PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 2 - WORKING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

FACILITATOR GUIDE

CONTENT

A.   Person-Centered Approach

B.   Department of Economic Security-Division of Developmental Disabilities Mission,
     Vision and Values

C.   Individual Rights

D.   Self-Determination

E.   Person First Language

F.   Positive Relationships

G.   Professional Relationships

Estimated time for this chapter: 2.5 hours

Materials Needed:
1.   Facilitator Guide
2.   Participant Guides
3.   Creative medium (newsprint paper, markers, molding clay, etc.)

COMPETENCIES:
(TO KNOW OR BE ABLE TO:)

1. Important rights for people with developmental disabilities.

2. Give examples of Person-First Language.

3. Ways to build a positive relationship.

4. What self determination means.

5. Give examples of self determination.

6. Ways to maintain a professional relationship with the person you work for.

KEY TERMS:

Division of Developmental Disabilities	Ethical Behavior	Mission, Vision, Values
Person-Centered Approach	Person 1st Language	Positive Relationships
Professional Relationships	Rights	Self-Determination

A. PERSON-CENTERED APPROACH

Note: Review the section on Philosophy in chapter 1 of the Fundamentals before doing the following exercises.

Exercise 1: List basic concepts and values of a person-centered approach.

> 1. *Give people choices (about foods, activities, when they want to bathe, etc.)*
>
> 2. *Let …*
>
> 3. *Ask …*

Exercise 2: Why are choice and self-determination important?

> 1. *Sometimes people feel useless if others do everything for them*
>
> 2. *Some people …*
>
> 3. *…*

B. DES – DIVISION OF DEVELOPMENTAL DISABILITIES (DDD) MISSION, VISION AND GOALS

> **Facilitator Note:**
> Provide a brief explanation of what the Department of Economic Security/Division of Developmental Disabilities (DES/DDD) is. Point out that chapter 3 will provide more information about DDD.
>
> Be sure to emphasize that following a person-centered approach means that the individual directs his or her own life, and we assist them in getting to where they want to be in their life. It also means that along that journey we honor their particular culture and beliefs and their personal preferences.

The Division of Developmental Disabilities (DDD) is the state agency that provides funding, support and services to individuals who have epilepsy, autism, cerebral palsy or a cognitive disability and who meet additional eligibility criteria. You will learn more about DDD in the next chapter.

Mission:

To support the choices of individuals with disabilities and their families by promoting and providing, within communities, flexible, quality, consumer-driven services and supports.

Vision:

Individuals with developmental disabilities are valued members of their communities and are involved and participating based on their own choices.

Values:

- Healthy relationships with people.
- Individual and family priorities and choices.
- Equal access to quality services and supports for all individuals and families.
- Partnerships and ongoing communication with individuals, family members, advocates, providers and community members.
- Developmental approaches – changing conditions that affect people rather than changing people who are affected by conditions.
- Individual freedom from abuse, neglect and exploitation with a balance between the right to make choices and experience life and individual safety.
- A diverse workforce that is motivated, skilled and knowledgeable of and uses the most effective practices known.
- An environment rich in diversity in which each person is respected and has the opportunity to reach their optimal potential.

- Individual's right to choose to participate in and contribute to all aspects of their home and community life.
- A system of services and supports which are:
  - Responsive
    - Timely and flexible responses to internal and external customers;
  - Strengths-based
    - Recognizing people's strengths, promoting self-reliance, enhancing confidence and building on community assets;
  - Effective
    - Ongoing identification of effective methods and practices and incorporation of those practices into operations; and
  - Accountable
    - To our customers and to the taxpayers.

Thoughts about the person-centered approach

Facilitator Note:
Be sure that the participants include on this page basic information about the principles of a person-centered approach, including: respecting cultural differences, individuals directing their own lives, and honoring preferences.

A person-centered approach to support involves:

_____
_____
_____
_____
_____
_____

Use this space to illustrate the mission, vision and values of DDD

Facilitator Note:
In the participant guide this space can be used for a creative representation of the Mission, Vision and Values either as a finished product or a place to work on a draft. If the participants will be using newsprint paper, whiteboards or another creative medium, this page can also be used for general notes.

Facilitator Notes (for section C. below):
Review the following information regarding individual rights with the group. Ask for VOLUNTEERS to read aloud. (Note: To help support a safe training environment for everyone you may want to allow participants who are uncomfortable reading aloud to "pass.")

Activity:
Brainstorm all of the rights that you (participants) have as a member of this society at this time in this place.

Facilitator will capture the brainstorming and fill the easel pad/board with what the class brainstorms. Some prompting can occur regarding constitutional rights, rights upon reaching adulthood, little rights exercised every day, etc.

Once pad/board is full, circle with a different color those rights that are explicitly protected by law. These will probably not be the majority, will only include those specifically mentioned in statute such as the bill of rights – to vote, free speech, legal representation, due process, bear arms, etc. or others protected explicitly by law such as privacy, education, non-discrimination, etc.

NOTE: Whoever teaches this section will need to have a good command and understanding of those rights that are explicitly protected by law and those rights that are implicit.

Explain that most of the rights that we enjoy are implicit, meaning that we have the rights and if someone violates them often there are criminal statutes to prosecute them, but these rights are not explicitly protected by law. In other words there is not a law that says "you have the right to...." It is important to make this distinction, because implicit rights are often the first ones violated. One way that implicit rights can become explicit is by including them in rule, policy and documenting them. That is why, in part, that we have the policy on individual rights and responsibility.

Note: If you believe that a review of "implicit" and "explicit" rights is not effective for your audience, then just have them brainstorm their rights to emphasize that our rights are the same as those of the people we serve and that we need to be more explicit about expressing them to offer additional protections to the people that we serve.

Source: Adapted from DES/DDD Individual Rights training developed by the Deb Stadle and the Positive Behavior Support Workgroup.

C. INDIVIDUAL RIGHTS

A person with a developmental disability has the same rights, benefits, and privileges guaranteed by the constitutions and laws of the United States and the State of Arizona.

Activity:
Brainstorm all of the rights that you (participants) have as a member of this society at this time in this place.

According to the Arizona Department of Economic Security, Division of Developmental Disabilities Policy 1500, the rights of an individual with a developmental disability receiving supports and services through the Division include, but are not limited to:

1. Right to an initial Individual Support Plan prior to receiving supports and services;
2. Right to participate in the initial Individual Support Plan, periodic reviews and whenever possible the opportunity to select among appropriate alternative supports and services;
3. Right (if accepted for supports and services) to participate in, share in decision making and receive a written Individual Support Plan based upon relevant results of the assessment.
4. Right to information regarding the supports and services available through a provider and about related charges, including any fees for supports and services not covered by a third-party payor;
5. Right to a periodic review of the Individual Support Plan;
6. Right to be given written notice of his/her rights;
7. Right to exercise his/her rights as citizens;
8. Right to live in the least restrictive setting;
9. Right to protection from physical, verbal, sexual or psychological abuse or punishment;
10. Right to equal employment opportunity;
11. Right to fair compensation for labor;
12. Right to own, rent or lease property;
13. Right to marry and have children;
14. Right to be free from involuntary sterilization;
15. Right to express human sexuality and receive appropriate training;
16. Right to consume alcoholic beverages if 21 years of age or older unless contraindicated by orders of his/her primary care physician;

17. Right to presumption of legal competency in guardianship proceedings;
18. Right to be free from unnecessary and excessive medication;
19. Right to be accorded privacy during treatment and care of personal needs;
20. Right to confidentiality of information and medical records;
21. Right of a school-age individual to receive publicly-supported educational services;
22. Right of a child to receive appropriate supports and services, subject to available appropriations, which do not require the relinquishment or restriction of parental rights or custody except as prescribed in Arizona Revised Statutes 8-533 which describes the grounds needed to justify the termination of the parent-child relationship;
23. Right to consent to or withhold consent from participation in a research project approved by the Division management team or any other research project; right to knowledge regarding the nature of the research, potential effects of a treatment procedure as part of a research project; right to confidentiality; and the right to withdraw from the research project at any time;
24. Right of an individual who believes his/her rights have been violated to petition the Superior Court for redress unless other remedies exist under federal or state laws.
25. Right to withdraw from programs, supports and services, unless the individual was assigned to the Department by the juvenile court or placed in a secure facility by the guardian and court;
26. Right to an administrative review, if in disagreement with a decision made by the Division (by filing a written request for such with the Division Office of Compliance and Review and the right to appeal the decision and;
27. Right to contact the Human Rights Committee.

When an individual with a developmental disability reaches his/her legal age (18 in Arizona except for drinking alcohol which is age 21) he/she has the following rights:

1. Right to register and vote;
2. Right to create and maintain financial contracts;
3. Right to sue and to be sued;
4. Right to counsel;
5. Right to be prosecuted as an adult; and
6. Right to choose to continue receiving supports and services or to terminate supports and services; thus residency in any residential setting is voluntary.

Explicit and Implicit Rights

Explicit (fully and clearly defined) rights would include those rights guaranteed us by the Constitution of the United States and by the Constitution of the State of Arizona. These are explicitly worded in the form "you have the right to... " or "citizens/persons have the right to ..." or "government shall make no law infringing on ...."

Explicit Rights

The following are examples of explicit rights:
- The right to free speech.
- The right to practice your own religion (or not).
- The right to assembly.
- The right to vote.
- The right to bear arms.
- The right to legal representation.
- The right to due process.
- The right to not incriminate oneself.
- The right to face one's accusers.
- The right to not be held without charges.
- The right to a trial by jury of peers.
- The right to confidentiality of information and privacy.
- The right to a free and appropriate public education.
- The right to public access.
- The right to non-discrimination due to culture, religion, ethnicity, race, gender, and disability in employment and housing.

Implicit Rights

Implicit (understood though not directly expressed) rights would include those rights we have by implication but are not necessarily stated in the law. Implicit right could include:

Facilitator Note:

These are often rights that we exercise everyday, of which we are not often conscience. These may be protected by implication of other laws (such as criminal). The following are examples of implicit rights.

- To choose
  - clothing,
  - food,
  - entertainment (music, television, movies, books, internet, etc.),
  - job/employment,
  - friends,
  - relationships,
  - bedtime,
  - mealtime,
  - providers of goods and services (e.g., where you shop, who fixes your plumbing, etc.).
- To marry or not.
- To have children or not.
- To smoke or not.
- To say "No."
- To engage in sexual behavior or not.
- To manage one's own funds and resources.

Facilitator Note:

Understanding the distinction between these rights is important, because for devalued and oppressed groups the implicit rights are often those which are violated and taken away first, because there is not explicit protection. If a group is severely devalued and oppressed, the violation of explicit rights will often follow. Our society has been steadily moving towards making more rights explicit to offer further protections.

Facilitator Note:
Facilitate a discussion about "everyday" situations that may require us to evaluate how to respond while still respecting a person's rights. For example, a person they are supporting may make the choice to sleep in, causing them to be late to work or school. Just as with anyone else in our society, that is within their rights. If, however, it becomes a health and safety issue, we will need to take additional action. For example, instead of simply sleeping late, a person is laying in soiled clothing/bedding and is refusing to get up or accept assistance for an extended period of time.

While in both these circumstances, it is certainly within the person's rights to make their own choices, we, as direct care workers, have a responsibility to ensure the health and safety of the person we are supporting. In situations where health and safety are in question, it may be necessary to refer to the Individual Support Plan, Behavior Plan, your supervisor and/or the responsible person for the individual (if applicable) for additional guidance.

D. SELF-DETERMINATION

Self-determination is the right of all people, including those with disabilities, to make choices about their own lives, to have the same rights and responsibilities as everyone else, and to speak and advocate for themselves.

Adapted from Disability Resources:
http://www.disabilityresources.org/SELF-DETERMINATION.html

Facilitator Note:
Read, or have a class participant read the definition of Self Determination above.

Ask: Ask the class participants to share why they think it's important for us to be aware of self-determination. Be sure to include the following topics if they do not come up in the course of discussion.
- Individuals with disabilities have the *right* to make decisions and express preferences.
- Self-Determination allows a person to create a life that is meaningful to them.
- Self-Determination allows a person to have the sense of accomplishment and pride that comes from taking responsibility for one's own life.

Read: Read or ask a volunteer to read the Five Principles of Self Determination (below).
Activity: Have the participants work in pairs or small groups to read, create, and present a creative representation of the Five Principles of Self Determination to the rest of the group.

PRINCIPLES OF SELF-DETERMINATION

Freedom: The ability for individuals with freely chosen family and/or friends to plan a life with necessary support rather than purchase a program.

Authority: The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports.

Support: The arranging of resources and personnel – both formal and informal – that will assist an individual with a disability to live a life in the community rich in community association and contribution.

Responsibility: The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities (Nerney/Shumway, 1996, pp 4, 5).

Confirmation: Affirming the central role you have in leadership and change.

Self-Determination means that individuals direct the course of their own lives!

E. PERSON FIRST LANGUAGE

Facilitator Note:

Person First Language is a way of communicating respect about the person you support. Person First Language isn't about being "politically correct", but instead, it's about ensuring that we are focused on each individual and his/her unique characteristics.

Language and terminology are continually evolving. The language included in this packet is what is currently recognized as acceptable. You can expect that over the course of your career newer and better terminology will evolve.

The following information from <u>People First Language</u> by Kathie Snow is provided as resource material. Although all the information is included in the Facilitator and Participant Guide, it is not necessary to go through the People First Language information point-by-point. As this information is also covered in the Fundamentals training, use your class time to only emphasize key points, and remind participants of their previous learning experience.

To ensure Inclusion, Freedom, and Respect for all, we must use

PEOPLE FIRST LANGUAGE

by Kathie Snow, www.disabilityisnatural.com

Did you know that people with disabilities constitute our nation's largest minority group (one in five Americans has a disability)? It is also the most inclusive and most diverse group: all ages, genders, religions, ethnicities, sexual orientations, and socioeconomic levels are represented.

Contrary to conventional wisdom, individuals with disabilities are not:

• People who *suffer* from the *tragedy* of *birth defects.*

• *Paraplegic heroes* who *struggle* to become *normal* again.

• *Victims* who *fight* to *overcome* their *challenges.*

Nor are they the *retarded, autistic, blind, deaf, learning disabled,* etc.—*ad nauseam!*

They are *people:* moms and dads; sons and daughters; employees and employers; friends and neighbors; students and teachers; scientists, reporters, doctors, actors, presidents, and more. People with disabilities are people, *first.*

They do *not* represent the stereotypical perception: a homogenous sub-species called "the handicapped" or "the disabled." Each person is a unique individual.

The only thing they may have in common with one another is being on the receiving end of societal ignorance, prejudice, and discrimination. Furthermore, this largest minority group is the only one that *any person can join at any time:* at birth or later—through an accident, illness, or the aging process. When it happens to *you,* will you have more in common with others who have disability diagnoses or with family, friends, and co-workers? How will you want to be described and how will you want to be treated?

What *is* a Disability?

Is there a universally-accepted definition of disability? No! First and foremost, a disability descriptor is simply a *medical diagnosis,* which may become a *sociopolitical passport* to services or legal status. Beyond that, the definition is up for grabs, depending on which service system is accessed. The "disability criteria" for early intervention is different from early childhood, which is different from special education, which is different from vocational-rehabilitation, which is different from worker's compensation, which is different from the military, and so on. Thus, "disability" is a governmental *social construct*, created to identify those entitled to specific services or legal protections.

The Power of Language and Labels

Words are powerful. Old, inaccurate descriptors and the inappropriate use of medical diagnoses perpetuate negative stereotypes and reinforce a significant and incredibly powerful attitudinal barrier. And this invisible, but potent, force—not the diagnosis itself—is the *greatest obstacle* facing individuals who have conditions we call disabilities.

When we see the diagnosis as the most important characteristic of a person, we devalue her as an individual. Do *you* want to be known for your psoriasis, arthritis, diabetes, sexual dysfunction, or any other condition?

Disability diagnoses are, unfortunately, often used to define a person's value and potential, and low expectations and a dismal future are the predicted norm. Too often, we make decisions about how/where the person will be educated, whether he'll work or not, where/how he'll live, and what services are offered, based on the person's *medical diagnosis,* instead on the person's unique and individual needs.

With the best of intentions, we work on people's bodies and brains, while paying scant attention to their hearts and minds. Far too often, the "help" provided can actually cause harm—*and can ruin people's lives*—for "special" services usually result in lifelong social isolation and physical segregation: in special ed classrooms, residential facilities, day programs, sheltered work environments, segregated recreational activities, and more. Are other people isolated, segregated, and devalued because of *their* medical conditions? No.

Inaccurate Descriptors

"Handicapped" is an archaic term (no longer used in federal legislation) that evokes negative images of pity, fear, and worse. The origin of the word is from an Old English bartering game, in which the loser was left with his "hand in his cap" and was said to be at a disadvantage. It was later applied to other people who were though to be "disadvantaged." A *legendary* origin of the word refers to a person with a disability begging with his "cap in his hand." Regardless of origin, this antiquated term perpetuates the negative perception that people with disabilities are a homogenous group of pitiful, needy people! But others who share a certain characteristic are not all alike, and individuals who happen to have disabilities are not all alike. In fact, people with disabilities are more *like* people *without* disabilities than different!

"Handicapped" is often used to describe modified parking spaces, hotel rooms, restrooms, etc. But these usually provide *access* for people with physical or mobility needs—and they may provide *no benefit* for people with visual, hearing, or other conditions. This is one example of the misuse of the H-word as a *generic descriptor.* (The accurate term for modified parking spaces, hotel rooms, etc. is "accessible.")

"Disabled" is also not appropriate. Traffic reporters often say, "disabled vehicle." They once said, "stalled car." Sports reporters say an athlete is on "the disabled list." They once said, "injured reserve." Other uses of this word today mean "broken/non-functioning." *People with disabilities are not broken!*

If a new toaster doesn't work, we say it's "defective" or "damaged" and return it. Shall we return babies with "birth defects" or adults with "brain damage"? The accurate and respectful descriptors are "congenital disability" and "brain injury."

Many parents say, "My child has special needs." This term generates *pity,* as demonstrated by the usual response: "Oh, I'm *so sorry*," accompanied by a sad look or a sympathetic pat on the arm. *(Gag!)* A person's needs aren't "special" to him—they're ordinary! Many adults have said they detested this descriptor as children. Let's learn from them, and *stop using this pity-laden term!*

"Suffers from," "afflicted with," "victim of," "low/high functioning," and similar descriptors are inaccurate, inappropriate, and archaic. A person simply "has" a disability or a medical diagnosis.

Disability is *Not* the "Problem"

We seem to spend more time talking about the "problems" of a person with a disability than anything else. People *without* disabilities, however, don't constantly talk about *their* problems. This would result in an inaccurate perception, and would also be counterproductive to creating a positive image. A person who wears glasses, for example, doesn't say, "I have a *problem* seeing." She says, "I wear [or need] glasses."

What is routinely called a "problem" actually reflects a *need.* Thus, Susan doesn't "have a problem walking," she "needs/uses a wheelchair." Ryan doesn't "have behavior problems," he "needs behavior supports." Do *you* want to be known by your "problems" or by the many positive characteristics that make you the unique individual you are? When will people *without* disabilities begin speaking about people *with* disabilities in the respectful way they speak about themselves?

Then there's the use of "wrong" as in, "We knew there was something *wrong* because..." What must it feel like when a child hears his parents repeat this over and over and over again? How would *you* feel if those who are supposed to love and support you constantly talked about what's "wrong" with you? Isn't it time to stop using the many words that cause harm?

The Real Problems are Attitudinal and Environmental Barriers

The real problem is *never* a person's disability, but the attitudes of others! A change in our attitudes leads to changes in our actions. Attitudes drive actions.

If educators believed in the potential of *all* children, and if they recognized that boys and girls with disabilities need a quality education so they can become successful in the adult world of work, millions of children would no longer be *segregated and undereducated* in special ed classrooms. If employers believed adults with disabilities have (or could learn) valuable job skills, we wouldn't have an estimated *(and shameful)* 75 percent unemployment rate of people with disabilities. If merchants saw people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms, and more. If the service system identified people with disabilities as "customers," instead of "clients/consumers/recipients," perhaps it would begin to meet a person's *real* needs (like inclusion, friendships, etc.) instead of trying to remediate the person's "problems."

If individuals with disabilities and family members saw *themselves* as first-class citizens who can and should be fully included in all areas of society, we might focus on what's really important: living a *Real Life in the Real World*, enjoying ordinary relationships and experiences, and dreaming big dreams (like people without disabilities), instead of living a *Special Life in Disability World,* where services, low expectations, segregation, poverty, dependence, and hopelessness are the norm.

A New Paradigm

"Disability is a natural part of the human experience..."

U.S. Developmental Disabilities/Bill of Rights Act

Like gender, ethnicity, and other traits, a disability is simply one of many natural characteristics of being human. Are *you* defined by your gender, ethnicity, religion, age, sexual orientation, or other trait? No! So how can we define others by a characteristic that is known as a "disability"?

Yes, *disability is natural,* and it can be *redefined* as "a body part that works differently." A person with spina bifida may have legs that work differently, a person with Down syndrome may learn differently, and so forth. And the body parts of people *without* disabilities are also different—it's the *way* these differences impact a person that creates the eligibility for services, entitlements, or legal protections.

In addition, a disability is often a *consequence of the environment.* For example, many children with attention-deficit disorder (ADD) and similar conditions are not diagnosed until they enter public school. Why then? Perhaps when they were younger, their learning styles were *supported* by parents and preschool teachers. But once in public school, if the child's learning style doesn't match an educator's teaching style, the child is said to have a "disability," and is shipped off to the special ed department. Why do we blame the child, label him, and segregate him in a special classroom? Shouldn't we, per special ed law, modify the regular curriculum and/or provide supports so he can learn in ways that are best for him? It seems that ADD and other conditions may be "environmentally-induced disabilities"!

When a person is in a welcoming, accessible environment, with appropriate supports, accommodations, and tools, where she can be successful, does she still have a disability? No. *Disability is not a constant state.* The *diagnosis* may be constant, but whether it's a disability is more a *consequence of the environment* than what a person's body or mind can/cannot do. We don't need to change people with disabilities through therapies or interventions. We need to change the *environment,* by providing assistive technology devices, supports, and accommodations to ensure a person's success.

Using People First Language is Crucial

People First Language puts the person before the disability, and describes what a person *has,* not who a person *is.*

Are you myopic or do you wear glasses?

Are you cancerous or do you have cancer?

Is a person handicapped/disabled or does she have a disability?

If people with disabilities are to be included in all aspects of society, and if they're to be respected and valued as our fellow citizens, we must stop using language that marginalizes and sets them apart. History tells us that the first way to devalue a person is through language.

The use of disability descriptors is appropriate *only* in the service system, at IFSP, IEP, ISP meetings, and/or in medical or legal settings. Medical diagnoses have no place—*and they should be irrelevant*—within families, among friends, and in the community.

Many people share a person's diagnosis in an attempt to provide helpful information, as when a parent says, "My child has Down syndrome," hoping others will understand what the child needs. But this can lead to disastrous outcomes! The diagnosis can scare people, generate pity, and/or set up exclusion ("We can't handle people *like that...*"). Thus, in certain circumstances, *and when it's appropriate,* we can simply share information about what the person needs in a respectful, dignified manner, and *omit the diagnosis.*

Besides, *the diagnosis is nobody's business!* Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do *you* routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And we often talk about people with disabilities *in front of them, as if they're not there.* It's time to stop this demeaning practice.

My son, Benjamin, is 23 years old. His interests, strengths, and dreams are more important than his diagnosis. He loves politics, American history, classic rock, and movies; he's earned two karate belts, performed in plays, and won a national award for his *Thumbs Down to Pity* film. Benj has earned his Associate's degree, and he's now working toward his Bachelor's. He has blonde hair, blue eyes, and cerebral palsy. His diagnosis is just one of many characteristics of his whole persona. *He is not his disability, and his potential cannot be predicted by his diagnosis.*

When I meet new people, I don't whine that I'll never be a prima ballerina. I focus on what I can do, not what I can't. Don't you do the same? So when speaking about my son, I don't say, "Benj can't write with a pencil." I say, "Benj writes on a computer." I don't say, "He can't walk." I say, "He uses a power chair." It's a simple, *but vitally important,* matter of perspective. If I want others to know what a great young man he is—more importantly, *if I want <u>him</u> to know what a great young man he is*—I must use positive and accurate descriptors that portray him as a wonderful, valuable, and respected person.

The words used *about* a person have a powerful impact *on* the person. For generations, the hearts and minds of people with disabilities have been crushed by negative, stereotypical descriptors that, in turn, led to segregation, abuse, devaluation, forced sterilization, and worse. We must stop believing and perpetuating the myths—*the lies*—of labels. Children and adults who have conditions called "disabilities" are unique individuals with unlimited potential, like everyone else!

The Civil Rights and Women's Movements prompted changes in language, attitudes, and actions. The Disability Rights Movement is following in those important footsteps. People First Language was created by individuals who said, "We are *not* our disabilities; we are people, first." It's not "political correctness," but good manners and respect.

We can create a new paradigm of disability. In the process, we'll change ourselves and our world—and also   generate positive change in the lives of people with disabilities. It's time to care about how our words impact the people we're talking *about,* and to be mindful of the *attitudes and actions* generated by the words we use.

> ***Isn't it time to make this change? If not now, when? If not you, who?***
> ***Using People First Language is the right thing to do, so let's do it!***

EXAMPLES OF PEOPLE FIRST LANGUAGE

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
Paul has a cognitive disability (diagnosis).	He's mentally retarded.
Kate has autism (or a diagnosis of…)	She's autistic.
Ryan has Down syndrome (or a diagnosis of…)	He's Down's; a Down's person; mongoloid.
Sara has a learning disability (diagnosis).	She's learning disabled.
Bob has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
Mary is of short stature/Mary's a little person.	She's a dwarf/midget.
Tom has a mental health condition	He's emotionally disturbed/mentally ill.
Nora uses a wheelchair/mobility chair	She's confined to/is wheelchair bound.
Steve receives special ed services	He's in special ed; is a sped student/inclusion student.
Tonya has a developmental delay	She's developmentally delayed.
Children without disabilities	Normal, healthy, typical kids.
Communicates with her eyes/device/etc.	Is non-verbal.
Customer.	Client, consumer, recipient, etc.
Congenital disability	Birth defect.
Brain injury	Brain damaged.
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs . . . or she uses	She has a problem with…/She has special needs.

Keep thinking—there are many other descriptors we need to change!

Facilitator Note:

After reviewing the information from the <u>People First Language</u> from Disability is Natural facilitate a discussion with the large group about why Person First Language is important. Be sure to include the following concepts if they do not come up during the discussion:

    A. Person First Language communicates respect
    B. Person First Language communicates value
    C. Person First Language de-emphasizes the disability
    D. Person First Language emphasizes ability!

It's good practice to listen carefully to how language is used in the class. Don't ever put someone on the spot or call them out if they don't use Person First Language perfectly. Instead, listen for correct usage and offer generous praise and positive reinforcement for use of Person First Language!

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F. POSITIVE RELATIONSHIPS

> **Facilitator Note:**
> Emphasize: Having a positive relationship with the person that you support and their family is critical to your success as a direct support worker!

Having a positive relationship with anyone takes time. It won't happen overnight, but there are some things you can do to ensure that you start off in the right way, and then stay on the right path to maintain that good relationship.

All good relationships share some basic characteristics.

> **Facilitator Note:**
> **Activity:** Ask the group to brainstorm some of the characteristics of positive relationships and write them in their guidebooks. Below are some examples that you may want to include:

Characteristics of Positive Relationships

Trust	Positive Problem solving	Respect
Openness	Communication	Warmness / Fondness
Flexibility	Supportiveness	Listening
Kindness	Compassion	Patience

> **Facilitator Note:**
> Tell participants: These aren't all the characteristics of positive relationships, but they will get you off to a good start! On the next page is a place for you to write down other ideas about developing a positive relationship with the individuals that you support.
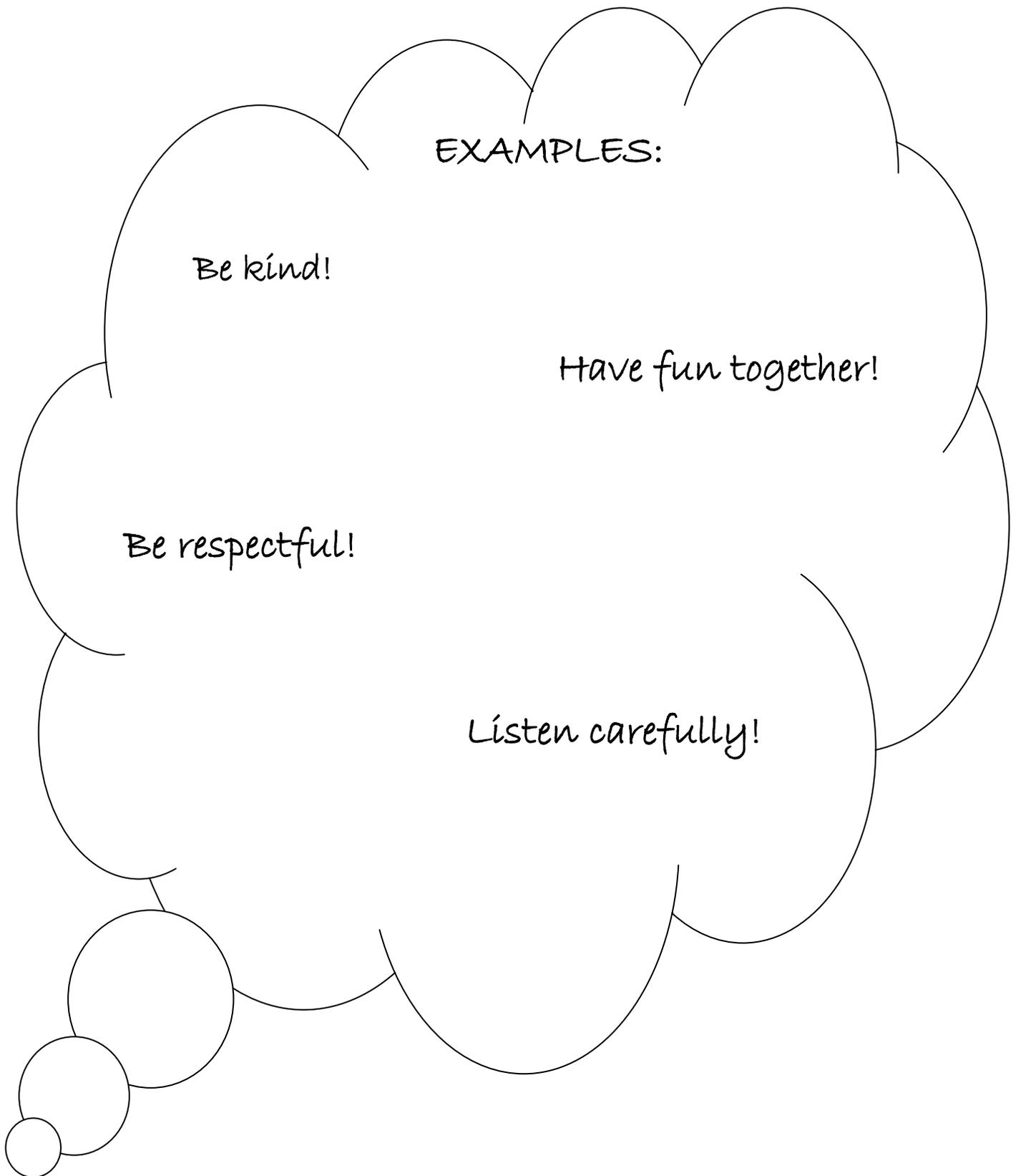
Facilitator Notes:

DEVELOPING POSITIVE RELATIONSHIPS (exercise on next page)
There are as many different ways to develop relationships as there are people! The intent of this section is to help the participants identify the core principles involved in developing a positive relationship with anyone.

ASK: Ask the group to work with a partner to brainstorm ways to develop a relationship with the person they are supporting. The participants can write notes in their guidebooks. Below you will find a list of thoughts that you may want to include.

- Be trustworthy – follow through on what you say. Show integrity in your service.
- Be open – don't have any "hidden agendas."
- Communicate clearly and openly. Safeguard personal information.
- Smile! Even challenging tasks can be more fun when you are smiling and cheerful.
- Be flexible. Get the job done, but "go with the flow" as much as possible.
- Talk about things that are interesting to the other person. Find common ground that you can have some discuss.
- Be dependable. Be on-time to work. Complete the tasks that have been assigned to you. Go the extra mile when you can. Leave the individual and the family with the reassurance that in these uncertain times they can count on you!
- Be sincere and honest with the individual and the family. When there are difficult things that need to be said, say them gently and honestly. A strong relationship is based on a sense that the parties involved can be counted on to share truthful information and feelings.
- Be accountable. When you make a mistake, don't make excuses or try to cover it up. Accept responsibility for the error and do what you can to fix it. A sincere apology can help clean up a messy situation.
- Respect and listen to the person that you support and their families.
- Be dedicated and enthusiastic while at work.
- Offer positive feedback on a regular basis.
- If you don't know an answer to a question posed by the individual or their family, be honest. State that you don't know the answer, and that you will take the steps necessary to help them find out the information they need.   Be sure to follow through!

DEVEOPING POSITIVE RELATIONSHIPS – BRAINSTORMING

EXAMPLES:

Be kind!

Have fun together!

Be respectful!

Listen carefully!

G. PROFESSIONAL RELATIONSHIPS

Facilitator Note:
Introduce this topic by talking about the importance of positive professional relationships at work. You may want to say something like, "Sometimes we get so excited and wrapped up in the dreams and goals of the person that we are supporting that the boundary lines defining our relationship can become blurred." It is important that we are clear about our role in the lives of the person we are supporting and their families.

ASK:
Ask the group to brainstorm some characteristics of professional relationships, and then personal relationships. Ensure that you include the topics in the table on the next page, (and also included in the participant guide) if they do not come up in the course of the discussion.

ASK:
Ask the group to identify some problems that could come up if there is confusion and ambiguity about the boundaries of our relationship with the person we support.

- Disappointment
- Violation of trust
- Misplaced expectations
- Hurt feelings
- Feelings of being taken advantage of
- Feelings of being used

Family members who are also paid providers may have additional questions about the distinction between personal and professional relationships while they are being paid. Ask for family members in the group to discuss how to balance their close relationship versus their roles as a paid provider.

Expected responses could include:
Place your role as a parent/family member into the background.
Focus on the person and their wants and needs during time you are paid to support them.

PROFESSIONAL RELATIONSHIPS	PERSONAL RELATIONSHIPS
Contribute to the effective operation of the agency that you work for, the state of Arizona and the community at large.	Are strongly influenced by emotion.
Contribute to the quality of life for the person that you are supporting.	Involve all parties sharing personal information and feelings.
Contribute to the quality of life for the family of the person you are supporting.	Contribute to the quality of life for all parties involved.
Are driven by a vision of achieving a common goal.	Are a result of a mutual enjoyment of each other's company.
Are more formal.	Are more casual.
Result in compensation.	Do not result in compensation.
Are appropriate while you are at work.	Are not appropriate while you are at work.

Facilitator Note:
Cornell University's ILR School Employment and Disability Institute has some wonderful information about the topics we have been discussing today. The following information is from Michael Kendrick, "When People Matter More Than Systems,"(March 2000 Keynote Presentation for the Conference "The Promise of Opportunity"), posted at the Person-Centered Planning Education Site, Course 1: Introduction to Person-Centered Planning, http://www.ilr.cornell.edu/edi/pcp/course01.html.

"Our deep-seated belief systems guide the way in which we interact with other human beings. … Simply thinking that we are being person-centered does not make us person-centered; it is what we actually do that ultimately reveals our true priorities. It requires a personal commitment to engaging conscious awareness and self-reflection about the relationship between how one feels, thinks, and acts. It is beliefs forming thoughts giving rise to words leading to action that, in turn, create experiences….

Person-*centeredness* is about intentionally being with people that may or may not include planning. In considering our thoughts about the people with whom we are planning, it is helpful to reflect upon our actions against the following seven touchstones condensed from Kendrick's paper:

- A commitment to know and seek to understand.
- A conscious resolve to be of genuine service.
- An openness to being guided by the person.
- A willingness to struggle for difficult goals.
- Flexibility, creativity, and openness to trying what *might* be possible.
- A willingness to enhance the humanity and dignity of the person.
- To look for the good in people and help to bring it out."

Closing Activity:
As a final activity for the class, you may want to break a larger group into pairs or smaller groups and assign a topic area from the Seven Touchstones listed above. The small group assignment is to "become the teachers" for the topic area(s) they were assigned, and using the information presented throughout the class, and the information from the Cornell University website to teach the topic to the rest of the group. If you have a very small group, you can do the same exercise by only assigning a few of the topics to the group.

- Tell the groups about any resources that may be available to them as they prepare, i.e. the use of whiteboards, newsprint pads, or other available materials.
- Tell the group that everyone must participate in the preparation and presentation of the material.
- Tell the group that they should be sure to include all information on the topic, not just the information from the Cornell University website. Information presented earlier in the class should be included as well as any personal knowledge they have on the topic.

- Remind the group that they need to maintain confidentiality and that presentations must be in good taste and respectful.
- Tell the participants that the length of the presentation is 2-5 minutes (or whatever you decide depending on the length of time left in the class.
- Allowing the group 10-15 minutes to prepare, tell them when presentations will begin.
- While the group(s) are preparing the presentations circulate between the groups providing assistance and feedback as needed.
- As the group(s) present their information, be sure to positively reinforce their efforts! Remember they only had a few minutes to prepare and many people are uncomfortable presenting in front of a group. Make it as positive and safe as possible. If any major points are left out, or if any misinformation is presented, those topics can be discussed between presentations to ensure that everyone learns what is needed.