

Basic Training Manual for
Direct Support Workers (DSW)
Supporting People in their Homes and
Communities



United Cerebral Palsy of Arkansas
Administration Offices
9720 N. Rodney Parham Rd.
Little Rock, AR 72227

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Introduction

“What you do makes a difference, and you have to decide what kind of a difference you want to make.”

- Jane Goodall

Working with individuals with disabilities is often described as “rewarding.” Certainly approaching it with the right mindset and skill set will make it rewarding not only for you, as a direct support worker, but also for the individuals with disabilities with whom you interact.

The purpose of this manual is to encourage you to think about and interact with individuals with disabilities in mutually positive ways. In order to be most successful, it is important to not only read the information in this manual, but also to discuss it with your supervisor and to ask questions as needed. Once you have learned the material, passed the test with a score of 80% or better and received your certificate of completion, you have taken the first step in being a direct support worker. However, UCP of Arkansas staff hopes this is just the beginning of your learning process in how to be a great direct support worker. Please take every opportunity to learn more, not only from “professionals,” but most especially from the individuals you support.

Thanks

This manual has been modeled after the Orientation Manual for Direct Support Professionals (DSP) developed by the Virginia Office of Developmental Services of the Department of Behavioral Health and Developmental Services.

“Always remember, you have within you the strength, the patience, and the passion to reach for the stars to change the world.”

- Harriet Tubman

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Section I: The Values that Support Life in the Community

The goal of this chapter is to familiarize you with the mission, vision, and values that should guide you in your support of persons with intellectual and other developmental disabilities as an employee of UCP of Arkansas.

Introduction:

The mission of United Cerebral Palsy of Arkansas is to advance the independence, productivity, and full citizenship of people with disabilities.

Arkansas' Principles of Person-Centered Practices

We see Arkansas where individuals of all ages and abilities have the support they need to enjoy the rights of life, liberty, and the pursuit of happiness and the opportunity to have a good life.

Having a good life means different things to different people. It includes joy and happiness, health and safety, hopes, meaningful activities, intimate relationships with family and friends, having a home, transportation, work, money (bank account), and opportunities to contribute to family and community.

We believe that a good life is best led by the voice of the individual and by following these person – centered principles.

Principle 1: Listening

Individuals are listened to and their choices are respected.

Principle 2: Community

Relationships with families and friends and involvement in the community are supported.

Principle 3: Self- Direction

Individuals have informed choices and control over decisions that affect them.

Principle 4: Talents and Gifts

Individuals have opportunities to use and share their gifts and talents

Principle 5: Responsibility

There is shared responsibility for support and choices

Mission Vision Values

UCP of Arkansas was founded by a group of parents with children with disabilities in 1957 and we still refer to those that receive and provide services as family.

The UCP family has five core values:

- 1) Customer Driven
- 2) Compassionate
- 3) Committed
- 4) Innovative
- 5) Quality Conscious

These core values help us in meeting our mission “To advance the independence, productivity, and full citizenship of people with disabilities.” For people with disabilities, life should be without limits.

UCP is achieving its mission through the Home and Community –Based (HCB) Waiver. HCB Waivers allow Medicaid funding for supports to people in their communities instead of only in an institution (such as a human development center or nursing home).

The support to individuals in the Home and Community Based Waiver is provided by direct support workers (DSWs). UCP expects the support provided to be person-centered and to lead to a good life for the individuals. Characteristics of DSWs that are valued by UCP are:

- Considerate of the wants & needs of the individual
- Realizes everyone has talents
- Asks the individual and others who know him/her well for input
- Supports a person’s self-expression, self-worth, self-reliance & decision making

- Is flexible
- Listens to all people
- Is respectful of all people
- Responds quickly to the individual’s requests
- Pursues partnerships and teamwork
- Communicates clearly, openly and honestly
- Thinks outside of the box for new ways of doing things or solving problems
- Makes decisions and resolves issues at the root
- Strives for win-win solutions
- Works to ensure that people are healthy, safe and valued by others
- Encourages and supports others to be successful
- Recognizes and celebrates successes
- Uses person-centered practices

- Delivers on promises
- Values and takes care of oneself and one's co-workers
- Follows the individual's plan as decided upon by the team

How many of these characteristics do you think you have?

REMEMBER: People with disabilities are valuable and contributing members of the community. Everyone can experience a good life in the community. People using supports should have control over how they live their lives. People who provide supports should be focused on promoting rich and fulfilling lives in the community.

This chapter of the manual focuses on the values that will guide you in your support of individuals with disabilities. The concepts below are built on person-centered thinking and the work of Michael Smull, and others from The Learning Community, whose focus of research has been moving individuals with disabilities from a "service life" to a "community life."¹

The Value of PERSON- CENTERED THINKING

"I am listened to." "I have a voice." "I listen to others."

Person- centered thinking is a set of core skills that the paid DSW uses to see beyond a disability to support an individual in obtaining a life that he or she would like. Core person-centered thinking skills for DSWs are the ability to:

- Understand the importance of being listened to, even when individuals communicate in non-traditional ways.
- Understand the importance of and guide others in having positive control over their lives.
- Understand the significance of an individual's own daily rituals and routines
- Discover what is important to an individual's health, safety and value in the community.
- Respectfully address significant issues of health and safety, while supporting the individual's choice and control over his or her life.
- Define the core roles and responsibilities of a DSW
- Pay attention and record new things you learn about the individual and his or her preferences.
- Support the individual's dreams, relationships and community connections.
- Recognize that the individual's dreams and preferences are ever changing and that being person-centered is an on-going journey; not a destination.

UCP believes it is more important to be respectful than to always try and be right.

The Value of PERSEON-CENTERED PLANNING

The core of person-centered service planning (PCSP) is to empower the individual receiving paid supports to make decisions and choices that direct and shape his or her own life. The goal is to move from a needs-based system to a support-based approach. The support-based approach helps to develop personal goals and a life that is meaningful to the person receiving supports, while still addressing the individual's health and safety. Person-centered planning practices always include participation by the individual and/or his/her representative/guardian. This leads to the achievement of goals that are meaningful to that individual.

Person-centered planning approaches vary, but according to O'Brien And Lovett in *Finding a Way Toward Every Day Lives* (1996), they are all characterized by the following five elements:

- 1) The individual is at the focus of planning and those who love the individual are the primary authorities on the individual's life direction. The essential questions are, "Who is this person?" and "What community opportunities will enable this person to pursue his or her interests in a meaningful way?"
- 2) Person-centered planning aims to change common patterns of community life. It stimulates community members in assisting the individual to define and work toward a desirable future. It helps create positive community roles for people with disabilities.
- 3) Person-centered planning requires learning through experiences of everyone working and thinking together and strives to eliminate separating people from the community, or controlling someone else's life.
- 4) Honest person-centered planning comes from respectfully treating all individuals as contributing members of society.

Consider for a moment: It is Saturday and you are planning on sleeping late after a really hard week at work. Just as you start a really good dream, a lady comes into your bedroom, throws open your curtains, and says, "Good morning, Sam! How are you today?" You glance at the clock, 7am, and then try to roll over thinking it is just a nightmare, but the lady comes over to your bed and pulls the covers off. "Are you ready to get up Sam? Breakfast is hot and you need to eat." You wonder where you are, but then it hits you. You were in an accident that left you without the use of your arms or legs, without your voice. Your mind is as it was before your wreck. Without supports at home, you were forced to live in a nursing home. You are now told when you would get up, go to bed, what to wear, what you will do with your day, whom you spend time with, where you go. They feed you food you hate, and don't seem to notice or care that you're trying to tell them that. If you spit out the food and refuse to eat, you are told to stop misbehaving. Is this the kind of life you want to lead? Do you understand the importance of person-centered planning?

- 5) Assisting individuals to define and pursue a desirable future requires the DSW to focus on the goals of the individual, make a commitment to help the individual, and have the determination and courage to help break down barriers.

Person-centered planning promotes the value that the wishes of the individual are to be honored, based on what he or she considers important- “what’s **important to me.**” These wishes might be stated verbally, communicated in non-traditional ways (such as through a person’s behavior) or identified by other people who know the individual well.

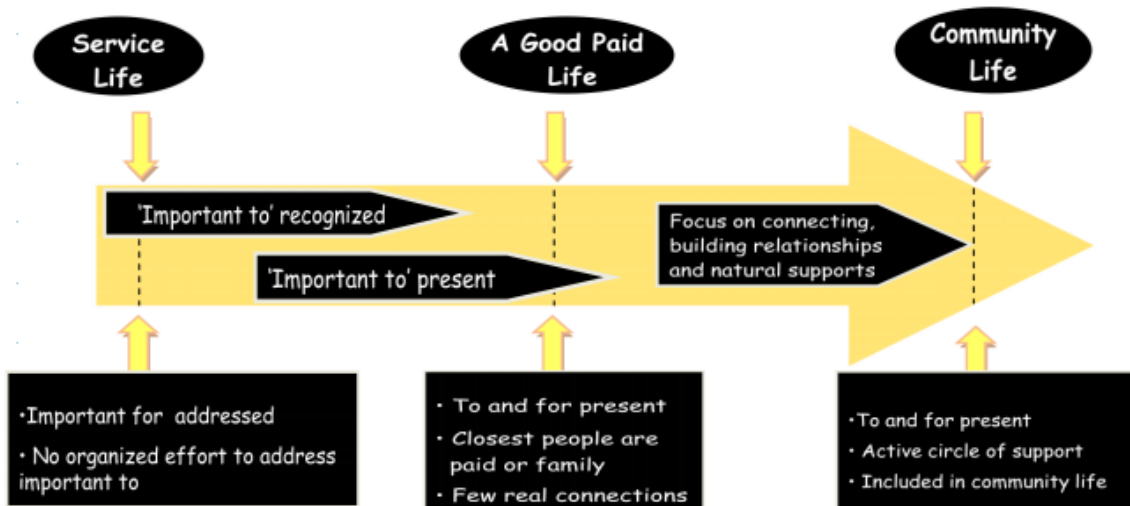
It is important that individuals know their wishes are not just written in a plan, but are “heard” and honored through positive acceptance, regular encouragement and daily actions. DSWs must be creative to ensure that individuals are “heard” by those who support them, and that their choices are respected and followed.

Person-centered planning ensures an Individual’s wishes (“important to”) are respectfully balanced with his or her need for support to stay healthy, safe and a valued member of the community (“important for”).

We can accomplish anything if we operate on the basis of “mutual purpose and mutual respect.”

From the standpoint of individuals you support:

1. Focus less on the records and what others have said about us. Get to know us as people.
2. Listen and hear our “Voice.” We’ve got a lot to say.
3. Treat us like you want to be treated.
4. Ask us how we feel about things.
5. Make it your goal to help us accomplish ours.
6. Take time to explain things. Some of us take longer to understand what you’re saying.
7. Put yourself in our shoes and walk our walk.
8. Always tell us the truth.
9. Believe in us and our dreams
10. Be good to yourself too. We need you to be energized and to enjoy what you do.



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The Value of Dignity of Risk

The concept of *dignity of risk* is the right of an individual to make an informed choice to engage in experiences meaningful to him or her, which are necessary for personal growth and development. Normal living often includes risks. Dignity of risk allows people to lead normal lives. Overprotection of people with disabilities keeps them from many life situations that they have the right to experience, and it may prevent meaningful connections and fulfillment of their hopes and dreams.

Rather than protecting individuals with disabilities from disappointments and sorrows, which are natural parts of life, support individuals to make informed decisions. This enables them to experience the possibility of success and the natural risk of possible failure. Occasionally, as support staff, we believe we know the outcome for individuals who “dream too big.” Dignity of risk demands we try to help people investigate and reach for their dreams, while keeping health and safety at the forefront of our services.

Dignity of Risk: What's your role and what does it look like?

- Support individuals to choose attractive/fashionable, well fitting clothing that is appropriate to the person's age and social setting.

You are shopping with Joseph, who is drawn to a particular t-shirt. You know that if he buys it, it will upset others. What do you do? First, explain what others may think or do if he wears it in public. Next, show him 2 or 3 shirts in the same color or style that are not offensive and explain why these are more appropriate. Ask him if he would rather pick one of those or another one on the rack and compliment wise choices. **BUT** the bottom line is, once he's informed (understands the consequences), if Joseph still wants to buy the shirt, he can buy the shirt. It is his right to buy and wear the shirt of his choice.

- Support people *individually* (rather than in groups) when going to a community/neighborhood event.
- Include the individual in conversation.
- Be clear about your role: what is your core responsibility? How will you use creativity and judgment? What is not your paid responsibility? This means removing your own personal values and beliefs about the individuals' situations and choices.
- Support a person to get a job or set up a date.

In her meeting, Sandra announced she'd love to be an airplane pilot. She has poor eyesight and cannot read. How do you help support her finding a job? Maybe she'd like to work at an airport. She could learn more about what airplane pilots do in their jobs. You may need to role play the conversations she might have at the airport when looking for a job. Talk about job possibilities before going to the airport. It might be a good idea to talk with the airport staff prior to going with Sandra to prepare them for the interviews. Your role is to create win-win situations.

The Value of COMMUNITY CONNECTIONS

Community is a group of people that come together for a common reason. An important characteristic of the community is the different types of people who live in the community. People within a community can be very different from one another. Being part of a neighborhood brings people together, and people will learn that it is okay to be different. Positive and regular interactions bring the community together.

Just because you *live* in the community does not mean you are a part *of* the community. Are you part of a community if you never talk to your neighbor or participate in any of the community activities? Sometimes people in the community are afraid of differences and change. We cannot change who we are or change those individuals we support. It is the responsibility of the DSW to

provide the supports an individual needs to succeed in the community, rather than expect the person to change in order to become part of the community.

The DSW should help the individual learn how to be an accepted member of the community. Without focused effort, people with disabilities risk being *separated* from everyday settings by living in separate facilities, having separate activities and schedules. Going out to ordinary places is the first step. As a DSW, you must follow through to ensure that the individuals you support achieve ordinary community lives by helping each one get involved in activities that he or she wants to do and finds valuable.

There are three ways to be part of your community – presence, participation and connection.

Community presence is being known, accepted and considered part of the community by members that live in that community.

“I have friends and family I see often.”

“I am part of my community.”

“I have found groups, organizations and social activities that interest me.”

Community participation is shopping at the local stores and getting to know other members of the community by name and holding conversations about their lives.

Community connection is having a job in the community or volunteering with a local civic organization where you share mutual interests with others and have personal conversations. A DSW’s goal should be to support people to be connected to their community.

Community Connections: What's your role?

- Step back and support the individual to participate to the best of his or her ability.
- Do not assume that the person needs your help.
- Help the individual locate and attend community events and activities that best reflect his/her interests and the best match what others of his/her age group seek out.
- Find the gatekeeper of the group – the one who will introduce the individual to members of the group.
- Avoid “special programs” or going out in large groups that only bring attention to someone’s disability. This is not how most people participate in the community.
- Go *into* the bank or the restaurant instead of using drive-through windows.
- Encourage individuals to make their own purchases rather than purchasing items for them.

The Value of NATURAL SUPPORTS

The term natural supports refers to the resources that are already present and available to all persons in community environments. This includes family, friends, co-workers and neighbors, members of clubs or civic groups and local merchants.

Imagine for a minute what it would be like to wake up every morning knowing that the only people you will interact with all day will be those paid to be with you.

This is what natural supports are all about. It is the responsibility of the DSW to find and set up flexible ways of supporting the individual in community settings so he/she can develop natural relationships. The goal is to move away from dependence on paid supports and move towards supports from friends and family or other people who are genuinely interested in the individual. Creative strategies must be found to support and maintain these relationships. These may include introducing the person to the organizer of the group, frequenting the same places and including the person in conversation. Any routine, service or activity that an individual needs, wants or enjoys should be arranged through the same resources as those used by persons without disabilities (such as the family doctor, dentist, barber, YMCA for recreation, community pool for swimming).

Natural supports: What's your role?

- Support the individual to meet his or her neighbors. Sponsor a block party at the individuals home or help the individual bake cookies to take to a sick neighbor.
- Support the individual to join a synagogue, mosque or church of his/her choice. Further, support him or her in participating, volunteering and attending activities within the faith community.
- Involve the individual in routine activities that pertain to his or her life, such as shopping for groceries or going to the bank.
- Locate a club or civic group of interest to the individual. Further, support him or her in participating, volunteering and attending activities sponsored by the organization.
- Find a volunteer to accompany the individual on a specific activity in which they are both interested. Consider that the individual may have an interest he or she has never had a chance to put into action, such as going to baseball games, hiking, listening to music, taking a cooking class, walking around the neighborhood and/or taking a drive in the country.

The Value of WORK

Our culture values work. It is expected that adults will work to earn money to support themselves. This value is true for people with disabilities also. Additionally, we recognize that working in the community provides so much more than just a paycheck. Numerous studies have shown that people with disabilities who are working in the community report other non-monetary benefits to working.

- Working people have higher levels of self efficacy: they have higher expectations of what they can accomplish, and this spreads to other areas of their lives.
- Working people feel more connected to the greater community. People report having a higher number of friendships with people without disabilities through work.
- Working people report having better health and a sense of well-being than non-working people.
- Working people report having meaning in their lives. Being employed makes people feel that they are engaged in meaningful activities; there is a purpose to their lives.
- Working people make money. Most people with intellectual and developmental disabilities live in or near poverty. Income from paying jobs helps supplement their resources and improves the quality of the lives they can live.

Any vocational activity is a good thing, as long as it is time-limited and has as the expected outcome an integrated, community job. An integrated, community job is defined as work providing a minimum or commensurate wage and related benefits in a typical work setting where the employee with a disability has the opportunity to interact with co-workers without disabilities and has an opportunity for career advancement.

Employment First

Employment first is a value that means offering the option of integrated, community employment as the first choice of day activity to people entering services. If the person has no reference for choosing work (has no work experience), the person should have an opportunity to do a work assessment to see what it is like. Individuals who are not currently working should have the opportunity to choose work at least every year at their annual planning meeting.

Work: What's your role?

- Support the person in believing that he/she can work in the community if desired.
- Talk to the person about what he/she wants to do for a job. When out in the community talk about the tasks people are doing in their jobs. Ask if the individual would like to do any of those tasks as a job.
- Help the employment team develop ways to apply a person's strengths to workplace requirements and think of supports needed to help the person work.
- Allow a person to enter into a new situation, provide the supports the individuals needs, but no more than are necessary. Help build the person's networks and natural support on the job.
- Believe in the person. Believe in his or her dreams, and be supportive if things don't go right the first time.

People should work as many hours a week as they are able and willing.

The Value of ALTERNA



With the focus on a community life, there is no longer a need for specialized programs that restrict or exclude individuals from an ordinary or extraordinary life. Receiving paid supports does not mean the individual with disabilities has to participate in specialized programs or groups of people with similar disabilities, with little to no access to ordinary activities.

Alternatives to restrictive programming means supporting individuals in natural settings, with families and friends, by providing flexible supports that work well for that person. People with disabilities, should live in comfortable homes in safe neighborhoods. They should have the choice to work a regular job or to engage in other typical activities that they and the community value.

Alternatives to restrictive programs: What's your role?

- Try to avoid “homelike facilities” in a business or isolated from other people. If considering buying a home where you like to live with a person with disabilities, look at nice neighborhoods which provide many opportunities for everyone to be a part of the community.
- Support the person to find a job with a plan for them to one day work independently or as independently as possible. Try to help the person find natural resources in the work place, like another employee who can provide reminders, support and encouragement. Instead of paid transportation, find someone with whom he/she can catch a ride to work. These supports are more natural.
- Find creative ways for people to participate in their home, work and community. If the individual can't do a particular thing, keep trying until you find something he or she can do. Remember, everyone has contributions to make to their community, it is up to us to find their talents.

If you don't have anything nice to say, don't say anything at all.

The Value of PERSONAL CHOICE AND DECISION-MAKING

Personal choice means making decisions about all the details of our lives. Each day, as soon as we awaken, we are engaged in making choices. We ask ourselves, “Should I hit the snooze button or get up?” “Should I call in or go to work?” “What should I wear?” We also make major decisions about who to live with and what sort of work we want to do. We are in control and it feels good to be empowered and able to make our own decisions. Everyone is entitled to make decisions about their life.

An important goal of all DSWs should be to provide individuals with opportunities to make both small, everyday choices in the here-and-now, as well as bigger, more important decisions for the future. This goal must drive the Person-Centered Service Plans that are developed (see Section III), the way provider agencies operate, the staffing patterns (what staff do and when they do it) and especially the daily actions of the DSWs. Choice should occur naturally and should be expected without unnecessary restrictions. Many individuals entered supportive services with little to no choice. It is the DSW’s responsibility to promote personal choice by noticing likes and dislikes and opinions as forms of choice.



Helping others who are less fortunate through no fault of their own is a blessing and an honor.

Methods of Helping People Learn to Make Choices

- When teaching someone with no prior experience with making choices, you need to start small, but teach the small steps throughout the individual's day. There are many chances to make choices during an individual's day.
- Start with offering choices when the person gets up. First offer a drink or washing up. Then offer coffee or another favorite drink. Further offer the choice to take a bath or shower.
- Ask what he or she would like to wear and give two or three options. If the person doesn't speak with words, you can ask him/her to look at or touch the preferred clothing.
- Once picking from two or three options is mastered, you can use color coded clothes hangers to foster choice without your support. You can teach him/her that all shirts and pants that match are on the same colored hangers. This also leads to teaching matching clothes when doing laundry and it helps to support the individual in hanging clothes on the proper colored hanger.
- This color coding can also be used to separate food into food groups, by using yellow containers for breads, blue for proteins, red for vegetables, and green for fruits. Teach individuals to eat healthfully by teaching how many foods need to come from each container for the day. The individuals can plan meals daily. This can also be done with pictures of foods. These pictures can be used in actual grocery shopping.
- When planning trips to restaurants, go by the restaurant in advance to get a copy of the menu. Teach the individual how to make choices before he/she goes into the social situation.
- If an individual is physically and verbally challenged, and cannot feed or dress himself, or verbally tell you what he wants, he can still make choices. Have him eye gaze at what he wants to wear or wants to eat, and confirm that choice by saying something like, "Oh, okay, you would like some eggs now." This reinforces the individual's communication while encouraging decision making.

Informed consent refers to one's ability to make a decision based on a clear understanding of the facts, results of the choice, and possible future consequences. Some individuals do not show the capacity for informed consent and need supports from family members, an authorized representative or a legal guardian. This is typically reserved for decisions or choices that might have an effect on the individual's health and safety. This does not mean that the day-to-day choices or expression of hopes and dreams should be restricted. DSWs are responsible for encouraging choice and consulting with alternate decision-makers when unsure.

Personal choice and decision making: What's your role?

- For an individual with limited or no verbal skills, DSWs can use eye movements, touch or adaptive tools to elicit personal choice in clothes, food, people, touch and activities.
- Develop a visual display of daily choices (with real photos). Regular use will encourage self direction by the individual you support.
- Find out what is important to the individual from his or her perspective and write down what you learn about the individual's likes and dislikes. Then share what you learn with others.
- Remember, in order for a person to have true choice, there must be more than one option.
- Rather than saying no to a perceived risky choice, work towards supporting the choice in a meaningful way and seeking help with making decisions from the individual's designated authorized representative or guardian if necessary.
- When you ask an individual what he or she would like for breakfast, offer choices, such as, "Would you like toast and cereal or yogurt and fruit?" Instead of saying, "It's Thursday, so we're having cereal."
- Help individuals to make choices in naturally occurring situations.

The Value of RESPECT

The term “**respect**” has many types of meanings, including a positive feeling towards another person or the person’s skills, opinions or other characteristics and the honoring of a person’s beliefs, ideas or culture. Respect requires seeing the individual as a person first.

Lack of exposure to people who are different from our custom or standards contributes to a lack of respect.

“I have choices.” “I am responsible for my choices.” “I am respected.”



All people, including those with disabilities, are thought of more positively when in a position to contribute to the community. People with disabilities can get the respect of others by being supported to perform useful and meaningful activities. As a DSW, respect for individuals you support can be achieved by first listening and developing an understanding of their culture, background, hopes and dreams, and then supporting each person to follow through on things that are important to him or her.

There is a tendency to have lowered expectation of individuals with disabilities. Low expectations limit individuals' opportunities to try new things and interfere with their achievements. It is your responsibility to move away from a focus on the limitations and turn towards a focus on talents and abilities. This enables the focus to shift to respect and empowerment.

It is important to remember that people with disabilities want and need the same things others do - love, security, the satisfaction of personal accomplishment, the opportunity to exercise control over their days, environment and experiences and to laugh and communicate with others. The way a person experiences these things is different for each, but the desire to have them is the same for everyone. Have high expectations for people with disabilities. Just like us, they want to do what they're capable of.

A TRUE STORY:

A therapist worked with a man for many years, before he finally got a new wheelchair. When demonstrating all the features of this chair to the direct support staff that worked with the man, the therapist heard the staff gasp. The staff told the therapist, “We didn’t know Sam could get out of his chair by himself or stand up just by holding onto the grab bar. We’ve been lifting him in and out of his chair for years. What’s your secret?”

The therapist looked at them and said, “I didn’t know any better, and I just asked Sam to get out of his chair by himself and stand by holding the bar. I expected him to do these things. I was there to protect him should he lose his balance, but I knew he could do these tasks for himself.”

Have HIGH EXPECTATIONS.

Respect: What’s your role?

- Always ask the person’s permission before you touch him/her. For example, if you are assisting a person to stand up from a seated position, ask, “May I help you?” Besides gaining permission to physically touch him/her, you may find that the individual is able to complete the action without any physical help from you.
- Avoid talking to others about things that could be embarrassing or personal for the individual. If information must be shared, do it in a private, respectful manner.
- Don’t talk about the individual you support in their presence; talk to them and encourage community members to do the same.
- When accompanying an individual to a medical appointment, encourage the individual to speak for him/herself. If the medical staff directs questions to you, defer to the individual whenever possible.
- Be aware of practices that are important to the individual and support those practices.

The Value of INDIVIDUAL RIGHTS



All people, no matter their ability, retain basic human rights. Like you, individuals with disabilities are entitled to enjoy the rights and freedoms to privacy, to have personal possessions, to marry, to exercise free speech, to live in neighborhoods, to complain, to vote, etc. It is also the right of the person to be free from abuse, neglect and not to have restrictions on his or her rights and freedoms.

As a DSW, you are considered a “mandated reporter,” and are required to report violations of individuals’ rights, including suspicion of abuse or neglect. Though policies vary, you are required to report to your agency’s designated employee and cannot be prohibited from reporting to Adult Protective Services directly.

Some individuals may have had a few of their legal rights limited through the appointment of a guardian, conservator or another legal process. This does not mean that the individual cannot make day-to-day choices and decisions or should have their dreams or plans go unheard. It is the DSW’s responsibility to seek guidance and help with decision making when appropriate and/or needed to preserve the health and safety of the individual.

As an employee of a community agency providing supports to individuals with intellectual and other developmental disabilities, it is your responsibility to be aware of these basic human rights, as well as any specific human rights policies followed by your agency. Ask your supervisor/agency representative to give you a copy and to explain your agency’s policy to you.

Individual Rights: What’s your role?

- You should carefully read the human rights policy of the agency for which you work. List any questions and discuss them with your supervisor.
- Immediately report suspected abuse, neglect or human rights violations according to your agency’s policy.
- Talk with your supervisor and family/representatives as needed regarding decisions that directly affect the health and safety of the individual.
- Work out acceptable risk with the individual and his or her family, authorized representative or legal guardian.

The Value of CONFIDENTIALITY

Confidentiality is a right each of us has to privacy and respect of information given to and shared among professionals about us. People generally expect that their medical records, financial records, psychological records, criminal records, driving records, etc. are going to be kept in a confidential manner. DSWs must remember to have this same respect for the private information about individuals whom they support. No one would like to think that his or her doctor or counselor openly discusses his or her diagnosis, illnesses or care plan at home or a party. While DSWs generally read and sign a confidentiality agreement related to employment, it is important to avoid sharing confidential information about the individuals being supported.

Confidentiality: What's your risk?

- When accompanying an individual to a doctor or dentist appointment, encourage him to speak for himself. If the doctor asks you questions, as if the individual is unable to speak for himself, look at the person to answer the question. This is a teachable moment for both the individual as well as the professional.
- When out in the community and seeing a friend, encourage the individual to introduce himself and don't identify him as your "client," "consumer" or "patient."
- When in a social situation in which your job is being discussed, don't give details about the individuals you support. Never mention names, diagnosis, family names or any other identifying facts.

A TRUE STORY:

During a CPR class, several people from three neighboring counties were in attendance. The class members were all volunteers for area rescue squads. The members were talking about different cases and jobs. The conversation turned to seizure disorders. One the rescue squad member started describing an individual's seizures in detail. He did not give the individual's name, but did state where the individual lived, told that the person had grand mal seizures after returning from home visits and shared his theory on why this happened. A few days later, the squad member was fired from his job for a privacy violation. As it turned out, one of the other class members was related to the individual and filed a complaint for the sharing of personal health issues.

NEVER discuss anything about individuals you support with anyone who is not authorized to know this information.

Section II: INTRODUCTION TO INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

In this section, we will discuss the definitions of intellectual and developmental disabilities, as well as some of the causes. While this information is important for a better understanding of the individuals you will support and will help you in your work, it is just as important to understand the myths and misunderstandings which get in the way of people living meaningful lives in the community. We will also discuss how you can become a “**roadblock remover**” for the individuals you support.

The Definition of Intellectual Disability

Intellectual disability (ID) is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior. An intellectual disability occurs before the age of 22. “Limitations in intellectual functioning” means the individual has an IQ of below 70 (the average IQ is around 100). “Limitations in adaptive behavior” means the individual is lacking skills in areas such as communication or daily living tasks like bathing, cooking, etc.

On the basis of multiple evaluations, professionals can determine whether an individual has an intellectual disability and can make recommendations for supports for the individual.

Factors to consider

In assessing and diagnosing intellectual disability, the American Association on Intellectual and Developmental Disabilities (AAIDD) stresses that professionals must take additional factors into account and consider things such as:

- the typical environment of the individual’s peers without disabilities
- language differences
- cultural differences in the way people
 - communicate
 - move
 - behave

Finally, assessments must also assume that:

- everybody has strength and weaknesses
- people will become more independent if given the right supports, a chance to do things for themselves and enough time to learn new skills.

Developmental disability is an umbrella term that includes intellectual disability, but also includes certain physical, neurological and sensory disabilities. It refers to a lifelong disability that occurs before the age of 22, and results in significant limitations and a need for supports in three or more of the following areas:

- Self care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction - making choices and decisions for oneself
- Independent living- ability to earn a living and handle one's own finances.

Intellectual disability is only one type of developmental disability.

1. The developmental disability may be strictly physical, cerebral palsy or spina-bifida from birth or childhood.
2. Individuals with autism, Down syndrome, epilepsy and other mental or neurological conditions (seizures) are considered to have a developmental disability.

Individuals with any of the above developmental disabilities may or may not also have intellectual disability. Some developmental disabilities, such as Down syndrome, fetal alcohol syndrome and Fragile X syndrome, almost always occur with an intellectual disability.

Myths and Misconceptions

People with intellectual or other developmental disabilities are all alike and all require the same supports.

- o Over the years, people with intellectual and other developmental disabilities have been placed in group settings partly because people have decided that it is cheaper and easier, and partly because people do not understand their various disabilities. The individuals in a given group often have nothing in common other than the fact that they all have at least one developmental disability. It is important to note that people with different disabilities are often best supported using very different approaches.
- o Understanding individuals' unique disabilities is a key to determining an approach that best supports them. Individuals with intellectual and developmental disabilities have personalities, likes and dislikes, needs and desires that vary as widely as any other random group of people. Having a developmental disability might mean needing supports to reach an outcome that a person without a developmental disability might reach by himself.
- o The presence of a developmental disability does not change the fact that the individual has his own, self-determined goals. Each person with a developmental disability might need some supports, just as we all do in different areas of our lives. However, the same amount and types of supports needed for one person may not be needed for another.

Some Causes of Intellectual Disability

Some individuals have an intellectual disability that occurs from:

Genetics – something you are born with that is passed down by parents (e.g., Down syndrome, Fragile X).

Other physical causes - (e.g., fetal alcohol syndrome, car accidents, shaken baby syndrome).

Social or environmental factors – (e.g., lack of stimulation trauma/abuse during the developmental years, lack of family and educational supports to promote mental development and adaptive skills).

Approximately – 40% to 50% of individuals with ID have no known cause of their disability.

- **People with intellectual or other developmental disabilities are ill or sick.**
 - An intellectual or developmental disability is not an illness, and people living with intellectual or developmental disabilities are not “patients” (unless they happen to be temporarily hospitalized). You can’t catch intellectual or developmental disabilities, and they cannot be cured.
 - While intellectual and developmental disabilities cannot be cured, individualized and age-appropriate supports are likely to enable individuals to reach their personal outcomes and increase their level of independence.
 - Just like anyone else, an individual with an intellectual or developmental disability may or may not have co-occurring conditions such as medical conditions, physical disabilities or a mental illness.

- People with intellectual/developmental disabilities need specialized services to meet all of their needs.
 - Each of us, including those of us with intellectual or developmental disabilities, has very different strengths and support needs.
 - We all continually grow and change in terms of the supports we need to be successful. One individual may not need support or assistance with a certain task, while another individual may require support to successfully complete the same task. Similarly, an individual who needs support today to complete a certain task may or may not need the same support tomorrow to be successful in accomplishing the same task.
 - People with an intellectual or developmental disability can shop at the same store as people without an intellectual or developmental disability. They may or may not need support and assistance to do their shopping and money management.
 - A person with an intellectual or developmental disability who has a medical condition can be treated by the same doctor as a person without an intellectual or developmental disability who has the same medical condition. Persons with an intellectual or developmental disability may or may not need some help telling the doctor how they feel, understanding the diagnosis or taking prescribed medication.
 - Just as for all of us, the supports provided must be individualized.

Supporting people with intellectual disability: What's your role?

1. **Be a “roadblock remover”** – Refuse to look at the label before the person. See people as the individuals they are, not for the disabilities they have. For example, don't think of or describe someone as a “behavior problem” or “a wheelchair user.”
2. **Be creative, provide thoughtful support, and make the effort to figure out the best way to help individuals achieve their outcomes.** If an individual tells you (by words or behavior) that he/she wants to do something, focus your energy on how the person can achieve his or her desired outcome. A person with an intellectual or developmental disability may need supports to find an alternative way to achieve an outcome that might not be needed by someone without a disability.
3. **Take each person's interests and goals seriously.** Remember that it is never helpful to focus on perceived impossibilities, based on an individual's disability or for any reason. We shouldn't say things like, “Latasha says she wants to drive a car, but she could never do that because of her disability.” Instead, discuss ways Latasha might be able to come as close as possible to her desired outcome of driving a car. For example, if Latasha has never had the chance to see what driving might feel like, consider offering the use of a video game system with driving simulators options.
4. **Try to figure out what an individual really wants when he or she tells you about an outcome.** If Latasha is saying she wants to drive a car, explore what the idea of driving may mean to her (freedom, independence, being on one's own, being an adult). Maybe you can think of other things she can do that would also make her feel that way, such as having a set of keys to her house, taking a walk in her neighborhood by herself or going to a movie with a trusted friend but no staff.
5. **Be positive.** Focus your energies on thinking and acting on, “people with intellectual or developmental disabilities can . . .” thoughts; not on “can't” thoughts.
6. **Do not base your interactions or your attitude about an individual on his or her history.** It's true that an individual's history may often provide valuable information, but it should not be used to limit opportunities. The field of intellectual or developmental disability services is full of success stories where individuals with “bad histories” have become successful because the people supporting them were able to see who they could be, rather than judging them based upon past “bad behaviors.”
7. **Model for others.** Treat those you support as equals. In doing so, people in the community will be more likely to treat people with intellectual or developmental disabilities as capable, productive citizens. For example, when you are in a store with an individual, make your support as invisible as possible. Talk to and treat the person as you would a friend. Encourage the individual to be independent. The tone you set will teach others in the community that people with intellectual or developmental disabilities are capable and interested in having full, well-rounded lives, just like everyone else.

Section III: NUTS AND BOLTS OF THE INTELLECTUAL DISABILITY AND DAY SUPPORT WAIVERS

Developmental Disabilities Services (DDS) Home and Community-Based Waiver

The ACS Waiver began in Arkansas in 1990 and provides a way to pay for certain long-term services in communities instead of in institutions. As did other states, Arkansas applied to the Center for Medicare and Medicaid Services (CMS) for a waiver of specific federal Medicaid requirements. Since that time, the waiver has provided funding to allow over 4000 individuals who would have required institutional services to receive a variety of needed services and supports in the community.



The Arkansas Home and Community-based Waiver for individuals with DD is built upon the idea of individualized supports. Services are developed and funded based on a person-centered approach, which allows each individual (and authorized representative if needed) to choose different types and levels of supports based on his/her desired goals, outcomes, choices, and needs..

The following types of services are available through the DDS Home and Community Based Waiver:

- **Supported Living** - A service to support the individual in his/her home and out in the community. As with all waiver services, supports provided to the individual must reflect his/her preferences and choices regarding daily routines, health & safety and achieving a “good life” in the community.
- **Respite** - A temporary service provided when the individual’s usual, unpaid caregivers are not available or need that time away.
- **Assistive Technology** – A service to provide specialized equipment to individuals to improve their ability to perform activities of daily living, to communicate and use their community more effectively.
- **Environmental Modifications** - A service that makes physical changes to an individual’s home or automobile that will improve his/her health, welfare, mobility and safety.
- **Therapeutic Consultation in the areas of Nursing Psychology, Behavior, Speech and Language Therapy, Occupational Therapy, Physical Therapy, Recreational Therapy, and Rehabilitation Engineering** - A service that provides expertise, training and consultation to family members, caregivers and other support providers in order to more effectively support the individual in one or more of these areas.

- **Personal Emergency Response System (PERS)** - An electronic device used to call for help in emergency situations. This may also include a device to automatically dispense medications at predetermined times.

- **Positive Behavioral Supports** - A temporary service to support individuals experiencing serious psychiatric or behavioral challenges through specially trained consultants as part of the Arkansas START Statewide Program operated by the DD Cooperative of Arkansas.

- **Supported Employment** - A service that helps individuals find work in settings where people without disabilities are employed and provides supports to learn the skills necessary to do the job and remain employed.

- **Transition Services** – A service that pays for certain expenses related to setting up one’s own home when the individual is moving from either an institution or a small ICF/DD Facility./

- **Developmental Day Treatment Clinic Services (DDTCS)** - A service that provides opportunities for an individual to learn new things away from his/her home and spend time with other people in a clinic type environment. This service specializes in habilitative care and training.

- **Case Management** - Case Management Services assists individuals and/or parents/guardians in accessing, coordination, and monitoring needed services and supports.

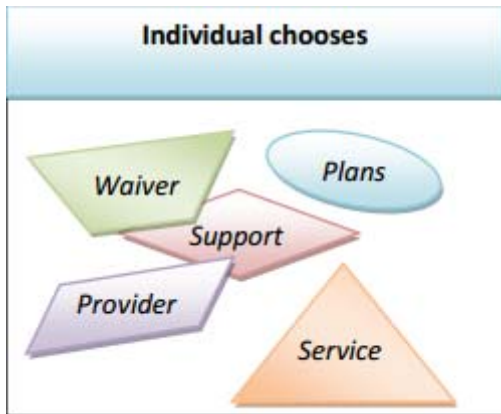
“No one has ever come into my office complaining that they are receiving too much praise.” Larry Stang, UCP CEO

Waiver Eligibility

In order to be eligible for services funded through the ACS Home & Community Based Waiver, a person must meet the following criteria:

- **Diagnostic:** Have a developmental disability.
- **Financial:** The person must meet financial eligibility criteria for receiving Medicaid. Different income rules are applied to individuals who receive services under a Waiver. Financial eligibility is determined by the Department of Human Services, Division of Developmental Disabilities
- **Functioning level:** The need for Waiver services is demonstrated by meeting institutional level of care criteria. Functional eligibility is determined by the Division of Developmental Disabilities Services Psychology Team.

The three criteria Waivers include: diagnostic, financial and functional.



Choice

Eligible individuals must be allowed to choose:

- Whether they want to participate in the program,
- What services they will receive,
- Who the service provider(s) will be,
- What's in their plan and
- The supports to be provided.

Service Authorization

All Waiver Services must be authorized by the Division of Developmental Disabilities Services (DDS) prior to the start of services. The case manager must review service providers' service plans (called Person Centered Service Plans) to ensure that the plans match what was decided at the planning meeting. The case manager also ensures that the individual's choices are the focus and driving force of the plan prior to requesting authorization. Changes in type and amount of services can be made only with prior authorization from DDS.

Service Planning

Planning Team



The Person Centered Service Plan is developed by a team with the individual at the center of planning. Other members of the team include family members, guardian/authorized representative (if there is one), friends of the individual, the case manager and service provider/supervisor. The team must meet at least once a year to develop the PCSP for the coming year.

- **Meeting format:** These meetings should be fun and informal, with all team members helping the person feel comfortable expressing his/her hopes, desires and worries about services and supports. Team members (with permission from the individual) present what they've learned about the person and make suggestions related to his/her desired outcomes, preferences and supports to be provided in the upcoming year. Provider roles and responsibilities are decided upon and the shared plan is agreed to by all team members.

Plan for Supports

Each individual has a Person Centered Service Plan (PCSP) that is the responsibility of the assigned case manager to complete, utilizing input from all team members. This PCSP identifies the desired outcomes of the individual as well as the service to be provided to achieve the stated outcomes.

Person Centered (quarterly) Reviews

The PCSP must be reviewed in writing once every three months to make sure it is still working for the individual. This review looks at whether services are being delivered as described in the PCSP, how well they support the individual and whether the person is satisfied with the services. The person-centered review helps determine the appropriateness of the services and whether the supports being provided are moving him/her closer to achieving his/her desired outcomes. All Waiver providers' person-centered reviews are sent to the case manager for his/her review. Revisions to the plan can occur at any time, but must receive approval by DDS prior to implementation. If an emergency exists, the case manager must notify DDS in writing and submit revision as soon as possible after an emergency is declared.

Assessment

All Waiver services must be delivered according to the written Person Centered Service Plan. The PCSP is based on information learned about the person, such as:

- what is important to him/her in order to live his/her idea of a good life,
- what is important for helping him/her stay healthy, safe and a valued member of the community,
- what he/she is interested in doing,
- what he/she does well and
- what he/she needs help with from the provider (support).

In some instances, an individual may have difficulty communicating. In these situations, much of the information may be provided by the case manager, direct services supervisor/or family on behalf of the individual, particularly if he/she is new to a provider. Once the individual is receiving supports, a great deal will be learned about the person from spending time with him/her in different settings, seeing what he/she can and cannot do, learning what he/she likes and doesn't like, and by talking to him/her and others who know the person well.

You will be asked to participate in a team approach to providing supports, which may include answering questions, attending team meetings or actually completing an individual's assessment. As a team member in providing supports, you will make contributions to the individual's Person Centered Service Plan – especially the Personal Futures Plan (PFP), which is

The Personal Futures Plan addresses what is **important to** and **important for** the person. His/her desired outcomes and supports in important life areas, including work, home community, and recreation are identified.

a personal description of the individual to help the team focus on what's important to the individual, what needs to stay the same and what needs to change for the individual to have a good life.

Personal Future Plan (PFP)

This Document is extremely important to you as a caregiver as it documents the likes, dislikes, fears and dreams of the individual served. The information will give you a better understanding of the individual you work with and it is your responsibility to make sure the information in the PFP is updated when needed.

Documentation

Each provider must maintain documentation that shows:

- Supports were provided as described in the PCSP.
- What supports were provided and when
- That the PCSP is being reviewed on a regular basis to determine status, movement or progress towards outcomes
- That changes to the PCSP are made as needed or desired by the individual.



There is a famous saying that “A picture is worth 10,000 words”, but direct care workers must use words to paint a picture for others.

Documentation: What's your role?

1. **Keep accurate documentation.** Never "fudge" on required documentation. If you don't understand how to document something, ask your supervisor.
2. **Be sure to sign and date all entries you make when you make them, whether in staff notes, learning logs or checklists.**
3. **Learn to write objectively.** Write down what you see, hear, or otherwise observe. Do not include your conclusions or opinions in documentation unless you say that it is YOUR opinion. For example if you have an idea or a hunch about why an individual might act a certain way, make sure you write that it is your opinion.
4. **Know the Plans for Supports for individuals you support.** You are responsible for providing services as outlined in the plan and writing down what you do, what you learned and things that are important to know for supporting the individual. When you know what both you and the individual are supposed to be doing, your documentation will reflect this knowledge.
5. **Know why you are documenting.** If you are unsure or question why a piece of documentation is needed, ask your supervisor to explain. You will be more likely to complete better documentation if you understand the reason for the requirement.
6. **Share ideas you have.** As you get to know an individual, share with your team or your supervisor your ideas for changes or improvements to Person Centered Plan, such as ways to make the plan better match the person's strengths, interests and support needs.
7. **Provide accurate, clear and detailed information.** Remember that all documentation is subject to review by licensing and funding agencies and, in some cases, could be subpoenaed for an appeal hearing or other legal action.
8. **Never use white-out or erase ink.** Mark through errors with a single line, initial and when making late corrections date any changes made to the record.
9. **Record information about the person's likes and dislikes,** as well as other input he/she shares in appropriate places in the record.
10. **Documentation must be recorded daily.** DO NOT try and record documentation on a weekly basis for you will not have accurate and descriptive notes that reflect the true work you do each day addressing the identified goals and objectives of the PCSP.

Section IV: COMMUNICATION

Introduction

Communication is the sharing and exchanging of information between people through a system of symbols (pictures, letters and numbers), language (talking), signs, gestures or body language and actions (behaviors). Actions may be smiling, laughing, kicking, head banging, or even hurting oneself. All people have the need to communicate to express choice, feelings, emotions, needs, likes and dislikes.

Every individual communicates in some way. Some people use words to communicate; however, we do not need to use words to communicate. We can communicate with facial expressions (smiles, frowns, eye blinking), pointing or other physical gestures, vocal sounds, eye contact, body movements or with our actions or behaviors.

For example, if you give someone Brussels sprouts and he/she makes a grimace or spits them out, that person is communicating that he/she does not like this food. If you give the individual ice cream and he/she smiles and gestures for more, that person is communicating what he/she does like. Just because an individual communicates through signs, symbols, behavior or assistive technology, does not mean that he/she cannot understand what others are saying. Intellectual or physical challenges may be the reason some people lack the ability to talk.



Types of Communication

There are two types of communication: expressing information (expressive skills) or receiving information (receptive skills). **Expressive communication** means talking or communicating in any form and receptive communication means understanding what someone is trying to tell you. Expressive communication refers to how people “share or express” information. **Receptive communication** refers to how people “receive” information, or “what information they take in.”

Some people cannot speak (expressive skills), but may understand what is being said to them (receptive skills). Some individuals can speak clearly and are easily understood (expressive skills), yet may not understand what is said to them (receptive skills).

Ability to Communicate

Most people learn language as infants and children through interacting with others and exploring the world around them. Some individuals with intellectual or developmental disabilities may have had fewer chances to interact with others and to explore their environment when they were infants. This can affect the development of language and communication skills.

Some individuals have challenges with communication due to physical (e.g., a hearing or visual impairment) or genetic factors related to their intellectual or other developmental disability. Sometimes medications affect verbal communication, and when medications are changed, the ability to communicate may reappear. Do not assume language stops developing at a certain age.

Communication occurs between at least two people. It is an interactive process in which one person expresses him/herself and the other listens or receives the information. As a direct support professional, you need to pay close attention to all forms of communication. Individuals who communicate without using language or signs need a means to express their likes and dislikes, ask for things and show pleasure, displeasure, pain or unhappiness. The usual way such communication occurs is through the individual's movements and behaviors.

It is important that DSW's focus on what the behavior is trying to tell you, and not the behavior itself.

“Behavior is a form of communication.”

Communication: What’s your role?

1. **Listen to the speaker.** In order to listen, you have to stop talking. Effective communication begins with good listening.
2. **Make eye contact.** Look the individual in the eye when talking or listening.
3. **Pay close attention to gestures, facial expressions, vocal sounds and movements used by the individuals you support.** Remember that “actions speak louder than words. Even people who use words to communicate will use other means to get their point across. Sometimes what they say is not really what they want. Be observant, watch for patterns and share what you have learned with your co-workers.
4. **Talk to the individual’s parents, family members and friends.** Chances are they understand his/her communication efforts quite well.
5. **Use a positive, age-appropriate and respectful tone of voice.** Do not use baby talk, a child-like or authoritative voice when you are talking to an adult.
6. **Ask questions.** This helps you gather information and shows you are interested in what the person is saying.
7. **Avoid asking why questions.** “Why” questions can make people defensive or feel you disapprove.
8. **Use new words, gesture with your hands, vary the tone and volume of your voice.** If you are not being understood, repeating yourself in different ways can be helpful.
9. **Be patient.** Allow the individual time to process what you have said before you continue talking. Giving several seconds between each sentence is especially important for some people.

Pitfalls to Avoid When Communicating with Individuals You Support

1. **Do not shout.** Speak in a normal tone. Some people with intellectual disability are hearing impaired, but most are not. Be aware if you have a loud voice, you may need to lower your volume.
2. **Do not talk or act like a parent.** Ask the individual to perform a task. Do not issue orders. Treat individuals with respect regardless of age or ability.
3. **Do not say you understand if you do not.** That will only frustrate the individual. Ask a co-worker or someone who knows the individual well for assistance.
4. **Do not rush the individual.** Some people take longer than others to form their thoughts and words. Give the individual more time to process what you are saying before asking him/her again.

The Effect of Language

Your choice of words in speaking and your attitude (conveyed through the tone of your voice) are very important to how individuals see themselves, as well as how others see them. Many members of the community have had little or no interaction with individuals with intellectual or developmental disabilities. How you talk to the individuals you support will influence the attitudes and interactions of others.

“Person First” language emphasizes the person and not the disability. Do not say “an autistic person,” because that is disrespectful and emphasizes the disability of autism rather than the person. You should say, “a person with autism,” or if it’s not necessary, don’t refer to the disability at all. Referring to the person first downplays the disability and lets others know he or she is, first and foremost, a person who deserves respect.

Language: What’s your role?

1. Use person first language.
2. Model age appropriate and positive communication at all times.
3. Gently redirect doctors, store personnel, restaurant workers and others who communicate with you to speak instead to the individual.

The Role of Behaviors in Communication

A person's behaviors, even undesirable behaviors, are attempts to communicate. A major cause of frustration and resulting challenging behaviors is the inability to make oneself understood. Knowing what you want and being unable to express it to others is an endless battle for people with limited or poor expressive skills. Think about how you might behave if others could not understand you. As a DSP, it is your responsibility to "listen" well and help the individuals you support to find appropriate ways to express themselves and deal with stresses that frustrate them.

Behavior and communication: What's your role?

1. **Think about why the individual might be exhibiting challenging behaviors.** Is she trying to tell you she's frustrated, in pain or bored? Put yourself in the person's shoes.
2. **Respect that all individuals need to communicate** in order to express themselves, be understood and have control over their environments.
3. **Think about how you would feel if you were unable to speak or write** and had to develop another means of communication. What would you do?

Section V: POSITIVE BEHAVIORAL SUPPORT

Introduction

This section provides introductory information about Positive Behavioral Supports by discussing some principles and practices which have been effective in supporting many people with intellectual and developmental disabilities. Positive Behavioral Supports is a person-centered approach to addressing challenging behavior by changing the surroundings and supports, while teaching the person new skills that result in better communication and more choice and control over one's life. Positive Behavioral Supports (PBS) is the preferred approach adopted by UCP. PBS initially evolved within the field of developmental disabilities and emerged from three sources:

- Applied Behavioral Analysis
- The inclusion movement (see Section I)
- Person-Centered values (See Section I).

PBS stresses personal growth with the end result being an improved quality of life for the individual. Minimizing problem or challenging behavior is a secondary goal. More training about Positive Behavioral Support practices may be obtained from UCP or the DD Cooperative of Arkansas' ArkSTART program.

It's important to know the four basic values of PBS:

1. Respect for the rights of ALL citizens (with or without disabilities)
2. The importance of the individual (person-centeredness)
3. Dignified treatment of people (treat people as people first, not disability first)
4. Assurance that individuals with disabilities are not abused or neglected.²

² Reid, D., & Parsons, M. (2004). Positive Behavior Support Training Curriculum. Washington, DC. American Association on Mental Retardation.

All Behavior Is Communication

Individuals with intellectual disability often have communication difficulties (such as being unable to talk or understand spoken language) that get in the way of expressing their needs and feelings in usual ways. This may lead to expressing those needs through behavior that appears unusual or disturbing. In the past, individuals who had challenging behaviors that were difficult to manage were considered

in need of institutionalization or more restrictive environments until they learned behaviors that “showed” that they were “ready” for life in the community. This has proven to be WRONG. Current research shows that giving individuals choice and control over their own lives often minimizes challenging behaviors. Teaching positive behavior in the individual’s community home and work setting is a better way to help individuals with intellectual and developmental disabilities.

For example, the person who is never asked what she wants for breakfast may start to throw her oatmeal across the kitchen every morning.

For example, the staff’s idea of a community outing is to load up the group home van with all 5 residents and go to McDonald’s every Friday night. Bob resists getting in the van and has begun taking off his seatbelt and hitting whoever is sitting next to him.

In order to be successful with behavioral supports, staff must treat individuals with dignity and respect. Support staff must view behavior as a way for individuals to control and direct their own lives. If the desire for personal choice and control is not respected, the result may be that an individual adopts negative behaviors in order to gain some control.

Individuals who have few opportunities to participate in enjoyable, meaningful activities with people they like are more likely to display challenging behaviors out of boredom or unhappiness.

In this case, helping the person to find and participate in enjoyable activities with people he likes may go a long way toward removing the reason for the negative behavior.

People (with or without developmental disabilities) generally do not behave their best when they are feeling pain or discomfort. A person who is hungry, thirsty or tired may act in a negative way to express these feelings. Some problem behaviors result from the side effects of medications. Others result from unhappiness, which may be due to missing family or friends, the absence of a favorite person, dislike of work or an argument with a housemate or coworker. Reasons for behavior are as

unique as individuals. If we are to support people in successfully changing challenging behaviors, we must first do our best to know these individuals and what is happening in their lives.

Positive Behavior Support Plans

A Positive Behavior Support Plan (PBSP) outlines what changes are needed in the environment or the individual's schedule or routines, how staff should support the individual and respond when the behavior occurs, what new behavior the individual can use to get what he needs and wants, and how to teach the person the new, positive behavior. Positive Behavior Support Plans are designed to help DPWs to act in the same way in supporting the individual. PBSP's change over time to meet the needs of the individual in order to remain effective.

Writing a Positive Behavior Support Plan will not be one of your responsibilities as a DSW. However, the professional who does develop the Positive Behavior Support Plan might seek your help in trying to figure out the purpose of the behavior for the individual. You may be asked to provide the following information in order to help him/her to pinpoint the purpose of the behavior to the individual when the behavior occurs:

- what is going on around the person at the time
- who else is present
- what happens immediately following the behavior.

It is learned that Bob hates going places in large groups and he also doesn't like burgers. A companion is found to take Bob, one-on-one, to some local restaurants on Friday evenings.

Some Other Important Things to Remember about Challenging Behaviors:

If a behavior will not harm the person or others, it may be best to ignore it.

When behavior places the individual or others in danger, ensuring safety and decreasing risk are most important. **Staff should not try to teach desired behaviors during a time when dangerous behavior is occurring.** It's more important for everyone to be safe and calm.

Listed in the chart that follows are things that you can do, as a DSP, to best support individuals who are expressing themselves using unusual or disturbing means.

Positive Behavioral Support: What's your role?

1. **Be a good role model.** It will be difficult for people to look to you to teach them anger management if they see you yell and scream when you get angry.
2. **Be a good observer.** As a DSP, you will have the most contact with the individual and will generally be the first to notice changes in behavior or behaviors that are interfering with his or her life.
3. **Keep good documentation.** Your observations of what's happening before and after the challenging behavior are critical in determining the purpose of the behavior. Record accurate, factual information about patterns of behavior: times, places, surrounding events, what happens after he/she does it. In our example of Bob, staff might be making notes such as: "At first Bob refused to get on the van for a trip to McDonalds." "Once on the van he began hitting his neighbor." "At the intersection, Bob took off his seatbelt." "Bob ate little of his dinner tonight. Ate most of his salad and pie, but only took one bite of his hamburger."
4. **Follow behavior support plans.** In order to support individuals effectively, the same (consistent) teaching strategies must be used by all staff. In addition, behavior plans must follow human rights guidelines. By carefully following behavior support plans, you help make sure that the individual's rights are protected and that the new, positive behavior is successfully taught.
5. **Be a good communicator.** If individuals communicate with words, listen to what they tell you about their choices with words and behavior. If individuals do not communicate with words, pay close attention to what they tell you through behavior. By doing this, you will often be able to assist people in exercising choice and control, which will make it less likely that negative behavior will develop.
6. **Be supportive and respectful.** The individuals with whom you work have the same desire you have to be accepted in the community. Socially unacceptable behaviors may have been learned for a variety of reasons based on the individual's life history and experiences. When you treat people with respect, they are more likely to trust that you are trying to help them reach their goals and, thus, you will be a better DSP.
7. **Commit to problem-solving.** When an individual lives in the community, problems may arise due to behaviors that keep the person from fully participating in community life. Put your creativity and energy into helping find solutions that increase the individual's ability to become a valued, participating community member.

Section VI: HEALTH AND SAFETY

Introduction

An important part of your role as a DSW is to make sure that the individuals you support are as healthy and safe as possible. Your responsibilities will depend on the type of program in which you work. For instance, staff who support people in day and residential services play a vital role in carefully observing individuals and in reporting any changes in their behavior, appearance or eating habits that may relate to good health. Congregate residential staff often has the additional responsibility of arranging for and accompanying individuals to doctor or dental appointments.

In addition to the information in this chapter, you will receive First Aid and CPR training to assist you in helping people stay healthy and safe. This chapter is not intended to replace that training. Your role is to help the individuals you support access quality health care when they need it, assist them in learning and using skills that maintain good health and help them to be aware and informed regarding their own health concerns.

Maintaining Good Health through Good Nutrition

People with an intellectual disability have the same needs for good nutrition and proper weight management as people without disabilities. Since intellectual and other developmental disabilities are often associated with other medical conditions, such as epilepsy, allergies, diabetes and heart problems, you may support people who are required to follow a special diet for health reasons or food allergies.

Fortunately, today there are a variety of food products available for people who have specific food allergies. Many restaurants offer a range of meals and are accustomed to responding to the needs, likes and dislikes of individual diners. Depending on the needs and interests of the individual you support, your role may vary. You may help the individual plan nutritious and well-balanced meals, oversee meal preparation, monitor and encourage appropriate amounts of foods or help in making healthy food choices when dining out.

Your help will be especially important with aging adults, whose nutritional needs, appetite and vulnerability to illness are changing. Just as most of us hope to stay in our home as we grow older, so do the individuals we support. The supports you provide will play a critical role in helping to make that possible.

Important Point: As a DSW, you must resist the temptation to reward or coax the person you support with food. **Food should never be earned**, and the individuals you support experience the same problems with excess weight as anyone else. When you wish to recognize someone for positive behaviors, offer a meaningful, non-edible reward, such as a:

- a fifteen minute walk around the neighborhood
- a telephone call to a relative or friend
- a short shopping trip
- a visit to the library.

Health and Safety: What's your role?

1. Know the medical and social history for all individuals you support.
 - Who is on a special diet and why?
 - Who has food or other allergies and what are they?
 - Make sure you know where this information is located.
2. Monitor what and how much the individual eats, but do so in a respectful, helpful manner.
 - Encourage proper portion sizes by helping the person measure his/her food in a container that is the correct portion size before placing it on his/her plate.
3. Educate yourself on proper portion control.
 - Did you know that one serving of meat is about the size of a deck of cards?
Using smaller bowls and plates help us to naturally limit the size of our portions.
4. Prepare foods in as healthful a manner as possible.
 - Bake or grill, whenever possible. Avoid frying foods.
 - Use dairy items with lower fat content.
 - Use nutrition charts when helping plan meals.
5. Help people find fun ways to get up and moving.
 - Being active benefits our well-being, and just walking 30 minutes several times a week can help us both physically and psychologically



Recommended Daily Servings

2-3 daily servings of milk, yogurt or cheese
3-5 daily servings of vegetables
2-3 daily servings of meat, poultry
2-4 daily servings of fruit
6-11 daily servings of breads, cereals

Personal Hygiene

Personal hygiene plays a major role in how others view a person. It is important for all of us to wear clean clothing, keep our hair clean and healthy and bathe regularly. Because people with disabilities, are often seen by others as “different,” it is even more important to have good personal hygiene. Dirty clothing and sloppy appearances get in the way of meeting new people and making friends. When dressed in clean, well-fitting and stylish clothing, individuals are more likely to be seen in a positive manner.

It is possible that you will support some people who need reminders or help to keep up their personal appearance. Depending on the needs of the individual, your assistance could range from physically bathing to helping someone shop for attractive shirts that are appropriate for his new job. Many of the individuals we support need reminders to bathe themselves, shampoo their hair, shave, brush their teeth or use the toilet. Others may need you to do much of the task for them, such as changing a disposable brief or putting on deodorant.

Important Point: You should expect the personal hygiene of the individual you support to be kept at a level equal to your own, you child or your spouse. It is no less important.

Good hygiene, especially dental care, is also important for health reasons. Lack of attention to bathing or to routine care of teeth and gums can lead to serious medical conditions. Some of the people you support may not understand this or may not like doing these activities. It will be your role to find creative ways to encourage individuals to participate in necessary bathing, shampooing and other personal hygiene activities if needed.

Personal Hygiene: What's your role?

1. You provide supports to a young man who drools due to a severe cleft palate. To assist him with maintaining his personal appearance, you might take him to purchase several sets of men's handkerchiefs, teach him how to wipe his chin if needed, or do it for him on a routine basis.
2. You help a person find a dentist who accepts Medicaid or offers reduced rates for low income patients.
3. One of the individuals in your day support program has a new concern with wetting themselves. You alert the program manager, residential staff or support coordinator, so the team can identify the cause, such as medical problems, behavioral communication, or depression, and find a solution. In the meantime, you find short-term fixes, such as keeping an extra change of clothing at the day program or using disposable briefs.
4. The individual comes to breakfast wearing sweatpants and a long-sleeved shirt on a hot August morning. He works outside at Wal-Mart. You help him select and change into clothing that is more appropriate for the weather.

Regular Medical and Dental Care

Regular medical and dental care is crucial in helping individuals with intellectual disability enjoy a healthy life. Typically appointments are scheduled and the individual is taken by either the residential staff or family members, depending on where the individual lives. It is important to work closely with each individual's primary care physician and other medical professionals to make sure regular routine tests and screenings are completed. DSWs often play an important role in communicating to the health professional what an individual might be experiencing.

All DSWs supporting individuals with disabilities should be on the lookout for changes in appearance or behavior that may indicate some symptom of illness. Individuals with intellectual disability may not be able to fully communicate what they are feeling (physically and emotionally). You need to be diligent in observing, monitoring and reporting any of these changes. The following is a list of areas in which changes may indicate signs of illness or a change in health status.

Important Point: Dental care is equally important as medical care. Helping individuals maintain a healthy mouth by regular brushing, flossing and routine dental visits can dramatically decrease health related issues such as infections and discomfort.

A. Changes in Daily Patterns

1. Decrease in appetite or difficulty digesting food
2. Increased sleeping or unable to sleep
3. Pain associated with illness or injury
4. Medication changes and reactions

**Be on the lookout
for these!**

B. Changes in Appearances

1. Weight gain or loss
2. Condition of skin (pale, sweating) or hair (unusually dry/oily, falling out)
3. Appearance or sensitivity in eyes
4. Swelling/redness
5. Hygiene deterioration (such as body odor, untidy clothing, bad breath)

C. Changes in Bodily Functions

1. Breathing
2. Balance/dizziness
3. Pulse and blood pressure
4. Bowel movements and bladder control
5. Use of hands, arms, and legs
6. Senses - seeing, hearing, touch, taste and smell

D. Changes in Behavior

1. Obvious change in mood (depressed, agitated or crying)
2. Combative/argumentative
3. Withdrawn
4. Anxious, restless
5. Obvious change for that individual (previously energetic person appears tired or a typically quiet individual talks nonstop).

Regular medical and dental care: What's your role?

If you notice any of the changes listed above, you should:

1. **Note it in the individual's support log (or progress notes) and be sure to inform your supervisor and follow your agency's procedures so others can be aware and observant.** Documenting these changes can indicate patterns and may be important to diagnosing a problem if one exists.
2. **Get a perspective on the person's history.** If you are new to supporting an individual and note changes or have concerns, speak to your supervisor, a co-worker or another person who knows the individual.
3. When in doubt, and if symptoms persist, **a doctor should be called**

Medication and Side Effects

Important Point: As someone who spends a lot of time with the individual, your role is to ensure that the doctor has all the available information to decide if the prescribed medications are having the desired effect or a change is needed. It is a good practice to have all prescribed medications for an individual filled at one pharmacy to prevent the risk of a negative reaction between two different medications. Ask the pharmacist to review all medications when a new medication is prescribed, since different doctors can prescribe medications for one individual.

A number of the individuals we support take multiple daily medications. All medications, despite the good they do, have side effects – some of which can be harmful. Side effects may indicate that the medication dosage or type may need to change. In addition, persons on more than one medication may experience symptoms related to the interactions of their medications.

As a DSW, you should become familiar with how medications affect the persons you support. Side effects are sent by the dispensing pharmacy and are maintained in the Medication Administration Record (MAR) for each individual. In addition to the known side effects, the changes in daily patterns, described previously, may be a sign of a negative drug reaction. **Always report a concern.**

Emergency Care

It is best that all staff receive training in First Aid and Cardiopulmonary Resuscitation (CPR) prior to supporting individuals alone. This will enable you to react appropriately and possibly to save someone's life while medical care is on the way.

Other Health Concerns

In addition to the potential for illness and injury, you may find yourself supporting individuals with ongoing health concerns including (but not limited to) seizures, diabetes, Alzheimer's, sleep apnea, arthritis, visual/hearing impairments, food/drug allergies and mobility concerns. All DSW's are responsible to be aware of and knowledgeable about the signs and symptoms of the health concerns of those you support.

Each staff person should also be aware of individuals' mobility issues. This information should be available and relevant strategies from a professional on how best to support an individual who is at risk of falling in their daily routine should be understood.. It is critical you know the individual's Personal Futures Plan (PFP)

Important Point: It goes without saying that any condition which would be considered an emergency if it happened to a member of your family is also an emergency if it occurs to a person with an intellectual disability.

Call 911 at the *first* sign of a medical emergency!

Exercise

Along with regular medical care and good nutrition, exercise is another important element to a healthy life. Many individuals we support have never experienced a regular exercise program. Though they may face some physical challenges, there are a variety of activities designed for older adults and people with disabilities. Exercise can be fun and exciting. We all benefit from moving more, so find something the individual enjoys doing that gets him/her moving.



Important Point: DSWs must get to know the people they support. Being observant, responsive and attentive to medical needs is the key to assuring health, safety and a good quality of life for the individuals you support.

Most major health organizations recommend at **least 30 minutes of exercise most days of the week**, using a combination of cardiovascular exercise (walking, swimming, and/or aerobics) and resistance exercise (weights). There are many ways to incorporate exercise into an individual's daily routine that can be creative and interesting.

Some ideas are:

1. Visit a nearby school and walk around the track.
2. Find a local park with walking trails and other attractions and do a combination of walking/sightseeing.
3. Plant and maintain a small garden.
4. Grocery shop (pushing the cart and reaching for items from shelves).
5. Dance.
6. Join a gym and take classes or use the equipment.
7. Even household chores are better than being Sedentary.
8. Use of light weights for those in wheelchairs.
9. Solicit an exercise program from a physical therapist that is working with the individual.



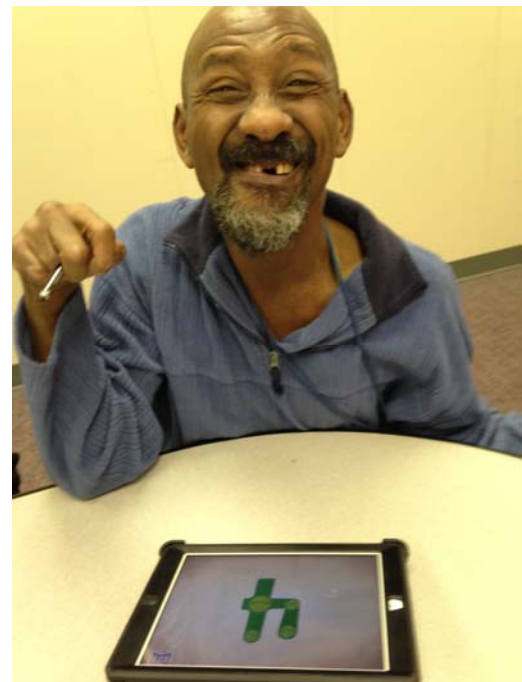
Important Point: Always check with the individual's medical professional before starting an exercise program.

Assistive Technology

Assistive technology refers to any item, device, piece of equipment or set of products that is used to maintain or improve the ability of a person with a disability. Assistive technology allows an individual to function with more independence, gives him/her more choices and gives him/her an increased sense of confidence. Assistive technology devices may range from simple and inexpensive everyday items to complex computer systems. Some devices are not designed just for persons with disabilities but can make life easier for anyone.

Examples of assistive technology that enable individuals to carry out daily living activities include: eating and cooking utensils fitted with oversize handles for easier gripping, shower benches and bathtub lifts, wheelchair ramps, programmable telephones and picture boards. Another type of assistive technology which may benefit many of the individuals we support is communication devices. Any system that assists individuals who do not communicate using words is known as a communication device. The device can include speech, gestures, sign language, symbols, synthesized speech, dedicated communications aids or microcomputers.

Assistive technology benefits all of us as we age. It may be a key element in helping the individuals we support remain in their home and community as they age. It also helps them maintain as much independence as possible, as their physical and cognitive abilities change due to the aging process. If someone you support could benefit from any of the devices mentioned above or other equipment, mention this to your supervisor, the individual's support coordinator or family member. It is possible that the needed item may be available to the individual through Medicaid.



References and Suggested Readings

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