers to the purpose of the behavior. The form refers to the specific means to accomplish the function. The function states what needs to be accomplished, without specifying how or exactly by whom. Form refers to the specific motor action. Too often, we focus our attention only on assessing whether a person can perform a specific form. But in practice – the function is what is important.

Many assessments use standard behavioral checklists which list very specific behavior forms. These are usually lists of "typical" behaviors which are performed by "typical" people. They are, most often, lists of behaviors which "most" people perform in "most" settings under "most" conditions. They are seldom designed specifically for a particular person under particular conditions in a particular setting.

Examples of functions and forms that may be needed to live independently include:

<table>
<thead>
<tr>
<th>Behavioral Functions Required to Live in a Typical Setting</th>
<th>Behavioral Forms (Means) to Accomplish Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal hygiene &amp; grooming must be maintained at acceptable levels:</td>
<td>- individual bathes self independently</td>
</tr>
<tr>
<td></td>
<td>- a staff person comes into the apartment to assist</td>
</tr>
<tr>
<td></td>
<td>- a relative comes into the apartment to assist</td>
</tr>
<tr>
<td></td>
<td>- a live-in companion assists</td>
</tr>
<tr>
<td>Nutritious, well balanced meals must be provided:</td>
<td>- individual prepares meals</td>
</tr>
<tr>
<td></td>
<td>- roommate prepares meals</td>
</tr>
<tr>
<td></td>
<td>- staff cook &amp; freeze meals weekly; the person</td>
</tr>
<tr>
<td></td>
<td>- rooms as needed</td>
</tr>
<tr>
<td></td>
<td>- TV dinners</td>
</tr>
<tr>
<td></td>
<td>- meals on wheels</td>
</tr>
<tr>
<td></td>
<td>- eats out for all meals</td>
</tr>
<tr>
<td></td>
<td>- family members provide meals and/or assistance</td>
</tr>
<tr>
<td></td>
<td>- eats in restaurant</td>
</tr>
<tr>
<td>Nutritious, well-balanced meals must be eaten:</td>
<td>- individual feeds self using typical utensils</td>
</tr>
<tr>
<td></td>
<td>- individual feeds self using adaptive equipment</td>
</tr>
<tr>
<td></td>
<td>- staff assists the person to eat</td>
</tr>
<tr>
<td></td>
<td>- family member assists the individual</td>
</tr>
</tbody>
</table>
### Gets to and from work:
- rides the bus
- staff transports
- walks
- takes a cab
- rides with co-worker
- drives own car
- family transports
- rides a bike

### Needs and wants are communicated:
- uses facilitated communication
- shakes head
- uses sign language
- talks
- writes notes
- gestures
- blinks
- types

Goals and objectives should be accomplished as quickly as possible in a manner that draws the least undue attention to the individual. People with the most significant disabilities may never be able to do things exactly the same way as a "typical" person does. Focusing attention on solely assessing typical behavior is inappropriate.

After the team develops a list of "forms" or options, it is time to evaluate which makes the most sense for right now. Peter Kinselia (2000) suggested using an Options appraisal to evaluate the forms and decide which most matches “who the person is” and the life he or she wants. Here is an example of an options appraisal grid that was developed to evaluate various living arrangements for one individual who wanted to live with his best friend from high school. Typically, this would help the person and their team narrow possibilities down to the best two or three.

#### Options Appraisal

<table>
<thead>
<tr>
<th></th>
<th>Option 1</th>
<th>Option 2</th>
<th>Option 3</th>
<th>Option 4</th>
<th>Option 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fit with the person’s picture of life</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Fit with who person may want to live</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Fit with where person may want to live</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fit with how person may want to spend their day</td>
<td>x</td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Fit with pattern of</td>
<td>x</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>
When Persons have Significant Support Needs: People with significant support needs due to cognitive disabilities will need additional support to engage in goal setting. The team will need to consider the extent to which the person is even aware of a potential goal, how that person will be supported to find meaning in the goal, what choice the person will have when it comes to participation and how we will know if the person is starting to buy-into or put effort towards that goal.

DISCOVERY OF MEANING:

The following levels of engagement help people to find activities to be meaningful.

a) Awareness of an outcome or related activity through inclusion/direct experience.
b) Acting on related materials
c) Communicate about goal-related activities, events or materials
d) Predict or control involvement in goal-related activities
e) Gain skills and experience with a specific goal
f) Become aware of choices and outcomes related to a goal.

What would this look like? Suppose a team wanted to set a goal for someone to work in the community by delivering cookies to a local business. That sounds good. But what happens if the person is not even aware that goal is being written into his or her plan? The person does not speak or clearly answer questions about what they would like to do. How do we know this is their goal and not just ours? What will it take for delivering cookies to be meaningful for this person? How will we know if they have adopted this goal as their own?

QUALITY OF LIFE OUTCOMES

When services and supports are customized around the individual’s needs and preferences, better outcomes are achieved. Personal outcomes are as unique as the individuals themselves. In general, individuals want relationships, meaningful things to do with their day, to feel safe, to feel valued, to be healthy as possible, to have access to community life, and to have ample money to live modestly. (Melda, et al. 2009)
Feedback Exercise IV

1. List briefly and describe two ways of identifying an individual's personal goals.

2. Think about a new setting or activity you wanted to access but you did not have all the skills needed to be successful in this new setting or activity. How were you made aware of the gap between your current skills and what was required. What steps did you take to bridge the gap between current skills and required skills.

3. Develop a list of all the skills needed to buy groceries at the grocery store. List the skills required to be completely independent. Do not include transportation issues-start with entering the store. For each step in the task, indicate the kind of support a specific person might need to complete that step. For example, (Does on his own, tell the person to “reminder,” point to the checklist, do that step for the person).

4. Think of a person with a developmental disability that you know. Use the list you developed and simulate comparing the list of needed skills with what the person is able to perform. (The only accurate way to make this comparison is to actually observe the person perform the skills in the actual setting.) Mark "+" by those skills the person performs independently and "-" for those the person would need assistance performing.

5. What is the difference between behavioral function and behavioral form? (Give two examples).
6. People with the most significant disabilities may never be able to do things exactly the same way as a “typical” person would. Teams who help folks accomplish their goals as quickly as possible will focus on ______________ rather than specific forms.

7. For the following function, list at least 3 forms or methods for accomplishing the function:

   Function: Residence must be kept clean and reasonably neat
   a. 
   b. 
   c. 
LESSON V: USE TECHNOLOGY TO SUPPORT PERSONAL OUTCOMES AND GOAL ATTAINMENT

OBJECTIVES:

After completing this lesson staff members will be able to:

- Describe how assistive technology can increase the independence of the user
- Describe at least 3 ways remote monitoring can be used to coach and/or supervise.
- List the advantages and disadvantages that staff supervision has on skill acquisition.
- Identify questions to address when considering assistive technology for remote monitoring.
- Discuss the issue of privacy in remote monitoring of residential settings.

INTRODUCTION

There is an abundance of tools that help us with receiving, sorting, and using the avalanche of information we receive daily. Some devices help us check our messages, make and receive phone calls, receive alerts, give reminders on appointments, take pictures and movies, and transmit images instantly to another viewer, make plans, buy groceries, provide surveillance, and take care of particular functions in our houses. Many life activities have been augmented or assisted by these devices which give the user more personal freedom to do even more tasks more efficiently.

With tools and technology many low-level tasks can now be done automatically. Our lives are fuller because we have more time to devote to higher-level tasks -- more interesting tasks. Technology can have the same benefits for people with disabilities. These tools can increase independence, autonomy, and self-determination for people with cognitive and physical disabilities. These devices can help people depend less on rote memory and reduce the need for complex organizational skills.

For example: As Shauna waits for the city bus, her GPS (global positioning system) PDA (personal digital assistant) transmits real-time data from the GPS enabled bus to her PDA and to a direct support professional who supports her but is not with her. This real-time data transmits visual data of both Shauna and the bus. As the bus approaches, the PDA is triggered and prompts Shauna audibly, “Get ready”. As the stop is made the prompt, “Get on the bus,” is heard. When Shauna approaches her destination, the prompt, “Please pull the stop cord,” is given. The PDA also has the capability to monitor and detect if Shauna gets on the wrong bus or misses the bus.

PDAs can be programmed with a panic button. If the individual needs assistance, he or she just pushes the button. With the capability of real-time monitoring, direct support professionals can see and hear the nature of the problem and provide the appropriate level of support. It might be the person only needs verbal assistance or information about what to do next. When
on-site staff support is needed, the staff make arrangements to get someone to the person’s location. The data collected on the PDAs alerts the team for needed changes in support and alert direct support professionals about the need for intervention. Learning what is unique about the individual makes the device more personalized to their needs and problem areas.

*David is learning to deliver mail on his new job. His personal prompting system is scripted with a set of tasks that have audio and visual prompts. After completing the first in a sequence of tasks, David moves to another task. The personal prompting system is triggered to give visual and auditory prompts for the next stop. The prompting system sends data back to Susan, a job coach monitoring at a remote site. Susan can see that the task has been completed and another task is started. The prompting sequence and scripts can be changed as David progresses in his learning. Associated with each step are constraints that define problem areas for David (time limits, location boundaries, length of time for returning to task after breaks). This data is stored and used for decisions on when to fade monitoring or instruction.*

Technology for people with cognitive disabilities should reduce the complexity of the task or circumstance and help them problem solve when system errors occur or when circumstances change unexpectedly. In the previous example, using the local bus system was simplified through real-time monitoring and communication to problem solve via auditory and visual support. Staff could also alert nearby direct support professionals when an individual needed help. Safety nets like these are critical to service providers, families, and individuals with disabilities striving for true community membership.

*Annie lives at home with her parents. She is 23 and has Down Syndrome. Annie used more technology when she was in school. Now she just uses her cell phone and occasionally a computer. She is active in the community and holds two-part time jobs. The role the cellular phone has had in her independence was very large initially. Annie used her phone to call when she arrived at the bus stop, then from the bus, then when she got to Middletown, and then when she got to work. Now she only calls home a few times a week. Her parents feel that without the cell phone she would not have gotten the job.* (Dawe, 2006)

Technology with mobile devices can track the activities of a person over time. The device “learns” the user’s typical routines and monitors for any variations. This information can be used to change or reduce prompts, change task sequence prompts, alert direct support professionals if an intervention is needed, or assess the need for increasing or decreasing the level and type of monitoring. Stationary touch screens distributed around a person’s home can be used to provide prompts that aid in simple domestic tasks. These systems give visual and auditory prompts on a timed basis (according to calendar or clock) when certain tasks need to be completed.

Sensing devices can make it possible for direct support professionals to monitor the activities of a person either in real time or to gather data for review at a later time. One sophisticated
system uses sensors in private rooms such as bathroom and bedroom to indicate the person’s presence. The system uses video or webcam real time streaming in other less private rooms to help direct support professionals “see” the person and talk with them. “Smart sheets” (sheets with sensors) can even be used to check vital signs for health monitoring.

Motes, or sometimes referred to as “smart dust”, are a system of several tiny sensors connected to a small, low powered and cheap computer and a radio transmitter. The computer monitors many different sensors in a mote. These sensors can measure light, acceleration, position, stress, pressure, humidity, sound, and vibration among others. Motes can be programmed to gather information about the number of doses left in a pill bottle, what clothes a person wore, if the person had coffee for the morning meal, or how long the person slept that night. The possibilities are endless.

**STAFF SUPPORT VS TECHNOLOGY SUPPORT**

Traditional staff support in vocational and residential settings involves direct support professionals being present to prompt and give assistance when the need is apparent. In each of the previous examples, direct support professionals would not be present but available when the individual made a mistake, does something outside of the normal routine, or personally makes the decision to ask for help. Traditional support with staff always present tends to diminish decision-making and problem-solving because staff intervene before the person has a chance to figure out what to do. When a problem is imminent, staff usually alert the individual and prevent mistakes from occurring. Direct support professionals may see individuals as capable of completing day-to-day tasks but provide constant reminders or prompts to perform all steps out of habit. When a person is constantly monitored, true independence is limited.

Often budgetary constraints, staff schedules, and some times agency policy makes it easier and safer for direct support professionals to simply prepare a meal for everyone in the residence rather than guide each person in preparing what they are going to eat. The incentive to actually learn to cook is decreased as staff may be perceived as the “cook” or “caretaker” and not the teacher/supporter. In group living, activities and choices depend largely on staff availability. If constant monitoring is part of the agency service, most activities outside the residence depend on staff schedules and available transportation (either provided by the agency or staff escort). Activities may also be restricted to environments and schedules that will accommodate individuals who have the most needs, e.g. accessible areas or medication and/or care schedules. Group living can actually limit independence and self-determination.

Does actual physical presence of direct support professionals hinder development of self-determination and independence? Is it less likely to develop because the individual is given less practice in actual self-
determining circumstances? Levine & Langness (1985) found that competence at supermarket shopping was unrelated to age, sex, IQ, or amount of training. They found that most competent shoppers were those whose circumstances required them to shop independently as adults. Their findings supported the premise that being independent is related to higher levels of participation and self-determination. The person didn’t need to wait for assistance before participation.

Lazano (1993) found that the real experience of independent living accounted for improvement or maintenance of a skill, **NOT** the amount of training. This study concluded that effective support involved social, emotional, and practical support, not a focus on skill acquisition. These findings are in alignment with the premise of Supported Employment. Rather than train a person for a job and then obtain the job, the model of “Choose-Get-Keep” allows the person to learn on the job and keep the job. The actual skill development occurs through participation. Lazano concluded that poor support makes you over reliant on direct support professionals.

Cognitive Levers, a project directed by the LifeLong Learning and Design Center at the University of Colorado in Boulder, CO, evaluated the use of remote monitoring for people with developmental disabilities in residential settings. One of the conclusions reached was that technology (remote chat and video communication) provided residents opportunities to complete tasks at their own pace and caregivers’ roles shifted from directing to coaching (RERC-ACT, 2008). In some instances, skills that had not previously and formally been taught were performed without incident, e.g. cooking meals. Staff support with the individual was more related to incidents of finding something that was missing, inattentiveness (something is present but being overlooked), forgetting an instruction and providing emotional support such as overcoming frustration.

A Lafayette, Illinois agency that uses a remote monitoring system by RestAssured primarily for the third shift (over night) care, reports that people served feel an increased sense of independence since the caregiver is not physically present. Motion, temperature, carbon monoxide, and door brake sensors, in addition to a personal emergency response system, are used. Remote supervision is accomplished via a two-way audio/video communication with the caregiver. The direct support professional monitors several apartment settings simultaneously.

Including personal technologies as individualized supports has the potential to transform the way supports are provided. The desire for aging parents and people with disabilities to stay in their homes rather than move to congregate settings and the fiscal and labor force issues that force agencies to find ways to decrease the onsite staff hours are growing. Personal technologies hold the promise of increasing the level of safety, independence, and social connectedness for all people. This shift in how caregiving is delivered will not only be necessary because of the shrinking pool of potential caregivers but also the need to provide services that increase or maintain independence. How will this affect the planning activities of person
centered teams? What will assessments and goal setting methods look like? How will rights, responsibilities, and security be addressed in these environments?

Services are shaped by several variables. The desires and dreams of the people served are primary. Strengths and needs of the person will shape the supports and family values will certainly play a part also. Services are also influenced by availability of resources. Staff, money, housing, creativity of team members, and other factors that sometimes are not directly controlled by the teams also shape the individual support plans of people served. New ways of providing support to people must be considered during transitions from living arrangements, school to work, or as other life events occur. Assistive technology and remote monitoring have the potential to be a major element in support designs.

TEAM DECISIONS ABOUT TECHNOLOGY AND REMOTE MONITORING

Creating effective technological tools to assist individuals in this population is a challenging task. Augmenting and supporting people with cognitive disabilities with technology is not as concrete as it is with people with physical disabilities. Technology that can help people with developmental disabilities reach goals will vary between individuals and over time. It is not easy to know where ability ends and technology can or should begin. Cognitive abilities vary widely and each person has a unique set of strengths/abilities. The tool must match the individual and augment his or her skills.

A framework for considering how “remote support” can increase quality of life for the individual and provide safeguards is a complex assessment process, one that continues to be refined. Dawe (2006) suggests an ethnographic approach for assessing individuals with cognitive disabilities. This approach would involve on-site, interviews, observations, and other data collections that give a rich view of the day-to-day needs and opportunities for technology. It would provide a deeper understanding of the network of caregivers that typically surround an individual with developmental disabilities. This network may include parents, extended family, doctors, case workers, teachers, and others.

Some standard questions that teams ask when considering assistive technology are:

- What can the technology do for the person that he or she is not able to do now?
- What is the desired end result?
- What are the person’s customary environments?
- What are the person’s biggest challenges?
- What technology is available to help overcome these challenges?
- What criteria will be used to determine if the technology is or is not successful?
- What are the person’s preferences?
Another set of questions developed by Kelker (1997) are: Does the device . . .

- Enable an individual to perform functions that can be achieved by no other means?
- Enable the person to approximate normal fluency, rate, or standards?
- Support participation in activities which otherwise would be closed to the individual?
- Increase the ability to sustain effort on tasks that are otherwise too difficult.
- Enable people to concentrate on learning or employment rather than mechanical tasks?
- Provide greater access to information?
- Support more social interactions?
- Support participation in the least restrictive environment?

Fifield (2007) recommended that teams consider these four application levels of technology supports during the assessment and goal setting processes:

**Level 1: Individual Controls** – Devices that give the person greater control of personal living or work environments. Examples: Remote control devices to turn lights on and off, to control air conditioning, and to operate appliances that are difficult to reach. Many assistive technology tools fit into this category.

**Level 2: Monitoring Systems** – Technology to reduce the physical presence of support staff. Examples: Passive camera systems, movement sensors, video recording systems, door/window sensors that signal when they are opened or closed.

**Level 3: Daily Schedule Supports** – Technology that can be used to provide cues to assist a person in following a daily or weekly schedule or to complete a task. Examples: Lighting tied to timers. Prompting systems such as recorded prompts about what has to happen next (e.g., get out of bed, get showered, get dressed, have breakfast, make lunch, go to work, etc.). Sensors to indicate movement around an apartment in response to scheduled prompts. Power controls to turn off lights and television during certain times.

**Level 4: Behavior Supports** – Technology to help a person learn and maintain new skills or routines. Examples: Use of media to prompt consumer regarding the next behavior in a chain and input switches to indicate progress; use of movement sensors to indicate and record movement around an apartment or work site.

The following questions may be used to evaluate the appropriateness of remote support. If the team determines that remote support is a feasible alternative, other considerations need to be made:

- Does the potential user genuinely desire change in what they can do?
• Is the potential user willing to learn how to use the tool in their daily routine?
• Do the user/caregivers understand assessment and customization will be ongoing?
• Does the user have the support of the caregivers in using the tool (learning how to troubleshoot, reprogram, assess and integrate into new routines)?

Other considerations to make are:
• Does the device decrease dependency on rote memory?
• Does the device or system use as many modes as possible (visual, audio, multigraphic (different types of graphics/pictures/charts))?
• Does it reduce the need for complex organizational skills?
• Does it use a format that is understandable (language and reading level)?

Decision making in what is the right assistive device, system, or mode of service, e.g., remote support can be complex, due to rapid changes in the industry and proliferation of new devices. RERC-ACT conducted extensive research in technology for people with cognitive disabilities – especially in remote support. They report:

• Innovative ideas about support models and the appropriate technologies to carry these out are not ready for teams and agencies to buy off the shelf and adopt. Devices have been and will continue to be developed but the use of these devices is dependent on the creativity of teams, parents, guardians, people served, and technology professionals.
• Technology may be the change agent that may redefine the problems we face. If a person with cognitive disabilities can now use public transportation with the assistance of a cell phone then social connections are more likely but now the problem is no longer how to make the connections but what connections are safe, appropriate, or of choice.

RERC-ACT recommends the participative model as the best approach in determining the best combination of technology, participants, and environments. The participative model includes interviews, on-site observations, re-evaluation, and continued problem solving and re-assessment. Rodney Cole, Coleman Institute Consultant (nd), recommends that remote support start small, expand incrementally, adapt gradually, change core procedures, assess needs, weigh costs vs. benefits and risks, and plan and evaluate. This cycle will be ongoing as the needs of the individual change and as technology changes.

Remote support or monitoring via technology may require a change in thinking by agencies and person-centered team members. A paradigm is defined as a thought pattern in a discipline such as parenting, education, or medicine. Services to people with disabilities have undergone several shifts in thought since the 1950s. We made the shift from totally segregated services to inclusive opportunities in the community. Many leaders, researchers, and futurists in the field of disabilities see the need for another shift for service delivery to individuals with disabilities and their families. The need for this shift is evident in the escalating numbers of individuals
who will require long term care and the dwindling numbers in the population who now fill the role of caregivers. The aging population, returning veterans, and healthcare trends predict the need for more care to be given outside of congregate settings. This situation demands that solutions be sought to provide more efficient models of residential and vocational supports for people with developmental disabilities.

With remote monitoring it is possible to record and expose details of a person’s life from routine events to highly personal information. Sensors and cameras can detect how much a person has tossed and turned in bed, how much time they spent in the bathroom, or who and how long a visitor stayed. A ‘picture’ can develop of a person’s daily life. This data is collected, used, and stored to monitor, develop person-centered plans and make changes in services. The rational is generally to reduce risk of harm, provide security, and monitor health. This provides reassurance to family, friends, and providers that quality of life is maintained. But...is the right to privacy being upheld? Privacy not only in one’s living space but the data collected and stored that is personal and health related is at stake.

When the right to privacy intersects with safety, independent living and working opportunities, and health maintenance, the issue becomes more complex. Privacy issues are complicated. For instance:

A person with mobility challenges is monitored in their home by sensors that check for signs that they have fallen or not completed other personal hygiene tasks. It also monitors use of the bathroom and bed. This information is sent via a wireless network to the guardian and a monitoring agency. The agency only shares this information with the guardian and people who need to know internally.

In the previous example, the guardian and agency are monitoring the person’s activities for safety and health reasons. What is ethically troubling about ensuring these outcomes in a person’s life? Questions of how the information will be used, where the data will be stored, who might have access to the data, security of data, and the person’s ability and option to turn off the information flow, are all aspects the team needs to consider.

In any case of monitoring or supporting people with disabilities, either on site or remotely, privacy will be tenuous. The question to ask is, “To what degree can a reasonable level of privacy be maintained?” Issues that should be raised both on the individual level and on the agency level should be:

- Who has access to data and how will it be used?
- How will privacy, confidentiality and security of information be assured?
- Can the user control the monitoring system?
- How is the privacy of others protected?
• What constitutes informed consent particularly with users that do not have an understanding of the technology?
• Autonomy vs. dependence. Does remote monitoring foster autonomy and independence or does it create more dependence on the technology?
• Does the capability to “watch” a person open the door for more paternalistic monitoring, monitoring that really isn’t necessary? Are the strengths of the person being considered?
• Does it improve overall care or does the monitoring method create less trust, compassion, or empathy? Does the removal of on-site staff create a less personal relationship between the agency and the person served?

Can anyone expect complete privacy when they are dependent on others for personal care, for supervision, for assistance in making choices and decisions? The overall question should be what can be used as tools in this person’s life to help them meet their goals? What do they define as quality in their life and how can technology and other tools be used to help them achieve quality?

It is important to remember, ethical issues posed by assistive technology or any new technology is not really that different from those posed by any new invention or social change. These issues are part of the discussion in new medical procedures such as cloning. It should be remembered, there are many things that may drive the need for new technological solutions; but technology is just a tool that can help achieve certain goals. Like any tool it must be used properly – we cannot avoid the tool or blame the tool. How we use the tool is what counts.
Feedback Exercise V

1. List three ways a PDA could provide support for a person who is learning to make pizzas at a pizza shop.

2. List two uses a cell phone with a camera capable of still and video photography could have for a person learning to use the public transportation system.

3. Traditional staff support in vocational and residential settings:
   a. Involves direct support professionals being present to __________ and give assistance when needed.
   b. Alert the person and prevent ______________.
   c. Tends to __________ decision making and problem-solving because staff __________ before giving the person a chance to figure it out

4. An example of a daily schedule support is:
   a. recorded prompts on a PDA that tell a person what to do at a certain point in their routine.
   b. A monitor that can tell when a person opens the refrigerator.
   c. A webcam in the living room.

5. True False It is difficult for a person to be truly independent with 24-hour on-site staff support.

6. What are some privacy issues related to remote monitoring?

7. What are some privacy issues associated with traditional on-site staff support?

8. List some additional considerations during the decision making process about using assistive technology to monitor someone remotely.

9. True False There are few applications where technology or remote support would be beneficial for people with the most significant disabilities.
LESSON VI: DEVELOPING A SUMMARY FOR THE TEAM

OBJECTIVES

After completing this lesson, staff members will be able to:

- Explain how a summary for a comprehensive assessment is prepared.
- List the team members' responsibilities in the assessment process.
- Discuss assessment findings with the participant and support them in preparing a summary for the meeting.

INTRODUCTION

Before preparing the summary, meet with the person and share what was learned during the assessment process. Explain the assessment results in a manner that he or she understands. Use pictures or graphics to help clarify the information. Use words that match their level of understanding. Help them identify how they want the information shared. If there is information that they don’t want shared in the meeting, find a way to share information privately with the team members that need to know. Check with the person to verify that the assessment results are accurate and that they answer the critical questions the team will need to support them in developing a plan that will help them achieve their goals. It is important that this meeting take place at least a week or two before the meeting in case there is a need to reevaluate the findings or follow up with additional assessments.

PREPARING A SUMMARY

The amount of information generated in comprehensive assessments can be overwhelming. If not prioritized for the team, the sheer volume can actually slow down the work of the team. To assist with this process, each evaluator is asked to develop a summary for the team.

The individual may need staff support to prepare a summary of the results of his or her self-assessment. If necessary, a direct support professional or family member who knows the person well may speak for him or her at the planning meeting. However, it is best to find a way for the individual to share as much information as possible. With current technology, there are many creative ways to assist the person to tell his/her story. Using alternative communication methods or visual representations such as a scrapbook, posters, video, power point presentation, or photographs showing his current situation and his vision, the person will be able to share what is important to him or her. If there is a written summary, the individual should be the one to distribute it to everyone at the meeting.
The terminology in summaries should be easy to understand. All medical and other technical terms should be defined so staff and families can use the information. Jargon and abbreviations familiar to only people within the agency should not be used.

Terms used should be specific, observable and measurable. Describing an individual by saying, “she/he has good grooming skills” or “she hates her job” won't help the team establish priorities. It would be more helpful to the team to identify specific competencies, preferences, and support needs (i.e., fixes dinner without assistance; needs reminders to wait for change at the grocery store; complains of back pain after work; initiates interactions with coworkers during breaks).

Each summary concludes with recommendations. The summary should prioritize those strengths and support needs which will have the greatest impact on the person’s progress towards his/her goals. Recommendations should be functional or relevant to the individual’s life situation and desired future. Summaries should suggest ways to enable the individual to build on strengths and expressed interests resulting in a plan that stresses the growth of the individual. Plans built around weaknesses indicate only what the person cannot do and will limit the individual. For example: How could we build on the individual's ability to grasp objects and preference to spend much of the day walking around? Could he or she push a delivery cart, walk dogs, vacuum, play croquet, or water flowers?

Also include a discussion of environmental variables that impact the individual's skill performance such lighting, noise, room temperature, time of day, and number of people present. Indicate ways the setting can help ensure the individual will be successful. What physical adaptations lead to greater independence? What types of prompts or help and staff approaches are effective with this person? Include preferences (likes and dislikes) that will aid in daily interaction. What issues regarding reinforcement are important for the team to know?

Read the summary over as if you were a parent, brother or sister of the individual who has been assessed. What sort of picture does the report paint? While the report should be an accurate reflection of skills and support needs, it should have a positive tone, reflect plans for the future, and opportunities for growth that are age appropriate and value-based. It is not respectful to paint a picture of a person that is an exaggeration of the person’s abilities.

**RESPONSIBILITIES OF THE TEAM**

Teams have expectations for their members. Person-centered planning team members are responsible to complete assessments by the deadlines assigned by the plan coordinator. In some agencies, team members share summaries with each other prior to the meeting. This allows each team member to not only think about the individual from his or her area of expertise, but carefully consider information from the other team members as well.
**Example:** A vocational assessment may indicate that the person would be well suited for a janitorial job, while the residential assessment may indicate that the individual refuses all cleaning tasks and prefers laundry chores. The occupational therapist may recommend that the person only stand for short periods of time. These conflicting recommendations will need to be reconciled before setting goals. When teams have information from other assessments prior to the meeting, they can start to think about recommendations to share.

Team members are responsible for interpreting their assessment findings and presenting recommendations. The team meeting provides an opportunity for communication and planning among the individual, their family if appropriate, and direct support and other professionals.

We need to remember that the assessment process doesn't end when the reports are given at the meeting. The assessment process is ongoing. The diagram below illustrates the interconnectedness of assessing, developing the person-centered plan, implementing the plan, and evaluating the plan. Throughout the process, we are continuing to listen and learn.

When the goals and objectives are implemented, direct support professionals collect data. Every time we record data, we are assessing. This data should be tabulated and forwarded to the plan coordinator at least monthly. Direct support professionals are encouraged to comment on the data. If the person is making progress, why has the progress occurred? If there is lack of progress, what might be the problem (i.e. not enough trials, reinforcement not strong enough,
inconsistent implementation, prompt level not appropriate, task analysis too complex, need for staff training, individual is not interested in activity, medical problem, change in staff, problems with family, etc.?)?

The individual plan coordinator is responsible to observe implementation of each program monthly on site, to review the data, comparing it from month to month and make recommendations for revisions. Direct support professionals are responsible for asking for help if they don’t understand parts of the plan or if they are having trouble implementing the plan or recording the data.

In addition, the need to assess individuals may arise at times during the year other than in preparation for the annual team meeting. It may become necessary to start collecting data based on changing needs of the individual. (i.e., behavioral incident reports, health changes, new work tasks, changing preferences of the individual). It is critical that team decisions be made objectively based on data and preferences of the individual. Direct support professionals work with the plan coordinator to develop specialized assessments. Rarely does a problem develop overnight. Direct support professionals alert to changes in the status and preferences of the individuals they support will begin to track changes as soon as they are noted.

Most of us experience some twists and turns on our way to goal achievement. Maybe the job we took didn’t quite meet our expectations or the neighbors in our apartment building were too noisy. We tolerate our dissatisfaction for a time, but eventually decide we need a change. The same is true for people with disabilities who are supported in planning their goals. The current plan is our best guess at the time. As the person learns from the choices he or she makes, preferences and hopes for the future may change. The plan is simply the organization of the information that we have at the time. New information may require revising the plan.

**Plan for Turn-Over:** What would you do if the quality of your life depended on how familiar people were with your dreams, plans and goals and how actively and consistently they supported you to succeed in achieving those goals? Now suppose that person who knows you well and a new supervisor start working in the home or apartment where you live. Suppose you don’t have the words to describe what your goal is and how all the little things throughout the day connect to that goal? You would have to start over with each new “team” that comes into your life. What if reading the plan doesn’t tell someone how far you have come, what worked and what didn’t work? Video records of your progress can help to convey what is important.

**CLOSING THOUGHTS**

There have been great strides made since the days of custodial, institutional practices. Today, individuals with developmental disabilities are extended rightful opportunities to grow, to develop, and to become increasingly independent. Regardless of exact assessment instruments or techniques used, the intent should be to identify personal preferences, strengths and adaptations that enhance the inclusive opportunities and support the individual in attaining personal goals.
Feedback Exercise VI

1. What are some important factors to keep in mind when writing a summary?

2. What should the assessment summary suggest?

3. What are the responsibilities of the team?

4. True False The assessment process is finished at the end of the team meeting.

Matching

5. _____ Direct Support Professionals a. Prepare assessment summaries, share with other team members, and read assessment summaries before the meeting

6. _____ Individual Plan Coordinator (QMRP) b. Ask for help if they have trouble implementing the plan, collect data, provide comments to explain data when necessary

7. _____ All Team Members c. Observe implementation of the plan, review the data, compare it from month to month, and make recommendations for revisions.
Answer Key

Answer Key Feedback Exercise I

1. The process of collecting and interpreting information to plan individualized supports.

2. In person-centered approaches, the major reason for performing assessments is to provide information. The data is used for planning individualized supports.

3. Today, the emphasis is upon discovering the capacity, the presence of or potential to develop skills and abilities in people.

4. a. What is important to the individual?
   b. What new skills and competencies would enhance the quality of life?
   c. How can relationships of all kinds be fostered?

5. In the Developmental Model, you are assessing individuals to determine their performance in the development sequences in specific domains and comparing the person’s current skills to the skills of people of the same age without disabilities.

6. The Habilitation Model is focused upon teaching those skills which are relevant to a person's life. Like the Developmental Model, it is based on readiness.

7. With this model, skill development is not considered to be the goal of services, but the result. Options for living, working, and recreating are not determined by the skills and competencies possessed by the person, but by the type and amount of support needed.

Four basic parts:
1. Community Integration: Individuals choose their own church, doctor, clubs, etc.
2. Opportunities for Participation: At the heart of this model is the belief that all people, regardless of the extent of disability, are capable of participation when appropriate supports are provided.
3. Formation of Meaningful Relationships: Quality of life is found in the varied relationships one develops.
4. Personal Outcomes: Choice, personal preferences, and self-determination are recognized as the foundation of quality of life.

8. Clearly defining the general direction and desired outcomes helps the team individualize supports in the plan.

9. A functional assessment is person-centered. It focuses on things most important to the person, including personal goals and abilities. Everything assessed should be assessed for a reason specific to the person.
10. a. General
   b. futuristic
   c. individual's
   d. before/prior to
   e. direction
   f. first
   g. deficits

11. support

12. family, friends, community experts related to the person’s decision.

13. opportunity, risk, safety

14. Answers should include these approaches for dealing with what may be unrealistic choices:
   - Provide information and/or experience that will allow the person to make a more realistic goal
   - Keep asking and listening to what lies beneath the surface to find out what is really important to the person
   - Invite people from law enforcement or the fire department to help the team identify a more realistic goal

Answer Key Feedback Exercise II

1. a. Freedom of Speech
   b. Association
   c. Marry, procreate and raise children
   d. Vote
   e. Contract and the right to own and dispose of property
     - Equal protection and due process of law
     - Equal employment opportunity
     - Services provided in the least restrictive setting

2. The major benefit or protection provided by Section 504 of the 1973 Rehabilitation Act is **equal opportunity** for an appropriate education, for employment, health care, and so forth.

3. ADA gives civil rights protection to individuals with disabilities in private sector employment, all public services, public accommodations, transportation, and telecommunications.

4. Employers may not refuse to hire or promote a person with a disability because of the person’s disability, if he or she is qualified to perform the job. Employers’ must make reasonable accommodations.
5. ADA requires that new vehicles bought by public and private transit entities be accessible to people with disabilities. Para-transit services for people with disabilities who cannot use the mainline system are required unless providing such service would result in an undue financial burden.

6. State and local governments may not discriminate against qualified individuals with disabilities. All government facilities, services, and communications must be accessible.

7. Segregated settings can only be chosen when they are necessary to meet the service needs of the individual. In other words, any major goal which involves a segregated setting would be acceptable only if the team shows that it is the least restrictive alternative for meeting the service needs of the person.

8. a. Individuals and Guardian Preferred: Involving both the person and his or her guardian (if appropriate). Important for establishing goals. Participation in decisions that affect an individual is a basic right that should be extended to all.

   b. Increasing Environments and Social Contacts: People with disabilities typically experience fewer environments than their same age peers who do not have disabilities. Expanding the number of different places a person goes each day, week and year and increase opportunities to connect with people who do not have disabilities.

   c. Functionality and Continued Practice: Will the skill be needed in the places and activities the person selected. If the person themselves cannot do the task, would someone else need to do it for them? Is it a required task for their desired lifestyle? The team also ensures that the person will have opportunities to practice this skill.

   d. Chronological Age Appropriateness: When a team is considering goals and objectives, teaching skills that will facilitate integration of the individual with his or her age group must be included into the plan. Keep these factors in mind:
   - space and settings
   - program scheduling
   - performance criteria

   e. Physical Enhancement: When planning goals and objectives for this person, the team must consider objectives not only to teach skills, but also to enhance the person's physical well being.

   f. Competence Enhancement: Whether one is welcomed to, tolerated in, or excluded from vital community settings will be greatly influenced by the degree of competence one has to offer the people in those settings. Competence is - a skill or attribute that someone has that not everyone has that is wanted and needed by others. It is directly tied to social values and social perceptions.

   g. Status Enhancement: Acquiring a new competence, especially one that is widely valued.
h. Acquisition Probability: Refers to the relative likelihood that a skill will be acquired, if reasonable resources are devoted to its instruction.

9. b, e, f

10. c, d, e

11. What is important TO a person includes what people say with their words and their behavior (dreams), interest, quality of life, etc.). What is important FOR people includes issues of health or safety; what others see as important and issues that are mandated to be covered in the plan. Service providers have responsibilities to funding sources, government regulators and accreditation standards in addition to their responsibilities to the person served.

12. live a meaningful life

13. competence

14. deviance

   b. Health and Safety: Sexuality, self-care (dressing, bathing, toileting, etc.), nutrition, privacy, self-medication, first aid, crime prevention.
   c. Relationships and Community Participation: Communication, contribution and initiation, recreation and leisure skills, social skills, relationship skills, use of public facilities including transportation, recognition of common community signs.
   d. Vocational and Functional Skills: Money management and budgeting, functional time concepts, shopping, home care, and employment skills.

16. Many answers are correct. See examples on page 25 - 26 of this manual

**Answer Key Feedback Exercise III**

1. a. assessment of the person’s ability to exercise their rights, especially those rights that are most important to them.
   b. personal preference assessments
   c. existing a potential natural supports
   d. the person’s satisfaction with the extent and frequency of social contacts
   e. the person’s ability to report abuse, neglect, and exploitation and needs related to past incidents of abuse, neglect, mistreatment or exploitation.
   f. the person’s ability to self-administer medication and treatments.
g. the person’s understanding of his or her health status, medication conditions, and health care preferences.

h. the person’s ability to be safe and feelings about safety

2. Formal assessments are conducted by professionals who have received special training in giving specific tests and interpreting the results.
   • Tests of intellectual ability (learning aptitude)
   • Achievement tests
   • Measures of specific abilities (such as motor abilities, auditory discrimination, color discrimination, adaptive behavior, language abilities, and others)
   • Social adjustment or behavior rating scales/checklists

3. A screening is limited in scope and intensity. It is used to determine whether or not further evaluation/intervention is required.

4. See pages 32-36 for your answers.

5. Interviews: Conversations with a purpose. Can be expanded to take new paths and directions
   Questionnaires: Informal assessment technique with a fixed format that is structured to limited topics and provides a permanent product for reviewing and combining with other information.
   Inventories: Comprehensive listings. Can be quite individualized
   Observations: Observing the individual in natural environments. May use a variety of tools to organize the observation and record the information obtained.

6. open-ended

7. a. Observation checklist is a record of behaviors that have been observed in the person
   b. Running narrative (anecdotal records): Describes what a person is doing minute by minute during the observation period.
   c. ABC Record: A systematic observation of the behavior and its antecedents and consequences.

8. Validity refers to the extent the assessment measures what it claims to measure.

9. Reliability refers to the extent to which the assessment tool or strategy is consistent in what it is measuring.

10. D

11. a. directions
    b. objective
    c. accurate
12. a  
13. b  
14. c

**Answer Key Feedback Exercise IV**

1. a. **Interview the person and significant others in their lives.** Individuals with good communication skills and a range of experience can tell you about their personal goals. Family members and those who know the person well often have insights into the person's goals, as well. During the planning process, it is important to encourage these people to share their information.

   b. **Sample activities.** Sometimes the individual may not have enough information to make informed, realistic choices. It may be helpful for the person to try out some activities to get the information needed to make optimistic, but realistic, choices.

   c. **Observe the person.** Much can be learned about personal preferences by observing an individual participate in activities he or she selects.

   - **Observe or sample with inference.** When an individual does not communicate readily, clearly indicate preferences, or try activities without support, we may need to infer general preferences from our observation.

   - **Match to a person of the same age with no disability.** Although every person, regardless of disability or age, is different, and the strategy of matching to age needs to be used cautiously, a consideration for choice-making is, "What would a person of the same age without a disability want?" While one doesn't want to compare, looking at what is "typical" can foster inclusion into society.

2. Answers will vary but should include a combination of skill development and/or supports that didn’t require a change in the person’s behavior.

3. (Answer will vary)
   - Push door open
   - Obtain cart
   - Push cart up and down aisle
   - Select needed grocery items
   - Put fruit in plastic bags
   - Ask clerk for assistance (meat department, deli, bakery, etc.)
   - Obtain frozen food from pull open freezer section
   - Select open/shorter checkout line
   - Move cart forward as line progresses
   - Remove items from cart and place on conveyer belt
   - Pay cashier and receive change
   - Exit automatic door
   - Carry groceries/push cart to automobile
Place groceries in automobile
Return cart to supermarket

4. Answers will vary

5. The function of behavior refers to the purpose of the behavior. It states what needs to be accomplished. The form refers to the specific means you use to accomplish the function, without specifying how or exactly by whom. Behavioral form refers to the specific motor action. Examples should be different from those on pages 42-43 & 45.

6. function

7. a. individual does all cleaning : 
   b. individual and roommate share cleaning 
   c. staff and individual share cleaning 
   d. family assists 
   e. individual hires a "cleaning person"

Answer Key Feedback Exercise V

1. - prompts that are programmed to tell the person what equipment to get for the task.  
   - audible cues to remind a person to do a particular task.  
   - picture list of the skill sequence in a task along with verbal explanation of the task.  
   - picture list of steps in a task.

2. - the phone can be used to monitor the person’s location  
   - The phone can be used to take a picture of where a person is, in case they are lost  
   - The owner can call at certain time intervals to check in with a supervisor

3. a. prompt  
   b. mistake  
   c. diminish; intervene

4. C

5. True

6. Answers may vary but it should point to the possibility of privacy and the data that comes with remote monitoring being overused, misused, data not being protected and given to people who do not need to know, not allowing the person to determine what will be monitored, protecting the privacy of others, and giving the person some control over the monitoring. It should also include the statement that ensuring safety will always produce questions on privacy.
7. Answers will vary but many of the same issues from the previous question. Does the person have time to be alone and choice in the times that the staff are present? Will the staff members who provide supervision keep confidential what they observe that is unrelated to their reason for being there?

8. Answers will vary but it should include:
- Will the technology allow the person to do something they are not able to do now?
- Does it support participation in the least restrictive environment?
- Will remote monitoring decrease dependency on rote memory and/or complex organizational skills?
- Does the technology improve the overall care of the person?
- Does the technology foster autonomy and independence?
- Can the user control the monitoring system?
- Are the strengths of the person considered?

9. False

**Answer Key Feedback Exercise VI**

1. The evaluator needs to use terminology that can be understood by all. All medical and other technical terms should be defined so staff and families can understand. You should not use jargon peculiar to a particular field of study or familiar to only people within the agency.

2. Suggest how to enable the individual to build on strengths and expressed interests of the individual, resulting in a plan that stresses the growth of the individual.

   Also include the effects of environmental variables on individual skill performance.

3. Members of the team are responsible to complete the assessment well ahead of the meeting. They should prepare their summaries and submit to the plan coordinator prior to the meeting following deadlines established by the agency. Not only do they evaluate carefully the individual from his or her area of expertise but carefully consider information from the other team members as well.

4. False

5. b

6. c

7. a
References

Assessment of Individuals with Severe Handicaps: *An Applied Approach to Life.*


