Section I: The Values That Support Life in the Community

The goal of this chapter is to familiarize you with the vision and values to guide you in your support of people with developmental disabilities (DD) in Virginia.
The Values that Support Life in the Community

The vision of Virginia is that all people with disabilities are provided the opportunities and supports needed to live a good life in their own homes and communities.

Virginia’s Principles of Person-Centered Practices

Several years ago, a group of people in Virginia developed principles to guide practice and, with a few updates, these remain our principles today.

We see a Virginia where people of all ages and abilities have the supports needed 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 accounts), and opportunities to contribute to family and community.

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

Principle 1: Listening
People 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
People have informed choice and control over decisions that affect them.

Principle 4: Talents and Gifts
People have opportunities to use and share their gifts and talents.

Principle 5: Responsibility
There is shared responsibility for supports and choices.
One significant way that Virginia is achieving this vision is through the Home and Community-Based Services (HCBS) Waivers. HCBS Waivers allow Medicaid to fund supports for people in their communities. There are six HCBS Waivers in Virginia.

Waiver services take place in a person’s home, in regular places in the community or in licensed settings or homes where staff provide Medicaid-funded supports. While all of the waivers listed at the left are under the authority of the Department of Medical Assistance Services (DMAS), the Building Independence, the Community Living, and the Family and Individual Supports Waivers are administered on a day-to-day basis by the Department of Behavioral Health and Developmental Services (DBHDS) and support people with developmental disabilities (DD).

Many of the supports and services that are available through the Waivers for people with DD are provided by direct support professionals (DSPs) who have the primary role of supporting people on a day-to-day basis with routine personal needs, social support, and physical assistance in a wide range of activities so that they can lead a self-directed life in their own community. DBHDS expects the supports provided to be person-centered and to lead to a good life for the person using Waiver services. There are characteristics of providers that are valued by Virginia’s service system. When providing supports and services, it is expected that all people providing support, including DSPs:

- Consider the wants and needs of the person first
- Realize everyone has talents
- Ask the person and those who know and love them for input
- Support a person’s self-expression, self-worth, self-reliance, and decision making
- Are flexible
- Listen to all people
- Respect all people
- Respond quickly to a person’s requests
- Pursue partnerships and teamwork
- Communicate clearly, openly, and honestly
- Think outside of the box for new ways of doing things or solving problems
- Make decisions and resolve issues
- Strive for win-win solutions
- Work to ensure that people are healthy, safe, and valued by others
- Encourage and support others to be successful
- Recognize and celebrate successes
- Develop and maintain a supportive learning environment
- Work continuously to improve services and supports
- Deliver on promises
- Follow a person’s plan as decided upon by the team
- Value and take care of oneself

How many of these characteristics do you think you have?
People with disabilities are valuable and contributing members of the community. Everyone can experience a good life in the community. People using supports should control how they live their lives. People who provide supports should focus on promoting rich and fulfilling lives in the community.

This section of the manual focuses on the values that will guide you in your support of people with disabilities. Many of the concepts are built on person-centered thinking and the work of Michael Smull and others from The Learning Community for Person Centered Practices, whose focus has been moving people with disabilities from a “service life” to a “community life.”

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1 For general reference purposes, the term “individual” or “person” is appropriate in referring to individuals with developmental disabilities (preferable to terms such as “client” or “consumer”). However, it should only be a placeholder for the name of the person using supports. Please be aware of language changes and other person-centered resources available at: http://www.dbhds.virginia.gov/ODS-PersonCenteredPractices.htm.
The Value of PERSON CENTERED THINKING

Person-centered thinking is a set of skills used to get to know a person. It is important for DSPs to learn and use the skills and tools. Getting to know someone then allows DSPs to act on the information and support a person in obtaining a life of their choosing.

At the base of all person centered thinking skills is the ability to discover what is important to a person while balancing what is important for them. This is true about all people, not just those with a disability. All of us have things in our lives that are important to us and important for us. We all struggle to strike a balance between doing things that are good for our health and having things in our lives we cherish.

“I am listened to. I have a voice. I listen to others.”

IMPORTANT TO
are those things in life which help us to be satisfied, content, comforted, fulfilled, and happy. They include:

- People to be with/relationships
- Status and control
- Things to do
- Places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have

IMPORTANT FOR
are those things that keep a person healthy and safe. They include:

- Prevention of illness
- Treatment of illness/medical conditions
- Promotion of wellness (e.g.: diet, exercise)
- Issues of safety: in the environment, physical and emotional well-being, including freedom from fear

They also include what others see as necessary for a person to:

- Be valued and
- Be a contributing member of their community
Person-Centered Thinking© skills describe the DSP’s ability to:

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

Because we are human, we all need and use support from others. We all contribute, not just through our jobs, but by how we spend time and through relationships. We all want to have control over our lives – to journey towards our dreams.

DBHDS would like all new providers and DSPs to enroll in a Person-Centered Thinking© class prior to providing supports. Go to www.personcenteredpractices.org to register. Click on the left link entitled Person Centered Thinking.
The Value of RESPECT

The term “respect” has many types of meanings. It includes 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 may contribute to a lack of respect.

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 DSP, 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/her.

There is a tendency to have lowered expectations of persons with disabilities. Low expectations limit opportunities to try new things and interfere with 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.
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 providers who support him, the therapist heard the staff members 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 this for himself.”

Have HIGH EXPECTATIONS.

The Role of Language

Your choice of words in speaking and your attitude (conveyed through the tone of your voice) are very important. Language can act as a separator when you use “special” language or professional jargon when talking about people with disabilities such as “client,” or “consumer.” Special language says people with disabilities are different. Instead, use everyday language, words, and phrases you would use when talking about co-workers, friends, and family members. For example, instead of saying John was placed in a job, say, he found a job or instead of saying Jane transitioned from high school, say, she graduated. As a DSP, how you talk will influence the attitudes and interactions of others.

“Person First” language emphasizes the person and not the disability. The first choice is always to call someone by their name. If you have to refer to someone and mention disability, always put the person first. The phrase, “a disabled person,” can be disrespectful and emphasizes the disability rather than the person. You should say, “a person with a disability.” Instead of saying “someone with Down’s,” say, “a person has Down syndrome.” Referring to the person first lets others know he or she is, first and foremost, a person who deserves respect.

Read: Person First Language by Kathie Snow
https://www.disabilityisnatural.com

Read: Language to Avoid
http://www.partnership.vcu.edu/DSP_orientation/downloadables/LANGUAGE%20TO%20AVOID.pdf
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 he/she 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 a person. If information must be shared, do it in a private, respectful manner.

- Don’t talk about someone you support in their presence; talk to them and encourage community members to do the same.

- When accompanying someone to a medical appointment, encourage them to speak for him/herself. If the medical staff directs questions to you, defer to the person you support whenever possible.

- Use every day language. Avoid jargon.
The Value of PERSON-CENTERED PLANNING

The core of person-centered planning is to empower the person who uses paid supports to make decisions and choices that direct and shape his/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 using supports, while still addressing their health and safety. Person-centered planning always includes the person who is the focus of the plan and other people who are selected by them to participate. This leads to the achievement of goals that are meaningful to that person.

Person-centered planning approaches vary, however, according to O’Brien and Lovett in *Finding a Way Toward Everyday Lives* (1992), they are all characterized by the following five elements:

1. The person at the focus of planning and those who love him/her are the primary authorities on their life direction. The essential questions are, “Who is this person?” and “What community opportunities will enable this person to pursue his/her interests in a meaningful way?”

2. Person-centered planning aims to change common patterns of community life. It stimulates community hospitality and enlists community members in assisting someone 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 people as contributing members of society.

5. Assisting people to define and pursue a desirable future requires DSPs to focus on the goals of those they support, make a commitment to assist them, and have the determination and courage to help break down barriers.
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, you are transported to another life. In this life, a woman comes into your bedroom, throws open your curtains, and says, “Good morning! How are you today?” You glance at the clock, 7am, and then try to roll over thinking it is just a nightmare, but the woman comes over to your bed and pulls the covers off. “Are you ready to get up? Breakfast is hot and you need to eat.” In this new life, someone else chooses where you live. In your new home, you are told what time you will get up, what time you will go to bed, what you will eat, what you will wear, what you will do with your day, whom you spend time with and where you go. In this new life no one asks what you prefer or cares what routines and rituals comfort you and add to your happiness. No one has asked who is important in your life, who you love and like to spend time around. Is this the kind of life you would want to lead? Do you see the importance of person-centered planning?

Person-centered planning promotes the value that the wishes of a person are to be honored, based on what he/she considers important to them. 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 them well.

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

Person-centered planning puts into practice ensuring that wishes (important to) are respectfully balanced with need for support to stay healthy, safe, and a valued member of the community (important for).

From the standpoint of those 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 are 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.

Read or listen to: A Credo for Support by Norman and Emma Kuntz for additional perspectives on support. See references for links.
The Value of DIGNITY OF RISK

The concept of dignity of risk is the right of a person to make an informed choice to engage in experiences meaningful to him/her and which are necessary for personal growth and development. Normal living often includes risks. Dignity of risk allows people to lead normal lives. Overprotecting 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 people with disabilities from disappointments and sorrows, which are natural parts of life, support them 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 those 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?

- 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 with ‘dicey’ graphics. 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 these 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. You follow-up by following your agency’s documentation requirements in describing the support you provided and the choice Joseph made.

- Openly discuss options a person may have when they are faced with making a decision.

- Often making an informed choice takes many conversations to understand the risk involved. Take time for this.

- 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 person’s situations and choices.

  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 in finding a job? Maybe she’d like to work at an airport. She could learn more about what airplane pilots have to do in their job. 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 who come together for a common reason. People may belong to several communities, some which are based on a common interest, others that are based on geography such as a neighborhood. People within a community may be very different from one another. Being part of a community brings people together, and people will learn that it is okay to be different. Positive and regular interactions bring a community together.

Just because you live in a community or attend activities in a 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 events going in the community? It is the responsibility of the DSP to provide the supports a person needs to become part of the community.

Sometimes people are afraid of differences or the unfamiliar. Without intentional effort to involve people with disabilities in their communities, they risk being separated from everyday life by living in segregated facilities and attending activities designed only for people with disabilities. As a DSP, you must ensure that people you support achieve ordinary community lives by helping each one get involved in activities that they want to do and find valuable. Going out to ordinary places is the first step.

Think of places you like to go, activities you like to participate in, organizations where you have memberships. What would be the potential challenges for people you support to enjoy those same experiences? How could you help the person overcome those barriers?

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

Community presence may include doing things in the community on a regular basis and being recognized by others who attend, but not really interacting with others. If a person is not there, they are not missed.

Community participation may include doing things in the community on a regular basis, knowing several people by name and having conversations with them about personal lives. The person does things at the event that others depend on and they would be missed if they were not there on a particular day.

Community connection may include a person being included in social gatherings outside of the primary connection, others recognizing and appreciating their contributions, and forming friendships that extend beyond the reason they are gathered. When a person is not there they are missed and people ask about them.

“I have friends and family I see often. I am a part of my community. I have found groups, organizations and social activities that interest me.”
A DSP’s goal is to support people to be connected to their community.

**Community Connections:** What’s your role?

- Support people individually (rather than in groups) when going to a community/neighborhood event.
- Step back and support the person to participate to the best of his/her ability.
- Do not assume that the person needs your help.
- Help the person locate and attend community events and activities that best reflect his/her interests and that best match what others of his/her age group seek out.
- Attend places on a regular basis so relationships have a chance to form.
- Find the gatekeeper of the group – the one who will introduce a person 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 people to make their own purchases rather than purchasing items for them.
- Model what it looks like to be part of a community by being friendly and introducing yourself to others.

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**Recommended Resource:**

*A Guide to Developing Community Connections* by Patsy Davies & Claudia Bolton

**Recommended Resource:**

*Friends: Connecting People with Disabilities and Community Members* by Angela Novak Amado
http://rtc.umn.edu/docs/Friends_Connecting_people_with_disabilities_and_community_members.pdf
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 not how most people live. Most people pay for some services and get assistance from others just because they care. It is the responsibility of DSPs to find and set up flexible ways of supporting a person 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, family, and others who are genuinely interested in the person.

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 a person 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?

- Find out who is already in a person’s life (including immediate and extended family members) and encourage/facilitate continuing and deepening those relationships.
- Figure out where people are already providing natural support in someone’s life and help this continue.
- As you are out and about in the community, take notice of people who show interest in getting to know the person you support. Don’t be afraid to help the person meet new people, which can lead to new friendships and more support in the person’s life.
- Also note when you meet people with similar interests as the person you support. Find a volunteer to accompany them on a specific activity in which they are both interested. Consider that the person you support may have an interest he/she has never had a chance to put into action, such as going to baseball games, hiking, listening to gospel 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. 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 believe more in their abilities: 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 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. Many people with 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 used to prepare for a job is beneficial, as long as it is time-limited and has as the expected outcome of an integrated, community job. An integrated, community job is defined as work providing a minimum wage or higher 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 concept that Virginia values. It 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), they should have an opportunity to do work assessments to see what it is like. Those who are not currently working should have frequent opportunities to learn about work, the types of jobs people do, and to be exposed to working people within their interest areas.
Work: What’s your role?

- Adopt the belief that everyone can work.
- Support a person in believing that he/she can work in the community.
- 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 person would like to do any of those tasks as a job.
- Encourage the employment team to look at a person’s gifts and abilities and what they can offer an employer.
- Think creatively about the types of organizations and jobs that could match a person’s skills and strengths.
- Document the type of supports a person will need to be successful on a job.
- Familiarize yourself with services that specialize in job development and job support.
- Believe in the person. Believe in his/her dreams, and be supportive if things don’t go right the first time.
The Value of ALTERNATIVES TO ISOLATING PROGRAMS

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

Alternatives to isolating programming refers to supporting a person in natural settings, with families and friends, by providing flexible supports that work well for them. 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 isolating programs: What’s your role?

- Try to avoid “homelike facilities” in a business district or isolated from other people. If considering buying a home where you would like to live with a person with disabilities, look at nice neighborhoods which offer 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 person can’t do a particular thing, keep trying until you find something he/she can do. Remember, everyone has contributions to make to their community; it is up to us to find their talents.
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 wake up 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?” and “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 lives.

An important goal of all DSPs should be to provide people 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 Individual Support Plans that are developed, the way provider agencies operate, the staffing patterns (what staff do and when they do it), and especially the daily actions of the DSPs. Choice should occur naturally and should be expected without unnecessary restrictions. Many people entered supportive services with little to no choice. It is the DSP’s responsibility to promote personal choice by noticing likes, dislikes, and opinions as forms of choice.

**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 people 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 a person’s health and safety. This does not mean that the day-to-day choices or expression of hopes and dreams should be restricted. DSPs are responsible for encouraging choice and consulting with alternate decision-makers when unsure.

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 person’s day. There are many chances to make choices during the 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/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 a person 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 about healthy eating by talking about how many foods need to come from each container for the day. A person can plan meals daily. This can also be done with pictures of foods. Pictures may also be used in grocery shopping.

When planning trips to restaurants, go by the restaurant in advance to get a copy of the menu. Teach how to make choices before going into a social situation.

A person who does not use words to communicate can still make choices. Have him/her look at what he/she 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 communication while encouraging decision making.

**Personal choice and decision making: What’s your role?**

- For someone with limited or no verbal skills, DSPs 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 person you support.
- When you ask someone 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.”
- Find out what is important to a person from his/her perspective and write down what you learn about a person’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 person’s designated authorized representative or guardian if necessary.
- Help people to make choices in naturally occurring situations.
The Value of INDIVIDUAL RIGHTS

All people, no matter their ability, retain basic human rights. Like you, people 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 DSP, 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 director.

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

As an employee of a community agency providing supports to people 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 a person.
- Work with your supervisor and the person’s team to figure out acceptable risk with the person 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, and other personal records are going to be kept in a confidential manner. DSPs must remember to have this same respect for the private information about those they support. This includes health information that is covered by the HIPAA (Health Insurance Portability and Accountability Act). No one would like to think that their doctor or counselor openly discusses diagnosis, illnesses, or care plan at home or a party. While DSPs generally sign a confidentiality agreement related to employment, it is important to avoid sharing confidential information about the people being supported. Your agency will provide additional information about confidentiality and requirements related to sharing information.

Confidentiality: What’s your role?

- When accompanying someone to a doctor or dentist appointment, encourage him to speak for himself. If the doctor asks you questions, as if the person is unable to speak for himself, look at the person to answer the question. This is a teachable moment for both the person you support as well as the professional.
- When out in the community and seeing a friend, encourage the person you support 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 story about confidentiality:

Two DSPs, Sally and Megan, went shopping together after work. While at the mall, they stepped on the escalator and Sally asked Megan if she had remembered to tell the supervisor about an upcoming medical appointment for John, a person in the program. Megan exclaimed “no!” As they rode up the escalator, they discussed John’s medical condition and how he’s not been sleeping well. Having this conversation in public is disrespectful, put’s John’s confidentiality at risk, and could result in losing their jobs.

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