Orientation Manual for Direct Support Professionals (DSPs) and Supervisors: Supporting People in their Homes and Communities

Virginia Division of Developmental Services
Department of Behavioral Health and Developmental Services
July 2016
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Introduction

Working with people with disabilities is often described as "rewarding." Certainly approaching it with the right mindset and skill set will make it rewarding for you as a direct support professional and also for the people you support.

The purpose of this manual is to encourage you to think about and interact with people with disabilities in much the same way you do with people who do not have disabilities. People with disabilities have the same wants and needs as anyone else. Their needs are not 'special.' Like most of us, people with disabilities want to feel a sense of belonging, they want to make contributions, and feel useful and productive. They want to love and be loved. They want to govern their own lives, including where and with whom they work, live, and play.

"When you see, meet, or think about a person with a disability, presume competence."
-Kathie Snow

In order to be most successful, it is important to not only read the information in this manual and view the training slides, but also to discuss it with your supervisor/trainer 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 may begin to provide services offered through three waivers in Virginia: the Family and Individual Supports Waiver, the Community Living Waiver, and the Building Independence Waiver. However, the Division of Developmental Services (DDS) staff members hope that this is just the beginning of your learning process in how to become a great direct support professional. Please take every opportunity to learn more from other professionals and from people you support.

Thanks

The ***Orientation Manual for Direct Support Professionals (DSPs) and Supervisors: Supporting People in their Homes and Communities*** has been updated several times through collaborative efforts with Community Services Boards, private providers, direct support professionals, people with disabilities and their families, and others in the disability field. Thanks to all who developed information and provided guidance over the years to inform practices in Virginia. We greatly appreciate your time to help improve the training of those who come after you.

"What you do makes a difference, and you have to decide what kind of difference you want to make."
-Jane Goodall

Orientation Manual Sections

This Manual also contains helpful information in various blocks and images throughout. Be certain to read these sections, which contain a variety of points, stories, and additional resources you will find helpful.

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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 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.

Virginia’s Six Waivers

1) Building Independence Waiver
2) Community Living Waiver
3) Family and Individual Supports Waiver
4) Alzheimer’s Assisted Living Waiver
5) Elderly or Disabled with Consumer Direction (EDCD) Waiver
6) Technology Assisted Waiver

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:

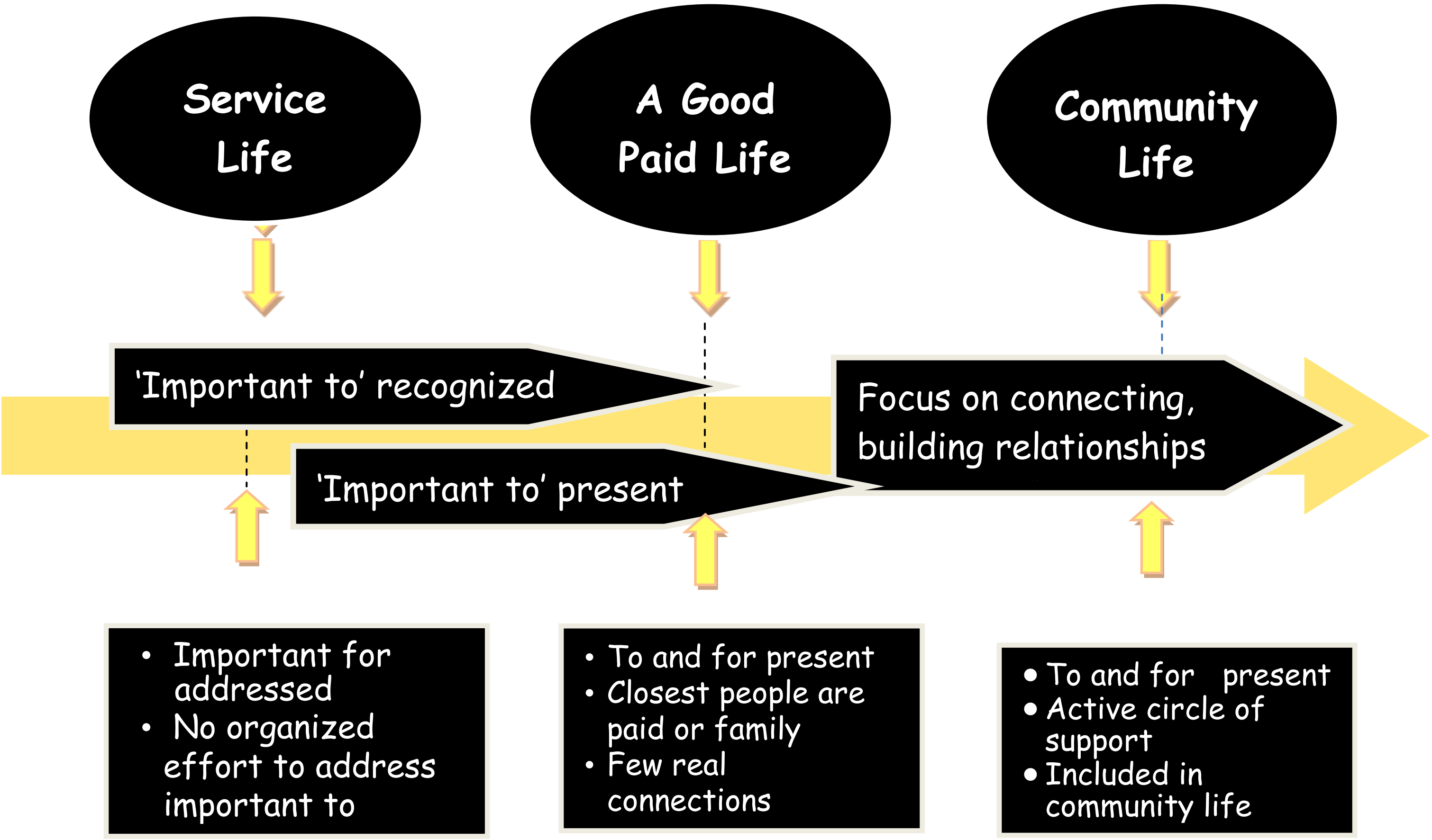
- Consider the wants and needs of the person first
- Realize everyone has talents
- Ask the person and those who know and love them for input
- Support a person’s self-expression, self-worth, self-reliance, and decision making
- Are flexible
- Listen to all people
- Respect all people
- Respond quickly 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."** [1]



Service Life

A Good Paid Life

Community Life

'Important to' recognized

'Important to' present

Focus on connecting, building relationships

- Important for addressed
- No organized effort to address important to

- To and for present
- Closest people are paid or family
- Few real connections

- To and for present
- Active circle of support
- Included in 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.

> ***"I have choices.***
> ***I am responsible for my choices.***
> ***I am respected."***

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.

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 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)**.

Read or listen to: ***A Credo for Support*** *by Norman and Emma Kuntz* for additional perspectives on support. See references for links.

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.

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.

> ***"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."***

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.

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.

Recommended Resource:

A Guide to Developing Community Connections by
Patsy Davies & Claudia Bolton
http://www.allenshea.com/CIRCL/connections.pdf

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.

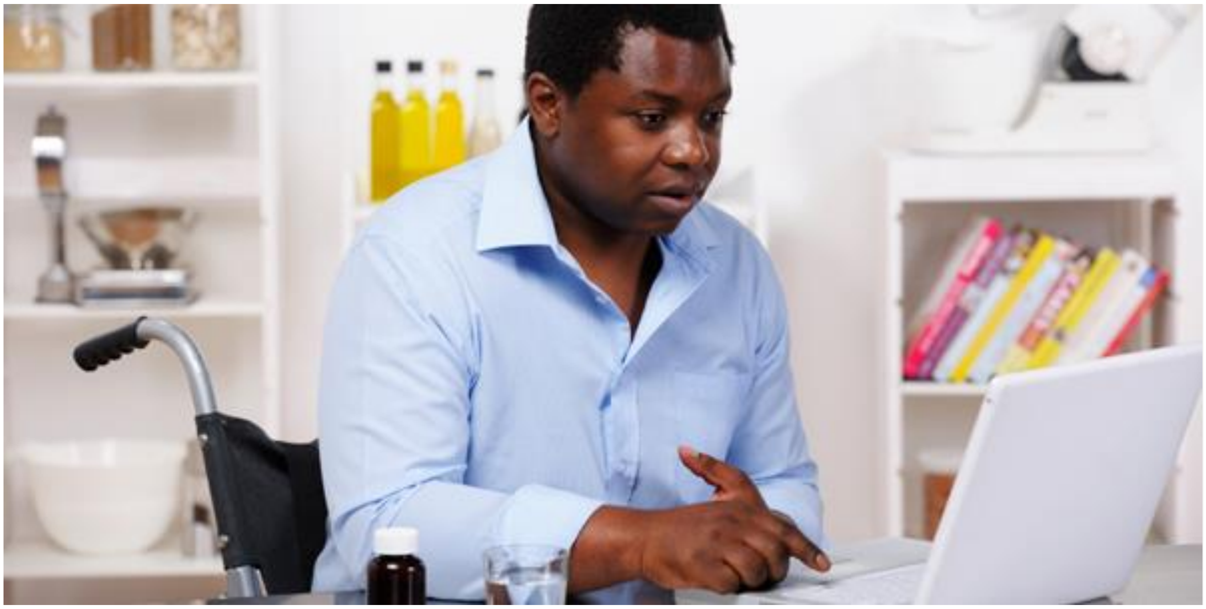
Any vocational activity used to prepare for a job is beneficial, as long as it is time-limited and has as the expected outcome of an integrated, community job. An integrated, community job is defined as *work providing a minimum wage or higher and related benefits in a typical work setting where the 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.

TRUE STORY

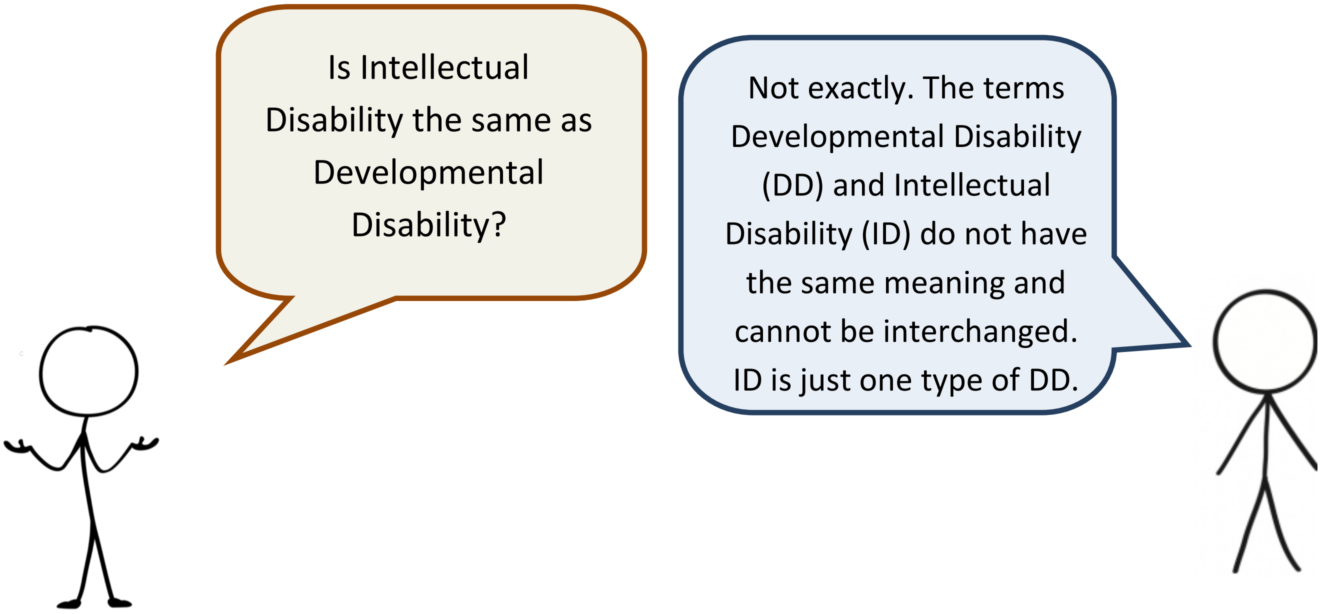
A story about confidentiality:
Two DSPs, Sally and Megan, went shopping together after work. While at the mall, they stepped on the escalator and Sally asked Megan if she had remembered to tell the supervisor about an upcoming medical appointment for John, a person in the program. Megan exclaimed "no!" 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.

SECTION II: INTRODUCTION TO DEVELOPMENTAL DISABILITIES

In this section, we discuss the definition of developmental disabilities, as well as some of the causes. While this information is important for a better understanding of the people 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 also discuss how you can become a **“roadblock remover”** for people you support.

Introduction to Developmental Disabilities



The Definition of Developmental Disability

The term **developmental disability** (as defined by the Developmental Disabilities Act and adopted by the Virginia General Assembly) means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental or physical impairments that are manifested before the individual attains age 22 and are likely to continue indefinitely. Developmental disabilities result in substantial limitations in three or more of the following functional areas:

- self-care
- receptive and expressive language
- learning
- mobility
- self-direction
- capacity for independent living
- capacity for economic self-sufficiency

An **Intellectual Disability** is a one type of Developmental Disability.

More about Developmental Disabilities

When we talk about developmental disabilities, we are talking about a variety of different conditions, which occur before individuals reach adulthood. For most developmental disabilities this age is 22, but for intellectual disability the age is before 18.

The term **intellectual disability** (as defined by the American Association of Intellectual and Developmental Disabilities- AAIDD) means a person has significant limitations in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. Thus disability originates before the age of 18.

People with *autism, cerebral palsy, and other mental or neurological conditions (seizures)* are also considered to have a developmental disability. Other developmental disabilities may be strictly physical, such as blindness or deafness from birth or childhood.

People with developmental disabilities may or may not also have an intellectual disability. Some developmental disabilities, such as Down syndrome, fetal alcohol syndrome and Fragile X syndrome, *almost always* occur with an intellectual disability.

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 an ID have no known cause of their disability.

Factors to Consider

On the basis of multiple evaluations, professionals can determine whether a person has a developmental disability and can make recommendations for supports for them.

In assessing and diagnosing disabilities, AAIDD stresses that professionals must take additional factors into account and consider things such as:

- the typical environment of the person’s peers without disabilities;
- language differences; and
- cultural differences in the way people communicate, move, and behave.

Assessments must also assume that:

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

Myths and Misconceptions

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

- 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.

- Disability is just one aspect of a person. It does not define them. Getting to know someone's personality, likes, dislikes, needs and desires along with understanding their disability is the best way to determine what supports may be needed. Having a developmental disability might mean needing supports to reach an outcome that a person without a disability might reach by himself.

- The presence of a developmental disability does not change the fact that someone 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.

People with developmental disabilities are ill or sick.

- A developmental disability is not an illness, and people living with developmental disabilities are not "patients" (unless they happen to be temporarily hospitalized). You cannot catch a disability.
- While developmental disabilities cannot be cured, individualized and age-appropriate supports are likely to enable people to reach their personal outcomes and increase their level of independence.
- Just like anyone else, a person with a developmental disability may or may not have conditions such as medical conditions, physical disabilities, or a mental illness.

People with developmental disabilities need specialized services to meet all of their needs.

- Each of us, including those of us with 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 person may not need support or assistance with a certain task, while another may require support to successfully complete the same task. Similarly, someone 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 a developmental disability can shop at the same store as people without a disability. They may or may not need support and assistance to do their shopping and money management.
- A person with a developmental disability who has a medical condition can be treated by the same doctor as a person without a disability who has the same medical condition. Persons with a developmental disability may or may not need 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.

Recommended Video*

Direct Support Professional Profile at ***https://www.youtube.com/watch?v=79_8lgkh_9c***

Recommended Video*

The Harley Story
https://www.youtube.com/watch?v=XWmcXHRMisU42/

***If you have difficulty with links, please type the title or link in your browser.**

Supporting people with developmental disabilities: What’s your **role**?

1. **Be a “roadblock remover”** See people as the people they are, not for the disabilities they have.
2. **Be creative, provide thoughtful support, and make the effort to figure out the best way to help people achieve their outcomes.** If someone 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 a 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 a person’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.” 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 means 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**. Think: “People with disabilities ***can*** . . .” --remove “***can’t***” from your vocabulary.
6. **Do not base your interactions or your attitude about a person on his/her history.** It’s true that a person’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 those 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. **Recognize that people with disabilities are lifelong learners.** Look for opportunities to provide new information or teach a new skill.
8. **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 someone, make your support as invisible as possible. Talk to and treat the person as you would a friend. Encourage them to be independent. The tone you set will teach others in the community that people with disabilities are capable and interested in having full, well-rounded lives, just like everyone else.

SECTION III: WAIVERS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

In this section, you will learn about the variety of supports and services that are available through Waivers and how people become eligible for Waiver supports and services. The assessment, planning, implementing, and documenting activities are also discussed.

Waivers for People with Developmental Disabilities

The three Virginia Medicaid Waivers that support people with developmental disabilities (DD) provide a way to pay for certain long term supports and services in communities with a mix of state and federal funding. Federal funding comes from the Centers for Medicare and Medicaid Services (CMS) and "waives" specific federal Medicaid requirements. Waivers have provided funding to allow many individuals who would have required institutional services to receive a variety of needed services and supports in the community.

Virginia's Waivers are built on the idea of individualized supports. Services are developed and funded based on a person-centered approach as discussed in Section I. Each person (with assistance if needed) chooses different types and levels of supports based on his or her desired goals, outcomes, choices and needs. Most services are agency-directed services, in which the provider agency hires staff to work with the person. Some are consumer-directed services (also known as self-directed), in which the person (or his/her family) employs the staff person. People can also use a combination of both agency-directed and consumer-directed services.

Virginia recently redesigned the Waivers for people with DD and there is now one process to qualify for and access supports and services. The redesigned Waivers:

- Provide more targeted, flexible, needs-based services;
- Create more choices and opportunities;
- Promote consistency, equity, quality and accountability across the waivers; and
- Increase flexibility in service design.

As presented in Section 1, three Waivers support people with DD:

- Community Living Waiver
- Family and Individual Supports Waiver
- Building Independence Waiver

The "Community Living Waiver" is a comprehensive waiver that includes 24/7 residential services for those who require that level of support. It includes services and supports for adults and children, including those with intense medical and/or behavioral needs.

The "Family and Individual Supports Waiver" supports people who live with their families, friends, or in their own homes. It provides support to people with some medical or behavioral needs and is available to both children and adults.

The "Building Independence Waiver" supports adults 18 and older who are able to live in the community with minimal supports. This Waiver does not include 24/7 residential services. People using this Waiver own, lease, or control their own living arrangements.

Waiver Services

Waiver services are divided into the following categories:

- Employment and Alternate Day Options
- Self-directed and Agency-directed Options
- Residential Options
- Crisis Support Options
- Medical and Behavioral Support Options
- Additional Options

Each of the options contain multiple services which are available in one or more of the DD Waivers. Information about these services is available from your supervisor. It is important that you know about the variety of supports that are available so that you can assist in planning for each person you support. **You can refer to this document or other agency documents as needed to become familiar with the array of service options rather than trying to remember all of them.**

<u>Employment & Day Services</u>
Individual Supported Employment Group
Supported Employment
Workplace Assistance Services
Community Engagement
Community Coaching
Group Day Services

<u>Residential Options</u>
Independent Living Supports
Shared Living
Supported Living
In-home Support Services
Sponsored Residential
Group Home Residential

<u>Self-Directed and Agency-Directed Options</u>
Consumer-Directed Services Facilitation
Personal Assistance Services
Respite
Companion

<u>Crisis Support Options</u>
Community-Based Crisis Supports
Center-based Crisis Supports
Crisis Support Services

<u>Medical & Behavioral Options</u>
Skilled Nursing
Private Duty Nursing
Therapeutic Consultation
Personal Emergency Response System

<u>Additional Options</u>
Assistive Technology
Individual and Family/Caregiver Training
Electronic Home-Based Services
Environmental Modifications

All services aren't available in all three DD Waivers. Ask your supervisor more about these options.

USING Waiver Supports and Services

Eligibility for Waiver Services

In order to be eligible for services funded through Waivers, a person must meet the following criteria:

- **Have a diagnosis of developmental disability,**
- **Meet Medicaid financial eligibility,**
- **Meet the Level of Care Criteria as determined by the Virginia Individual DD Eligibility Survey (VIDES)**, and
- **Accept services within 30 days.**

The criteria for Waiver eligibility include: diagnostic, financial, and functional.

Eligibility Determination and Slot Assignment

In order to use services through the Waivers, a person needs to be determined eligible for services and assigned a slot. There are a limited number of slots and everyone who is eligible does not get to receive services right away. If a slot is not available, the SC determines the individual's priority needs level and places the person's name on the waiting list via Virginia Waiver Management System (WaMS). A Critical Needs Summary documenting the person's level of urgency is also completed by the SC.

The DDS electronic service authorization system is called WaMS (Waiver Management System).

When a slot becomes available, the DBHDS-supported regional committee will assign the slot to the person on the waiting list who is found to have the greatest need for services.

Determination of Support

When someone is determined eligible and a slot is available, the level of support needed is assessed. A tool that is used to determine individual support levels is the Supports Intensity Scale® (SIS) The SIS® measures support needs in the areas of home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy. It is administered by qualified, trained interviewers.

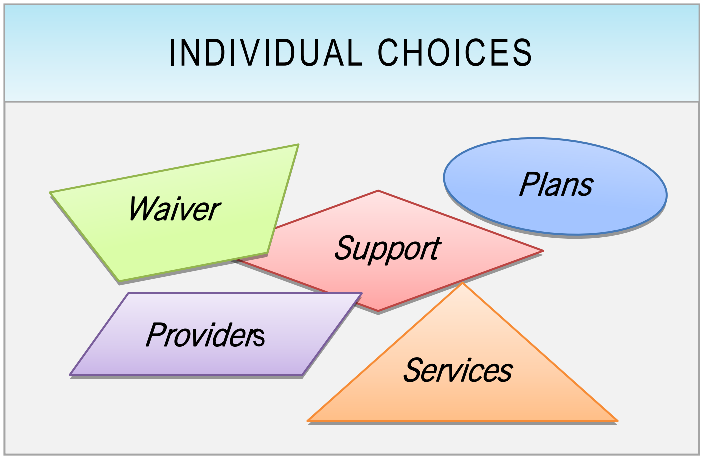
Support Coordination

Each person who is enrolled in a Waiver is assigned a support coordinator (SC). SCs work for or contract with the CSB that serves the area in which the person lives. The SC is responsible for linking the person with service providers, as well as coordinating and monitoring the services. The SC, Waiver service providers, the person's family members and others he/she chooses, meet together to help him/her develop an Individual Support Plan (ISP).

Choice

Eligible individuals for whom a slot is available must be allowed to choose:

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



Considerations in Community Settings

The Home and Community-Based Services (HCBS) settings regulations became effective in March 2014. The regulations are designed to enhance the quality of HCBS, provide additional protections, and ensure full access to the benefits of community living. They establish requirements for the qualities of settings where individuals live and/or receive Medicaid-reimbursable HCBS services. The rules focus on the quality of individuals' experiences so that people receiving Medicaid-funded HCBS have services that protect individual choice and promote community integration.

Service Authorization

All Waiver services must be authorized by the Division of Developmental Services (DDS) prior to the start of services. The SC must review service providers' service plans (called Plans for Supports) to ensure that the plans match what was decided at the planning meeting. The SC 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 and Support PLANNING

Assessment

All Waiver services must be delivered according to the written Individual Support Plan (ISP). The ISP 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).

*The Individual Support Plan is person-centered and addresses what is **important to** and **important for** the person. Desired outcomes and supports in important life areas, including work, home, community, and recreation are identified and included in the plan.*

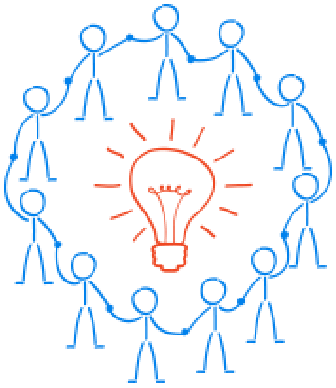
In some instances, a person may have difficulty communicating. In these situations, much of the information may be provided by the SC and/or family on behalf of the individual, particularly if he/she is new to a provider. Once a person is receiving supports, a great deal will be learned about the person 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 ISP – especially the "Personal Profile," which is a personal description of the person to help the team focus on what's important to the person, what needs to stay the same, and what needs to change for the person to have a good life.

Standardized Assessment for Virginia

Each person using Waiver services is assessed using the "Supports Intensity Scale" ® (SIS). This scale is completed every three years with the person and other people who know him/her well. This instrument gives service providers consistent information about the people they support. In addition, each person using Waiver services will have a "Risk Assessment" (which is part of the SIS) completed annually to determine health and safety needs and help plan supports for especially serious medical and/or behavioral issues. You may be asked questions about people you support in order to help complete one of these assessments.

Planning Team



The ISP is developed by a team with the person at the center of planning. Other members of the team include family members, guardian/authorized representative (if there is one), friends, SC, and service providers. The team must meet at least once a year to develop the ISP for the next 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 person) present what they've learned 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 provider develops a Plan for Supports with the person to address the outcomes that they agreed to at the meeting for their service area. In this way, the supports and activities that lead to reaching the desired outcomes are discussed and become a part of each Plan for Supports. A Plan for Supports is based on the role that each service fills in the person's life. For example, a group home (or residential) provider might not help the person learn a job, but would help him/her to meet more people in the neighborhood or become a better cook. Each Plan for Supports becomes a part of the larger ISP.

Integrated Supports

This work is part of a larger overall effort pertaining to system redesign to improve services to people with DD in Virginia and will become a part of the overall planning process. Several of the concepts underlying the planning tool are inspired by LifeCourse principles and related work from the University of Missouri – Kansas City (UMKC). Many of the materials are available for download at http://www.lifecoursetools.com/.

Person Centered (quarterly) Reviews

The Plan for Supports must be reviewed in writing once every three months to make sure it is still working for the person. This review looks at whether services are being delivered as described in the Plan for Supports, how well they support the person 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 SC for his/her review.

Documentation

Each provider must maintain documentation that shows:

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

Formats and styles for this documentation vary from agency to agency. Recommended formats are available on the DBHDS website. Specific requirements for the agency where you work will be explained to you by your supervisor.

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. Some agencies use Electronic Health Record or "EHR" systems of documentation, so you could be using a computer to document your work.
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 people you support. You are responsible for providing services as outlined in the plan and recording 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 person 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. Include ideas you have in your documentation. As you get to know an individual, share with your team or your supervisor your ideas for changes or improvements to the Plan for Supports, 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.

SECTION IV: COMMUNICATION

In this section, you will learn more about communication. The types of communication, pitfalls in communicating, and the use of behavior to communicate are discussed.

Communication

We usually think of communication as speaking or writing, but the definition of communication also includes information back and forth between people through a system of signs, or behaviors like gestures, body language and actions. Actions are things like 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.

Everyone communicates in some way. Some people use words to communicate, however, we do not need to use only words to communicate. We use behaviors to 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 broccoli and she makes a grimace or spits them out, that person is communicating that she does not like it. If you give a person ice cream and he smiles and gestures for more, he is communicating that he does like it. People may communicate through signs, symbols, behaviors, or by using an iPad or other assistive technology. Although some people may not use words to communicate, it does not mean that they cannot understand what others are saying. Intellectual or physical challenges may be the reason some people lack the ability to talk, but it does not mean that they do not understand what's happening around them.

TYPES of Communication

Communication works two ways: 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

Some people have trouble using words to communicate because of physical (e.g., a hearing or motor 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. Sometimes a brain injury can affect someone's ability to communicate. People's ability to speak language can appear at any age; therefore we should not assume language stops developing at a certain age.

As a DSP, you need to pay close attention to all forms of communication. People who communicate without using language usually develop a way to express their likes and dislikes, ask for things and show pleasure, displeasure, pain, or unhappiness through movements and behaviors. Sometimes, it can be hard to figure out what someone is trying to communicate, and you need to think like a detective to decode what they are trying to say with their behavior.

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. Sometimes this requires you to stop what you are doing to pay attention and to listen to what someone may be trying to say.
2. **Do not insist on eye contact.** Although someone may not be looking at you, they may be understanding to every word that you saying. Do not assume that because someone is not looking at you, they do not know what's happening. Even if someone does not look like they are paying attention, it's important that you not hold a conversation that ignores them, or speak about them as if they are not there.
3. **Pay close attention to gestures, facial expressions, vocal sounds and movements used by the people you support.** Remember that "actions speak louder than words." Even people who use words to communicate will use other ways to get their point across. Sometimes what they say is not really what they mean. Be observant, watch for patterns and share what you have learned with your co-workers.
4. **Talk to the person's parents, family members, and friends**. Chances are someone understands 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. Speak just as though you are speaking to your boss, a neighbor, or someone you care about.
6. **Ask questions.** This helps you gather information and shows you are interested in what the person is saying.
7. **Avoid asking accusatory "why" questions.** Some "why" questions can make people defensive or feel that you disapprove. For example, asking someone, "Why are you sitting there when I asked you to get in the car?" sounds negative and authoritarian.
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.** Somethings take a lot longer when you are a person with a disability. Allow the person some time to figure out what you have said before you continue talking. Some people need several seconds between each sentence.
10. **Keep things positive**! Ask people what you want them to do, NOT what you don't want them to do. For example, "Show me how you can keep your seatbelt on for the whole trip" is better than saying, "Don't unbuckle your seatbelt."

Pitfalls to Avoid When Communicating

1. **Do not shout.** Speak in a normal tone, as you would to your boss or someone you know. Some people with disabilities are hearing impaired, but most are not. Loud voices can be startling for some people. If you have a loud voice, be aware that you may need to lower your volume.
2. **Do not talk or act like a parent.** If you were asking your boss for something, would you yell out an order? Ask the person to perform a task. Become a role model using good manners. Do not issue orders. Treat people with respect regardless of age or ability.
3. **Do not say you understand if you do not.** That will only frustrate the person. Apologize and remind them that you are trying to understand them and do not give up. Ask a co-worker or someone who knows the personwell for assistance.
4. **Do not rush the person.** Some people take longer than others to form their thoughts and words. Give the person more time to process what you are saying before asking again.

The Role of Behaviors in Communication

A person's behaviors, even ones that we don't like, are attempts to communicate. If you can't make yourself understood, or to feel that no one is paying attention to your requests, you might become so frustrated that you use challenging behaviors. 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 to words and behaviors and help the people you support find appropriate ways to express themselves about things that stress and frustrate them.

Behavior and communication: What's your **role**?

1. **Be a detective. Think about why the person might be exhibiting challenging behaviors.** Is he/she trying to tell you that they are frustrated, in pain or bored? Put yourself in the person's shoes.
2. **Respect that all people 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 to let others know when you didn't want to do something?

TRAVELER
SCHWINN

SECTION V: POSITIVE BEHAVIOR SUPPORT

This section provides introductory information about Positive Behavior Support by discussing some principles and practices which have been effective in supporting many people with developmental disabilities. The Positive Behavior Support planning process and how people use behavior to communicate are also discussed.

Positive Behavior Support

Positive Behavior Support (PBS) is a person-centered approach to addressing challenging behavior by changing the surroundings and support, while teaching the person new skills to better communicate and provide more choice and control over his/her life. PBS is the preferred approach adopted by the DBHDS to ensure people have supports to be successful. Rather than eliminating difficult behaviors, PBS stresses personal growth with the end result being an improved quality of life for the person. Minimizing problem or challenging behavior is a secondary goal. More training about Positive Behavioral Support practices may be obtained from your agency or DBHDS staff.

Definition of Positive Behavior Support:
PBS is an approach to behavior support that includes an ongoing process of research-based assessment, intervention, and data based decision making. It is focused on building social and other functional competencies, creating supportive contexts, and preventing the occurrence of problem behaviors.

PBS relies on strategies that are respectful of a person's dignity and overall well-being, and that are drawn primarily from behavioral, educational, and social sciences, although other evidence-based approaches may be incorporated.

PBS may be applied within a multi-tiered framework at the level of the individual and at the level of larger systems (e.g., families, classrooms, schools social service programs and facilities) (Kincaid, Dunlap, Kern, Lanye, Bambara, Brown, Fox & Knoster, 2016).

It's important to note that PBS is committed to positive approaches that are not punishing or unpleasant and to strategies that are respectful of a person's dignity and their overall well-being. Those who use PBS strategies should look at everything that supports the person, at home, at work, and in the community to be sure that all strategies used are respectful to a person with behavioral needs and the staff who support him/her.

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

People 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.

All Behavior is Communication

Some people with disabilities 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 (See Section IV). This may lead to expressing those needs by using behaviors that appear unusual or disturbing to others. In the past, people who had difficult behaviors 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 someone choice and control over their own life often minimizes challenging behaviors, which is why using a person-centered approach is one of the foundations of PBS. Teaching positive behavior in someone’s home, work, or other community setting is a better way to help him/her learn ways to communicate that others will understand.

In order to be successful with behavioral supports, staff **must** treat people with dignity and respect. Support staff must view behavior as a way for the person to control and direct his or her own life. If the desire for personal choice and control is not respected, the result may be someone has learned negative behaviors in order to gain some control. If this has gone on for a long time, it can be very challenging for staff and others who live and work around the person.

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. A person who is worried about their safety and not sure what’s going to happen next may use difficult behaviors to express fear or anxiety. Some problem behaviors are a 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. For some, simply providing a few minutes of individual focused attention may eliminate a need for attention from staff. Reasons for behavior are as unique as individuals. If we are to support people in successfully reducing challenging behaviors, we must first do our best to know each person and what is happening in their lives.

Positive Behavior Support Plans

A positive behavior support plan looks carefully at someone's behavior and figures out what might need to change in his/her schedule or home or work environment. It will provide information about how you should support them and respond when the behavior occurs. It also determines what new behavior the person could use to get what he/she needs and wants, and how to teach the person the new, acceptable behavior. Positive behavior support plans are designed to help all of the staff in the person's life to respond in the same way. Just as you may not like the same things day after day, PBS plans need to change over time to meet the person's needs in order to remain effective.

Writing a Behavior Support Plan will not be one of your responsibilities as a DSP. However, the professional who does develop the PBS plan will need to seek your help in trying to figure why the behavior is occurring. If you regularly support the person, you may be an expert on the ways he/she behaves, and ***your input is extremely valuable*** to the person who is developing the plan. You may be asked to provide some information in order to help pinpoint the purpose of the behavior and when the behavior occurs. You should think about:

- what is going on around the person at the time?
- who else is present?
- what happens immediately after the behavior occurs?

Other Important Things to Remember about Challenging Behaviors

There are certain behaviors that may be irritating to us, but, sometimes, if a behavior does not harm anyone, it may be best to ignore it.

Some people with disabilities lead extremely lonely lives. Can you imagine what your life would be like if you had no one in your life who was available to listen to you or provide you with attention? It's very important that everyone knows that there is some time in each day where they can receive unconditional attention. Providing people with attention may eliminate their need to use negative attention-getting behaviors.

When behavior places anyone 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.** Discipline is intended to teach, not punish. When a dangerous behavior is happening, it is not a teachable moment! It's more important for everyone to be safe and calm.

Some things that you can do to best support people who are expressing themselves using unusual or disturbing behavior are listed on the following two pages.

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. Be respectful of those you are supporting, and show them that there are ways to express frustration without being disrespectful.
2. **Be a good observer.** As a DSP, you will have the most contact with the person and will generally be the first to notice changes in behavior or behaviors that are interfering in a person's life. Your input is extremely valuable!
3. **Keep good documentation**. Your observations of what's happening before and after the challenging behavior are critical in determining why the behavior occurs. Write down accurate, factual information about patterns of behavior: times, places, surrounding events, what happens after the behavior. In our example of Bob, staff might be making notes such as:

   "At first Bob would not 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 someone effectively, the same teaching strategies must be used by all staff members and others involved in the person's life. In addition, behavior plans must follow human rights guidelines. By carefully following behavior support plans, you help make sure that the person's rights are protected and that the new, positive behavior is successfully taught. Be sure to tell the person who developed the plan if it seems too difficult or complicated. It's important that the plan is designed so that you understand it and can carry it out. Make it a point to tell supervisors about what works and what does not work in the PBS plan.
5. **Be a good communicator.** If someone communicates with words, listen to what they tell you about their choices with words and behavior. If they 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 be necessary.
6. **Be supportive and respectful.** The people you support 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 person'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 someone 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 person's ability to become a valued, participating community member. The Arc of Virginia reminds us that people with intellectual disabilities deserve "A Life Like Yours" and have abbreviated that by using the acronym ALLY.
8. **Assist people with improving their quality of life**. Look at people's lives to see if they have opportunities to make friends, participate in activities they like, and take on new challenges. Find ways to help each person increase those opportunities. For example, try going with someone to join a club that focuses on his or her interests.
9. **Point out positive actions**. The people you support might make choices you don't agree with at times. Focus on helping people notice the positive effects of certain actions. Praise someone who has just combed his hair to a mirror and point out how good his hair looks. In time, he may go to the mirror alone and note whether the grooming was successful.

Read: ***10 Things You Can Do to Support a Person with Difficult Behaviors*** by David Pitonyak (http://www.dimagine.com/10things.pdf)

SECTION VI: HEALTH AND SAFETY

In this section, you will learn how to support people to maintain their safety and health, get good nutrition, and understand the importance of personal hygiene and regular medical and dental care. You will also learn about how to watch for eight health conditions that need special attention.

Health and Safety

As a DSP, you have important responsibilities for health and safety in home and community activities. Your agency will provide you with the processes that are used in day-to-day health and safety issues and what to do in case of an emergency. Additionally many health and safety issues will depend on the type of program in which you work. For instance, DSPs who support people in *employment and alternate day options* and *residential options* play a vital role in carefully observing people and in reporting any changes in their behavior, appearance, or habits that may relate to health and safety. Residential staff members often have the additional responsibility of arranging for and accompanying people to doctor or dental appointments. All programs have written guidelines to follow for health and safety and emergency situations and have procedures for reporting critical incidents. As a DSP, become familiar with all agency protocols.

In addition to the information in this section, you will likely receive First Aid and CPR training, as well as health and safety training related to your specific agency, to assist you in helping people stay healthy and safe. You may also receive training and be tested in procedures for safe administration of medication. This chapter is not intended to replace that training. Your role is to help the people you support be safe in all situations, access quality health care when they need it, assist them in learning and using skills that maintain health and safety, and help them to be aware and informed regarding their own health and safety concerns.

Maintaining Good Health through Good Nutrition

People with disabilities have the same needs for good nutrition and proper weight management as people without disabilities. Since 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 people you support, your role may vary. You may help people plan nutritious and well-balanced meals, oversee meal preparation, monitor and encourage appropriate amounts of foods, and/or assist in making healthy food choices when dining out.

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

Get More
INFORMATION

on good health through good nutrition go to: www.choosemyplate.gov

Important Point:

As a DSP, it is important to resist the temptation to reward or coax the person you support with food. Food should never be earned, and the people you support may 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, which leads to positive experiences such as a:

- a short walk around the neighborhood,
- a telephone call to a relative or friend,
- positive verbal praise,
- an opportunity to talk one-on-one, or
- a short shopping trip.

Safety: What's your **role**?

- **Know safety policies and procedures for people you support and your agency.**
  - Learn each person's needs regarding safety.
  - Know needs related to specific conditions such as mobility, vision, and hearing of the people you support.

Good Nutrition: What's your **role**?

1. **Know the medical and social history for all people you support.**
   - Who is on a special diet and why?
   - Who has food or other allergies and what are they? How do you respond to a reaction?
   - Make sure you know where this information is located.
2. **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.
3. **Monitor what and how much someone 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.
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.

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, we are more likely to be seen in a positive manner.

Important Point:

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

It is possible that you will support some people who need reminders or guidance to maintain their personal appearance. Depending on needs, your assistance could range from physically bathing to helping someone shop for attractive shirts that are appropriate for his new job. Some may need reminders to bathe themselves, shampoo their hair, shave, brush their teeth, or use the toilet. Others may need you to do many hygiene tasks for them, such as changing a disposable brief or putting on deodorant.

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 participation 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 reduced rates for low income patients.
3. One of the people 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.
4. A man you support 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 people enjoy a healthy life. Typically, appointments are scheduled and residential staff or family members accompany the person. It is important to work closely with each person's primary care physician and other medical and health professionals to make sure regular routine tests and screenings are completed. DSPs often play an important role in communicating to the health professional what someone might be experiencing.

All DSPs should be on the lookout for changes in appearance or behavior that may indicate some symptom of illness. Some people may not be able to fully communicate what they are feeling (physically and emotionally). It is important 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.

Be on the
Lookout for these !

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

B. Changes in Appearances

1. Weight gain or loss
2. Condition of skin (pale, sweating) or hair (unusually dry/oily, falling out)
3. Eyes appear watery or are itchy/red
4. Skin 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 someone (previously energetic person appears tired or a typically quiet person talks nonstop).

KNOW THE PROCESS FOR REPORTING CHANGES TO YOUR SUPERVISOR AND WHAT TO DOCUMENT IN YOUR NOTES.

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 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 for diagnosing a health condition if one exists.
2. **Get a perspective on the person's history.** If you are new to supporting someone and note changes or have concerns, speak to your supervisor, a co-worker or another person who knows the person well.
3. When in doubt, and if symptoms persist**, a doctor should be called!**

Medication and Side Effects

If you work for an agency licensed by DBHDS, you will complete training and testing in the required Medication Administration Procedures before administering medications. This is a course approved by the Virginia Board of Nursing. The safe and accurate administration of medications is one of the most important duties you will perform as a DSP. Medication errors can cause great harm or even death. Therefore, it is essential that, when giving either prescription or over-the-counter medications, you follow the procedures and safeguards you will be taught in this required course.

Important Point:

As someone who spends a lot of time with people using supports, you or your supervisor will 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 filled at one pharmacy to prevent the risk of a negative reaction between two different medications. Pharmacists can review all medications when a new medication is prescribed, since different doctors can prescribe medications for the same person.

Some people take multiple daily medications. All medications can 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, people on more than one medication may experience symptoms related to the interactions of their medications.

As a DSP, you should become familiar with how medications affect the people you support. Side effects are sent by the dispensing pharmacy and are maintained in each person's Medication Administration Record (MAR). In addition to the known side effects, the changes in daily behavior and patterns described above 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 people alone. This will enable you to react appropriately and possibly to save someone's life while medical care is on the way.

During a health or medical emergency (for example if a person stops breathing, has serious bleeding, becomes unconscious, or has other serious symptoms) be sure to follow your agencies emergency procedures including contacting administrative staff.

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 you support. Call 911 at the first sign of a medical emergency!

Other Health Concerns

In addition to the potential for illness and injury, you may find yourself supporting people with ongoing health conditions including (but not limited to) seizures, diabetes, Alzheimer's, sleep apnea, arthritis, heart disease, visual/hearing impairments, food/drug allergies, and concerns affecting their freedom of movement. All DSPs are responsible for being aware of and knowledgeable about the signs and symptoms of the health conditions of those you support.

Important Point:

It is essential that DSPs 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.

Each staff member should also be aware of mobility or freedom of movement issues. Information regarding these concerns should be available - along with ways to support someone who is at risk of falling in their daily routine. These supports should be included in the instructions as part of their Plan for Supports.

Exercise

Along with regular medical care and good nutrition, exercise is another important element for a healthy life. Many people 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 explore physical activities the person enjoys doing and find ways to include in their daily routine.

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 a daily routine that can be creative and interesting. Some ideas are:

- Visit a nearby school and walk around the track.
- Find a local park with walking trails and other attractions and do a combination of walking and sightseeing.
- Plant and maintain a small garden.
- Grocery shop (pushing the cart and reaching for items from shelves).
- Dance.
- Join a gym and take classes or use the equipment.
- Do household chores together while listening to music to keep moving.

! Important Point:

Always check with the person'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 abilities. Assistive technology allows us to function with more independence, provides more choices, and results in 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 people with disabilities; they can make life easier for anyone.

Examples of assistive technology that enable people to carry out daily 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. There are also assistive technology communication devices that provide assistance when people who do not communicate using words. The device can include speech, gestures, sign language, symbols, synthesized speech, dedicated communications aids, or microcomputers. As a DSP, learn how to properly use any specialized equipment so that you can provide assistance as needed.

Assistive technology benefits all of us as we age. It may be a key element in helping people remain in their home and community as they age. It also helps maintain as much independence as possible, as 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 person's coordinator, or family member. It is possible that the needed item may be available through Medicaid or Medicare.

IMPORTANT Health Conditions for People with DD

There are **8 health issues** that are often overlooked and need to be more carefully monitored. These conditions can progress rapidly and result in bigger problems, even death. They include:

1. **Skin Care (pressure sores; skin breakdown)**
2. **Aspiration Pneumonia**
3. **Falls**
4. **Urinary Tract Infections**
5. **Dehydration**
6. **Constipation and Bowel Obstruction**
7. **Sepsis**
8. **Seizures**

General process for you to follow if changes in the body are noted:

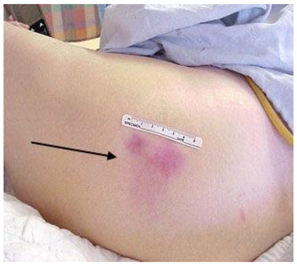
- Call 911 if there is an emergency.
- Immediately talk with your supervisor about the change you are observing.
- Follow all agency/program policies and procedures for contacting medical professionals, reporting medical issues, and documenting medical conditions.

Skin Care

Healthy skin aids in regulating body temperature, protecting internal organs from injury and environmental elements, and protecting against infection.

Signs and symptoms of possible skin problems include, but are not limited to:

- Unusual or abnormal color (pale, pink, red, or bluish);
- Rashes, cuts, open sores, raised bumps, blisters, bruises;
- Changes in skin temperature (such as moist, hot, or cool to the touch); and
- Parasites.



Your role if signs or symptoms are noted:

Whenever skin issues are noted, medical staff should be notified immediately and the reporting and documentation procedures for your program followed. Be sure to report any signs of skin breakdown or pressure sores or ulcers immediately to your supervisor.

- **Pressure sores** are areas of skin damage resulting from a lack of blood flow due to pressure, friction, or pulling on the skin (skin that gets worse over time, blisters, pain, itching, and crater-like appearance).

Preventing skin breakdown:

- Use adaptive items such as water or air mattresses, foam mattress pads, chair cushions, gel cushions, heel and elbow protectors;
- Close daily inspection of skin to detect early redness or discoloration;
- Prevent friction during lifting and re-positioning;
- Provide good skin care (skin clean and dry); free from moisture, urine, stool, and wound drainage – minimize skin exposure to moisture – avoid harsh scrubbing/rubbing of skin;
- Ensure frequent repositioning – if using a wheelchair assist in shifting weight every 15 minutes;
- Encourage activity;
- Protect bony areas with soft material; and
- Apply moisturizer to dry skin areas.

People at risk for skin breakdown include, but are not limited to, those who:

- Use a wheelchair or who are in bed a lot of the time;
- Require assistance when moving;
- Have loss of bowel or bladder control;
- Have poor nutrition and hydration;
- Have problem sensing pain or pressure;
- Have limited ability to communicate;
- Have circulatory problems; and/or
- Are older adults, or are obese or very thin.

Aspiration Pneumonia

Aspiration pneumonia is an inflammation of the lungs and airways to the lungs from breathing in foreign material. **Aspiration pneumonia develops from inhaling food, vomit, liquids, or saliva into the lungs**. This may occur when someone has difficulty swallowing and has watery eyes or coughing while consuming food or fluids.

<u>Signs and Symptoms</u> of aspiration pneumonia include, but are not limited to:

- Chest pain,
- Cough,
- Fatigue,
- Nausea,
- Fever,
- Shortness of breath, wheezing, and
- Bluish discoloration of the skin caused by lack of oxygen (e.g., mouth, nail beds, finger tips).

<u>Your role</u> if signs or symptoms are noted:

<u>Medical staff should be notified immediately</u> and reporting and documentation rules for your program followed. Be sure to report any signs of aspiration pneumonia immediately to your supervisor.

<u>Preventing</u> aspiration pneumonia:

- Correct position while eating and sleeping;
- Correct diet texture and fluid consistency to meet the person's needs;
- Good hand washing and respiratory hygiene;
- Not attempting to assist with meal if sedated;
- Up-to-date vaccinations and seasonal flu shots; and
- Healthy diet and adequate fluids.

<u>People at risk</u> for aspiration pneumonia include, but are not limited to, those who:

- Are less alert due to medicines or illnesses;
- Have a disorder of the esophagus (the tube that moves food from the mouth to the stomach);
- Have problems with swallowing;
- Have poor gag reflex;
- Have a Gastrostomy Tube (G-Tube);
- Vomit frequently;
- Are older

Falls

Falls refer to any situation in which someone descends (or falls) suddenly and involuntarily toward a lower surface or the ground. Fall risk is important to address as 1 in 3 older adults fall daily. Fall complications can include broken bones, head injuries, problem with daily activities, and need for home health care.

Factors that contribute to falls include, but are not limited to:

- Health issues and medication;
- Being shoved or running into a barrier;
- Cluttered rooms, area rugs, wet or slick surfaces, improper lighting;
- Wet or slick surfaces without non-skid footwear; and
- Lack of appropriate medical adaptive equipment, inappropriate footwear.

Your role if someone falls:

Once a fall occurs don't attempt to move the person until you have assessed him/her to see if there may be a fracture. Call 911 if you suspect injury, continue to monitor, and consult with a physician if the person starts to have frequent falls. No matter how minor the fall may be, remember to document and **REPORT ALL FALLS** as required because signs and symptoms of injury/fracture may not appear immediately.

Prevention of falls:

- Plan space so that it is well lit and without obstacles;
- Ensure people have appropriate adaptive equipment for mobility and vision (such as grab bars, walking cane, or walker);
- Make sure that regular medical checkups are scheduled (i.e., primary care physical, optometrist);
- Ensure use of non-skid shoes when in the bathroom or other areas where surfaces are slippery;
- Monitor medications and look for side effects;
- Provide adequate time for moving from place to place and walk at his/her own pace; and
- Lock wheels on wheelchairs and/or beds when transferring.

People at risk for falls include, but are not limited to those who:

- Are older and have loss of muscle;
- Have arthritis, diabetes, and skeletal problems;
- Have visual and/or hearing loss;
- Take medications that cause gait concerns; or
- Do not have appropriate adaptive equipment.

Urinary Tract Infections

A UTI is an infection of the urinary tract, which is the body's system for removing wastes and extra water. Women are more susceptible than men due to their anatomy and reduced bladder function later in life and symptoms vary by age and gender.

There are **two different types of UTIs** – the **lower UTI** relates to infections that occur in the urethra (a short narrow tube that carries urine from the bladder out of the body) and bladder – and the **upper UTI** is more severe and relates to infections that may involve the kidneys.

Lower UTI symptoms include, but are not limited to:

- Pain or burning during urination;
- Increased frequency, urgency of urination, incontinence;
- Lower abdominal, pelvic or rectal pain or pressure;
- Confusion, behavioral changes, increased falls;
- Mild fever or "just not feeling well;" and
- Changes in urine (such as milky, cloudy, bloody or foul-smelling).

Upper UTI symptoms develop rapidly and may not include the symptoms for a lower UTI and **require emergency care.** Symptoms include, but are not limited to:

- Fairly high fever (higher than 101F);
- Shaking chills;
- Nausea;
- Vomiting; and
- Flank pain (pain in the back or side, usually only on one side at waist level).

Your role if symptoms are noted:

People with UTI symptoms should see their health care professional as soon as possible or go to an emergency department for an evaluation. You should immediately notify your supervisor and follow your agency's documentation rules.

Preventing UTIs

- Drink plenty of fluids,
- Do not postpone urination – urinate when you feel the need,
- Keep genital areas dry and clean,
- Change clothes when incontinent
- Consider cotton underwear and avoid wearing tight pants
- Wipe from front to back to avoid introducing bacteria into the vagina or urethra, and
- Decrease length of time that catheters or tubes are placed in the urethra or bladder and change on schedule if prolonged use is needed.

People at risk for UTIs include, but are not limited to, those who have:

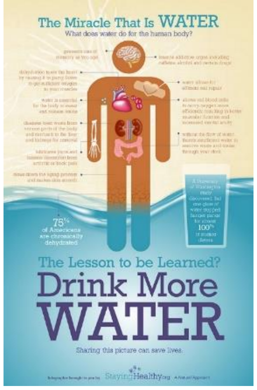
- Incontinence of bowel or bladder,
- Limited mobility,
- Extended periods of catheterization (a tube inserted into a person's bladder for urine drainage),
- A suppressed immune system, or
- A spinal cord injury or other nerve damage around the bladder that causes the bladder not to completely empty (which allows bacteria to grow).

Dehydration

Dehydration occurs when we lose more fluids than we are taking in. The lack of water in the body may result from either a decrease in fluid intake or an increase in fluid loss. 75% of our body weight is water. Water helps transport waste, supports tissue and cell hydration and helps regulate your temperature. Dehydration can be an important factor in illness and even death. Diarrhea and vomiting are the most common reasons why someone loses excess fluid.

Dehydration symptoms include, but are not limited to:

- Urine is concentrated and more yellow,
- Dry mouth and nose,
- Dry skin,
- Decreased tear production,
- Headache,
- Dizziness,
- Sleepy or tired, and
- Light headed (especially when standing)



SEVERE dehydration symptoms can include, but are not limited to confusion, lack of sweating, little or no urination, weakness, coma, organ failure (esp. kidney), changes in vital signs (increase in pulse and decrease in blood pressure), and “tenting” of skin (sticks together, stays upright when pinched together).

Your role if symptoms are noted:

People who have symptoms of dehydration should see their health care professional as soon as possible or go to an emergency department for an evaluation. You should immediately notify your supervisor and follow your agency’s documentation rules.

Preventing dehydration:

- Offer clear fluids including water, broths, popsicles, Jell-O;
- Have a variety of beverages available, as not everyone likes the same thing;
- Drink frequently during the daytime, rather than drinking large amounts at one time;
- Cool off indoors with a fan if person has been outside and temperature is high; and
- If appropriate, offer Pedialyte, Gatorade or Powerade (these contain electrolytes).

Hydration is important for everyone! Hydration considerations include:

- The average person requires 64 ounces (8 cups) of water daily;
- Some people cannot tolerate that much fluid and must have restrictions – their medical doctor should be consulted regarding the recommended amount for them based on health concerns (e.g., people with congestive heart failure and end stage renal disease);
- Good hydration is important with or without a g-tube, especially if a person drinks thickened liquids;
- Some people may have difficulty swallowing which can lead to a decrease in fluid intake (e.g., Parkinson’s disease, dementia, stroke); and
- If caring for someone who cannot communicate to ask for something to drink, remember to offer fluids frequently (every hour) to keep them hydrated.

Constipation and Bowel Obstruction

Constipation is the slow movement of feces through the intestine which results in infrequent bowel movements and hard, dry stools. The longer it takes for stool to move through the large intestines, the more fluid is absorbed and the harder stool becomes, making it difficult and sometimes impossible to pass.

Constipation signs and symptoms include, but are not limited to:

- Changes in bowel habits;
- Infrequent bowel movements (less than 3 a week or more than 3 days between);
- Difficulty passing stools – straining, painful;
- Hard, dry, lumpy, small stools;
- Belly pain relieved by bowel movements, swollen abdomen;
- Bright red blood in stools; and
- Leaks of wet, diarrhea-like stool between regular bowel movements.

Severe constipation can result in serious complications including rectal bleeding, nausea, vomiting, weight loss, bowel obstruction, fecal impaction, hemorrhoids, anal fissures and rectal prolapse. Two **serious constipation issues** are fecal impaction and bowel obstruction. **Fecal impaction** is when hard, dry stool is in the large intestines, often the rectum and cannot be passed. Individuals with fecal impactions often have breathing difficulties due to the collection of the stool in the colon. Fecal impaction can be life threatening. A **bowel obstruction** is either a partial or complete blockage of the small or large intestines and requires immediate medical attention!

Bowel obstruction signs and symptoms include, but are not limited to:

- Abdominal pain;
- Swelling and fullness;
- Vomiting;
- Diarrhea; and
- Odor to breath.

Your role if symptoms are noted:

You should immediately notify your supervisor and follow your agency's documentation rules if a person is constipated. A general rule to follow is that if there is no bowel movement in 2 days, report immediately to medical staff. If you suspect an individual has a bowel obstruction, **call 911**.

Constipation and Bowel Obstruction (continued)

Preventing constipation:

- Drink plenty of fluids (64 ounces of water daily);
- Avoid caffeine, high fat foods, and refined sugars;
- eat a well-balanced fiber-rich diet with fruits (raisins, prunes, apples), vegetables, whole grains;
- Exercise regularly;
- Establish regular bowel habits including providing privacy for individual using the bathroom; and
- Schedule regular toileting especially after meals when the urge to defecate is normally the highest.

People at risk for constipation include, but are not limited to, those who:

- Have diet changes, low fiber, high fat, high refined sugar, excessive caffeine;
- Lack regular exercise and are inactive or immobile;
- Do not have adequate fluid intake and hydration;
- Are stressed;
- Have a disruption of regular routine (travel, change in daily schedule);
- Have medical and psychological conditions;
- Take medications (e.g., pain meds, anxiety/depression meds, diuretics, vitamins, sleep meds);
- Have poor bowel habits (holding back bowel movements);
- Use laxatives and/or enemas excessively; and/or
- Are older.

Sepsis

Sepsis is a serious medical condition caused by an overwhelming immune response to infection. Sepsis can arise unpredictably and can progress rapidly. Sepsis springs from two factors: an infection (such as pneumonia or a urinary tract infection) and a powerful and harmful response by the body's own immune system.

In severe cases, one or more organs fail. In the worst cases, blood pressure drops, the heart weakens and the patient spirals towards septic shock. Once that happens, multiple organs – lungs, kidneys, liver – may quickly fail and the person can die.

Stages and symptoms of sepsis:

- Sepsis – fever, increased heart and respiratory rate, probably infection
- Severe sepsis – decreased urine output, change in mental status, decrease in platelet count, difficulty breathing, abdominal pain, abnormal heart pumping function
- Septic shock – severe sepsis symptoms plus extremely low blood pressure that doesn't adequately respond to simple fluid replacement

Your role if signs or symptoms are noted:

Medical staff should be notified immediately and documentation rules for your program followed. Be sure to report any signs of sepsis immediately to your supervisor.

Preventing sepsis: The best way to prevent sepsis is early diagnosis.
Treatment is most successful when treated quickly with antibiotics to fight the infection and fluids to maintain blood pressure. The most common cause of sepsis is acquired pneumonia so seek treatment early!

People at risk for sepsis include, but are not limited to, those who have:

- Weakened immune systems (children, infants, elderly);
- Chronic illnesses (diabetes, AIDS, cancer, kidney/liver disease);
- Severe burn or physical trauma resulting in damage to internal tissues; and
- An infection due to damage to internal tissues – invasive medical procedures – kidney infection – UTI and pneumonia.

Seizures

Seizures are defined as abnormal movements or behavior due to electrical activity in the brain. Seizures might include shaking and convulsions, and can last a few seconds or over 5 minutes. Seizures have many causes and can lead to brain damage or even death. **Epilepsy** is a disorder of the brain. Diagnosis occurs when a person has had two or more seizures. There are many types of seizures.

Possible signs of a seizure include, but are not limited to:

- Brief blackout followed by a period of confusion;
- Changes in behavior;
- Drooling or frothing at the mouth;
- Eye movements;
- Shaking of the entire body;
- Grunting or snorting;
- Loss of bladder or bowel control;
- Sudden falling;
- Teeth clenching;
- Tasting a bitter or metallic flavor;
- Temporary stop in breathing;
- Uncontrollable muscle spasms with twitching and jerking limbs; and
- Mood changes such as sudden anger, unexplainable fear, paranoia, joy or laughter

Your role if someone has a seizure:

Always follow the protocol provided by the person's healthcare provider. If there is no protocol, provide a cushion for their head and remove glasses; loosen tight clothing; turn on side; don't put anything in the person's mouth; don't hold the person down; as seizure ends, offer help. Most seizures are not medical emergencies, however call 911 if:

- The person's protocol says to call 911;
- The seizure last longer than 5 minutes or one seizure follows another;
- The person does not resume normal breathing after seizure;
- There is no medical ID and no history of seizures;
- There is an injury;
- The person is pregnant or has diabetes;
- The seizure happens in water; or
- The person requests an ambulance.

You should also immediately notify your supervisor and follow your agency's documentation rules.

People at risk for seizures include, but are not limited to, those who have:

- A history of seizures,
- Had a head injury,
- Had brain infections,
- Had a stroke,
- Had a brain tumor,
- Alzheimer's disease, and
- Genetic factors.

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