

PRINCIPLES OF CAREGIVING DEVELOPMENTAL DISABILITIES MODULE

CHAPTER 2 - WORKING WITH PEOPLE WITH DEVELOPMENTAL DISABILITIES

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

**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 1 st 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

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.

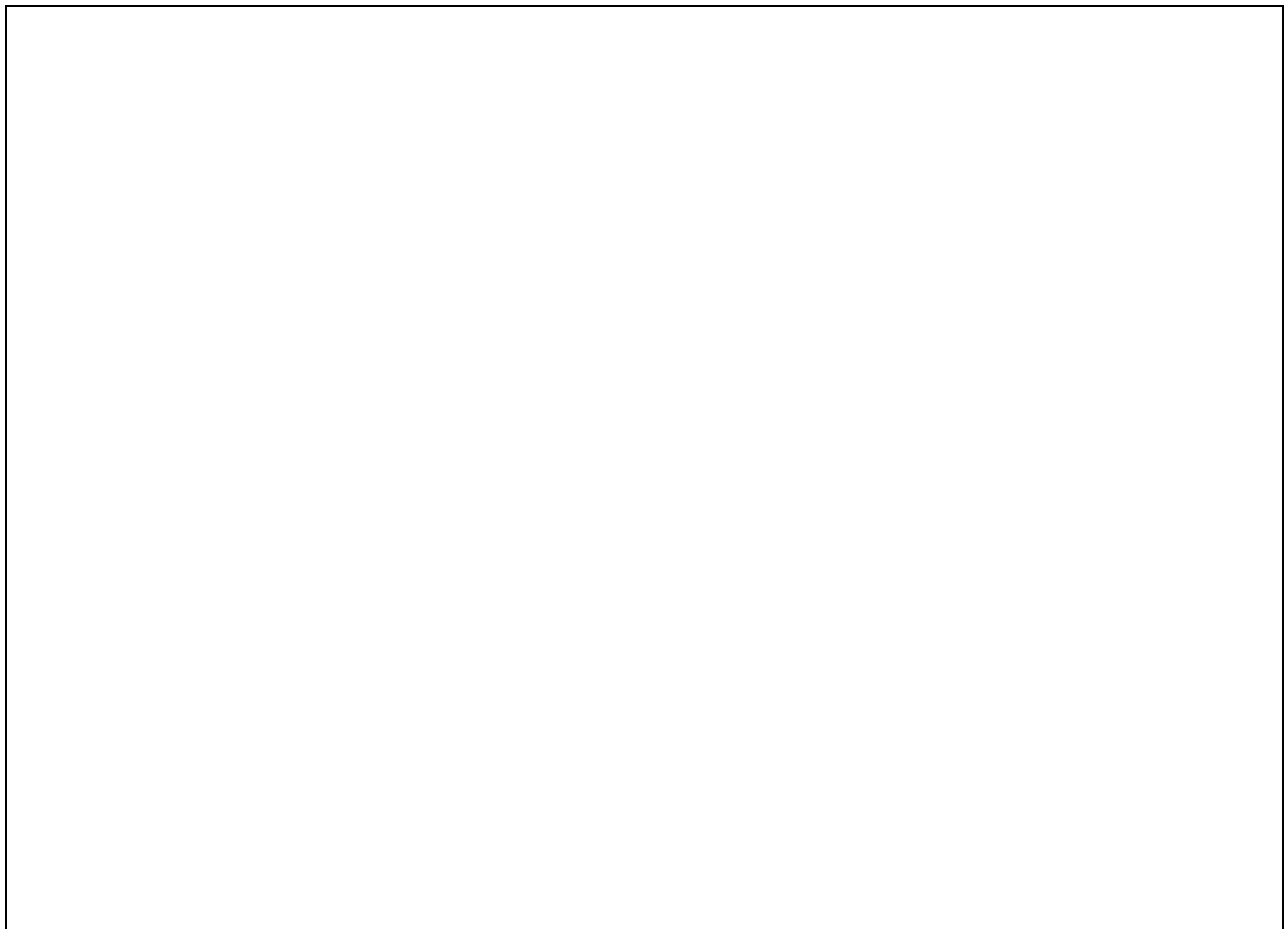
Values:

- 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

A person-centered approach to support involves:

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



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:

- 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.

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>

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

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 thought 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 him 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!

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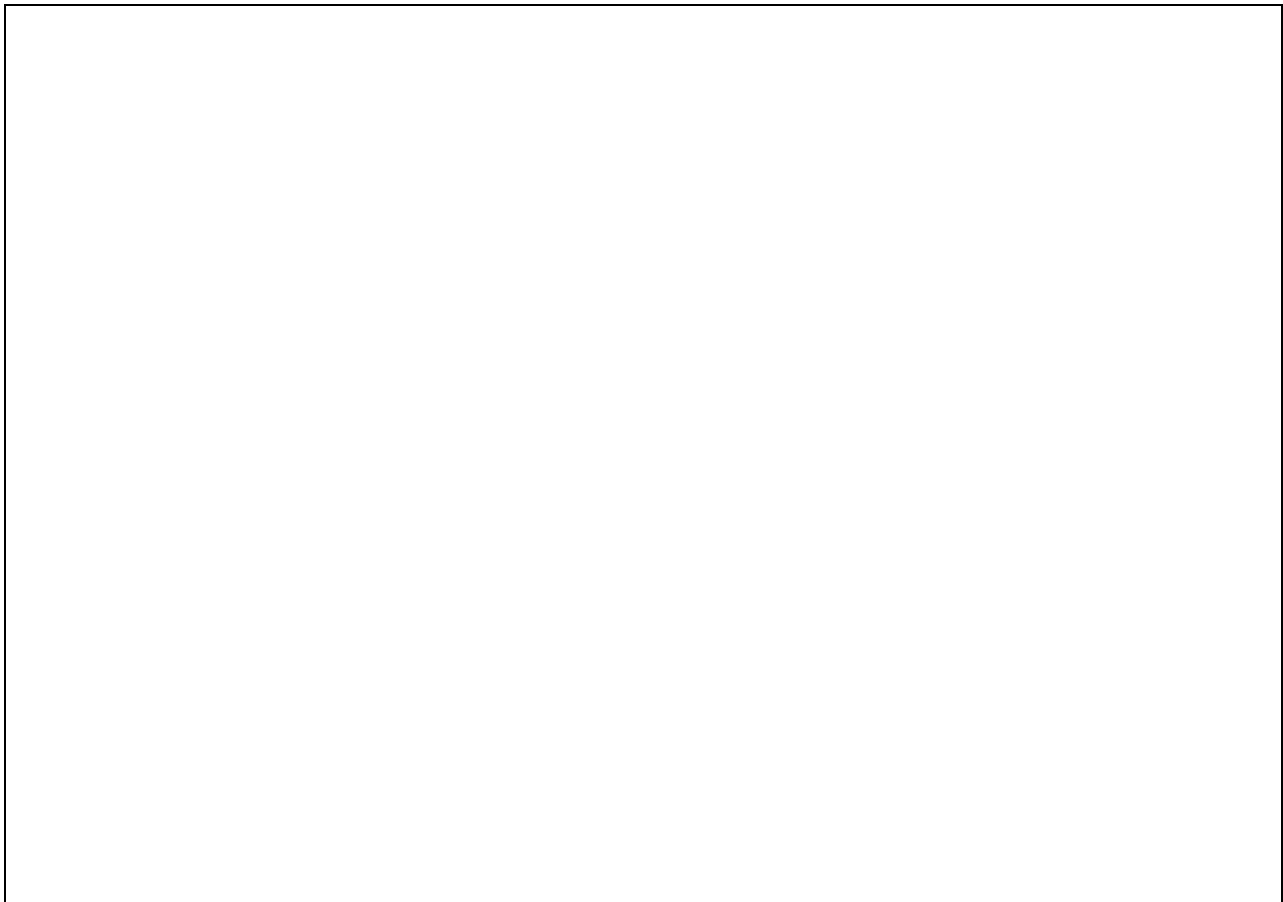
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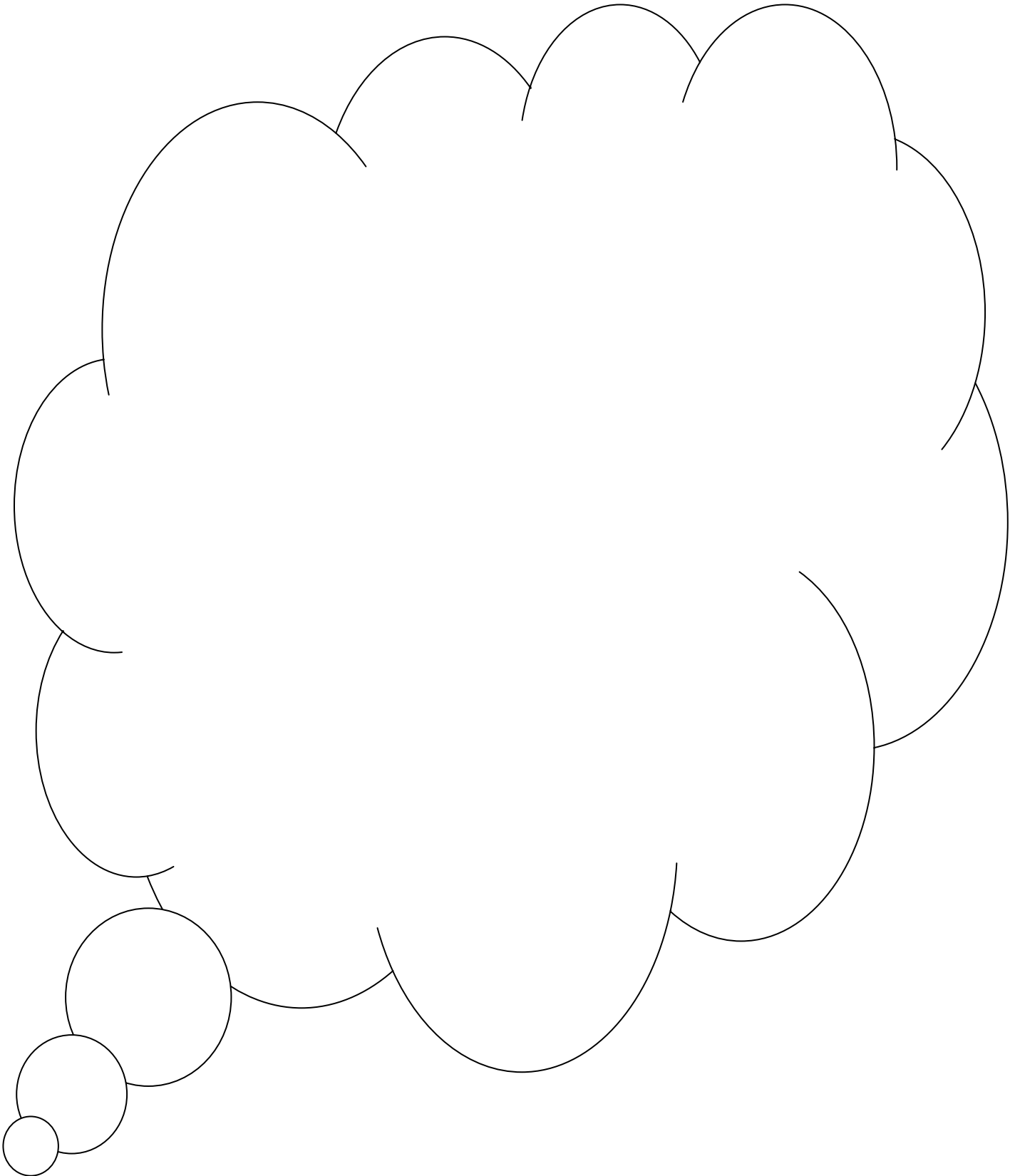
F. POSITIVE RELATIONSHIPS

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.



DEVELOPING POSITIVE RELATIONSHIPS – BRAINSTORMING



G. PROFESSIONAL RELATIONSHIPS

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.