

Introduction

Welcome!

You are about to take the **eight hour training course** that will enable you to become a provider of services for adults with developmental disabilities. There are waiver service definitions, and rules that correspond with those services. We will link those later in the course. Be sure to learn where to find them and how to follow them.

Once you are employed with House of New Hope, completion of this training material is required prior to providing services to individuals. After you start providing services, DODD requires providers to take **annual training**, as listed in the DODD rules.

Services in the state of Ohio are unique due to the structure of the county system. In 1967, the Ohio Senate passed Senate Bill 169, delegating responsibilities for care of children and adults with Mental retardation and developmental disabilities (MRDD), to county boards of MRDD. Most of these county boards have been operating both schools for special needs children and adult centers or workshops.

In 2009, the word mental retardation was dropped from the title in Ohio, using “developmentally disabled” as the main designation, making the titles of these county agencies “The (County name) Board of Developmental Disabilities.” Each of Ohio’s 88 counties has one.

In 2014 and 2015, many changes have been implemented, driven by CMS (Centers for Medicare and Medicaid Services), that will result in integrated employment opportunities for people with disabilities, as well as individual service plans being designed around what is important to the person, and for the person. Services will now originate from a person-centered planning focus, implemented with principles of self-determination, self-advocacy, and community integration. Read more about the Employment First initiative at ohioemploymentfirst.org.

In this course, we will direct you to the site for the Ohio Department of Developmental Disabilities (DODD), also known as “the department”. We will provide you with as much information about the terminology used in our field, in hopes of encouraging you to learn more about the people and the organizations that make up this unique helping profession!

CHAPTER 1: Overview of Services for people with Developmental Disabilities

Characteristics of individuals with developmental disabilities

In order for us to serve our population, we should be knowledgeable about exactly who we are serving. Not only does information empower us, it also gives us the ability to understand our participants, and their families, better.

The term “developmental disabilities” is a broad one, full of many diagnoses. Think of DD as an umbrella, with many diagnoses under it, such as autism, sensory processing disorder, Down syndrome, and other diagnoses. So before we can get into the different diagnoses and what those might look like, we need to understand the umbrella term first. Here is the definition for Developmental Disabilities (DD) in the Glossary on the DODD’s Website:

“Conditions that may impair physical or intellectual/cognitive functions or behavior, and occur before a person is age 22.”

This is a pretty broad definition, wouldn’t you say? That is because it is an umbrella term. Someone with DD might have a condition that causes physical impairment or intellectual impairment, or even behavior. But, something that is in common, is that all developmental disabilities, occur before the participant is 22 years old.

Consider Alzheimer’s disease. This brain disease typically affects the elderly (sometimes even as young as 50 years old in cases of early onset), and it affects the intellectual functions, physical functions and behavior of the person. Is this case considered a developmental disability? No, as the person did not have Alzheimer’s disease by the time he was 22.

Let’s look at another one. What about a 40 year old woman who gets into a motorcycle accident and is diagnosed with Traumatic Brain Injury (TBI)? Her physical functioning is fine, but she has intense aggression behavior issues due to her TBI. Is this woman considered a person with a developmental disability? No, as she did not have the condition prior to age 22.

Let's also take a look at the definition from another source. We are going to look at the Survey of Income and Program Participation, also known as SIPP.

According to SIPP, the distinguishing feature of developmental disability is that it manifests during childhood and severely interferes with the typical course of a person's development. Initially, the term developmental disabilities referred to persons with mental retardation, cerebral palsy, epilepsy, and autism. Since the late 1970s, the focus of the definition of developmental disabilities has shifted away from lists of specific conditions and now emphasizes limitations in specific life activities and individuals' needs to deal with these limitations.

We see here, from our SIPP definition, that there are a few points that are the same as the DODD definition: a condition that happens during childhood and that affects a person's development. Let's do one more definition, maybe a more detailed one.

Developmental disabilities are currently defined by the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 as:

A severe, chronic condition that is:

1. An impairment or a combination of mental or physical impairments
2. Manifested before the person attains age twenty-two
3. Likely to continue indefinitely
4. Results in substantial functional limitations in three or more of the following areas of major life activity:
 - Self-care
 - Receptive and expressive language
 - Learning
 - Mobility
 - Self-direction
 - Capacity for independent living
 - Economic self-sufficiency
5. A reflection of the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned or coordinated (US Department of Health and Human Services 1990).

As you can see, this definition is a bit more detailed.

Under the Umbrella: Looking at Diagnoses

Developmental disabilities can come in all shapes and sizes. Sometimes someone with a Developmental disability can be severely impaired, and sometimes the disability is hardly noticeable to the untrained eye. In order to know a few key points about some disabilities that you will likely see during your time serving this special population, we will highlight a few diagnoses below, along with different sites you can visit to learn even more. We encourage you to learn more about the diagnoses of the people that you work with, and remember that knowledge is power and can only help us serve our participants better.

However, we also want to remind you that just because a participant has a diagnosis, they will not present the same characteristics as another person with that diagnosis. People are still individuals and while a diagnosis can give us a better starting point of how we can serve them, our participants are NOT just their diagnosis.

Let's go ahead and review a few common diagnoses that you will likely encounter. However, you might find that you have a participant who has a different diagnosis, or secondary diagnosis, that is not outlined here and that is okay. We will be using this as our source (<https://www.nichd.nih.gov/health/topics/Pages/index.aspx>). You can easily keep this webpage address handy and use it to look up any other diagnoses or conditions that you might have questions about.

Autism Spectrum Disorder (ASD)

This is a great example of how a DD diagnosis can vary greatly from participant to participant. Your participant with an ASD diagnosis will be vastly different than your co-worker's participant with ASD, and each will come with their own abilities, behavior triggers, challenges, and strengths.

Once called autism, Autism Spectrum Disorder is now a better description for a complex diagnosis that affects how a person learns, communicates, behaves and interacts with others. It is considered a spectrum, because a participant can exhibit a wide variety of behaviors and obstacles. You may have heard a participant described as "on the spectrum". There is no way that we can cover all the nuances and science of ASD here

in this course, but we will do our best to keep it short and sweet, while still highlighting some important details.

More about ASD

Autism Spectrum Disorder affects the brain and nervous system of the participant. Typically, signs of ASD start early on in life and common practice says that the earlier it is identified the better; early intervention techniques such as different therapy treatments, can help the participant and the family acquire new coping and learning skills.

Often times, ASD can be identified by communication/interaction issues, restrictive interests and repetitive behaviors. That said, remember that everyone with ASD is a unique individual and might present those challenges differently.

At times, more than one child in a family may have ASD. They might share the same diagnosis, yet be entirely different. One may use a wheelchair, and present with significantly limited communication skills, while another child in the same family with an ASD diagnosis is physically fine, and may possess social skills deficits. Same family, same diagnosis, drastically different strengths and weaknesses.

When you work with participants with Autism Spectrum Disorder, you might also run across other diagnoses that sometimes can go hand in hand. For example, Fragile X syndrome can often lead to an ASD dual diagnosis.

Why not autism?

So, why don't we just call everything "autism" instead of Autism Spectrum Disorder? The new DSM-IV is the most recent guideline and groups all forms of autism into the same category. While you still might hear a diagnosis of "autism" or "Asperger syndrome", they are all considered ASD as of now. Of course, that might change when another DSM is released.

Cerebral Palsy

Cerebral Palsy, or CP, describes a group of neurological disorders that begin in infancy and early childhood. In most cases, CP affects physical movement. Participants with CP will often present with balance issues, strength issues, or problems with movement. In some more extreme cases, it can have an effect on cognitive functioning as well. While

at times the physical limitations can be significant, the problems do not seem to get worse with time. This is good news in the fact that the child can learn how to function with their limitations at an early age and continue through adulthood.

(<http://www.nichd.nih.gov/health/topics/cerebral-palsy/Pages/default.aspx>)

More about CP

There are different types of Cerebral Palsy, and each has its own set of challenges. While we will not review each of these types here, if you have a participant with CP, you should take time to learn a bit more about them and their specific diagnosis so that you can work with them more effectively. Extra education almost always makes a better caregiver.

Down syndrome

First, before we get started on what it is, notice the spelling. Many people will incorrectly refer to it as Down's syndrome. Instead, it is Down syndrome – no apostrophe and no capital letter before syndrome. Now that is all cleared up, let's learn a bit more about this diagnosis.

Down syndrome starts before a child is even born. For reasons that are uncertain, the child is formed with an extra 21 chromosome (or an extra piece of it). This extra chromosome causes intellectual disabilities ranging from mild to moderate.

More about Down syndrome

You are likely to be familiar with the physical characteristics that participants with Down syndrome have. A flattened facial profile and nose, upward slanting eyes, and wide hands with short fingers are just a few. While there are certainly intellectual challenges and disabilities associated with Down syndrome, most children are able to still meet major milestones; it will probably just happen later than their healthy peers.

As with Autism Spectrum Disorder, early intervention upon diagnosis is key to hitting milestones and gaining important life skills. Intellectually, you might notice that a participant with Down syndrome has poor judgment or a short attention span. Be sure to consult your ISP so that you know how best to complement and work with the team in order to continue life skill learning and independence.

Fragile X syndrome

Since we're talking chromosomes with Down syndrome, it seems like we should hit the most common inherited cause of intellectual and developmental disability. Let's take a look at Fragile X syndrome, caused by a mutation on the X chromosome. What is so interesting, and challenging about this syndrome is how it presents itself; people with Fragile X syndrome might show severe issues with physical and intellectual development, while some might not show any signs of the syndrome at all.

More about Fragile X syndrome

People with Fragile X syndrome who do show symptoms can have a variety of challenges. For example, people with Fragile X syndrome might have some level of sensory processing issues. Bright lights, loud noises, or overstimulating environments might cause behavioral issues or even discomfort. Fragile X may also cause intellectual disabilities and affect the way the person learns and even their independence. If a person cannot learn basic life skills, he might not be able to live independently during his life. People with Fragile X might be anxious in new situations, exhibit repetitive behaviors, or have hyperactivity challenges.

Part of our responsibility in serving our population is constant education about their specific diagnoses. However, as you saw from our examples, the diagnoses can look different from person to person. Everyone is unique and comes with a unique set of challenges and preferences. How do we get to know those person-specific things? We consult the Individual Service Plan, or ISP. Let's take some time to introduce the team process next.

Service Planning, Team Process, and Communication

As a provider, you will need to understand the acronyms and definitions associated with this profession. Please become familiar with them and keep a reference handy. Always ask if you are unclear what the initials stand for. If you are in an ISP meeting and someone called an SSA asks if you can provide services to someone with TBI who needs additional help from ARC, you had better know what you are committing to do!

Go back to the [DODD Glossary](#) and learn the definitions for these:

- Advocacy
- Assessment
- ISP
- SSA
- HCBS Waiver
- Service Coordinator
- Supported Employment
- Supported Living
- MUI

The Individual Service Plan is developed and approved by the team which is led by the Services and Support Administrator, who is a county board employee.

The following services are all performed by the Services and Supports Administrator (SSA):

- Serves as the single point of contact for an individual accessing services;
- Coordinates intake and eligibility for services;
- Assesses individual needs for services;
- Facilitates the development of individual service plans;
- Establishes budgets for services based on the individual's assessed needs and preferred ways of meeting those needs;
- Assists individuals in making selections from among the providers they have chosen;
- Ensures that services are effectively coordinated and provided by appropriate providers;

- Establishes and implements an on-going system of monitoring the implementation of individualized service plans;
- Delivers the key responsibility that ensures that each individual has a designated person who is responsible on a continuing basis for day to day ordination of services;
- Makes recommendations for referrals to community agencies and provides follow-up;
- Schedules 24-hour crisis intervention services as needed;
- Works cooperatively with other staff, parents, caseworkers, medical personnel, specialists, etc.

The Interdisciplinary Team includes ***the individual, the individual's guardian, (if there is one), family members; individual's primary service providers, (including work supervisor or Adult Day Support professionals most familiar with the individual); and other service providers (therapists, residential staff, behavior support, etc.)*** as determined by the individual's needs. The individual or his or her guardian may also invite other individuals, perhaps a friend or significant other, to meet with the Interdisciplinary Team and participate in the process of identifying the individual's strengths and needs.

IT IS CRUCIAL THAT YOU UNDERSTAND THIS, IN YOUR ROLE AS A PROVIDER... *Communication between team members is important to the success of the team process.* Therefore, communication should be –

- Respectful of the rights of the individual, including the right to advocate for him or herself, determine personal goals and objectives, and make decisions about programming, employment, residential placement, and finances;
- Frequent and regular so the team can keep the lines of communication open and be kept informed of any changes, progress, problems, or issues that need addressing;
- Clear, concise, and understandable (no jargon or terminology not easily understood by all team members);
- Recorded and distributed among all members of the team so team members will be able to review what was said;
- Friendly and non-confrontational, even when dealing with a difficult issue or team member to foster good feelings and to keep hostility out of the team process;
- One that welcomes the individual's friends and family and includes them in the team process.

This is the most important element of your role as a provider...When the SSA writes something into the ISP and you have promised to provide those services...you must comply, and you must properly document that you have performed the services. The ISP is a legal document, and you will not be in compliance with the ISP if you fail to provide services written into the ISP. Later in the course, we will elaborate on how you will document the services you provide. If you don't document, it's as if it didn't happen.

Best Practices

In services for people with developmental disabilities, “Best Practices” are those services that support planning and principles including:

- Planning directed by the individual, (not a menu of services)
- Principles of self-determination
- Decision-making guided by self -advocacy
- A circle of support for individuals who cannot speak for themselves, as well as anyone with developmental disabilities needing advocacy

Learning how to work on an Interdisciplinary Team (IDT) is crucial, and you can learn a lot about the individual and services offered to them just by being a part of the meeting. During a Team Meeting, everyone at the table supports the individual and wants the best for them. Each person sitting in the meeting also sees the individual differently and offers a unique perspective. For example, the individual’s mother might see a situation differently than the speech therapist who works with the individual. The key to a successful Team meeting is to include the individual, for everyone to have an opinion based on their expertise, and for the entire team to be willing to learn from one another.

Team Meetings are held on an annual basis to review progress and preferences. However, Team Meetings can also be called when the team needs to work together to find a solution to a problem or solve a situation together. It is in these meetings that the Team can best work together to benefit the individual.

Let’s take a look at a few case stories and see what a successful Team Meeting can look like.

Wake Up Call

Richard is an individual living with autism. He lives at home with his mom and his dad and receives adult day support services at ABC Day Services. Richard has always been a late sleeper, and he prefers to sleep in until 9am. After he gets up and ready for the day and the non-medical transportation provider picks him up, Richard arrives at ABC Day Services at 10am and stays until 4 pm when his Dad picks him up on the way home from work. Richard currently has orders for Occupational Therapy twice a week, and the therapist would like to work with him at ABC Day Services. However, the therapist wants to meet with Richard at 9am and would like for him to come to the

program earlier than he has in the past. Richard is upset by this and has been skipping his therapy sessions. His parents are worried that he will no longer be eligible for therapy services if he continues to miss the sessions and want to discuss it during the next Team Meeting, which is scheduled for next week.

During the meeting, Richard is present, along with his parents, the occupational therapist, a representative from ABC Day Services, and the transportation provider. Richard expresses his preference to sleep in until 9am. He says that he just feels better when he can sleep in until 9am and doesn't feel rushed as he gets ready for the day and for the transportation provider to arrive. ABC Day Services says that while their designated therapy space is not available at 10am, they do have an empty office space available for therapy services for Richard at 10am, right when he gets there. The occupational therapist hears how important it is for Richard to dictate his own schedule and express his preferences, as well as that there can be a room available for their session at 10am, and agrees to change her schedule to match his preference of meeting at 10am at ABC. Everyone listened to one another, worked together, and Richard left happy, with his needs met and his preferences honored.

Everyone won in that scenario: Richard was heard and honored, his parents were able to leave with a plan in place so they knew Richard would still be receiving therapy services, the occupational therapist changed her schedule, and ABC Day Services were able to provide the space for them to meet. By listening to one another, as well as putting the individual first, the Team was able to make a difference in Richard's satisfaction with the therapy program.

Let's take a look at another meeting.

Best Friends

Jill and Tyler are both people living with Down syndrome. They each live with their own parents and attend day services at ABC Day Services. Jill's parents have started to express concern that she is becoming too close with Tyler. Her parents are worried that both Jill and Tyler are too young (they are both 26) and too naïve to be in a more serious relationship. Tyler's parents are not concerned about the nature of the relationship. However, Jill is becoming more and more anxious when her parents arrive to pick her up from services. Jill's parents have also spoke openly, though gently, with Tyler, about his intentions with Jill, and have asked him to stay away from her as much as possible. Tyler has been upset since that incident and his parents have noticed that he seems sad more often on days when Jill's parents are around the day program. The Director of ABC Day Services sets up a Team Meeting to address the issue.

Attending the meeting are Jill, her parents, the Director of ABC Day Services, a counselor that ABC works with on a regular basis for family intervention, and a representative from the transportation company. During the meeting, Jill expresses that she and Tyler are just best friends and sometimes they hold hands. She says that she enjoys his company and that he makes her happy. Jill's parents express their disapproval, but after the counselor speaks up during the meeting, Jill's parents realize that their disapproval is mostly just worry and sadness. Jill's parents set up weekly counseling sessions with the counselor and ask that the Director of ABC keep an eye on Jill and Tyler's relationship to assure that it is safe for everyone. The transportation company representative states that they can start picking up Jill after day services daily and drop her off at her home so that Jill's parents aren't there to inadvertently upset Tyler. While Jill's parents are still upset about the situation, they leave the meeting knowing that Jill is safe and making good decisions. Jill's preferences were heard and honored, and Tyler's mental health was taken into consideration with the addition of a transportation company agreeing to provide appropriate services.

While this particular meeting was probably uncomfortable and heated since Jill's parents were somewhat upset and angry, it turned out okay. The Director of ABC had the foresight to invite the trusted counselor into the meeting so that expertise was readily available to diffuse the situation and so that the counselor could offer her services to Jill's parents, as they were hurting as well. What a great example of different backgrounds offering their services and expertise, all to benefit Jill and support her family.

Let's take one additional look at another example.

Reading Between The Lines

Sandy is a woman living with significant speech and motor delays. She is mostly non-verbal and when upset, she can become combative. Sandy lives with her aunt and attends ABC Day Services each day through the week. Lately, Sandy has been quite combative in the afternoons, and ABC has had to call her aunt to come in and help to calm Sandy. The Director of ABC is concerned with this behavior, as it has lasted for a week, and calls a Team Meeting to discuss the situation.

The meeting is held in the morning and is attended by Sandy, her aunt, multiple staff members from ABC, and her therapists. Sandy's aunt reminds everyone that Sandy becomes combative most often when she is upset by something and cannot express herself through words. One of the ABC staff mentions that the only change in Sandy's day has been the addition of a visit from a local pet therapy dog in the afternoon. However, as the ABC staff members talk about the pet, Sandy's aunt mentions that Sandy loves pets and has never been afraid of an animal. As the group talks more, they realize together that the behavior happens as the pet is getting ready to leave and believe that Sandy is getting upset that the dog is leaving and that is why she becomes disruptive. Going forward, the team works together to come up with the intervention of letting Sandy know when the dog is coming, what time the dog leaves, and then to give Sandy a heads up that the dog is leaving in 15 minutes, in 10 minutes, and again in 5 minutes. Once the team dismisses from the meeting and implements their plan, Sandy no longer is combative during the pet exit.

This example shows the family member and the ABC staff members working together to find the cause of the behavior, and then to come up with a plan that could decrease Sandy's negative reaction to the pet leaving.

If you haven't had the opportunity to join in a Team Meeting, ask your supervisor if you can sit in on a few and observe. When running the way that they should, Team Meetings are classrooms in action, with each person giving their own unique perspective and expertise. The opinion of each person around the table is valuable and each meeting is different, based on the individual and his or her issues.

CHAPTER 2: Rights of Individuals

Includes: The provisions governing rights of individuals set forth in sections 5123.62 to 5123.64 of the Ohio Revised Code

1. Review of each right as written in statute
2. Examples that demonstrate how the rights are exercised in the everyday life of a person with a development disability, with emphasis on the following:
 - Dignity and Respect
 - Principles of the Positive Culture Initiative
 - Privacy
 - Decision Making
 - Principles of Self-Determination
 - Consent for services and treatment
 - Advocacy – relationship to guardians and personal representatives
 - Financial Management – relationship to payees
 - Confidentiality

Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.

The Developmental Disabilities Assistance and Bill of Rights Act

Originally authorized in 1963, and last reauthorized in 2000, the Developmental Disabilities Assistance and Bill of Rights Act (DD act), Public Law 106-402, focuses on the needs of the estimated 4.5 million individuals with developmental disabilities. The DD Act ensures that individuals with developmental disabilities participate fully in their communities through full integration and inclusion in the economic, political, social, cultural, religious and educational sectors of our society. The DD Act further ensures that individuals with developmental disabilities and their families participate in the design of, and have access to, culturally competent services, supports and other assistance and opportunities that promote independence, productivity, integration and inclusion in the community.

Rules and Laws

From Ohio Revised Code: Distributing copies of rights.

Summarized:

Each provider serving the individual is required to

- Honor the rights of individuals as listed in the law.
- Make copies of the rights and distribute to each individual the provider serves.
- Communicate the rights in a manner the individual can understand.
- Provide a written copy of the rights, so the individual, or parent, guardian, or advocate, signs receipt of the list of rights; any special instructions given in the explanation shall be documented in the individual's file.
- Document when rights are given/explained to individuals.
- Make available a copy of the rights to employees, individuals receiving services, and visitors; also provide addresses and phone numbers for the legal rights service, DODD, and the county board of DD in which services are provided.

From 5123.63

Amended by 128th General Assembly ch. 7, SB 79, § 1, eff. 10/6/2009.

Effective Date: 09-22-2000

From Ohio Revised Code: Enforcement duties.

Summarized:

- Providers must develop written policies educating all staff with the rights in 5123.62, and ensure that contact with individuals is in compliance with the Individual's rights. No policy or procedure should conflict with the rights, and each provider must establish written procedures for resolving complaints of violations of rights; these procedures should be available to individuals, guardians, and parents.
- An individual who believes rights have been violated may ask the provider for resolution, or report to the county board of DD, Disability Rights Ohio, or the Ohio Department of DD. The individuals may also take legal action if appropriate.

From 5123.64 Amended by 128th General Assembly ch. 7, SB 79, § 1, eff. 10/6/2009.

Effective Date: 09-22-2000

From the Ohio Revised Code:

5123.62 Rights of persons with a developmental disability.

Each right is listed below (lettered) as written in the Code, then followed by an adapted version from DODD website, adapted to read to individuals with disabilities.

Rights of Individuals

Let's take some time to review the rights of the individuals we serve. Just as you and I have certain rights, it is important to note and recognize the rights of our participants. Rights of individuals should be covered and reviewed with participants upon admission to your program as well as annually. In fact, we think that it is best practice to review a few rights each month – you can talk about a few at a time if your agency hosts Participant Council meetings, Family meetings; these can also be discussed at your staff meetings; information about featured rights can also be posted on bulletin boards. Rights can be covered more frequently than once per year; instead, rights should be a part of the culture of your care and agency.

You can find the Individual Bill of Rights laid out in an easy to read format on the My DODD page of the DODD website. They have already put the rights into terms that are easy for everyone – staff, individuals, and family members – to understand. Because we know that it is important to cover Rights of Individuals often and thoroughly, we will talk a bit about each one below. After we cover the basics, we'll add some case stories, so that you can see what those rights may look like in your daily work.

The rights of persons with a developmental disability include, but are not limited to, the following:

Dignity and respect

(A) The right to be treated at all times with courtesy and respect and with full recognition of their dignity and individuality; **Be treated nicely at all times and as a person.**

Health and Safety

(B) The right to an appropriate, safe, and sanitary living environment that complies with local, state, and federal standards and recognizes the persons' need for privacy and independence; **Have a clean safe place to live in and a place to be alone should you choose to be.**

Healthy food

(C) The right to food adequate to meet accepted standards of nutrition; **Have food that is healthy.**

Freedom of religion

(D) The right to practice the religion of their choice or to abstain from the practice of religion; **Be able to go, if you want, to any church, temple, mosque.**

Access to medical care

(E) The right of timely access to appropriate medical or dental treatment; **Be able to go to a doctor or dentist when you need to..**

Access to Therapeutic Services

(F) The right of access to necessary ancillary services, including, but not limited to, occupational therapy, physical therapy, speech therapy, and behavior modification and other psychological services; **You have the right to get other health care services, like speech therapy or physical therapy if you want to. And you have the right to get mental health services if you want to talk about your feelings. You have the right to get these services in a way that makes you feel comfortable.**

Respectful treatment/Confidentiality

(G) The right to receive appropriate care and treatment in the least intrusive manner; **Be able to have people help and teach you, if you want, in a way that makes you feel as comfortable as possible.**

Right to Privacy

(H) The right to privacy, including both periods of privacy and places of privacy; **Be able to have time and a place to go to be by yourself. You also have the right to be able to keep things private if you want to.**

Communicate freely

(I) The right to communicate freely with persons of their choice in any reasonable manner they choose; **Be able to call, write letters or talk to anyone you want about anything you want.**

Personal possessions

(J) The right to ownership and use of personal possessions so as to maintain individuality and personal dignity; **Be able to have your own things and be able to use them.**

Socialization

(K) The right to social interaction with members of either sex; **Be able to have men and women as friends.**

Community involvement/decision-making

(L) The right of access to opportunities that enable individuals to develop their full human potential; **Be able to join in activities and do things that will help you grow to be the best person you can be and reach your personal goals.**

Right to work

(M) The right to pursue vocational opportunities that will promote and enhance economic independence; **Be able to work and earn money.**

Civil rights

(N) The right to be treated equally as citizens under the law; **Be treated fairly.**

Safety from Harm

(O) The right to be free from emotional, psychological, and physical abuse; **You have the right to live without bullying or abuse.**

Choosing community involvement/Self-determination

(P) The right to participate in appropriate programs of education, training, social development, and habilitation and in programs of reasonable recreation; **Be able to learn new things, make friends, have activities to do, and go out in your community. Be able to do things that you enjoy.**

Self-determination

(Q) The right to participate in decisions that affect their lives; **Be able to tell people what you want and be part of making plans or decisions about your life.**

The right to choose

(R) The right to select a parent or advocate to act on their behalf; **You have the right to choose someone to help you make decisions.**

Money management

(S) The right to manage their personal financial affairs, based on individual ability to do so; **You have the right to earn money and pay your bills. You have the right to save your money and to spend your money. And you have the right to choose someone to help you with your money.**

Confidentiality

(T) The right to confidential treatment of all information in their personal and medical records, except to the extent that disclosure or release of records is permitted under sections [5123.89](#) and [5126.044](#) of the Revised Code; **You have the right to say who can see information about you and your disability.**

Self Advocacy

(U) The right to voice grievances and recommend changes in policies and services without restraint, interference, coercion, discrimination, or reprisal; **You have the right**

to ask for changes when you don't like something. And you have the right to ask for changes without being afraid of getting into trouble.

Dignity and respect

(V) The right to be free from unnecessary chemical or physical restraints; **You have the right to refuse to take medicine you don't think you need. You have the right to be in control of your own body. You have the right not to be held down if you are not hurting yourself or someone else.**

Right to vote

(W) The right to participate in the political process; **To vote and learn about laws and your community.**

The right to deny consent

(X) The right to refuse to participate in medical, psychological, or other research or experiments. **You have the right to decide if you want to take part in a study or an experiment if someone asks you to. You have the right to say no to taking part in a study or experiment.**

Effective Date: 09-22-2000

Fictional Case Stories

Please read these fictional case stories and consider the rights issues faced by each individual. All characters, situations, and stories described here are fictional; No reference to persons, events, or institutions is intended or assumed.

Case 1: Have A Blessed Day! (Religious choice)

Ginger lives in a group home with 3 other ladies. Her staff is enthusiastic and positive. Ginger had a tough adjustment moving there; she'd lost her mom, whom she was very close to, and she misses her. Mom used to take her to church every Sunday. Now, Ginger attends a Roman Catholic Church with the residents of the group home. It is close to the group home, and one of the staff knows the priest. There's a luncheon afterwards, and everyone gets to sit around and talk. It's very pleasant.

Ginger hasn't been able to say this, but she would really prefer to go to her old church, the one where she still knows some of the families. It's a nondenominational congregation that had helped her mom and welcomed Ginger when they attended. Once Ginger asked the group home manager if she could go there, and he said..."Well, everyone goes to St John's now. Don't you like it there?" Ginger knew all of the hymns at her old church and was used to the ceremony. She misses it. She misses the ladies who wave goodbye and say "Have a blessed day!" She even started saying that to her staff at work; it made her feel good and it made her think of her mom. She keeps thinking about asking again, but she doesn't want to embarrass herself by complaining.

Does Ginger have a right to attend her own church, even if it is different from the others in her home? Does the group home staff have an obligation to make sure she can get there? Is this something that could be written into her ISP? If so, would that obligate the provider to comply?

Case 2: Stay home! (Dignity and Respect)

Jack is prone to having accidents. He doesn't mean to do it, he just can't always get to the restroom quickly enough. Once he was on an outing with his group home, and this happened. He felt really embarrassed already...then, one of the staff told him he couldn't go on any outings anymore because he "made it bad" for all the others. He couldn't help it! He even heard the staff talking about him when they thought he was already in bed. One of them laughed.

Could Jack's staff help him with this problem? Are they obligated to accommodate him? Do they have a professional responsibility to refrain from making fun of him? Is it ethical for them to keep him home from outings if he wants to go out?

Case 3:It's My Place Too! (Privacy)

Scotty shares an apartment with Tim. They get along well most of the time. When Scotty lived with his mom, he would have friends over, and they would go to his room and play cards. They could laugh loudly, play music, and not bother anyone. Now, it seems like Tim wants to be in on everything Scotty is doing, when his friends come over. Tim keeps knocking on Scotty's door and trying to get in on their fun. Scotty can see Tim anytime, but he hardly ever sees his friends anymore.

Is it realistic for Scotty to have any privacy when his friends visit? If he talked to Tim ahead of time, do you think it would help? Would it work better if Scotty included Tim once in a while, or should he schedule his friends to come over when Tim is busy with something else?

Case 4: That's my style (Decision-Making)

Rowynn lives in an ICF (intermediate care facility) and rides the bus to workshop every day. Each morning is a struggle. While she can have breakfast and get herself dressed and ready in time to catch the bus, the staff always stops her on the way down the hall and tries to get her to change clothes. Rowynn likes to wear something special every day... Sometimes clips in her hair and bangle bracelets, or her leggings and boots outfit, or a Disney tee shirt with a Mickey Mouse belt. The staff gets really irritable when they see this. Rowynn keeps telling them...there is a dress code at workshop and she knows how to follow it: no short shorts (Check!) and no flip flops (check!).

Sometimes, her shirts contain colorful phrases, and sometimes her hairclips are sticking up all over her head. But all the 'bling' kind of gets her through the day, and after all, her style is her choice. Her staff keeps saying, "If you want to be considered for a community job, you need to look the part." Well, there was that time she got called for an interview on the same day and couldn't change clothes...

Does Rowynn's staff have a point? Could she express her style in an age-appropriate and work-appropriate way? Could they find a way to compromise?

Case 5: Mom, I Wanna Move Out! (Self-Determination)

Stefanie is 27, and she works a community job. For the last two years she has been taking a class on money management and learning how to save up for the things that she wants to buy. Some of her friends are living in group homes, and she does not think that is for her. Two of her friends moved into an apartment building that is on the city bus route. They go shopping on Saturdays and are always telling Stefanie how fun it is to live on their own.

There is an apartment available in their building. When Stefanie told her mom she was thinking about moving there, it did not go well. Her mom had several objections. “How will you remember to wash your clothes and take care of things? Living on your own is more complicated than you think! Are you just doing this so you can get a boyfriend?” Stefanie is upset; she doesn’t want to do this without her mom’s blessing, but she feels like she is missing out on being a grownup.

Does Stefanie have the right to take the steps to live on her own? Is her mom overprotective or legitimately concerned? Should they be prepared to let her move back home if it doesn’t work out?

Case 6: You Don't Have to Work (Right to Work and Earn Money)

Oliver has been taking employment readiness courses for a few years now, and has worked with his ISP team to develop a goal to work a few hours per week by next month. He wants to start putting out his resume, in the hopes of finding work at the local park district. His ISP team is behind him and has developed a person-first ISP that notes that finding a job is important to Oliver, and the plan addresses action steps important for Oliver to reach those outcomes.

However, Oliver's parents are not too excited about the idea of him getting a job. After all, Oliver lives with his parents, and they are sure to take care of all of his expenses. Oliver's parents know that it is important to Oliver to have spending money, and they work with him to manage his funds. They just don't think that working would be beneficial for Oliver – they believe he gets stressed out easily, and that he will be unable to adapt to a new schedule that includes work at the park district. His parents express their concerns during the ISP meeting and then call Oliver's social worker afterwards to tell her that they would like him to not get the job at the park district. Oliver does not know that his parents called.

What right is at risk here? How should Oliver's social worker handle this situation with his parents? Should Oliver continue to try to gain employment at the park district?

Case 7: I want to go on vacation! (Relationship to Guardians and Personal Representatives; Community involvement/Decision-making)

Donna lives in a home with 3 other women. She likes her staff and her roommates; they do a lot of outings together. However, sometimes she would just like to get away. One of her friends from work attends trips with a disability travel group. They take vacations on buses, and sometimes they fly to Florida! They offer supervision around the clock and the chaperones are really helpful.

Donna has saved up some money and would like to try one of these trips. Her SSA told her she has a right to reasonable programs of recreation, a right to spend her money how she chooses, and the right to socialize with men and women. The problem is, her guardian, her brother, has to sign for her to go, and he is not cooperating. Donna thinks he doesn't understand; after all, he never goes anywhere! He works all the time. He lives alone and does not know what it is like to live in a house full of people.

Could Donna's guardian talk to the parents of other recreation participants from that group and get some questions answered?

Could Donna ask her team to consider this request? Does Donna have the right to participate in activities?

Case 8: You can't afford it! (Financial Management)

Mark shares an apartment with another guy. His roommate likes to watch television late at night. This is one of the things they enjoy doing together. No one can tell them to turn down the volume. If they stay up too late and are tired the next day, oh well, that's their problem!

One night, they see a commercial for an exercise machine. The actors on the commercial show how muscular your arms will get if you use this, and then... get this! Pretty girls will stand around admiring you all the time, if you use this machine! Mark really wants to order it. He has a credit card. He starts to make the call and his roommate yells... "Hey! You can't afford it!" Mark can hardly believe it. He would let his roommate use it too. Why would he say that? Then he starts to remember the time he couldn't pay his share of the electric bill, because he bought some lottery tickets. There weren't even any winners on there! Maybe he should think about it, but the commercial says "call now!"

Does Mark's roommate have a legitimate concern? If Mark is in charge of his own finances, would he benefit from financial counseling? Are there ethical issues involved in use of credit cards for people with disabilities?

Case 9: That was a secret! (Confidentiality)

Amy lives in a group home. Recently, there is a new staff person. This person was supposed to read over the ISP for every resident, so she could work with them effectively. Amy's file contains some information that is embarrassing to her now---she used to have a hard time controlling herself from calling her boyfriend in the middle of the night. On weekends, she called him 15-20 times. His staff even thought she was stalking him! She had to be restricted from using the phone for a long time, until she could learn not to do this. The new staff, after reading this, teased Amy about 'not using the phone' and 'not stalking people'! It was so humiliating.

Did the new staff need to know about Amy's former behavior? Should she have been inserviced on the behavior and on how to refrain from bringing it up? Is this a breach of confidentiality?

Case 10: Rock the Vote (Right to vote)

Chrissy wants to vote in the next election. However, since voting day is on a Tuesday, she will be at her day agency instead of at her home; her mom would take her to vote, but her mom works on Tuesday. The day agency is providing transportation on Election Day to certain polling places. Unfortunately, Chrissy's location is not one of the drop off points for the agency bus. The election is still a few weeks away, but Chrissy is upset and anxious about missing the chance to vote.

How can the staff help Chrissy and meet her right to vote? Would voting early be a solution? If Chrissy does not vote on Election Day, will her rights have been violated, or did the agency do everything possible to help her?

Case 11: That's All She Wrote (Right to communicate freely)

Anna lives with her mom and sisters. Her dad was readily available in her life up to two years ago, when he divorced her mom and stopped contacting Anna or her sisters. While her sisters and mom are still quite angry with Anna's father for leaving all of them without any further contact, Anna has been speaking to agency staff about feeling sad and wanting to contact her father. During her ISP meeting, Anna told her mom and her support team that she would like to write her father an email or mail him a letter. Anna's mother does not support this decision. After the meeting, Anna's mother stops by the staff lounge and asks a caregiver if she could just not mail the letter that Anna writes. "She'll never know that it didn't get mailed," says her mom. "Besides, he probably wouldn't write her back anyway. It's for the best if her letter gets lost – she gets to write out her emotions and feel better, but she isn't inserted back into that man's life."

What should the staff member and agency do? How can they protect Anna's right to communicate with her father, or should they? What should the staff say to Anna's mom while respecting everyone's feelings?

Case 12: Study Time (Right to Deny Consent)

Your day agency is really excited that it was chosen to participate in a grant funded recreation activity program. Monthly, there will be athletes from your town's professional hockey team that come to your agency. These athletes, along with a few recreation therapists, will lead activity groups. Then, participants will take surveys throughout the months that measure their depression and medication use. In order to be approved for this service, participants will need to sign a waiver to consent to this research program. You lead a brief meeting explaining the program to your participants and almost every participant signs the waiver without any hesitation. However, two participants named Justine and Alex do not sign the waiver. They are concerned that their history of depression and their medication use is confidential, and they do not feel comfortable for so many people outside of the agency being privy to that information. If Justine and Alex do not sign the waiver, they will not be able to attend the monthly recreation groups with the hockey athletes. You know they are both big hockey fans and continue to encourage them to sign the waivers; they continue to decline.

What can you do in this situation? Are Justine and Alex within their rights to decline involvement in this program? What should your next steps be? Is it possible for them to enjoy some level of participation without compromising their personal information?

CHAPTER 3: Positive Culture Initiative and What is Important to/for the Person

Introduction to a Shift in Thinking

Every industry has certain initiatives that push the industry forward. For the past few years, those of us who work with adults with developmental disabilities have found ourselves in the middle of a major movement toward “person-centered” and “positive-culture”. In fact, you may have heard these words or other phrases like “A Good Life” or “What is important TO and FOR the person”.

This is an exciting time in our industry. The momentum of how we have provided care in the past is shifting and is headed in a more positive direction. DODD is requiring us to serve individuals with developmental disabilities in a manner that sets them up for success, driven by their own ideas and achievements.

The Centers for Medicare and Medicaid Services (CMS) now requires services to be based upon person-centered planning and what matters to and for the person. Gone are the days when others decide what is best for the individual. Here instead are the days when we take the time to listen, investigate, and discover what is important to and for the individual.

Positive Culture Initiative

The building block of this change in thinking came in the form of the launch of the Positive Culture Initiative in 2008. DODD Director John Martin rang in a new era of relationship building with PCI, in the hopes that this initiative would bring about a lasting change within the Ohio system and open the door for conversations that could lead to individuals telling us what was important to them.

Initially, the Positive Culture Initiative focused on bringing professionals the tools to eliminate aversive behavior management techniques. Instead of handling the challenging behaviors once the behaviors started, the PCI aimed to give professionals the tools to find out what caused the behavior in the first place so that it never has to start or be managed. Behavior prevention is always better than behavior management, but it requires more investigation, conversation, and problem solving.

The PCI also aimed to go from a “here’s how to do it” mentality to one of learning how to do it side by side with the individual.

PCI wants us to step out of the “I’ll do it for you” or “just do it this way” mentality. Instead, it invites us on a much more exciting road of discovering the world and its options through the eyes of the individuals that we serve. Instead of leading the charge for them, we are walking alongside them for the journey.

The Positive Intervention Culture Initiative included an initial goal of eliminating timeouts and restraints (except for emergency intervention), and an ultimate goal of an aversive-free approach to behavior supports. Focus was placed upon improving the environment, as well as the quality of life for the individuals we support.

<http://dodd.ohio.gov/Initiatives-and-Partnerships/Pages/PCI.aspx>

The Positive Culture Initiative (PCI) is now in place and centers on:

- The positive attributes the individual contributes, shifting focus away from limitations
- Respect toward the individuals we support
- Creating an environment of trust
- Building relationships that are safe and healthy
- Striving to meet the needs of individuals
- Working to understand individuals, regardless of their means of communication
- Choice-making
- Assisting individuals to feel and be safe

This shift in approach is about changing the way we view, support and interact with individuals with disabilities, rather than striving to change them. The individual is the central focus of the planning team. Rather than program-centered, the focus is person-centered. We also use tools to support the person by encouraging them on their journey, and showing that we believe in their ability to succeed. We accomplish this by changing our approach to one of acceptance, affirmation, and speaking respectfully to the person—and by using language that addresses the person rather than focusing on the disability.

Discovering the Individual

So, all this sounds great – the individual leads the charge and essentially gives us the outcomes for the ISP – but how can we make it happen. Sometimes the people that we serve are nonverbal. Sometimes they are verbal but find the decision of what to have for dinner overwhelming, let alone what they want to do for a career. These challenges and roadblocks are very real, but they are not excuses to revert back to the “I’ll do it for you” line of thinking.

In order to find out what makes individuals tick, you need to start the conversation. That conversation might include a cup of coffee before lunchtime, asking yes/no questions while on a routine walk outside, or pointing at things on a conversation board. The most important things to remember are that these conversations should be ongoing and that you won’t get real answers unless you have a relationship of trust with the individual. To find out what is important to the person, you must make an effort to get to know them. Here are some techniques for achieving that:

Keeping the Conversation Going

You aren’t going to find out what is important to and for the individual in one quick conversation. Goodness, we all change our minds on a weekly basis. People with disabilities are the same way, and the best part of our job is that we get to watch them grow and change over the course of many years.

In order to find out what is important to and for the person, consider keeping some questions in your mind and asking them throughout your time together when you feel that the timing is right. Here are a few to get you started:

- What is your favorite part of the day?
- When is the last time that you felt sad?
- Why are you feeling scared today?
- I’m proud of you for completing that task. How do you feel?
- What makes you happy?
- When did you feel brave today?
- When do you feel important or loved?
- What makes you smart?
- What are you good at?
- What frustrates you?
- When did you practice something and get better at it?

- What do you need more practice on?
- What is your favorite thing to do?
- What makes it a bad day?
- What makes it a good day?
- Who do you like to hang out with?
- What can you teach others?
- What do you like to learn about?

One of my favorite things to remember is that everyone is a teacher and everyone is a student. If you are able to see yourself as a student of the people that you serve, you will start to see their talents quickly. I learned this in working with a resident with dementia who was nonverbal, and at times aggressive. However, when I was able to see him as a teacher and me as a student, our relationship changed. He spent his afternoons teaching me how to dead-head the moss roses that we had planted around the facility's patio. Without a word, we formed a relationship dead-heading every afternoon. Within just a few weeks, his behaviors disappeared and I found that I looked forward to my quiet and productive time with him every day. In fact, I still plant my own moss roses every spring in the backyard; now though, I teach my son how to dead-head them. Everyone is a teacher, everyone is a student. What will your individuals teach you?

Building Trust

Before you can expect anyone to open up to you, there must be a relationship built on trust. Here are a few ways that you can start that relationship off on the right foot.

You start building that relationship and trust immediately, even as soon as you first meet one another. Don't underestimate the power of a first impression! When you first meet your individual (and his/her family), be sure that you are on time, dressed appropriately, and are interested in interacting. Ask questions about the person's preferences and interests, and get to know a little bit about him or her. Showing that you are genuinely interested in him or her as a person, and not just as a job, is a wonderful way to establish trust and start a relationship.

Remember, building a relationship takes time. Also, your relationship with one individual might look a lot different from a relationship that you have with another individual; that is okay. As you get to know them, your relationship will grow. The key is to be sure that the relationship is helpful and fulfilling for all involved.

Building a relationship takes effort, too. You will need to learn about the person, and let them know a little bit about you. Be sure to not to disclose all of your life's details (that can be unprofessional), but you want the relationship to feel natural for both of you. You can find out about the person's likes and dislikes, as well as interests, by simply asking. Then, when he/she answers, listen and try out different interventions and interactions based on those answers. Be genuinely engaged and ready to learn about him or her; turn off your cell phone and be present during any interactions you have with one another.

You can also work towards building a relationship by trying new things together and creating memories together. Grabbing ice cream together after his work day ends, or going to the zoo during one of your days with him, are fun ways to connect. You can also read a book together (or read the same book, at the same time) and discuss it once a week, or talk about a favorite television show each week. These rituals that are special to the two of you can create a feeling of connection and build a solid relationship. Of course, you can only accomplish this through time spent together, so be patient. If you feel like your relationship is not working, be patient. Not everyone forms friendships and relationships quickly, and that is okay. Your patience with the individuals you work with will be a sign that you are here to serve him/her for the long haul, and that you are invested in your relationship.

No matter how good you are at creating opportunities to build relationship, you are likely to never have a good one if you cannot establish a feeling of trust between you and the individual. Remember, to them you are simply a stranger when you arrive to work with him or her the first time. You might know that you have a caring heart and the best intentions to provide quality care, but that person does not know that. Building trust takes a lot of time and effort, but it is crucial to giving the best care possible. When it comes to trust, consistency is key.

While not everyone or every situation is the same, so here are some ways that you can establish trust:

- Show up to work and appointments on time; this shows that you respect everyone's time and that the person you are serving is your priority.
- Keep confidentiality and respect the privacy of each individual. (Remember, though, that keeping secrets that could cause harm to the individual or others is never okay.)
- Do what you say you will do, as often as possible.
- Apologize when necessary, and mean it.

- Be as honest as possible during interactions.
- Act consistently in similar situations, especially when it comes to working with behaviors or drawing boundaries.

You will find that over time, if you are consistent, the trust will develop naturally. Remember, too, that building trust does not mean that you give your individual whatever he or she wants. This can make you seem like a pushover and it can be detrimental to your individual's behavior and life goals. Instead, be consistent and follow the plan of care.

If it is important to the person, for instance, to make more friends, then ask:

- ***How might we accomplish that?***
- ***What can we provide to reach that outcome?***
- ***What kind of guidance might be helpful to set this up for success?***

Here are some suggestions of what to do for the person to reach that outcome:

- ***Engage with the person about his/her interests***
- ***Find ways to help locate others with common interests***
- ***Discuss how to distinguish acquaintances from friends***
- ***Model how to reach out to potential friends***

Always remember that if you know the person well enough, you'll recognize what is important to the person, and that will lead you to carry out what is for the person.

Person-First Language

Person-first language is commonly presented as addressing, describing or writing about someone who possesses a disability or challenge by reversing what might be our traditional order of words and, instead, referencing the person first and the diagnosis second. Professionals such as a Licensed Social Worker, Therapeutic Recreation Specialist, QIDP (Qualified Intellectual Disabilities Professional), Speech Language Pathologist, Special Education Teacher and Intervention Specialist, as well as Physicians and Nurses, are expected to practice this with the individuals they treat or serve. We are also obligated as professionals to model the proper format for other professionals. Practicing and modeling person-first language is considered tedious by some, and in fact, not all disability groups approve of its use. On the other hand, person-first language has been shown to be crucial to those with disabilities who are leading the movement to change how we describe them in speech, in writing and in legislation.

How should professionals address people with disabilities?

The community of individuals with disabilities include, among others:

- Adults who were born with a disability
- Adults who have acquired a disability
- Children with disabilities
- Adults with a cognitive, physical or emotional disability

Professionals who treat or care for someone with a disability, while addressing them by name in a practice setting, will introduce or describe the people they treat on a daily basis. Modeling the respectful language is an important piece of the professional's obligation to the person.

Terms used to describe disability

Many of the terms used to describe people with disabilities originated from diagnostic terms. The next step was to label people by utilizing the disability as an adjective, as in "handicapped person". Parents and advocates for people with disabilities then began asking for these labels to be removed, or made to be more respectful. Individuals

themselves, through involvement in self-advocacy groups, began asking for words to list the person-first and not lead with the disability. Some groups representing people with Asperger's use "Aspies" and some prefer other terms.

In a study examining the terms the media use to refer to people with disabilities, Haller et. al (2006) compared the New York Times' and Washington Post's use of disability terminology in 1990, 1995 and 2000. Of the words examined, there was a general decrease in the use of 'handicapped' and an increase in the use of 'wheel-chair user' (as opposed to 'wheel-chair-bound').

Changes in terminology are in part attributed to the American's with Disabilities Act (ADA) endorsement of person-first language, leading to government agency handouts and policies following suit. Use of person-first language has become something of a mandate in writing and speech in disability services. Post-ADA, the media increased use of person-first terminology as well.

Since the passage of the ADA, advocacy groups made up of parents, siblings, advocates and various stakeholders, as well as self-advocacy groups made up of individuals with disabilities, have called for use of person-first language. Many government organizations provide informational handouts on disability etiquette.

This link on Disability Etiquette from Easter Seals is helpful. Please read through the sections on conversation and common courtesies.

http://www.easterseals.com/site/PageServer?pagename=ntl_etiquette

Remember that the individuals who are being described ought to be the ones to define the language.

The movement for removing the MR from MRDD

This specific scenario illustrates how a community of people with disabilities, as well as those who care about them, created a movement to change the language used to describe them. It makes this strong statement: We struggle with whether or not the adjective or the noun comes first, while people with disabilities point out that some of the words themselves are still insulting no matter where you place them in the sentence.

It may be useful to view 3 examples, illustrating of how this issue has been presented by:

1. People with disabilities
2. A sibling
3. A legislator

Example 1

The words “mental retardation and developmental disability” commonly referred to as “MRDD” were traditionally used to refer to agencies and service systems serving those with a diagnosis of cognitive disability. Not everyone with a developmental disability has mental retardation, but mental retardation is in the subset of developmental disability. Removing the words “mental retardation” has been the focus of a state by state movement, led by advocacy groups, Self-advocates, professional agencies, families, and even the Special Olympics’ campaign “Spread the word to end the word” (www.r-word.org, 2009).

Name changing by national organizations such as The Arc of the United States, (formerly “Association for Retarded Citizens”) and the “American Association on Mental Retardation” now called AAIDD (American Association on Intellectual and Developmental Disabilities) have begun to influence professionals to re-think the use of the term “mental retardation”. Part of the argument is that “Mental retardation” is, technically, a developmental disability, as it manifests itself prior to the age of 18 (www.thearc.org, 12-31-09). Using both “mental retardation” and “developmental disability” is actually redundant.

Adults with developmental disabilities have advocated removing all forms of the term. Governor Ted Strickland signed a bill into law on July 7, 2009 to remove the word from state and local boards of mental retardation and developmental disabilities. These are now known as County Boards of Developmental Disabilities. (Read, C. and Scott, B. 2009).

Please view this link which contains interviews on the subject featuring adults with developmental disabilities from the Butler County Board of DD:

<http://www.youtube.com/watch?v=VVCgJTcaIRY>

Example 2

The movie “Tropic Thunder” was boycotted by advocacy groups for its use of the r-word as well as insulting images of people with disabilities. The continued use of this word has influenced families and advocates to renew the fight against name-calling on behalf of their loved ones. (Lang, 2008).

A young man whose sister has a disability has made a name for himself on websites of agencies serving people with disabilities, as well as news stories. Soeren Palumbo delivered a speech at his high school’s writer’s conference explaining what is bad about the “R” word and why he thinks all of us should take it upon ourselves to not let others use the word in our presence.

Please watch either the news story about Soeren:

<http://www.youtube.com/watch?v=9k4Ekz3cWjQ>

Or Soeren’s speech:

<http://www.youtube.com/watch?v=CoqaNG0Ozqc>

Example 3

Senator Barbara Mikulski (D-Md) introduced “Rosa’s Law”---a bill that eliminates “mental retardation” and “mentally retarded” from the federal law books, replacing them with “intellectual disability” and “individuals with an intellectual disability” in federal education, health, and labor law. U.S. Senator Michael B. Enzi (R-Wyo.), Ranking Member of the Health, Education, Labor and Pensions Committee, was the Republican sponsor of the bill.

It's been stressed that the bill does not expand or diminish services, rights or educational opportunities, but instead would make the federal law language consistent with that used by the Centers for Disease Control, the World Health Organization and the President of the United States, through his Committee on Individuals with Intellectual Disabilities. Senator Mikulski had attended roundtable discussions for families and met Rosa, an eight year old girl, whose parents were concerned that her IEP (Individualized Education Plan) listed her as "mentally retarded" even though her diagnosis is Down Syndrome. Her brother and parents were concerned that she would be improperly labeled rather than using updated terminology that references the type of disability she has. President Obama signed Rosa's Law October 5th, 2010.

Questions in practice and in the community

Some of the questions this raises for practitioners

- Can we accept that people with disabilities, groups or individuals, may wish to be addressed differently?
- Is it possible that some of the terminology we use now, such as "special needs" or "high functioning" will be considered insulting to people with disabilities, now or in the future?
- Does it matter how the media refers to people with disabilities?
- Are we carrying respectful language into our everyday life?
- Are we paying attention to the person with the disability, as well as the advocate or family member with involvement?
- Is person-first terminology, or even changing terminology, tedious and sometimes costly?

Perhaps the most valuable role we can play is to model for others how to respect each person's preference.

CHAPTER 4: Provider's Roles and Responsibilities in Person-centered Planning, Community Integration, Self-determination, and Self-advocacy

Introduction

As a professional who works with people with Developmental Disabilities, you probably already have a set of qualities. Chances are, you are compassionate and empathetic, helpful and generally joyful. You probably display patience, and are a people-person.

You are likely a caregiver by nature. One cannot teach compassion, empathy, patience, and a general tendency towards helpfulness. No matter how much someone wants to work with this population, if they lack those qualities, they will not be successful.

Let's review the language for our industry. Over the next pages, we will focus on getting to know some important phrases in our industry: person-centered planning, community integration, self-determination, and self-advocacy. Each of these philosophies of care are important, leading to empowerment and choice.

Take plenty of notes and consider how you will put these philosophies to work in your daily interactions. Let's get started!

Person-Centered Planning

Person-centered planning is important in all aspects of our work, from the ISP and the assessment process all the way to helping out with daily care. The phrase person-centered refers to putting the participant at the center of everything that we do. While you may already be familiar with this, you might be surprised to know that this hasn't always been the case in our industry or in other healthcare industries such as senior care.

Here is an example of how some services were conducted before the person-centered movement started. In services with seniors (in a recreation capacity), everything was all about the convenience of the staff. For example, there were "wake up lists" of residents who needed to get up as early as 5 am, even if it wasn't the resident's preference.

Instead, it was more convenient for the care staff if the night shift could have some residents up and ready to go by the time the 7am shift rolled in. But here's the thing – it wasn't person-centered, and residents who had to get up early were often back asleep in couches and wheelchairs by the time breakfast was served. It was not the best plan, but in some settings, it was normal practice.

Then a push for more person-centered thinking happened. In Illinois, in long term care, it was called the Pioneer Movement (Illinois Department on Aging, Pioneer Approach to Long-term Care). Recreation professionals really liked it. It gave us the chance to get to know residents even more, and use their interests and preferences to shape their day. We ended up finding that a few residents were farmers and were used to getting up with the sun; these residents wanted to wake up at 5am, and were encouraged to do so. Other residents who preferred to sleep in were also allowed to do so as well. Everything was noted in the plan of care.

Things started changing for the better after those wake up times were person-centered. For example, those farmers preferred the early morning wake up call. They started to all congregate in the living room area around 6 am. I put in a request to have strong coffee set up in that area by 6 am, and the residents formed a before-business-hours coffee club. They were laughing and chatting long before breakfast was served, and they loved the companionship. Meanwhile, the residents who preferred to sleep in until 8:30 am got a late start breakfast club going as well; these residents all sat together at one table eating breakfast while the dining room staff cleaned up the other tables from the morning rush. Everyone won once we decided to adapt our schedule to our residents' needs and preferences. So, what took us so long?

Can you think of a time when you were trying to get your participant to bend to what was more convenient for someone else? I'm sure we all have had these moments. For example, a resident, Miss Molly, was told by staff that she didn't need makeup to attend our outing. Well, if anyone knew Miss Molly, they knew that she was always in full make-up, complete with a pearl necklace and matching earrings. She hadn't signed up to go to the outing, but we had an extra spot on the bus and felt that she would enjoy the outing. Trying to help out, we tried to hurry Miss Molly into the bus for our breakfast trip, without her make-up. After an earful from her, we never tried to get her to go anywhere without a little blush and lipstick. Lesson learned.

Let's take a deeper look at what person-centered planning looks like when working with people who have developmental disabilities.

We will start by reviewing DODD's "Five Key Principles", which outlines DODD's person-centered philosophy. We will be reviewing these five principles one at a time, giving real life examples of how to make these a part of your regular care. Chances are, you are probably already doing quite a bit of person-centered planning and care already. But, it is good to review each principle of the DODD's person-centered philosophy one by one. Here we go!

Why Person-Centered In the First Place?

Person-centered planning makes the participant the star of the show, which makes sense because it is the participant that we are all serving and (hopefully) setting up for success. However, when you take a look at the DODD's explanation, you can see that the push for more person-centered planning started in the federal arena. A 2014 rule by CMS, or Centers for Medicare and Medicaid Services, has declared that any person who receives services funded by waivers must receive person-centered planning, access to community living, and services in the most integrated setting possible.

Person-centered planning puts the participant at the forefront, assuring that decisions made and services provided all point the participant in the right direction for success. It takes the concerns, preferences, interests, and goals of the participant into consideration; it makes what they want and need the true outcome of services.

As we take on the five principles of DODD's person-centered planning philosophy, please note that you will be learning about three other important approaches: self-determination, self-advocacy, and community integration. Let's get started with the first principle.

Principle #1: Beginning with a comprehensive understanding of the person is essential.

If we are going to do person-centered planning, it is best that we first know the person, right? The first principle tackles just this, going on to say:

A thorough knowledge about the person receiving services – their unique history and experiences, their likes and dislikes, their risks and concerns, their interests and culture, and their strengths, talents and goals – is essential to planning supports. Person-centered planning philosophy, dodd.ohio.gov

Each of our participants is unique, and comes with a unique set of stories and experiences that make them who they are. Just as you come with a unique set of stories and experiences as well. It is our goal to find out as much as we can about our participants, and we can do this through assessments, individual-specific training.

Assessments

The assessment process is done for new participants so that the team can get a base knowledge about who they are serving. As an individual provider, or an entry-level staff, you may not be the person who conducts the assessment. Your roles may include:

- Reading the results of the assessment taken by the SSA or other professionals; this would be included in the ISP.
- Providing information for an assessment if you are the person working most closely with the individual.

Components of the assessment might include medical history, behavior triggers and solutions, work history, family/friend support network, recreation and leisure interests, preferences, and goals. The assessment will likely be charted in some way, either in narrative form or by using a preset form.

In working with individuals, we are constantly getting to know our participants, informally, throughout the time we spend with them. This process is call informal

assessment. Daily interactions that serve as informal assessments are vital to the health and wellbeing of your participant. Here is an example:

A few years ago, in working with a senior named Rose who had a sweet disposition, and was always on time for the Bible Study group, it was noticed that she came in about 15 minutes late and was extremely disruptive during the group. She was cursing and criticizing the verse we were discussing, both of which were very unlike her. Through my informal assessment, I knew that something was wrong. After my group, I let the nurse know about my experience with Rose in Bible Study, telling the nurse that Rose was exhibiting behavior that was unlike her, citing examples. The nurse investigated further and we found out that Rose had a urinary tract infection, which can cause pain and confusion in seniors. Rose was started on antibiotics and was back to her normal self within a few days. In this case, our informal assessment was an important part of getting Rose healthy.

Other times, your informal assessments can give good information about your participant's preferences or interests. Let's take a look at that example here:

Carly is a caregiver who works consistently with Jake, her client. Jake has autism and typically dreads the day of his dentist appointment. However, over the past year of taking him to and from appointments, Carly has noticed that Jake has less anxiety while at the dentist when the appointment is in the morning. When Carly brings up her observation to Jake, he agrees and tells her that it is easy to go to the dentist when he knows that they will stop for donuts after. From that point on, Carly makes sure that everyone knows to schedule Jake's dentist appointments for the mornings and to swing by for a donut after the appointment. Since then, Jake has had no dentist-related anxiety and his dental health is much better. Win-win here for everyone involved, all thanks to an informal assessment and observation by Carly.

Principle #2: Empowering informed choices increases independence.

This particular principle is rooted in self-determination and self-advocacy, two terms that have been important to the DD professional community for quite some time. We will review self-determination here, but before we get to that, let's go ahead and read the DODD's explanation of this second principle:

Increasing opportunities for decision making in small everyday matters and life-defining matters encourages self-expression, self-determination, advocacy, and independence. Person-centered planning philosophy, dodd.ohio.gov

Choice matters, and choice gives us control over our situation and environment. Our desire to have a choice presents itself very early on in life. For instance, choosing what to wear every day is empowering to some, and choosing what music or television shows one enjoys is empowering to another. Our desire for choice, to have our opinion heard, does not deter with age either. People may feel empowered by something as simple as a choice for what they would like for dinner, when they would like to go to sleep, if they would like a shower or a bath. These are decisions that we make every day, but these decisions are game changers compared to a world where everyone was deciding for the person.

Consider your own role as a caregiver – whether at work or at home. Have you ever made a decision for someone? How did that make them feel? Further, can you recall a time when someone made a decision for you? I'm guessing that you wouldn't like it if someone was attempting to micromanage your life and make decisions on your behalf.

The DODD principle recognizes the value and importance of choice for both small everyday matters and in decisions that can be life-defining. So how can people gain confidence decision making skills? Practice.

As we aim to relax control over others' decisions and situations, we need to offer plenty of times to practice making decisions. The more our participants have the chance to make a decision and directly impact their situation or environment, the more comfortable they may become with the decision making process. They learn how to weigh the pros and cons of a decision, and they learn how to make their decision known in a socially appropriate way. Choosing which outfit to wear to work, choosing which bus

to take grocery shopping, choosing which outings to spend money on for the month – these decisions give good practice so that participants feel confident and comfortable weighing in on more life-altering decisions like choosing a job to apply for or choosing a living situation. Practice makes perfect.

Do you know what else makes decision making a bit easier for our participants?

Rallying the troops – developing supports that can assist the participant when needed. We'll cover a bit more of that as we learn about self-determination.

Promoting Self Determination

Self-determination refers to a person's right to make decisions without outside influence. Self-determination for adults with developmental disabilities must include a system of supports to assist them, access to funding that allows them to exercise choices, and a plan for teaching that individual how to speak up for him or herself. All settings must be taken into consideration--home, recreation, work, and community. While skills may be learned in a teaching setting, each individual deserves to learn how to use these skills in other settings.

Check out the definition of self-determination from the DODD glossary:

Self-determination is an initiative built on the principles of freedom, authority, support, responsibility, and confirmation. Self-Determination gives people with disabilities the freedom to decide how they will live, work and participate in the community; the authority to decide how the money allocated to them will be spent; the supports that will allow that person to lead the life they choose; the responsibility of assuring that the money they are using is spent in a useful and appropriate manner; and confirmation that the person and his or her family are critical to making life decisions and designing the system to help them.

Success in community settings often hinges on one's ability to exert independence and express needs and wants effectively. Individuals with disabilities often need guidance and encouragement regarding issues of advocacy. At times, advocacy skills come naturally, and at other times, individuals are less confident, and too concerned about the opinions of those around them.

Parents, educators, and therapists must be cautious about the influence they exert; our roles have changed. It is no longer our responsibility to advocate FOR or choose FOR the participant. Instead, self-determination shows us that our role is to teach the participant how to decide for him/herself, and giving safe opportunities to practice this

skill. Even further, it is our responsibility to let the decision take its course, offering support and help along the way if the participant requests it, offering the person as much control as they are equipped to handle.

Developing self-advocacy skills.

Self-advocacy has its own definition in the DODD glossary.

People with developmental disabilities, either individually or in groups, speaking or acting on behalf of themselves, or on behalf of issues that affect people with disabilities.

Learning how to essentially stand up for themselves and their rights is a life skill that people must learn and practice. Take a look at the ISP to see what skills your participant is currently working to improve upon. It might be education about their rights or diagnosis, assertiveness training, or another skill. Do your best to assist your participant by giving them situations to practice their self-advocacy skills as often as possible.

Exercise civil rights.

As a part of self-determination, your participants should be given the opportunity to vote, as well as the opportunity to be educated on the issues and research candidates. This can include national elections as well as local or community elections.

Exercise control and responsibility over the services received.

Participants should feel empowered and confident to make decisions about their care and services. While each participant will be different, it is important that each feel that their opinion is valued and taken into consideration. Be sure your participant is invited to ISP or other care meetings, as well as having the opportunity to actively participate. As we know from our ISP section, it is imperative that the participant drives the entire ISP in order to make it a true person-centered practice.

Acquire skills that enable the participant to become more independent, productive, and integrated within the community.

We should be working as an interdisciplinary team to give our participants the chance to be more independent. Even better, our participant should be the center of that interdisciplinary teamwork. From therapeutic recreation activities, to physical/occupational therapy sessions, to family counseling sessions, to life skill

practice, we are offering the chance for our participants to become their most independent and productive selves.

Now on to the third principle.

Principle #3: Involving trusted supports increases opportunities for success.

All of our participants could benefit from having a supportive person, or two, in their lives. Everyone can use a network of supportive people in life, DD diagnosis or not. The phrase “it takes a village” is not just for raising children – it’s for raising good humans. In order to increase success, we must not only be person-centered, but we must also be experts in rallying the villages of our participants.

Let’s take a look at what the DODD says about this third principle of its person-centered philosophy:

Having a valued place in a network of personal relationships that includes close friends promotes physical and emotional well-being. Person-centered planning philosophy, dodd.ohio.gov

Having a valued place in a network of friends and family makes us all better people. Feeling like people are on our team and want us to succeed in life make us all emotionally and physically better.

However, it isn’t always easy for our participants to find a social network. It can be difficult for family members, or service providers, to know when they are hindering a person instead of helping them. This natural support dance can be difficult for everyone to learn, including us.

Developing Natural Supports

Have you heard the term "natural supports" before? If you haven't heard the phrase, you likely have plenty of your own natural supports in your own life. Think about people in your life who you can trust and count on, people who have been around during major turning points in your life. These important people in your life are your natural supports. In your life, your natural supports might be your parents, your partner, your friends, or even your co-workers.

Natural supports play an important part in our lives. They help us out when we need advice or an extra hand, they bring us dinner after we have a new baby. Our natural supports answer the phone when we call and give us a new perspective. Our natural

supports help keep us socially connected and make us feel important, loved and taken care of.

Our participants most likely have a web of natural supports in their lives as well. If you find that they do not have at least one natural support to call on, talk to your supervisor and co-workers about it to see if there is something that the agency can do to assist in building that natural support relationship. That person might need some education on why natural supports are important to his/her life, or to work on some life skill development on how to make and maintain meaningful relationships with these natural supports. Your agency might also be able to facilitate bringing the family in for some natural supports education sessions, or can offer resources to family members that might want to help out the participant, but are not sure how to do so.

Natural supports can range from family members to friends to fellow church parishioners. These are important relationships in their lives that not only add to their quality of life, but also can provide help and guidance outside the walls of your agency. Additionally, natural supports do not necessarily teach participants how to do things, they simply just offer support and encouragement. Under these conditions, the relationship thrives and the person often thrives as well.

Sometimes, maintaining a positive relationship with natural supports can be a challenge. But it is not something that is impossible. If our participants have no natural supports, and no prospects of people even interested in being a natural support, the challenge goes outside of education and life skill development. The natural supports need to be found. Your agency, and you, can play a large role in finding candidates for natural supports for your participants. You just have to know where to look. First, consider the actual geographic location of where your participant lives or spends most of his time. Are their neighbors nearby, or churches, or community organizations that you could encourage to connect so that relationships might naturally develop? Work with your agency, supervisor, and social work team to see what your role is in helping to assist the natural support relationship.

Other Considerations about Natural Supports

We've covered a bit about why natural supports are important to our participants, in addition of how to foster successful natural support relationships. However, natural supports are not all rainbows and flowers of trust and love. There are many other sides of natural support relationships that you need to be aware of. Let's review a few common issues here.

1. Natural Support vs. Caregiving

- Often, a participant's natural supports can end up in a caregiver role of some type. This can happen naturally and without issue, especially if the participant lives with the natural support. For example, a participant who lives with his parents will likely get some care from his parents. Mom makes dinner, and might assist with some personal care as needed. Mom likely does not mind this at all and sees it as her duty. However, there have been multiple studies about caregiver burnout that show that without a social and emotional connection outside of the participant, Mom might begin to burnout. Mom might get sick more often, might be stressed out and get high blood pressure, and might not know her role outside of just his caregiver. This isn't a good quality of life for Mom, and it certainly isn't a good quality of life for your participant if/when Mom goes into the hospital.
- If you feel that a natural support is becoming too stressed, talk to your supervisor or your agency's social worker. If you feel that the natural supports for participants are not acting like themselves, or need some extra help, don't be afraid to mention it to the appropriate person at your agency.

2. When Is It Too Much?

- Natural supports typically provide extra help or care without the expectation of being paid. A participant's sister, for example, might love going grocery shopping with her brother once a week. She enjoys helping him shop for the week; they get to visit and catch up, and grab lunch on the way home. However, that same sister might not want to have her brother move in for a few months during a transition time. It is not the sister's fault, and it doesn't make her a bad person. She just knows her limitations as a natural support and might feel that helping out more than a phone call a few times a week, and grocery shopping and lunch once a week is beyond her field of expertise. She might feel that the additional care that she would need to supply to her brother is something that she does not want to do on an unpaid basis, and would prefer to find a caregiver that she could pay to live with her brother for a few months.
- We, as DD professionals, need to be able to offer understanding and nonjudgmental assistance to natural supports who do not want to provide a lot of extra care. Further, we need to help that natural support maintain their preferences and offer resources to that extent. In our example, we should connect the sister with recommended and preferred caregivers

who can help during the brother's transition for a few months. We should also point the sister in the right direction to get some financial assistance for her brother, as needed.

3. When Does It Cross the Line?

- Natural supports are typically unpaid. However, sometimes the amount of care provided really does constitute a paid person. It is important to realize when the amount of care provided does indeed cross that line; that line varies from person to person.
- If you find that you are being approached by a family member of a participant to do a little extra help outside of work hours, unpaid, for the participant, you need to take a step back to consider a few things. First, does your agency allow this type of interaction outside of business hours? Second, do you mind helping out the participant/natural support for no return payment? And finally, can you maintain your own boundaries with the participant/natural support and let them know when they are asking you to do too much?

Again, natural supports overall are a fabulous addition to our participants' lives. However, we must be sure that we are taking care of those natural supports as well so that they can continue to be a positive influence in the lives of the participants.

Principle three in a nutshell? Build the village, keep the village healthy, watch participant feel loved and succeed.

Principle #4: Enhancing natural supports increases community membership.

We covered natural supports in our review of the third principle, and it is a great transition into the DODD's fourth principle of its person-centered philosophy. Before we get started on this principle, let's take a look at what the DODD says about it:

Expanding community engagement and employment opportunities that promote involvement in meaningful and fulfilling activities enhances a person's network of personal relationships and their role in their community. Person-centered planning philosophy, dodd.ohio.gov

Community integration and engagement is a core value in our profession.

Not only is it a right for our participants to be an active part of the greater community, it is also beneficial. We can be better person-centered planners if we take the natural supports our participants have and use those to get our participants out and about in the community. Community engagement might look like a community job through a program such as Employment First, or it might look like a recreation opportunity within the greater community. How will you tell what it looks like? Why, you'll ask the participant of course.

What Community Engagement Can Look Like - Recreation

The people that we serve are a part of not only our agency, but also a part of the greater community - the neighborhood, the town, the state, the country. In order to offer the people that we serve the best quality of life that we can, we must remember to give them the opportunities to be active in the communities that they are a part of.

It isn't just fun to get involved in communities, but it may also be empowering for the people we serve. Here are a few ideas to get you thinking of ways you can inspire them to get involved.

Getting involved in the community at your agency.

Your agency is a primary community for the people that you serve. Be sure that you offer opportunities for the participants to get involved in various ways to make an impact

in the agency. If they would like to, start a Participant Council that has monthly or quarterly meetings to give ideas about everything from food served to activities offered. Your Council can have elected officers, but make it clear that anyone who is interested can attend. This is a wonderful way to give your participants some say about what happens at the agency.

Additionally, consider offering volunteer opportunities at your agency that are specifically for participants who are interested. You can base your volunteer opportunities on the strengths and preferences of the participant who is interested, but a few ideas could include a "Welcome Wagon" to have participants welcome new people to the agency, setting tables for meals, passing out information during out trips, or helping to make copies.

It is important to note that getting your participants involved in agency volunteerism is great, but you can't have them doing enough work to replace a paid person. Be sure to maintain a line of volunteer and paid staff person.

Getting involved in the community in your town.

Your participants likely all come from a few surrounding cities or towns where they live on their own, with caregivers, or with family. You can encourage involvement in this community by providing opportunities to get involved within your agency, as well as making participants aware of upcoming events in the town.

When thinking about offering city events within your agency, remember that not every participant may partake, but it is still good to offer the opportunity. For example, work with your local County Clerk to make your agency a polling place for your participants to vote on Election Day or early. Invite your Clerk to come in and register those interested to vote. Invite local public officials to come in to your agency to give presentations or to simply come in and have lunch or a snack with your participants. A "Coffee with the Mayor" can be fun and informational for your participants and for the mayor!

You also want to be sure that you are offering the chance for your participants to get involved with the city outside of your agency. Post signs about upcoming Village Meetings, city festivals, or other activities throughout your agency so that participants know about them. Encourage interested participants to attend by themselves, with friends, or with family, and then come back the next day and tell the group about their experience. You can always arrange bus transportation as well and make the event an agency activity too.

Getting involved in the community in your state.

If you live near or in your state's capital, giving your participants the chance to become involved with state-happenings can be easier than if you live farther away. If you do live close, consider offering opportunities (or advertise the opportunities) for attending the State Fair, or for visiting the capital when government sessions are happening.

If you find yourself far away from the capital, you can still help your participants feel like active members of the state. Try writing letters to your local representative or inviting state government officials to come in for a presentation. Your goal is to make your participants feel a part of something larger than themselves. Empower them to get involved and feel comfortable within each of the different communities that they are a part of.

What Community Engagement Can Look Like – Employment

Employment in the greater community has been getting quite a bit of attention and buzz lately. And for good reason. Our industry is moving in a new direction - we are moving our participants out of the facility or home, and into the community - when it comes to employment opportunities, that is. People with disabilities are certainly able to work in the greater community, and should not always work in a facility environment.

Recently, in July 2014, President Obama signed into law the Workforce Innovation and Opportunity Act. This legislation significantly reduces the chance for participants to work in sheltered care environments, for less than minimum wage. Additionally, the law brings schools into the mix, to provide transition services

Paying subminimum wages to employees with disabilities is not uncommon. In fact, many of these sheltered workshops had good intentions in mind years ago when they started to hire people with disabilities. The workshop got their needs met with workers who did the required jobs, and the employees with disabilities were able to work and be compensated for their efforts. However, with the Workforce Innovation and Opportunity Act, employees with disabilities will no longer be allowed to work for subminimum wages.

As with any of our interventions, Employment First begins with the participant. Using a person-centered approach assures that everyone on the team is focused on the needs, goals, interests and abilities of the participant. In order to get the person centered approach ball rolling, we have to make sure that our participant's needs (and age)

doesn't sneak up on us. The DODD Rule requires that the team plans ahead, starting to work on Supported Employment goals and activities by the time the participant hits working age. Better yet, we should get started while the participant is taking transition classes, even before he or she is working age.

During the person centered planning process, the team should review both formal and informal assessments, along with any other information that might cover the abilities, needs, preferences, and goals of the participant. In order to make it a bit easier, the Rule lays out specifics that should be identified and documented during the process. Let's cover them together.

The individual's place on the path to community employment

When you are considering where the participant is on the path to employment in the greater community, consider a few different options. First of all, if the participant is already engaged in community employment, you already have a starting point on the path. As a team, with the participant included, discuss how the participant is doing in their current employment. Should you work with the participant to advance his/her career? Perhaps your participant needs to work on improving the job, or even stabilizing his/her employment? Consider each of these when developing a plan for a participant who is already working in a community setting.

If the participant isn't already working in the community, find out if he/she has a desire to work in the greater community. Your plan should include steps that the participant, and the team, needs to take to get the participant working. Get a resume started, start looking for employment opportunities, and practice interview skills and techniques.

You might find that the participant is unsure about working in the community. In this case, the planning process should include working with the participant to identify career options and employment opportunities available. Also, the participant should be educated about the economic impact to the life of the participant if he/she was working.

Sometimes, you might find that the participant is not interested in working in the community at all. In this case, the planning process should include plenty of education and empowerment of the individual to learn more about careers and employment opportunities available. And of course, be sure that the participant is educated about the economic impact of being gainfully employed.

The individual's desired community employment outcome

Remember, this is a person centered planning process. While the team, or you, might have different opinions about what the participant actually wants regarding employment, the participant is at the center. Using tools, assessments, and the participant, find out what exactly the participant wants from employment. Does the thought of full time work stress him out? Then perhaps your plan could start with a part time opportunity and then re-evaluate after a year or so. Does he love the idea of working with animals? Your plan should include finding opportunities that range from a veterinarian office to a dog walking service.

Clearly defined activities, services, and supports necessary for the individual to achieve or maintain community employment, job improvement, or career advancement

The planning process should include each member of the team's role in helping the participant find and then maintain employment in the greater community. You know as well as anyone that getting the participant a job is a process that includes plenty of time and effort. Be sure that you outline each of those activities and services.

Principle #5: Ensuring plans and services are driven by the person is vital.

We are turning the corner and headed for home with this fifth principle. Stick with me here as we finish up this part of our training. Again, let's take a look at the explanation from the DODD regarding its fifth principle of the person-centered care philosophy:

Developing a plan starts with the person receiving services – what is important to them and for them – and involves others chosen by that individual to aid in informed decision-making. Person-centered planning philosophy, dodd.ohio.gov

It looks like we are circling back to the person-centered ISP process right here, doesn't it? We cannot state it enough that any plans of care – the Individual Service Plan (ISP) or Behavior Service Plans (BSP) – need to keep the participant at the center. Here are just a few tips on how you can make sure that you are keeping the participant at the center of the ISP process:

Ask the participant, and ask frequently

In order for the participant to express his opinions and interests, you need to ask him often. The individual at the center of the plan will complete a “one page profile” that is updated often and stays at the front of the ISP file.

CHAPTER 5: Individual-Specific Training

What Individual-Specific Training Should Include:

For each individual served, you should review and cover certain elements of the ISP and individual profile. In order to get you started, here is a comprehensive list of items:

- Preferences and Strengths
- Diagnosis and individualized needs
- ISP review that includes:
 - Outcomes
 - Service/Support activities
 - Behavior support plan, if applicable
 - Planned interventions
 - Any related documentation requirements
- Care needs including:
 - Nutrition
 - Diet and mealtime support
 - Restroom assistance
 - Mobility needs
 - Lifting
 - General supervision/support requirements
- Medication administration and delegated nursing, as applicable
- Management of the individual's funds, if applicable

In order to be sure that you are covering each required aspect of this individual-specific training, use the following document as a checklist for each individual you review; revise the topics as necessary.

CHAPTER 6: Implementation of Individual Service Plans

What Is a Waiver?

You are going to be providing services for individuals who are approved for waiver services. In order for you to best understand waiver services, you need to understand waivers and the differences between them. Let's go ahead and get into that before we continue on to documentation requirements for billing.

Medicaid Home and Community –Based Services Waivers (HCBS) are programs that give individuals with disabilities funds to stay at home or in a community residential setting, rather than be cared for in an institution or nursing home. If a person with DD lives in an intermediate care facility or a developmental center, waiver services and payments do not apply. In contrast, a person wishing to live in a group home, their own apartment, or home with parents in a community setting, would be a candidate for waiver services.

But not just anyone gets a waiver. There is a process to complete that includes a variety of different offices throughout the county. To obtain a waiver, the individual must progress through these steps:

- Be assessed for eligibility for county board of DD services;
- Apply for Medicaid eligibility through their local Job and Family Services office;
- Be placed on a waiting list with the county board of DD for either an Individual Options waiver or a Level One waiver.

Waiver waiting lists can be years long. Once a waiver is granted, it is intended to provide funds for the lifetime of the person. The following services are examples of some of the services covered by Medicaid waivers:

- Transportation: either nonmedical transportation for attending a day services program, or for homemaker personal care (HPC) transportation, to and from medical appointments, family visits, and recreation or leisure outings;
- Homemaker personal care services (HPC): including assistance with activities of daily living, and skill development in a number of categories;

- Vocational or habilitation training, or adult day support, in a county workshop setting or with a certified private provider; county workshops are also in that subset.
- Adaptive equipment;
- Home modifications for accessibility, and
- (Limited) Therapy services for developmentally disabled individuals.

Currently, there are four HCBS waivers for Developmental Disabilities consumers. Each of these waivers covers specific services and is aimed at different needs.

So, what are the waivers? You have four of them: the Individual Options (IO) Waiver, the Level 1 Waiver, the Self Empowered Life Funding (SELF) Waiver, and the Transition Waiver.

The Individual Options Waiver, or IO waiver, covers services that can be provided in the individual's home. This home can be defined as either a supported living or family residence. As per the DODD website, the IO waiver is for individuals who require the care that is provided in an intermediate care facility, but prefer to live in the family home or with friends/roommates. Services covered are:

- | | |
|--|---------------------------|
| • Homemaker/Personal Care | • Interpreter Services |
| • Home-delivered meals | • Adult Day Support |
| • Remote Monitoring | • Residential Respite |
| • Accessibility Adaptations | • Vocational Habilitation |
| • Supported Employment
(Community or Enclave) | • Adult Foster Care |
| • Community Respite | • Adult Family Living |
| • Social Work | • Medical Equipment |
| • Nutrition | • Transportation |

The Level 1 Waiver provides resources to families helping them to maintain their child/adult in the family home. The IO waiver has a substantially higher budget allotment for homemaker personal care; the Level One waiver is not designed to cover a person's residential care. In fact, the Level 1 Waiver cannot exceed the IO waiver cost of assistance. Both waivers have a budget for Day Programming Services and for transportation, and both the IO and the Level 1 waivers cover essentially the same services. The Level 1 Waiver has set spending limits for certain service packages.

The Self Empowered Life Funding Waiver, or SELF Waiver, went into effect on July 1, 2012. This SELF waiver is unique and different from the other two that we covered already. In fact, the SELF waiver is more person-centered. This waiver allows more discretion from the individual and empowers him or her to make additional decisions about where his granted money will go and how he will receive services that he pays for. The waiver refers to this decision making aspect as self-direction.

Finally, the Transition Waiver, or TDD Waiver, is now covered by DODD. Before 2011, the TDD Waiver was managed by the Ohio Department of Job and Family Services. Since 2011 it has been the responsibility of DODD. By 12/31/16 all TDD enrollees will be transitioned to either a self, Level 1, or I.O. waiver, based upon the person's needs for services.

Now that you know about waivers and the services that they cover (essentially that list that we covered in the IO Waiver section), we can dive in to what kind of documentation you must provide in order to bill for services.

If you are doing your job correctly, you should find yourself face-to-face with a participant's ISP and you will likely implement the interventions on a daily basis during your interactions with your participant. In order to know how to best utilize, and support, this document, you need to know all the ins and outs. Let's learn about the ISP.

I'm sure you can guess where we will start our quest to find out all we need to know about the ISP-- the DODD website. Let's hit the glossary section of the DODD site to find its definition of ISP:

Developed to identify specific services and supports needed and desired by an individual. The ISP describes all services and supports necessary, regardless of payment source, for a particular individual to maintain health and safety. The ISP should explain how each support service is intended to meet a need, as indicated in the most recent assessment of the individual's functioning levels.

This definition reflects that the ISP is the one-stop-shop to find out anything and everything about your participant. It will cover information that ranges from medical diagnoses to preferences to interventions to goals to services provided. Ideally, the ISP should be an overview of care and support for the participant; everyone who cares for that particular participant should have access to the billing.

What an ISP is: The legal document that drives the individual's services.

The ISP may not look exactly the same in each county in Ohio. Be clear about the expectations from your county board of DD.

Personalized Outcomes and Action Steps

Individual Service Plans need to be person-centered for a few reasons. First of all, our industry is focused on keeping the person at the front of our care decisions. The ISP is no good if we are using canned, one size fits all, outcomes or action steps. So, how can we make the outcomes and action steps personalized? By involving the participant, the care team, and the natural supports.

Personalized outcomes

Just a few years ago, you might have heard the word “goals” instead of “outcomes”. Now we use the word “outcomes” because outcomes are related to what is important to (or for) the person. The outcomes are the results of the services and interventions. Essentially, outcomes = end results that are directly tied to the person’s wants/needs.

In order to be person-centered when planning outcomes for the ISP, the participant needs to be involved in the process as much as possible. Through individual interviews, interactions, and assessments, staff can determine what is important to, and for, the person.

Also, when we wrote ISP “goals” a few years ago, we often used very tangible measurements. For example, a goal might have read “Sam will exercise daily by walking to the bus stop at least 5 times per week with verbal cueing.” However, now our outcome statements are written so that we can directly address who is involved and why the activity/outcome is important to/for the participant. Our outcome statement might now read “Sam walks to the bus stop so that he can get moving and feel good about himself.” Can you tell the difference? Let’s take a look at more examples. Some examples of what personalized outcomes may be:

- John applies to jobs because working would make him feel good about himself.
- Holly listens to music in her room because it makes her feel calm and relaxed.
- Abe plays Scrabble because he has fun doing it and because it helps him feel smart.
- Joshua watches television after dinner because it makes him relaxed and ready for bed.
- Gina plays basketball during the afternoon because it helps her feel calm.

- Wanda carries a daily schedule with her because it makes her feel relaxed when she knows what is coming next.
- Carrie wears her red hat when she goes on outings because it keeps the sun out of her face and makes her feel pretty.

Personalized Action Plan and Steps

Our outcome statements are great, but without the supportive steps to help the participant achieve their outcome, the statements are useless. The action plan is where the team and the person work together to come up with ways to get the participant from here to there. So, how are we going to get Sam to walk to the bus stop? He wants to get moving and feel good about himself and walking to the bus stop, instead of hitching a ride, is a great outcome. But, how can we get Sam walking to the bus stop when he really doesn't want to? How can we make it a habit? These are the questions that the team should be asking when developing the action plan statements.

Remembering that the action plan is essentially a list of 2-3 things that will help the person attain the desired outcome, what could we do for Sam and his bus stop dilemma? Personalized action plan items might be:

- Assure that Sam has the most recent bus schedule so that he knows when the buses are coming.
- Practice walking the route from Sam's house to his bus stop so that he knows how long it takes him to walk there.
- High five Sam when he makes the trip to the bus stop. This makes Sam feel proud of himself.

Our action plan makes sure that we give ideas on how to set the participant up for success. But the action steps, or activities, that make plans come to life are really up to the direct care providers. The nitty gritty of getting Sam from point A to point B comes during the daily interventions and actions that you, the care provider, provide. The ISP lists the action plan steps, or activities, typically after the action plan. Here is what the action steps or activities might look like for our friend Sam:

- Review the bus schedule with Sam during breakfast, because he tends to concentrate best in the morning.
- During the day, verbally review the plan for the day with Sam. Include walking to the bus stop as part of his plan.

- When Sam looks anxious in the afternoon, encourage him to walk around the agency on the walking trails (or inside the agency building if the weather is poor).
- High five Sam when he asks to leave for the bus stop at the appropriate time. Celebrate a week's worth of bus stop walks on Friday with an afternoon dance party to the song "We Will Rock You" by Queen (it's his favorite).

Can you tell how these action steps support the action plan, but are even more personalized to his preferences and his daily care routine? Action steps can also include other services that are provided for the participant. Let's look at some other action steps for Sam that include other services:

- Physical therapist walks to and from the bus stop with Sam at least weekly so that he can work on his endurance.
- Sam's speech therapist includes time walking to and from the bus stop on his schedule board for the day.
- Remind Sam to pack a healthy snack for the bus, as per his dietician's list of food ideas.

The ISP is a place where everyone can come together and work on setting the participant up for success in the chosen outcomes. Remember, the team, the participant, and the supports should be involved with developing the ISP, and updating it on a regular basis. The participant should always be at the center of the equation, giving his opinion on his desired outcomes.

What else is on the ISP

The ISP isn't just outcomes, action plans, and action steps. There is other information listed within the ISP. Each ISP template is going to look different from county to county, but here are a few items that you are likely to find on the ISP, no matter where you are working:

- Name and demographic information
 - The ISP is often a great place to start when you need to get some basic information about your participant. Name, birthday, address, emergency contact – it should all be listed on the ISP.
- Medical information
 - The ISP often offers a place to house medical information for your participant. Items can include medical diagnoses, medical histories, any

medical implications (weight bearing status, etc.), allergies, doctor names, doctor contact information, and medications.

- Lifestyle and recreation preferences
 - The ISP should include information about the interests and lifestyle preferences of your participant. Look for religious affiliations and hobbies.
- Communication preferences
 - If your participant is hard of hearing in one ear, or cannot see far away without glasses, you will find that here on the ISP. You will also find if the participant can speak without difficulties, or if he needs adaptations such as a communication board or a hearing aid.
- Dietary information
 - Check the ISP to find out if there are any dietary restrictions, allergies, or preferences for your participant.
- Home and support information
 - The ISP will include emergency contact information, as well as who the participant lives with, the important players in his life, natural supports, and any other home history or information that might be helpful to the caregivers that support the participant.
- Services provided
 - While you will likely find services like speech therapy or occupational therapy listed in different action steps, there might also be separate sections for therapies and services to lay out their own schedules or information.

Major Unusual Incident (MUI) or Unusual Incident (UI) logs will not be in the ISP; while you might see some action steps or outcomes change due to repeated MUI or UI occurrences, the log itself is not located in the ISP.

The best way to get to know your participants is to start off by reading the ISP. While the paperwork can sometimes seem overwhelming, if you don't know your participant at all, the ISP can give you solid footing as you begin your relationship of care with him/her.

Chapter 7: The Provider's Role in Behavior Support

Why a Behavior Support Plan (BSP) is needed

When an individual is observed by members of the team-- including residential and vocational providers--as displaying behaviors that meet certain criteria, it becomes necessary to explore an assessment process to determine if a BSP will be required.

Some of the criteria include:

- Trends and patterns of UI's (Unusual Incidents) and MUI's (Major Unusual Incidents)
- Behavior that threatens the safety of the person or other people
- Behavior that involves property damage
- Behavior that prevents community acceptance
- Behavior that interferes with the individual's job performance or daily schedule
- Behavior that is of concern to the individual's caregivers

Once the team decides that this needs to be explored, a qualified professional conducts an assessment in an effort to identify how the behavior relates to the individual's environment, as well as the characteristics of the behavior---the frequency (how often), intensity (how serious), and duration (amount of time).

Other issues that are important include:

- Location of the behaviors
- Frequency of the behavior in certain environments
- Changes that may have recently occurred in the individual's life

Using the results of the assessment, the team develops interventions that may include a referral for counseling, modifying the ISP, and developing either positive behavior supports or a behavior support plan. Your role will be to follow the plan and document as the team requests. The individual has a greater chance of succeeding if the plan is followed consistently by all involved.

Basic Behavior Principles

Basic behavior principles (Skinner, 1938) are also taken into account when developing the BSP. You may need to become familiar with using ABC data collection and understanding the basics of positive and negative reinforcement.

ABC—Antecedent, behavior, consequence

What happens before the behavior is called the antecedent; what happens after is called the consequence. The consequence may be positive or negative; the behavior may be desirable or undesirable.

In logging behavior data, the consequence may be called the outcome, or what the staff/individual/others did after the incident.

Example 1

Cindy is a Cleveland Browns fan. She does not like the Pittsburgh Steelers.

When one of her housemates who knows this mentions the Steelers, Cindy begins throwing objects. After throwing objects, the other residents in her home stop speaking to her.

Antecedent: Someone asks Cindy if she would like to watch the Steelers

Behavior: Cindy throws her dinner plate

Consequence/outcome: Cindy's housemates ignore her

Example 2

Mark enjoys visiting with his family, but can sense when the end of the visit is drawing near. He becomes withdrawn and turns his head away from his mom, with his hand over his cheek. Coaxing him to 'look at Mom and tell her goodbye' causes him to become upset. *Allowing him to separate in his own way helps him to cope.*

Working with individuals, you will have to observe, document, and respond to behaviors. You will also have to recognize the triggers that seem to precede the behaviors, as well

as respecting the coping mechanisms an individual sometimes uses without any prompting.

Positive and negative reinforcement

Positive reinforcement is when something good happens after the behavior. As a result, the behavior increases.

With negative reinforcement, you are avoiding a negative outcome by performing a specific behavior.

Watch the examples in this video Positive versus Negative reinforcement, from Autism Training Solutions (2009)

<http://www.youtube.com/watch?v=wfraBsz9qX4&list=PL8C326E7D3FA79B65>

Development of the Behavior

Support Plan

Be sure you are familiar with the rules that address services you are providing, and if you have input or concerns, voice them. It is important that you know that measures are taken to assure that the plan meets the needs of the person. There are review boards, and, when applicable, a human rights committee, to be sure that no methods taken are harsher than needed; a separate set of people review the plan if it has aversive methods to make sure that the person with DD is having their needs met in a safe and appropriate manner.

If the individual you are working with has a BSP, (behavior support plan), **you would be in-serviced on the BSP prior to working with the individual.** This training would likely be initiated by the county board of DD; if you work for an agency, you may receive the training from your supervisor.

Elements of a Behavior Plan

If you work with an individual who has a Behavior Support Plan (BSP), you will be trained by a professional on elements of the interventions, your expected role, as well as the boundaries of your role, in carrying those out and documenting properly.

A behavior support plan includes:

- A case history (including medical information)
- Results of a behavior assessment
- Baseline data
- Behaviors to be increased and decreased
- Procedures to be used
- Persons responsible for implementation
- Review guidelines
- Signature/date blocks
- Space for dissenting opinions*
- Plan guidelines, with description of data collection process, who is responsible for implementation
- Guardian signature
- Definitions and guidelines of manual restraints, mechanical restraints, chemical restraints, and time-out definitions and guidelines

Not all of the individuals you work with will have a BSP. However, each individual may have positive supports embedded in the ISP.

Positive Supports may include:

- Environmental Changes (Removing something in the situation that triggers the person's behavior)
- Schedule Changes (Respecting that someone may be a morning person...or not)
- Activity Changes (Taking time to learn what the person would rather be doing instead of offering an activity menu of pre-planned choices that may not interest this person)
- Social Changes (Not pairing individuals together if one is bothered by the other)
- Offering Educational Opportunities (Acknowledging that individuals deserve to have information presented to them about their challenging behaviors and the associated risks)

- Implementing Increased Supervision (Providing a 1:1 staff when needed for extra support)
- Implementing Positive Reinforcement (Receiving a reward for desired behavior)
- Allowing Natural Consequences (A likely outcome of behavior---stay up late, you'll be tired at work)
- Time-away (When upset, the individual tries to gain back control over negative behaviors by leaving the environment willingly)
- Accompanying (The individual leaves an area willingly with staff direction or guidance)

***Dissenting opinions can be expressed by any team member who does not agree with something the team is planning to implement. This can be done formally or informally. Example: If a restriction is suggested that involves a visit with a friend or family member, and a team member disagrees with this, it can be formally documented. However, prior to dissenting formally, any team member can voice a disagreement and suggest alternatives based upon his or her experience in working with that individual. Disagreements and suggestions can be helpful if a plan has to be revised later.**

Prior to implementing the Behavior Support Plan (BSP):

The trained professional who authors the plan ensures that each provider expected to implement the supports is trained on the BSP, prior to working with the individual.

In a plan with restrictive measures...

A plan must be approved by a behavior support committee and a human rights committee. A monthly reporting system may be put in to place to track behaviors; this would be reviewed with you when you are trained on the plan. You would also be asked to submit this formally each month.

In a plan with positive interventions...

The provider's documentation should reflect the positive supports required by the ISP and should be available for any monitoring or review.

In a typical ISP, with no BSP...

Positive supports such as rewards and praise should be embedded into the plan.

Using Self-Efficacy Theory to provide positive supports

If I have the belief that I can do it, I shall surely acquire the capacity to do it even if I may not have it at the beginning

Mahatma Gandhi

"The basic idea behind Self-Efficacy Theory is that performance and motivation are in part determined by how effective people believe they can be. An intervention may employ the four "sources of information" involved in self-efficacy theory: (Bandura, 1977)"

- **Performance accomplishments**---establishing short-term goals which facilitate the development of skills
- **Vicarious experiences**---modeling examples of appropriate behaviors
- **Verbal persuasion**---verbal prompting with positive verbal reinforcement regarding the individual's abilities
- **Emotional arousal**---eliciting a positive emotional response (Savell, 1986).

Example

Julie wants to learn to dance and perform in a talent show at her church. She has had some instruction, but needs to learn a set routine in order to qualify. Her caregiver is taking her to a dance studio for lessons, but she must practice at home also. Julie wants to do this, but needs some encouragement in order to achieve her outcome. She cannot seem to picture what the show will be like, and whether or not she can focus without worrying about what the audience is doing or how they respond to her. She saw a show on TV where the dancers forgot their routines and started to cry; she does not want that to happen to her!

Here's how the people supporting Julie can assist her to achieve her outcome, using the four information sources in self-efficacy theory:

Performance accomplishments

Julie could be taught to break down the parts of her routine, so that she can practice them in stages. Once she learns the introduction really well, then she could move on to the next part. She can be reminded of tasks she has done well and build on those, remembering to use just enough challenge and not too much, so she does not become discouraged. Remind her that she is improving upon her own accomplishments and not competing with someone else. Engage her dance teacher with her caregiver, so they can work together.

Vicarious experiences

Julie needs to have her dance and the impending performance modeled for her, similar to ‘show, don’t tell’—with a practice partner. As she improves...Julie could possibly model it for herself, by having her best steps videotaped, thus **building her confidence as she watches herself improve.**

Verbal persuasion

Julie needs encouragement from someone she respects; she also needs accurate feedback. Telling someone they are doing really great when they are not doing well isn’t helpful...it may set them up for failure. But you can always recognize parts of the performance that deserve praise.

Emotional arousal

Individuals with DD may become overly excited when anticipating an event. Helping the person use that excitement in a good way can be challenging. Julie’s staff could teach her to pretend she is in a performance during some of her practices at home and work on taking deep breaths, looking out over the heads of the crowd, so she isn’t tempted to watch how they respond to her. They could also bring a few friends to watch her in a pretend dress rehearsal, so she can prepare herself for the real show.

Confidence, positive outlook, and optimism are traits useful to all of us. Some questions that arise when using this intervention with the population of people with developmental disabilities:

- Might someone with less capacity for abstract thought have a more difficult time picturing themselves succeeding?

- Are high emotions a way of moving toward success or do they stand in the way of success?
- If someone highly skilled models the success, might this discourage rather than encourage the person we are helping?

Professionals who are successful at building a person's self-efficacy navigate these issues carefully and can answer this question:

What do I need to know about the person to make sure I set them up to succeed and not to fail?

Behavior Support Strategies that Include Restrictive Measures

DODD Rule # 5123-2-2-06, effective January 2015, addresses Behavior support strategies that include restrictive measures. If you are working with an individual who has a BSP with restrictive measures, you should view DODD's 20 minute video on this rule. Find that at dodd.ohio.gov, go to the tab for training, Presentation title: Behavior support strategies that include restrictive measures.

Sometimes individuals might need serious interventions in order to keep themselves, and others, safe. The DODD Rule defines restrictive measures as:

“A method of last resort that may be used by persons or entities providing specialized services only when necessary to keep people safe and with prior approval of the human rights committee in accordance with paragraph F of this Rule.”

From DODD rule #5123-2-2-06

"This rule limits the use of, and sets forth requirements for, development and implementation of behavior support strategies that include restrictive measures for the purposes of ensuring that:

1. Restrictive measures are used only when necessary to keep people safe.
2. Individuals with developmental disabilities are supported in a caring and responsive manner that promotes dignity, respect, and trust and with recognition that they are equal citizens with the same rights and personal freedoms as other Ohioans without developmental disabilities.
3. Services and supports are based on an understanding of the individual, and the reasons for his or her actions.
4. Effort is directed at creating opportunities for individuals to exercise choice in matters affecting their everyday lives and supporting individuals to make choices that yield positive outcomes."

Restrictive Measures include:

- Manual Restraint
- Mechanical restraint
- Time-out
- Chemical restraint

The following is a list of prohibited measures, ones you should NEVER implement:

- Prone restraint (lying face down)
- Use of a manual or mechanical restraint that has the potential to inhibit or restrict the individual's ability to breathe
- Use of a manual or mechanical restraint that causes pain or harm to the person
- Disabling an individual's communication device
- Denial of breakfast, lunch, dinner, snacks, or beverages
- Placing a person in a room with no light
- Subjecting the individual to a painful or damaging sound
- Application of electric shock to an individual's body
- Subjecting the individual to any humiliating or derogatory treatment
- Squirting an individual with any substance as an inducement or consequence of a behavior
- Using any restrictive measure for punishment, retaliation, instruction, or teaching, convenience of providers, or as a substitute for specialized services

Consider the following case stories as examples of what might transpire even when caregivers are well-meaning.

It's easier this way

Susan is a caregiver at ABC Agency, and she is having a rough day. Not only did 2 of her co-workers call off today, which means she'll be working with only 1 other caregiver instead of 3, but almost all of the individuals are sick. Sick individuals mean cranky individuals. Four of them have cursed at Susan even before she could punch in for work that morning. It was going to be a long day.

Susan struggles through her morning care and activities, noting that almost all of the individuals were having behaviors that were escalating a lot easier than usual. Knowing that a particularly aggressive individual, Kyle, was on edge today, Susan started to get

nervous. By the time it was almost lunchtime, she could tell that Kyle was just one wrong look from going over the edge. No one was there to help her get everyone all settled in for lunch, and Susan was feeling alone and extra stressed out.

Knowing that it would be easier if Kyle would just skip lunch and all the extra lunchroom stimulation, she told him that the dining room was closed today and that he needed to stay in his room. Halfway through lunch, Kyle came out and requested a meal because he was hungry. Susan told him that she would bring it to him later because she was swamped. Unfortunately, she never got to it.

Susan was having a rough day. Did she follow the Rule guidelines of not denying meals? No she did not. After all, Kyle didn't receive the lunch he requested. As challenging as the day was, this was not an acceptable way of handling the situation.

Be quiet

Anna and Lucy are best friends, and participants at Awesome Agency. While they do tend to get along most of the time, they almost always get in some type of altercation every afternoon, when they settle in the living room to watch Ellen. Anna likes to watch it quietly, while Lucy likes to talk throughout the whole episode. Often times, Anna gets very frustrated and has some type of escalated behaviors which can be difficult to redirect.

Jeff is the caregiver on duty and has an idea. A few minutes before Ellen starts, he asks Anna to take out her hearing aid so that he can change the battery. Instead of changing the battery, Jeff turns the hearing aid down. He figures that if Anna can't hear Lucy talking, then everyone will be happy. In fact, if it works, he thinks that it will be the best intervention on the ISP.

Well intentioned or Rule violation? It's a prohibited measure, therefore a rule violation.

In working with every person for whom you are a caregiver, remember to follow DODD's person-centered philosophy, as well as your information on what is important to and for the person. Rely heavily on what you can provide in terms of positive supports for that person---including praise, and mutual respect. Your role is important, and has the potential to make a difference!

The new training requirements---Person-centered planning, community integration, self-advocacy and self-determination, along with positive intervention culture, reflect an emphasis on encouraging not only acceptance, but a genuine atmosphere of support that respectfully acknowledges the contributions and talents of individuals with disabilities. **This change in our point of view alters the focus from what is lacking in the person to focusing on what the person has to offer.** This change encourages professionals in the field to focus on the contribution the person makes and how we can encourage that to blossom, rather than 'fixing' the deficits or limitations of the disability. Approaches such as person-centered planning allow us to assess, plan, implement, and evaluate programs that effectively align with positive intervention culture and self-determination. Elements of Seligman's Positive Psychology—**looking at what is working, rather than what is not working**---fit the mindset of supporting the individual's contributions rather than focusing on their deficits. Self-efficacy theory (Bandura) offers steps to follow when encouraging the individual to succeed on his or her own. Concepts promoting normalization (Wolfensberger, 1972) and person-centered planning (O'Brien and O'Brien 1998), support individuals with disabilities as active participants in driving their own agenda toward community integration and acceptance. Lastly, self-advocacy---individuals speaking up for themselves---allows those individuals to engage in evaluating our progress as professionals, toward creating and affirming a positive culture.

CHAPTER 8: Service Documentation Review

Let's return to DODD's site and read the waiver service definitions.

Waiver Service Definitions

You can find these by visiting dodd.ohio.gov, click on Medicaid, and click on waiver service definitions.

You can find the rules corresponding to the services you provide by visiting dodd.ohio.gov, click on rules and laws, then laws in effect.

In addition to your individual-specific training, it is also important that you are confident with what to document when you provide services to the individual that you are assisting. If you work in an agency or as an individual provider, you essentially require the same service documentation. Let's review that list quickly, remembering that a unit of time is 15 minutes and that you must document your services – no one else can document it for you. Also, I know that documentation isn't always the best part of our job. However, it is necessary.

Our charts and records help us look back at months of information that we would have otherwise forgotten. We are able to scour our logbooks and find trends in behaviors or medical emergencies. By looking at our charting and records, we are also able to find out what we did in situations well and what we need to work on. Charting is good. It can be time consuming, but we must not forget it. Charting is a crucial part of your job.

Below is the information that needs to be completed, as per Ohio DODD's rule. This is all service documentation to validate payment for Medicaid services:

- Date of service
- Place of service
- Name of service recipient
- Medicaid number of recipient
- Name of the provider
- Medicaid Contract number of the provider
- Signature of person providing services

- Type of service (if providing homemaker personal care, you must specify if service is routine, on-site/ on-call, or level one emergency).
- Number of units of the delivered service, i.e., 15 minutes is one unit, 5.5 hours of Adult Day Support or Vocational habilitation is 1 unit (1 day unit)
- Group size in which the service was provided
- Arrival and departure times of the provider to the individual's site, or if applicable, the individual to the provider's site
- Description and details of the services provided as described in the individuals' ISP (Individual Service Plan)
- Monthly notations regarding the individuals' response to services received (as relates to their outcomes)
- Forms that Identify the ISP services delivered—For instance, outcomes that can be checked off, indicating whether or not the individual accomplished those in a given day

Does that seem overwhelming? Don't worry, it isn't. Once you get the hang of it and designate some time during your shift to document, you will become familiar with being sure that the information required gets in to the chart of your client(s).

If you are certified in medication administration, you will also need to document your time and experience dispensing that medication to your clients. Refer to your agency for any specific forms that you might be required to fill out. The Ohio DODD's website has a specific section for Medication Administration, full of links and resources.

CHAPTER 9: Major Unusual Incidents

The requirements of Rule 5123:2-17-02 of the Administrative Code Relating to Addressing Major Unusual Incidents and Unusual Incidents to Ensure Health, Welfare and Continuous Quality Improvement

Included in this section is the following:

- Categories of **Major Unusual Incidents** (MUIs)
- Provider Reporting Responsibilities: MUI, Unusual Incident (UI), and Trends and Patterns
- Immediate Response
- Prevention Plans
- Role of Investigative Agent

- Abuser Registry
- Provider Requirements to Review DODD Health and Welfare Alerts

Health and Welfare Alert Requirement

Be sure you have read and studied DODDs Health and Welfare Alerts from the last year. Read them carefully, and review them throughout the year.

The alerts contain information that will help you become more efficient in your workday, as relates to the health and welfare of those in your care.

House of New hope will provide these alerts for you to read.

Definition of MUI and Categories

Learning and understanding the requirements of incident reporting is crucial to your effectiveness as a provider. Not only are you expected to protect the rights of the individuals you serve, you are mandated to maintain their health and safety while they are in your care. This should not be taken lightly.

Click below to read the rule whenever you need to refer to the rule itself; you could also reach it by visiting the homepage of dodd.ohio.gov, clicking on “**rules and laws**” on upper toolbar, then “**rules in effect**” on the left toolbar, and scrolling down to the rule’s number, 5123:2-17-02.

A few definitions:

- ITS: Incident Tracking System, accessed by county board of DD, to report MUI information
- IA: Investigative agent; works for ICF or county board of DD; investigates MUIs
- PPI: Primary person involved

What is a Major Unusual Incident? –MUI

A Major Unusual Incident (MUI) is the alleged, suspected, or actual occurrence of an incident when there is reason to believe the health or welfare of an individual may be adversely affected or an individual may be placed at a risk of harm, if such individual is receiving services or will be receiving such services as a result of the incident.

Incident reports of abuse, neglect, or major unusual incidents involving persons with developmental disabilities are an essential element in protecting the rights of individuals with developmental disabilities. The following three categories are from the rule 5123:2-17-02 and are summarized here. **Become familiar with all categories of MUIs.**

Category A

Category A incidents include the following:

- Accidental or Suspicious Death: The death of an individual due to an accident or under suspicious circumstances.
- Exploitation: Using an individual or an individual's resources for monetary or personal benefit or gain.

- Failure to report means that a person who is a mandated reporter of abuse, misappropriation or exploitation sees or hears of the incident happening and then *does not* report it to the proper authorities, or omits important information about the incident when filing it.
- Misappropriation: Defrauding, or otherwise obtaining personal property of an individual.
- Neglect: Failing to provide an individual treatment, care, goods, supervision or services to maintain health or welfare, when there is a duty to do so.
- Peer to peer acts involve two individuals served and include:
 - Exploitation: Using an individual or an individual's resources for monetary or personal benefit, profit, or gain.
 - Theft: Intentionally depriving another individual of real or personal property valued at \$20 or more, or property of significant personal value to the individual.
 - Physical act: An individual is targeting or firmly fixed on another individual. The act is NOT random or an act of circumstance. The act results in injury that is treated by a physician, physician's assistant, or nurse practitioner. Choking or any head and neck injuries such as a bloody nose, a bloody lip, a black eye or other injury to the eye is also included. Minor injuries such as scratches or reddened areas not involving the head or neck shall be considered unusual incidents (UIs).
 - Sexual acts: occur without the consent of the other individual
 - Verbal acts: occur when an individual uses words, gestures, or other communicative means (Facebook posts, texts, etc,) to purposefully threaten, coerce, or intimidate the other individual when there is the opportunity and ability to carry out the threat.
- Physical abuse is physical force that can be expected to result in physical harm or serious physical harm. This can include, but is not limited to, hitting, kicking, slapping, etc. The use of prone restraint is now considered an allegation of physical abuse.
- Prohibited sexual relations means an employee engages in consensual sexual conduct with an individual who is not the employee's spouse and whom the employee was employed or under contract to provide care at the time of the incident.
- Rights code violation means any violation of the rights in section 5123.62 of the Revised Code that causes a likely risk of harm to the health and welfare of the individual.

- Sexual abuse means unwanted touching, non-consensual sexual acts that can include sexual conduct or contact, public indecency and voyeurism.
- Verbal abuse is the use of words or gestures or other communicative means (text messages, Facebook posts, etc.) that are purposefully used to threaten, intimidate or humiliate an individual.

Category B

Category B incidents include the following:

- Attempted suicide: A physical attempt that results in treatment, observation or hospital admission.
- Death other than accidental or suspicious death: This is the death by natural causes of an individual by cause and without suspicious circumstance.

Remember, the accidental or suspicious death is a Category A incident.

- Medical Emergency: An incident where emergency medical intervention was required to save an individual's life.
- Missing Individual: An incident that is not considered neglect and the whereabouts of the individual is unknown, even after you search for them in the immediate area, and the individual is believed to be at risk for harm to self or others. If the individual's whereabouts are unknown longer than the period of time specified in the ISP, but the individual is not at imminent risk of harm to self or others, the incident is treated as an unusual incident, not a MUI.
- Significant injury: An injury of known or unknown cause that is not considered abuse or neglect and that results in concussion, broken bone, dislocation, second or third degree burns or that requires immobilization, casting or five or more sutures. These would be tracked in the ITS as either known or unknown.

Category C

Category C incidents are a new addition to the Rule as of September 2013. These incidents are investigated by the County Board and can be 'upgraded' to a Category A or B incident as the investigation moves forward.

- Law Enforcement Any incident that results in the individual being arrested, incarcerated or charged.

- Unapproved Behavior Support The use of an aversive strategy or intervention implemented without approval by the ISP, or the human rights committee, or without informed consent, that results in a likely risk to the individual's health and welfare.
- Unscheduled Hospitalization Any hospital admission that is not scheduled unless that hospitalization is due to a pre-existing condition that is specified in the Individual Service Plan.

Abuser Registry

What is the Abuser Registry?

Rule # 5123:2-17-03 fully explains the abuser registry. Prior to employing someone to work as a staff at an agency serving people with DD, the employer must check to see if the potential employee's name is listed. Yearly checks are also required.

The Department shall review all reported incidents where a registry offense may have been committed by a DD employee to determine whether the facts of the case may warrant placement of the DD employee's name on the registry.

DODD Rule Rule # 5123:2-17-03

- Failure to Report is when **a person, who is required to report** alleged, suspected, or actual abuse, neglect or misappropriation, has reason to believe an individual has suffered or faces **substantial risk** of suffering abuse, neglect, or misappropriation, and that person does not immediately report such information to a law enforcement agency or the county board of DD.

So...not properly reporting an MUI involving substantial risk to the person...is an MUI.

Case Examples of Common MUIs

It is good to not only review the information you are required to learn from the rule, but to also see how it applies in 'real life', with situations that might happen to you. Here are a few scenarios.

Identifying the Incident

MUIs are labeled by categories: A, B and C. Each category has different investigation protocols and incidents can shift around in category depending on what is found during the investigation process. It is acceptable to submit a report if you are unsure whether or not an incident may be categorized as a MUI or UI.

Let's take a look at a few common MUIs.

Unplanned Hospitalizations...Category C

Jimmy lives in a group home. His new staff took him to the park. She did not know that Jimmy was allergic to bees. After being stung, Jimmy's arm started to swell. He became upset and distraught. An epi-pen was NOT used. Jimmy and the staff member went to the emergency room, where the doctor treated Jimmy; however, the doctor decided to keep Jimmy overnight to make sure he was alright.

Exploitation...Category A

Jeannie is a provider who looks after several older women. They really like Jeannie, especially when she takes them shopping, because Jeannie doesn't bother with things like keeping receipts. Jeannie lets them buy her lunch and other gifts like lottery tickets.

Physical Abuse...Category A

Tony works at the workshop. One of the men in his work group is really stubborn. He will not get out of his chair after lunch and has almost missed his bus, because he simply will not get up. When Tony was helping another individual, he saw one of his co-workers shake the man out of his chair to get him to move. It went on for a few seconds, and the man was almost tipped out of his chair.

Neglect...Category A

Lisa lives in her own apartment in a supported living program. Her staff spends time with her teaching homemaking skills and facilitating community integration. Her ISP states that she is only to be alone for 2 hours maximum. One night her staff did not make it in to work. There was some kind of mix-up as to who was supposed to work that night. Lisa was alone for about 12 hours.

Medical Emergencies...Category B

Wendell just completed his CPR and First Aid training. He started working in a group home the next day. One of the residents started choking. He had to perform the Heimlich maneuver to assist.

Significant Injury....Category B

Michael lives in a facility with 24 hour care. One night, his behavior was inappropriate, and he threw something across the room. It broke, and he got cut with glass. He had to go to the emergency room and get 5 stitches. This is a known cause and would be tracked as such in the system.

Peer to Peer Act....Category A

John and Bruce live in the same facility. John has a history of aggressive behaviors. Bruce brings you his phone that shows a text message from John that says he will choke Bruce in the middle of the night while the night shift worker is on break. This is a Category A peer to peer verbal act.

Peer to Peer Act....Category A

Scott gets angry at Julie during dinner at their group home. He leans over the table and slaps her in the face. As a result, Julie gets a bloody lip. This is a Category A peer-to-peer physical act.

Peer to Peer Act....Unusual Incident (UI)

Jose becomes agitated during art class and wants to leave the room. As he is leaving the room, he forcefully pushes back his chair, and the chair hits Holly in the leg, causing her to fall. Since this act was not intentional, but was instead random and accidental,

and since the injury did not require physician care or involve the head and neck area, you would report this in your UI log.

Peer to Peer Act....Unusual Incident (UI)

Jorie takes \$1 from Crystal's purse, so that she can buy a soda. Since the \$1 was not of significant personal value to Crystal, and since the amount was less than \$20, this would be added to your UI log and NOT reported as an MUI.

Missing individual...Unusual Incident (UI)

Noah's service plan says that he sometimes likes to go to the coffee shop a few blocks away from his home when he feels stressed out. When his provider cannot find him, she searches the house immediately and cannot find him. Noah did not tell her where he was going, but he is not an imminent threat or risk to himself or others. After a few hours, she finds him at a coffee shop, as she knows that he goes there often, and she called the shop before she walked there herself. This should be reported as an Unusual Incident, NOT a MUI, as he was not a threat or in harm's way.

Significant Injury...Category B

James comes to you with a cut on his arm that he cannot get to stop bleeding. He is taken to Urgent Care and gets 10 stitches. This is a MUI and should be reported as such.

MUI (Major Unusual Incident) or UI (Unusual Incident)?

Let's take a moment to read a few scenarios and decide how you should report them-as a MUI or UI?

Scenario #1

Jason, Andy and Jessica are sitting in the living room of their facility watching television. Jessica turns off the television after the program they are watching is over. Jason becomes very upset and agitated. He starts to escalate, so a staff member comes over to offer to escort him back to his room, as per his individual service plan states. While he is being escorted out, he is waving his arms and kicking. He ends up kicking Andy in the shin, causing it to bleed and bruise. Is this a Peer-to-Peer physical act that you should report as an MUI or is it an UI?

If you said UI, you are CORRECT.

In order to be a MUI Peer-to-peer physical act, the act needed to be intentional and the individual needed to be firmly fixed on the other individual. In this case, Jason was upset and not firmly fixed and intentional about kicking Andy in the leg. If, in this case Jason would have become angry at Jessica for changing the channel, stood up and pushed her into the wall, causing a visit to the doctor, it would have met MUI criteria. In that case, Jason would have been firmly fixed on Jessica and physically harmed her. Let's try another scenario.

Scenario #2

Krystal and Kim used to live in the same group home and are Facebook friends. After having a disagreement about doing the dishes in their group home, Krystal posts on Kim's Facebook page that she is going to stab Kim in the hand the next time she sees her at the recreation trip they are both signed up for on Tuesday. Krystal posts on her Facebook wall the same threat every hour for the entire night. It is very upsetting to Kim, and she shows you the Facebook posts. Is this a MUI or UI?

If you said MUI, you are CORRECT.

This is a peer-to-peer verbal act, which is a Category A MUI. Even though Krystal isn't using her verbal words to harm Kim, she is using social media, which is included in the "other communicative means" part of the rule. This example also contains the opportunity and the ability to carry out the threat. Let's try another.

Scenario #3

Tim is out of your care and is at his job for the day. You later receive a call that he has been arrested at work. You don't know any other details at the time. Does this fit the criteria for MUI or UI?

If you said MUI, you are CORRECT.

Anytime an individual is arrested, charged or incarcerated, you must complete MUI reporting and paperwork, even if they were out of your care at the time. Let's do one more.

Scenario #4

You are with Adam on a hike at a local nature preserve. Adam has asthma and has his inhaler with him. His asthma is well documented in his individual service plan, and you both are aware of the concerns before your hike. Even though you take it easy during the hike, he becomes wheezy and uses his inhaler. His breathing does not improve, and he ends up in the hospital overnight for observation. MUI or UI?

If you said UI, you are CORRECT.

Adam's asthma was documented in his ISP and while his hospitalization was unscheduled for him, it was due to a pre-existing condition of asthma.

Reporting the Incident

If the MUI is a category A, you must call the county board MUI hotline within 4 hours. Be sure to have the phone number handy at all times in case you need it.

Now, let's take a moment to review what and how to report MUIs and UIs, as reporting is vital for you not only to maintain the health and safety of the individuals, but also to review trends and patterns.

Let's start with MUIs. Once you have learned about the MUI and assured immediate safety for everyone involved, you have until 3pm the next working day to get the report, with any information that you have, to the county board. So, let's apply it to a scenario you might encounter.

You find out that individual Susan accuses provider Greg of slapping her in the face at midnight first thing Monday morning when you arrive at work. Immediately, you assure the safety and welfare of everyone involved. Then, you should remove Greg from the premises and let him know that he is not to report to work or have contact with individuals until further notice. Then you must contact local law enforcement and then call the county board. You have until 3pm on Tuesday to file the initial written report of this Category A MUI to the county board. In your report, you need to tell them that Greg has been removed from the home. You need to notify Susan's guardian or person whom she has identified as well of the allegation and investigation.

A report of a MUI should take priority in your day. Do the investigation and fill out the information as completely and as **accurately as you can.**

Major Unusual Incidents should be recorded in a log that you have available. **You will need to submit these logs to your county board of DD any time they request them from you, and include information about how you are analyzing the patterns and trends that you see.**

Unusual Incidents are recorded in a log that providers should have available. Providers should review UI logs monthly and submit them only upon request. A provider should contact the SSA if a trend or pattern is found.

Reporting Responsibilities - MUI, Unusual Incident (UI)

After you have taken measures to assure that the individual is safe and their health and welfare is addressed, you need to start the reporting process for MUIs and UIs. The reporting process is important not only for tracking, but also to assure that all appropriate investigations take place and all appropriate parties are notified.

Reports regarding all MUI's involving an individual who resides in an intermediate care facility or who receives round-the-clock waiver services need to be filed regardless of where the incident occurred.

Reports of MUI's involving death, exploitation, failure to report, law enforcement, misappropriation, missing individual, neglect, abuse, peer-to-peer acts and prohibited sexual relations are filed regardless of where the incident occurred; and all requirements of the rule are to be followed.

The other categories of MUIs are only to be filed when the incident occurs in a program operated by a county board of DD or a certified provider.

If a worker or volunteer in DD services observes or has reason to believe that an MUI involving an individual with developmental disabilities has occurred, that person must report the incident to the provider/agency with which he or she is affiliated. The provider/agency must then report the incident to the investigative offices of the local county board of DD. **Such a report must be made no later than 4 hours after their knowledge of the incident and a written report about the incident must be made to the County Board of DD by 3 p.m. the next working day, on a form provided by the county board of DD.** The county board then enters info on the ITS (Incident Tracking System) by 3 pm on the day following the day of the notification.

Providers should immediately report the incident to law enforcement for any suspected exploitation, failure to report, misappropriation, neglect, peer-to-peer act or abuse which might be a criminal act. ***You need to report the time, date and name of person notified to the county board, so be sure to jot down that information as you make the call.*** You must contact the Ohio State Highway Patrol if any suspected exploitation, failure to report, misappropriation, neglect, peer-to-peer act or abuse that happens at a

developmental center. Again, you must report the time, date and name of person notified.

All suspected abuse or neglect of children (individuals under the age of 21) must be reported to the local public children's services agency.

If you are working for an agency, they will have a reporting form for incidents. If you are an individual provider, secure a form from your county board of DD, or use the forms we provide in the trends and patterns chapter.

Immediate Response

According to the rule, peer-to-peer acts do not refer to those involved as PPI and victim. This is why both individuals involved and their guardians are notified about what is going on, unless they feel that one might endanger the other if they are given information.

MUI's other than peer-to-peer identify the PPI: Primary Person Involved as the perpetrator, not the victim.

From the Rule 5123:2-17-02 "Primary person involved" (PPI) means the person alleged to have committed or to have been responsible for the abuse, exploitation, failure to report, misappropriation, neglect, prohibited sexual relations, rights code violation, or suspicious or accidental death. The protocol for contact with the person who is the PPI, even if it is the guardian or parent:

- **Do not inform the PPI of the investigation details**
- **Remove the individual who has allegedly been abused from the presence of the PPI**
- **The department may inform other agencies employing the PPI if they work for other DD agencies.**

The very first action a provider should take upon identification or notification of a MUI is to ensure the health and welfare of the individual served.

Appropriate actions might include:

- Immediate medical attention.
- Removal of an employee who is suspected of abuse.
- Any other necessary measures.
- If a provider's employee has been removed from serving individuals pending the MUI investigation, the county board of DD will keep the provider apprised of the investigation.
- Each county board of DD offers a 24 hour system of contacting to report MUIs. This info is made available to providers; Keep the number where you can find it quickly.

Notification requirements:

When an incident occurs during the time a provider is responsible for the individual, notification must be made to the:

1. Guardian or other person whom the individual has identified.
2. SSA (Service and Support Administrator)
3. Residential provider
4. Staff or family at the individuals' home who have responsibility for the individual's care
5. Support broker for an individual enrolled in the self-empowered life funding waiver.

***Document all efforts for notification; do not include the PPI, their spouse or significant other, if they are family member or guardian.**

In cases where law enforcement has been notified of an alleged crime, the department may notify other agencies where the PPI may be employed for the purpose of ensuring the health and safety of other individuals with DD.

Role of Investigative Agent

- Certified by the department (Ohio Department of DD)
- Trained annually by department-approved standards.
- Conducts MUI investigations, except for those that must be Department-directed.
- Conducts interviews for MUIs.
- Completes a report of the investigation and submits for closure in the ITS within thirty working days unless the department grants an extension.
- Includes in a report—the initial allegation, a list of the persons interviewed, summaries of interviews and documents reviewed, and a findings and conclusions section.

*A department-directed review takes place if the subject of the investigation is a superintendent, SSA, or a board member of the county board of DD.

Prevention Plans

Five calendar days after the report is closed, there is a written summary of the investigation, including the facts and findings, and whether the allegation was substantiated or unsubstantiated, as well as preventive measures.

This summary is sent to:

- The individual
- The individual's guardian or person whom the individual has identified
- The provider agency involved
- The SSA and support broker, if applicable

After the incident has been investigated, you will receive a report including findings, and any corrective actions expected to be carried out.

Findings of an incident

From DODD Rule #5123:2-17-02:

Findings in administrative investigations of major unusual incidents in category A shall be based upon a preponderance of evidence standard. "Preponderance of evidence" means that credible evidence indicates that it is more probable than not that the incident occurred.

There are three possible findings of a category A administrative investigation:

"Substantiated" means there is a preponderance of evidence that the alleged incident occurred.

"Unsubstantiated/insufficient evidence" means there is insufficient evidence to substantiate the allegation. "Insufficient evidence" means there is not a preponderance of evidence to support the allegation or there is conflicting evidence that is inconclusive.

"Unsubstantiated/unfounded" means the allegation is unfounded. "Unfounded" means the evidence supports a finding that the alleged incident did not or could not have occurred.

The individual's team shall collaborate on the development of preventive measures to address the causes and contributing factors to the incident. The team members shall jointly determine what constitutes reasonable steps necessary to prevent the reoccurrence of MUIs. If there is no service and support administrator, individual team, or agency provider involved with the individual, a county board of DD designee shall ensure that preventive measures that are reasonably possible, are fully implemented.

Some examples of preventive measures might include:

For an individual prone to falls:

- Offer physical assistance with transitions, and reminders to the individual to ask for assistance when standing up to transition;
- Encourage individual to take his time and to ask staff for assistance;
- Encourage individual to wear tennis shoes to ensure safety while walking;
- Refraining from wearing sandals and slip on shoes.

Trends and Patterns

Providers must send their county board of DD a log regarding MUI trends and patterns **on a semiannual basis**; typically, the report must be submitted even if there are no MUIs. (Submit these on forms as outlined by your specific county board.)

Providers should identify and address issues to prevent recurrence. **Criteria for trends and patterns: five within 6 months; ten within a year, or other pattern identified by the individual's team.**

After earning your provider certification, contact your county board of DD and ask about monthly provider meetings, so you can stay abreast of new information and county-specific policies. Most importantly, pay attention to the instructions in the Individual Service Plan, specifically the services you are contracted to deliver. Always document accurately, so that you can show you are complying with the plan and accountable to the team.

Major Unusual Incident Reviews and Analysis

Providers must also review Major Unusual Incident reports for trends and patterns.

Turn in the form semi-annually, twice each year, to your county board of DD.

Providers must review Unusual Incidents monthly for trends and patterns. **A monthly UI Log must be completed and maintained by all providers.** If you are an independent provider, ask your county board of DD, or if you are employed by an agency, ask the agency employing you for incident report and log forms, so that you meet compliance in this area.

Difference between MUI and UI

Unusual Incident: from DODD rule #5123:2-17-02

An event or occurrence involving an individual that is not consistent with routine operations, policies and procedures, or the individual's care or individual service plan, but is NOT a major unusual incident. Unusual incident includes, but is not limited to, dental injuries; falls; an injury that is not a significant injury; medication errors without a likely risk to health and welfare; overnight relocation of an individual due to a fire, natural disaster, or mechanical failure; incident involving two individuals served that is not a peer-to-peer act major unusual incident; and rights codes violations or unapproved behavior supports without a likely risk to health and welfare.

An Unusual Incident is less impactful than a major Unusual Incident. However, it doesn't change the fact that the most important point is to maintain the health and safety of the individual.

You are also responsible for reading and periodically reviewing the health and safety alerts listed by the Department of DD.

Be sure to read the alerts that relate to the individuals you work with, as well as all of the other alerts dated since your last training.

To find the alerts: Go to dodd.ohio.gov; click on health and welfare; click on the Toolkit tab; Click on Access the toolkit tab; read the health and welfare alerts dated since your last training.

Major Unusual Incidents Reporting

Major Unusual Incidents (MUIs) are required to be reported to the County Board, and any provider who serves persons with DD is required to do that reporting. That, my friend, means you. While MUIs might not happen often or at all on your shift, it is still important that you are familiar with MUI reporting so that when the time comes to do the report, you are ready with the information needed. Here is the low down on MUIs as it applies to you and your job.

MUIs are actual or alleged/suspected incidents where the health and safety of an individual may be at risk, and the individual may be placed at a reasonable risk of harm. If you see an MUI happen or you believe that a MUI has happened, you must report it to your agency. Report what you know and when you knew it.

Timing of reporting is important. Once you report the incident, your agency has 4 hours to report it to the County Board and then until 3 pm the next business day to complete a MUI report. Your agency has a mandated form that needs to be filled out when you report an MUI. Since timing is of the essence, be sure to jot down what you know about the incident, so that you have the information that your agency supervisor needs when they fill out the form. The more information you are able to provide, the better for everyone.

Name of individual-This is the individual that you serve that was the main part of the incident.

Date and time of the incident- Try to remember the time as best as you can as it can be helpful during the investigation if needed. It doesn't have to be exactly to the minute, but the closer you can get the better.

Location of the incident-Be as specific as possible (2nd floor bathroom of the movie theater)

Description of incident-Include as much information as possible, without giving your guess. Include what you saw or heard and try to include the who, what, where and when of the incident.

A good description of an incident would be: I was on an outing with 6 residents to watch a movie at Highland Park Movie Theaters. During the show, Annie told me she needed to use the restroom. When she hadn't come back in 10 minutes, I went to the restroom

to see if she needed help. She was in the 2nd floor restroom on the floor, lying on her side. She didn't respond to her name when I called her. A housekeeper from the movie theater was in the bathroom as well.

A less than good description would be: I was on an outing with 6 residents to watch a movie at Highland Park Movie Theaters. During the show, Annie told me she needed to use the restroom. I went in to help her and found her on the floor. She must have fallen and slipped on some water or maybe her shoes were untied, and she tripped on those. Annie always leaves her shoes untied, and we should probably talk to her caregivers about getting her better shoes without the ties, so she doesn't trip all the time. She tripped last Saturday before Bingo at the group home and though she didn't hurt herself, she could have.

Including your guesses about how Annie hurt her head are not relevant.

Report what *you* know, what *you* saw and what *you* heard.

While in our example Annie was not responsive, if you would have found Annie and she would have told you, "I fell down", be sure to include her comments to you in the incident report.

Injury-Describe the type and location. You're not a doctor, so you don't have to be clinical when you're describing the injury. Keep it simple and accurate. Example: Annie was bleeding from her head.

Immediate Action to Ensure Health and Safety of Individuals- This is the part that can sometimes be hard to recall because you do this without thinking about it. But, remember what you did to immediately help the situation. Example: I stayed with Annie and used my cellphone to call 911. I stayed with Annie until the paramedics came.

Witnesses to Incident-This can include anyone who saw what happened, whether they are with your agency or not. There was a housekeeper in the bathroom with Annie. Try to remember her first name, as your agency will probably call the theater to get her first and last name for the reporting process.

The key to giving your agency the information they need is to remember it is clearly as possible. This can sometimes be easier said than done, especially in a situation that is scary or gets your adrenaline pumping. As soon as the incident is over and everyone is safe, grab a piece of paper and write down the specifics-the who, what,

when, where-of what you can recall. Your chances of remembering all those details once you return to your agency, or once you finish your overnight shift, are low. Document as soon as possible!

CHAPTER 10: Universal Precautions/Health and Safety Reviews

Universal Precautions

In the course of your job working with people living with DD, you may be exposed to bodily fluids. If contact with bodily fluids happens during your work day, you want to be as informed as you can be about how to respond. It is your professional responsibility to be educated on how to minimize your risk and the risk of those around you. Much of the information we are going to cover will seem common sense and you might be inclined to just skim over it. Please take the time to read through everything! You'll need to feel comfortable with the information, knowledgeable and able to use it during times of emergency.

So, let's get started!

What are universal precautions, anyway?

Universal Precautions refers to an approach for infection control where you ***treat every bodily fluid as if it is infected with HIV and other blood borne pathogens***. The goal is for everyone to know these easy guidelines of infection control so that care providers, patients, and those helping will not become infected with disease. *Essentially, you need to treat everyone as though they are infected with a contagious disease while you are in contact with any bodily fluids.* This isn't to be taken as though you should avoid helping people at all costs because they might be diseased. Instead, Universal Precautions empowers people to help others in a manner that is most responsible and safe for all parties involved.

What are blood borne pathogens?

Blood borne pathogens are diseases or infections that can be transmitted through blood or other bodily fluids. These diseases can include HIV, Hepatitis, TB, Pneumonia, and Chicken Pox, to name only a few. Blood borne pathogens can be transmitted through blood or other bodily fluids from an infected person to another person's body via needle sticks, human bites, cuts, abrasions, or through mucous membranes.

What are bodily fluids?

As unappealing as it is to discuss, it is important that we outline what those bodily fluids are because you need to know what you are risking by exposing yourself to the bodily fluids of others. Technically, bodily fluids are any liquids that form inside a living body. More specifically, bodily fluids can include a variety of liquids and secretions from humans: blood, mucus, bile, sweat, urine, feces, pus, vomit, saliva, and semen. There are plenty of other bodily fluids, from ear wax to gastric juice, but the main ones that you might come into contact with are covered in the previous list.

Infection Control

What is infection control?

Germs are everywhere. Because germs are indeed everywhere, we need to be responsible for doing our part to keep germs away from us and away from others. Our intent is to give you information that might reinforce good habits that could keep you safe from exposure to bloodborne pathogens.

Infection control is actually part of healthcare organizations. In true infection control, the goal is to keep the infection rate down through prevention, surveillance, isolation, and management. Hospitals have entire staff teams, committees, and specialists for their infection control training and needs. We aren't going to get that technical for you today. Even though you might not work in a health care facility, using infection control practices in prevention are essential to keeping those around you healthier and infection-free.

What is good hand hygiene?

Be sure to wash your hands often in order to prevent germs from finding their way to you or the individuals in your care.

When you wash your hands, you can use warm, hot, or cold water. The temperature doesn't matter, as long as your hands are wet with water, you are already off to a great start. Soap up and work your hands into a lather, scrubbing your top and bottom of your hands and your nails. Singing the ABC song while you scrub isn't just a preschool trick, it is a good way to measure that you are washing for the recommended time - 20 seconds at minimum. If the ABC song isn't your favorite, you can sing Happy Birthday twice. Don't worry if you're not a great singer, just sing it in your head and not out loud. Rinse your hands and then dry on a clean towel or air dry. For more hand washing

resources, consult the Center for Disease Control at <http://www.cdc.gov/features/handwashing/>.

Alcohol based hand sanitizers (with at least 60% alcohol) are good to use in a pinch, but soap and water is the best way to assure you are getting rid of germs. But, it is nice to keep a bottle of sanitizer in your car or bag so that you can be prepared for good hand hygiene even if you aren't around a sink or bar of soap.

What about gloves and other protective items?

Properly use Personal Protective Equipment (PPE) to keep germs and blood borne pathogens at bay. While folks who work in health care environments, such as hospitals, will have access to more risk and therefore more pieces of PPE, it is still important for you to know a few key pieces.

Using gloves is a smart and responsible thing to do when you are working with bodily fluids including blood, torn skin, or vomit. Consider tucking a few pairs in your office drawer, bag, or car so that you are prepared in case of emergency. If you are leading a group trip or outing, it is wise to have a small bag that includes emergency contact information, participant lists, and gloves. If someone falls and scrapes their knee and cannot put on a gauze bandage that you give them on their own, put on gloves before you assist them. It is safer for you and your exposure to bodily fluids. It is also safer for them, as you might transfer an infection to them via their wound. After you use gloves, toss them **immediately** in the garbage! Then, wash hands/sanitize as soon as possible.

*Taking off gloves correctly—To begin with, pinch the cuff of the left hand glove with your right hand and then pull the cuff down over the left hand turning the glove inside out as you remove it. Hold the discarded glove tightly in your right palm and then slide the index finger of your left hand under the cuff of the glove on your right hand. Peel the glove off turning it inside out and trapping the left glove inside. Discard the gloves and wash your hands.

Another piece of equipment that you should have available and use when emergency situations strike is a CPR mask. CPR masks, or pocket masks, are used for administering CPR or rescue breathing. Remember, saliva is one of our bodily fluids and you will come into contact with saliva when performing CPR. Be safe and have a pocket mask available for use!

Can't I just avoid it?

Yes. If you are able to avoid contact with bodily fluids, do it. If you can hand a band aid to your client who is bleeding from his arm and he can put it on himself, do it and then have him wash his hands. Wash yours too.

Some bodily fluids can be avoided easier than others. For example, if your client has shingles (similar to chicken pox, except more painful), he is only contagious during the blister/pus phase of the pox. So, as long as he has his blisters covered by his clothing, you are safe.

Sharps and Stick Prevention

What about needles?

Needle sticks are a major source of blood borne pathogen infection. Needles, or sharps, should always be disposed of in a puncture-free container such as a biohazard plastic box, or metal box. If you provide care to individuals whose care involves needles, be sure they develop the habit of disposing of them correctly and safely. Needle sticks often happen when needles show up in places that they shouldn't be - for example, in linens or in a car.

Needles should never be recapped after use. Many sticks happen while trying to get the cap back on the used needle. Instead, put the needle in the sharps container without putting back on the cap.

Read this from the FDA website for clarification on proper sharps containers: <http://www.fda.gov/medicaldevices/productsandmedicalprocedures/homehealthandconsumer/consumerproducts/sharps/ucm263236.htm>

What should I do if I get stuck with a needle?

If you are ever stuck with a needle, **immediately** wash with soap and water. Don't use bleach or alcohol, just soap and water will do. Call your doctor and let him know what happened, as well as your supervisor.

Applying health and safety skills

Now that we've gotten a glimpse into universal precautions, let's take a few moments to apply it to your job and situations that you may see during your time with individuals.

Scenario #1

You are at your client's home. Shane, your client, is cooking in his kitchen. He slices open his finger while chopping green peppers for his dish. He is distraught and cannot follow directions. You have a First Aid kit in your work bag. What should you do?

Grab your first aid kit and put on gloves. Encourage Shane to take deep breaths and relax as you lead him to the sink to rinse his hand. Evaluate the wound, determine if a 911 call is necessary. Wrap the finger with gauze from your first aid kit. After the bleeding is in control, take off your gloves and dispose of them in garbage. Wash your hands. Fill out the UI report (unless he needs at least 5 stitches, then MUI).

What you *shouldn't* do:

Freak out, freak Shane out, or rush to his aid without gloves!

Scenario #2

You are grocery shopping with your client, Jill. In aisle 12, Jill says she isn't feeling well and she vomits on the floor. What should you do?

Give Jill a Kleenex or something else that you have available in your bag. Assist her out of the store with gloves on, let a staff person from the store know about the situation.

What you *shouldn't* do:

Freak out, freak Jill out, attempt to clean up the vomit using only a few Kleenex you have in your bag. Remember, vomit is a bodily fluid and you shouldn't touch it without a protective barrier in between you and it.

Scenario #3

Your client, Heather, is getting over a cold. She is sneezing throughout your time together, wiping her nose on her hands, and leaving her Kleenex on the table where you are working. What should you do?

Mucus is a bodily fluid, remember? But, common colds and viruses are par for the course, especially during winter months. Use this time to educate Heather on germs, as applicable to her abilities. Encourage frequent hand washing during your time together - her hands and your hands. Ask her to pick up the Kleenex and dispose of them in the garbage. Wipe down the table with disinfectant.

What you *shouldn't* do:

Get overly upset about the fact that Heather has a cold.

Fire and Weather Safety

While we are on the topic of safety, let's go ahead and use a few moments to refresh ourselves on how to stay safe during a fire and severe weather. If you work for a facility, you should take time to review the evacuation policy, fire policy, and severe weather policy for your place of employment. If you happen to visit clients in different settings, you need to become familiar with the emergency policies of each facility that you visit in your travels. However, generally speaking, staying safe when it comes to fire and severe weather is almost universal.

Fire

How do I use a fire extinguisher? First things first - do you know where the closest fire extinguisher is? It is important that you do and worth the time to ask someone if you don't know the answer. Once you have found a fire and an extinguisher, use the **PASS** method:

- **Pull the pin** - Pull the pin of the extinguisher so that you'll be able to squeeze the trigger when it is time.
- **Aim the extinguisher** - Aim it towards the base of the fire, not the flames. Shooting the flames will not put out the fire.
- **Squeeze the trigger** - Now's the time to squeeze the trigger to discharge the chemical out of the hose.
- **Sweep** - Use sweeping motions to spray the chemical all along the base of the fire.

If the fire goes out, great. If the fire is still going after your extinguishing attempts are over, call 911, get people out of the way, and let the professionals handle it.

What if the fire is too big? Be sure that you know a few tips on how to get out of a burning building safely. You'll need to be calm and able to lead your group of clients, if necessary. Again, each facility is different. Some facilities have fire-safe doors and zones that do not require evacuation, like a family home. Educate yourself on your facility's policy. For a family home situation, use these tips:

- **Know your way out** - know the quickest way out of the home, and if there is a spot that the family will meet up after they get out of the home.

- Touch and See - Touch a door before you open it. If the door is hot, do not open it. If you see any smoke coming from under the door, do not open it. Find alternate ways out.
- Stay low - Smoke rises, so stay low to the ground and crawl.
- Keep smoke away - If you are trapped and cannot get out of a room due to fire and smoke, use blankets or other fabrics to shove under the door and frame to keep as much smoke out as you can. Do not hide from the firefighters, let your presence be known, and follow instructions.

This link is a brief video that offers great information about fire safety for children and people with DD: <http://www.youtube.com/watch?v=dLps2vIY4AI&feature=relmfu>. Check it out now.

Severe Weather

Depending on where you are located geographically, you have specific weather that you are more prone to. From tornadoes to earthquakes, hurricanes to ice storms, severe weather can cause breaks in communication, power outages, and major structural and home damage. Most all severe weather comes on quickly, and you have little time to prepare.

The Midwest part of America is home to many severe weather patterns including tornadoes, floods, snowstorms, and ice storms. Being prepared for all scenarios is the best way to stay safe and keep your clients safe. Be sure to check with the facility or facilities that you work with to see what severe weather policies they have in place. If you work with families who live in family homes, be sure that you encourage them to be prepared in case of severe weather. Here's a great website that includes information for adults and for kids: <http://www.weathersafety.ohio.gov/> Check it out now.

Emergency Preparedness

The Ohio Emergency Management Agency and ReadyOhio urge communities across the nation to take a Pledge of Preparedness. Consider assembling an emergency kit for the individuals you serve.

Read this section: [Preparing Makes Sense for People with Disabilities](#)

<http://www.ready.gov/document/preparing-makes-sense-people-disabilities-and-special-needs>

Winter Weather

But remember, not all weather has to be severe in order for it to cause problems. We live in the Midwest and our winters can be brutal. The DODD, in the health and welfare alerts, gives us some good information about what to do when winter weather happens. Not only are these tips great for our participants, they are also great tips for us.

- Layer clothing.
- Wear a heavy coat and water resistant boots.
- Cover up with a hat, gloves and scarf.

Hold on to railings when possible and walk slowly and carefully to avoid slips.

When possible, stay indoors. When you must go outdoors, limit time spent there as much as you can, especially when the temperature or wind chill temperature is below zero.

Frostbite and hypothermia are two serious possibilities when winter weather arrives. If participants show signs of being too cold, move them to a warm place. Cover participants with blankets and encourage them to drink warm fluids. Call the doctor as appropriate, as well.

Let's take a look at this in action.

Susan and Taylor are staff members taking a few participants on an outing to lunch about 40 minutes away from the agency. Taylor is driving the agency bus and Susan is sitting and visiting with the participants. Everyone has a great lunch together but on their way back home to the agency, the bus breaks down on the side of the road. Taylor

starts the steps in the emergency plan that he has been trained to conduct. He immediately calls roadside assistance and the agency. Due to an especially cold day, roadside assistance says that the earliest they can be to the bus is 30 minutes.

During the 30 minutes that they are waiting for the bus, Taylor is unable to start it up for heat. It is below zero outside and the bus cools off quickly (because really, buses are never that warm to begin with it seems). Participants begin to express that they are cold, and Taylor and Susan are quite cold too. To make matters worse, since the trip planned was a quick one, no one is wearing gloves or hats. There are no blankets in the bus, or any emergency warming gear.

When roadside assistance finally makes it to the bus, the participants are cold and uncomfortable. One participant has a yellowish and waxy look to his fingers, and when they arrive back at the agency, they take him to the doctor.

When it comes to this particular situation, Taylor and Susan did plenty of things well. Taylor followed his emergency plan to get help when the bus broke down, and they were able to keep participants calm until help arrived. However, they misjudged how cold it could get in an unheated bus and didn't pack any additional gear for their winter outings.

If you were Taylor and Susan, or their agency supervisor, what are some steps that you could take in the future to make sure that participants could be warm?

Warm Weather

Once winter leaves and the wind loses its chill, we are well on our way to spring and summer. Hot weather can be just as dangerous as cold weather, if not more so. With many events happening outside during summer months, and everyone being excited to be outdoors, people can overheat quickly and without much warning.

When you are with participants, keep these tips in mind.

Wear loose fitting clothing. If participants insist on clothing that is inappropriate (unsafe) for the weather conditions, work with agency staff to create a dress code for outdoor activities. Add interventions to the care plan as well.

Avoid dehydration by drinking plenty of fluids. Try to stick with water, as it is really the best option for keeping your body well hydrated.

Watch for shaded areas and try to spend as much time there as possible. Hanging out in the open on a sunny day can lead to overheating and a nasty sunburn.

Speaking of sunburn, be sure that you have plenty of sunblock for everyone. Reapply it after more than a few hours, as well as after any time in the water or excessive sweating.

Someone who is overheated can present with a variety of symptoms, including a lack of sweating, confusion, and nausea. Don't mess around with these symptoms; get the person cooled off quickly with cold fluids, and by placing cool washcloths on their wrists or the back of their neck. If their symptoms do not subside, or if they get worse, follow your agency's emergency procedures.

A lot can happen in the summer with the hot weather. Let's take a look at a few scenarios that might happen.

You are helping out with your local Special Olympics. While there, one of your participants passes out during their running race. It is quite hot outside and even though you have been encouraging him to drink water throughout the day, you doubt he has because he doesn't like to go to the bathroom in public places. You go over to check on him. What should you do? How could you (and the event coordinators) have prevented something like this from happening in the first place?

Let's try another one. You are leading a group walk to the park down the street. It is only a few blocks away and most of the time you are walking on a shady sidewalk. You are already running late with your group, and you know that your supervisor hates when you don't start activities on time. So, instead of taking time to get everyone's sunblock on, you skip it. You toss the bottles in your backpack and try to remind yourself to apply it when you get to the park. But once you are there you forget. When you get home, you notice that a few of your participants have some very red noses and arms. What should you have done? How can you prevent something like this in the future?

Clothing during the summer months can be an issue. While you don't want to infringe on a participant's right to choose their own clothes and express themselves, sometimes poor judgment can lead to a clothing choice that could be dangerous.

Bug Bites and Epi Pens

Ok, so I realize that bug bites and epi pens don't always go together, I feel like it is a good transition to cover a few important topics at once. Let's start with bugs and bees and ticks and all that creepy, crawly good stuff.

When you are spending time outside, which you likely will with your participants (or at least I hope so!), your chances of being bit or stung increases. In order to decrease that chance, consider using bug or tick repellent if it is indicated for your activity. For example, if you are headed to the community park at noon, you might want to bring the bug spray but you will likely not need it. Mosquitos aren't out yet and unless your park is a heavily forested area, ticks won't hang out there. However, if you are planning a sparkler and spritzer party to celebrate the Fourth of July at 7pm, having mosquito and bug repellent available is a wise decision. Your participants will have a better time if they aren't getting eaten alive.

If you are leading a hike through your local forest preserve, encourage participants to put on tick repellent and hats. No one wants a tick bite and it can lead to more serious diseases.

What about bees or wasps, you ask. Sure, they have the ability to sting, but there aren't really any repellants to put on participants to avoid it. Instead, work with participants to stay away from noticeable hives or areas where there are lots of bees hanging out like garbage cans.

However, what do you do if someone does get stung? Chances are, your agency has a special procedure on just that scenario, but you want to get the stinger out and get some ice on it.

Now here comes our fancy segue to epi pens. Sometimes, people can have allergic reactions to things like bee or wasp stings. In these cases, epi pens can literally save their life while you wait on emergency personnel.

Keep in mind, too, that epi pens are not just used for severe allergic reactions to bee stings. Epi pens can be used to combat allergic symptoms from food like peanuts or fish, or other environmental factors. Before you head out with your participant(s), be sure to check out their ISP to see if you need to bring along their epi pen.

Remember that epi pens do you no good if they are out of reach or nowhere to be found. Only give epi pen injections to people who have a prescription from their doctor.

You have completed the eight hour training course that will enable you to become a provider of services for adults with developmental disabilities.

Please complete the associated QUIZ. It will be graded and, assuming that you pass you will receive a certificate of completion.

[Click here to take the Quiz](#)