Overview of Developmental Disabilities

Learner's Manual

Fourth Edition
January 1, 2009
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Overview of Developmental Disabilities

Getting Started

The curriculum provides a recommended sequence, but content may be rearranged due to the needs of the instructor and participants. **ALL** content must be covered. Any additional suggestions (i.e. content, video, activities, etc…) must be approved by the NJ Trainers Network.

Welcome

Welcome participants to this session of training for community-based program staff. Wish them success in the training and in their new position as a community program staff member.

Program Goals

Introduce yourself; describe your background and connection with the agency, using the P.E.P. model:

- Professional information
- Experience information
- Personal feelings about being at training

Describe the overall goal of this training, i.e., to prepare participants to work effectively as staff members in a program for persons with developmental disabilities.

Ask participants to join in a “get-acquainted” activity. Ask them to introduce themselves using the P.E.P. model.

Present the goals of this training program, giving a brief explanation of each. Share all of the objectives that will be covered during the entire session. If this module is being taught on separate days discuss the overall schedule, with dates, times, etc… This session should be included the first time the participants come together as a group, regardless of the topic area you decide to start with.

Please remind trainees that any specific agency questions should be directed to their supervisor. This training should not include any specific agency policies or procedures.

Expectations

Ask the participants to think about what they hope or expect to get from today’s training. Make a list of the group’s expectations. Try to capture each one in the individual’s words, and if you condense or reword the statement, get the participant’s agreement with the way you have paraphrased it.

Agenda

Present the agenda for the day, explaining when you will be addressing each expectation. If an expectation will not be addressed in this session, tell them when it will be addressed, or if appropriate, refer them to an additional resource for information.
Housekeeping and Time Needed
Review the day’s schedule, detailing times for breaks and meals. Discuss any materials they will need, smoking policy, etc...

The New Jersey Training Network has developed this training to be a seven-hour training. This includes a half an hour meal break & (2) 5 minute breaks.

Materials Needed

1. Instructor’s Manual
2. Projection Screen
3. Projector
4. Laptop
5. Videos: 1 hour maximum

   Required Video:
   Planning for Life: The Role of Direct Support Professionals in Self-Directed Supports (30 minutes)

   Optional Videos to equal a total of 30 minutes:
   a. A Little History Worth Knowing (22 minutes)
   b. And Then Came John (36 minutes)
   c. Collector of Bedford Street (35 minutes)
   d. Credo for Support (5 minutes)
   e. Fred’s Story (27 minutes)
   f. How to Recognize and Classify Seizures (24 minutes)
   g. I Belong Out There! (24 minutes)
   h. Open Your Eyes (5 minutes)
   i. Regular Lives (30 minutes)
   j. Ten Commandments for Communicating with People with Disabilities (30 minutes)
   k. The Potato Video, a Look at Misguided Effort (3 minutes)

6. VCR/DVD player and Television/screen
7. Learner’s Manual and/or PowerPoint Handouts
8. Paper and Pencils for participants
9. Flip Chart and Markers
This course covers the entire lifespan of individuals with developmental disabilities. It presents a wide range of topics designed to help you provide the best possible supports to those you serve. We have provided you with some history about how individuals with disabilities have been treated through the years, along with some background information on different types of developmental disabilities. Included in this manual are some important concepts, for instance Person Centered Supports and how they are incorporated into service planning, such as Individualized Habilitation Plans (IHP).

This course, however, includes more than background information and concepts. You will also find some very specific, practical tips on providing supports. The course concludes with important information about what your role as a Direct Support Professional is.
Goals of the Course

It is expected that each staff member working with people with developmental disabilities will recognize the following truths:

• People who have a developmental disability are people first.
• Our role is as an assistant or supporter, not a caretaker.
• We must teach decision making skills and strategies and understand the dignity of risk.
• Learning is a lifelong process.
• Each individual is a unique, capable person with gifts to share.
• We, as staff, can often grow through our interactions with the people that we serve.

Goals for this course (Expected Outcomes)

It is expected that each staff member working with people with developmental disabilities will recognize the following truths:

1. People who have a developmental disability are people first.
2. Our role is as an assistant or supporter, not a caretaker.
3. We must teach decision making skills and strategies and understand the dignity of risk.
4. Learning is a lifelong process.
5. Each individual is a unique, capable person with gifts to share.
6. We, as staff, can often grow through our interactions with the people that we serve.

It is also expected that each staff member working with people with developmental disabilities will take the following tools with them:

1. A basic understanding of some common developmental disabilities and ways to provide support.
2. A number of specific ways to provide support in relation to all aspects of life including community inclusion, relationships, and recreation.
3. Several tips on supporting people through challenging aspects of life such as health issues, dealing with grief, and dementia.
4. A clear understanding of the role of a Direct Support Professional as well as the ethics that are connected with that role.
Course Topics

- History of Developmental Disabilities
- Providing Supports
- Types of Developmental Disabilities
- Disability Across the Life Span
- Values and Choices
- Your role as a Direct Support Professional (DSP) (or other Support Staff)
Lesson 1

History

Objectives:
The staff member will be able to…

1a. understand the recent history of disability services.

1b. recognize the great strides that have been made to improve the lives of people with disabilities and that work still needs to be done in order to achieve an inclusive society.
History

1970’s
- Deinstitutionalization and community integration begin
- Concept of Normalization

1980’s
- Funding for community based services
- Employment Services

1990’s
- Americans with Disabilities Act (ADA)
- Person-Centered Services/Self-Directed Supports

2000
- Real Life Choices
- Full Inclusion

Future
- People living in the community with supports
- Continued growth of empowerment and self-advocacy

1970’s
- Deinstitutionalization and community integration begin
- Concept of Normalization – the acceptance of people with disabilities for who they are

1980’s
- Funding for community based services
- Employment Services-a shift from workshops to supported employment

1990’s
- Americans with Disabilities Act (ADA)-The Americans with Disabilities Act (ADA) gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. The ADA enables society to benefit from the skills and talents of individuals with disabilities, allows us all to gain from their increased purchasing power and the ability to use it, and leads to fuller, more productive lives for all Americans [http://www.usdoj.gov/crt/ada/adahome1.htm](http://www.usdoj.gov/crt/ada/adahome1.htm)
- Person-Centered Service/Self-Directed Supports -people started to receive services that were created based on what they needed and wanted instead of choosing from a list of services that were already predetermined.

2000
- Real Life Choices (2002)-method of self-directed services offered through the Division of Developmental Disabilities (DDD) to people with disabilities and their families.
- Full inclusion-continued push for full inclusion in school, employment, and the community

Future
- More people living in the community with supports
- Continued growth of empowerment & self-advocacy
What Do You Believe?
Instructions: Circle “yes” or “no” and explain your answer.

1. People who have a developmental disability are best cared for in institutions.
   Yes   No

2. All adults who have a developmental disability need to work in special workshops.
   Yes   No

3. Men and women who have a developmental disability should be given the opportunity to meet socially and express their feelings.
   Yes   No

4. In order to protect adults who have a severe disability, they should have surgery so that they cannot have children.
   Yes   No

5. Adults who have a developmental disability are supported by charity.
   Yes   No
6. Social and recreational activities specifically designed for persons who have a developmental disability will meet their needs better than typical community activities.

   Yes  No

7. The first consideration when selecting the furniture for the homes of people with developmental disabilities should be sturdiness and safety.

   Yes  No

8. People who have a developmental disability are more susceptible to infectious diseases.

   Yes  No
Lesson 2: Providing Supports

Use this slide to introduce the lesson. Briefly go over the objectives listed below.

Objectives:
The staff will be able to…

2a. describe common supports provided to people with certain learning needs.

2b. describe common supports provided to people with certain behavior needs.

2c. describe common supports provided to people with physical needs.

2d. describe effective ways of communicating with people with disabilities.
Why are Supports Important?

• Supports are strategies and resources necessary to promote the development, education, interests, and personal well being of a person with a disability.

• Supports can be provided by many people
  – Family members, friends, teachers, community members, doctors, agency professionals, etc…

• Supports can improve functioning, promote self-determination and inclusion and improve the person’s overall well-being.

(AAIDD, 2006)

Knowing how to support a person to achieve his/her goals in life and to keep him/her healthy and safe is more important than a person’s diagnosis.

What are supports?

Supports are the resources and strategies necessary to promote the development, education, interests, and personal well-being of a person with disabilities.

Supports can be provided by a family member, friend, teacher, psychologist, doctor or by any appropriate person or agency.

Why are supports important?

Providing individualized supports can increase skills, promote self-determination, enhance community inclusion, and improve personal well-being. Supports should be the focus to improve education, employment, recreation, and living environments.

http://www.aamr.org/Policies/faq_mental_retardation.shtml
Learning Styles

• Auditory
  - Spoken word/voice tone, keep sentences short and to the point, and use consistent language.

• Visual
  - Use props and tools, demonstration, signs, gestures, facial expressions, pictures, reading, etc...

• Tactile
  - Involve the individual in touching or pointing to a picture or object, picking up an item, or practicing a task.

Most people learn best when information is presented using more than one style. Think about how you can present the same information involving more than one sense at a time. This will increase the chances of the person learning.

Three major types of learning styles and ways to use them:

1. **Auditory** – Spoken word/voice tone, keep sentences short and to the point, and use consistent language.

2. **Visual** – Use props and tools, demonstration, signs, gestures, facial expressions, pictures, reading, etc...

3. **Tactile** – Involve the individual in touching or pointing to a picture or object, picking up an item, or practicing a task.
Supporting Learning, Working and Having Fun

- Be Patient
- Use “Real Life” and Meaningful Situations
- Model
- Repeat Teaching of Skills in New Situations
- Give Options
- Set Goals
- Problem Solving
- Maintain Consistency
- Give Breaks/Shorten Activity Time

Support people while learning, working, and having fun.

While these supports are often thought of as necessary during “learning” activities, it is important to know that some people need these types of supports during many of their daily activities.

It is important to get to know the people you are working with in order to know how to best support them.

1. **Be patient**
   Many people will not understand how to do something on the first try or may continue to need support to do a task. He/she may also need ongoing practice to maintain the skills that were learned. Staff members need to keep this in mind so that they do not give up on a person who does not learn quickly.

2. **Use “Real Life” situations, tools, pictures, objects**
   Many people have difficulty solving problems in their heads. It is often better to learn in a “real” situation. It is best to use real objects in the actual setting to assist with a task.

3. **Model**
   Often it will help a person learn a new task or skill if someone shows them how to do it first.
4. **Repeat teaching of skills in new situations**
   A person may not apply or carry over what is learned in one setting to a new setting or setting. It is more effective to teach skills in the places where people will use them.

5. **Give options**
   Some people have a hard time making choices, especially when the questions asked are open-ended. Many people have not had the opportunity to make choices. Many have difficulty weighing pros and cons. Structure questions so that you offer two or three specific, objective possibilities. Use visual, real life examples when possible.

6. **Set goals**
   Some people may need assistance and support from staff to plan long-term goals. Staff should help organize the steps necessary in meeting goals and consider the potential problems or obstacles to achieving these goals.

7. **Problem solving**
   Some people may need assistance and support from staff to recognize and solve problems. Staff should help the person determine a step-by-step way to address the problem.

8. **Maintain consistency**
   When participating in an activity and/or task that is not typically part of a person’s routine, s/he may not remember how to do the activity/task. Staff should be as consistent as possible and include practice and repetition. Staff should model or assist with practice.

9. **Give breaks/shorten activity time**
   Some people may have trouble keeping their attention on one activity for a period of time. In order to do this some people need the length of time spent on the activity to be short. Use breaks to maximize participation, attention, and success.
Supporting Behaviors

1. Be Encouraging
   Some people may appear to lack self-confidence. He/she may hesitate to try new things or to trust their own abilities. Staff members need to be sensitive to this and try to structure learning activities so that the person is more likely to do well.

   Keeping tasks broken down in small, manageable steps increases the likelihood of success.

   Give encouragement for any attempt and all progress. The encouragement should be directly related to the task (e.g. “Great job introducing yourself to everyone at your IHP meeting.”).

2. Recognize Wants & Needs
   Sometimes a person will constantly talk about a topic or an issue, sometimes repetitively, to such a point that s/he cannot concentrate on anything else. This is called perseveration. Perseveration is often a result of a neurological impairment. Perseveration is not attention-seeking behavior nor is it obsessive-compulsive behavior (OCD).

   Listen and respond with a positive attitude to the person’s remarks. Perseveration may lead to a person missing out on life’s activities.

   Staff can support a person by validating (acknowledging, telling the individual you understand what they are communicating) the individual’s concerns and assisting him/her to become involved in another activity or topic that the person enjoys.
3. Be Aware of Surroundings
Some individuals may act impulsively, without thinking of, or understanding the consequences. The results of these actions may be dangerous.

Be aware of those who can behave impulsively in order to assure the person’s safety and the safety of others. Staff can support a person by being constantly aware of potential dangers and teaching problem-solving skills before, during and after real-life situations.
Positive Behavior Support (PBS)

Positive Behavior Support is one process that is used today to figure out how to best support people with challenging behaviors. Positive Behavior Support involves changing situations and events in order to reduce the likelihood that challenging behaviors will occur.

PBS uses functional (behavioral) assessment to understand what may trigger a behavior. People often engage in a behavior because it serves a purpose; it helps get something desirable or pleasant or avoids something undesirable or unpleasant.

(Adapted from the Association for Positive Behavior Support (APBS) [http://www.apbs.org/PBSTopics.htm](http://www.apbs.org/PBSTopics.htm))
Physical Supports

1. Mobility Supports
   People who are not able to freely move around their environment may need assistance. Some people may need support with using a wheelchair, walker, cane, etc... Others may need to be assisted up and down stairs or stood close to in order to provide support when walking.

   Supports should be provided to help people with physical disabilities participate in the activities they choose.

   Remember that wheelchairs, walkers, canes, etc... are extensions of a person’s body. Do not lean or hang your personal items on a wheelchair without asking permission.

2. Muscle Tone Supports
   Some people, especially the aging population, have low muscle tone. They may need additional assistance with getting dressed, getting in and out of a car or bathtub, using the toilet, etc...

   Follow proper lifting and transferring techniques to ensure safety.

3. Motor Skill Supports
   Some individuals may have issues with motor skills. Some may need support to grasp and manipulate objects (i.e. fork, toothbrush, pen).

   Provide the person with adaptive equipment, hand-over-hand support, and/or extra time to complete the task.
Health Supports

• Recognizing Illness
• Responding Effectively
  – Calling 911 if needed
  – Arranging Doctor’s Appointments
  – Accompanying person to the visit
• Reporting

Health Supports

Supports that are often needed include recognizing and responding to any sign or symptom of illness in those that we support. The person may need assistance to recognize when a doctor’s appointment is needed and assistance in arranging appointments. Any signs of illness must be reported according to your agency’s policy.
Lifestyle Supports

- **Activities**: Support the person in making healthy choices.

- **Diet**: Support the person to recognize which foods could cause health issues while being respectful of the person’s individual choice.

- **Medications**: Support the person in taking medication by following the procedures that are taught in Pre-Service Medication Training.

Guidance in following through with the recommendations of health professionals may be needed.

1. **Activities**
   Support is often needed to recognize if there are activities that may be harmful to a person’s well-being. Staff must do this while being respectful of the person’s individual choice.

2. **Diet**
   When a person has a specific diet prescribed by a health professional, staff need to support the person to recognize which foods could cause health issues. Staff must do this while being respectful of the person’s individual choice.

   Staff must understand and follow the prescribed plan with regard to food textures (i.e. chopped, ground, pureed, blended, thickened liquids, etc…).

3. **Medications**
   When a person has medication(s) prescribed, staff need to support the person in taking this medication by following the procedures that are taught in Pre-Service Medication Training. Staff must successfully complete Pre-Service Medication Training prior to administering medications.
Assistive Technology

- Assistive, Adaptive and Rehabilitative devices
- Promote greater independence through assisting with the performance of tasks that they would be unable to complete without support

Adaptive Equipment/Assistive Technology (AT)

Assistive Technology includes assistive, adaptive, and rehabilitative devices. Assistive Technology is used by people with disabilities to promote greater independence through assisting with the performance of tasks that they would be unable to complete without support.

Assistive technology usually involves an enhancement to a device (i.e. changing it so it works better for the person – switches, grips, kitchen aids) or the addition of a device designed to do a specific activity (i.e. communication devices, wheelchairs, glasses, dentures, etc…).

Communication is essential for all of us and assistive technology can be very useful in this area. Some examples of ways communication can be enhanced through assistive technology include communication boards, Dynavox, pocket communicators, eye-gaze tracking software, Braille, writing boards, and TDD (telecommunication devices for the deaf)/TTY (telephone typewriter).
Communication

- All people communicate.
- People communicate for the same reasons – expression, build relationships, learn, etc…
- Behavior is communication.
- All communication is meaningful and should be “listened” to.

All communication is meaningful. Communication skills are needed for all people to build relationships, express wants and needs, participate in learning, and increase independence.

When a person’s communication is not understood or “listened to” s/he may become isolated, ill, and/or exhibit changes in behavior. Staff need to understand and interpret each individual’s communication style in order to support the person with meeting basic physical needs (eating, personal hygiene, relief from pain, etc…) and emotional needs (happiness, anger, sadness, etc…).
Supporting Communication

- Consider the person’s communication strengths and environmental factors.
- Use words that the person understands.
- Engage the person in communication during routine activities (e.g. meals, rides to work, etc…).
- Communication devices should always be available and in working order.
- Just because a person does not speak using words does not mean they cannot hear or understand.
- Speak clearly, maintain eye contact, and listen.

To communicate more effectively the staff will –

1. Consider the person’s communication strengths (i.e. reading lips) and environmental factors (i.e. loud noises in the room).

2. Use words that the person understands.

3. Engage the person in communication during routine activities (e.g. meals, rides to work, etc…).

4. Make sure that the person’s assistive communication device is always available, accessible, and in working order.

5. Not assume that because a person does not speak using words, they cannot hear or understand.

6. Speak clearly, maintain eye contact, and listen.

Often communication charts are used to record how a person communicates using behavior and what those supporting the person should do in response to that communication.
To communicate more effectively the staff will use the method of communication the person understands best, such as:

1. Spoken word
2. Voice tone
3. Facial expressions
4. Gestures
5. Pictures
6. Situational cues
7. Written word
8. Assistive Communication Devices
9. Sign language
Lesson 3: Types of Developmental Disabilities

Objectives:
The staff member will be able to...

3a. describe the most common types of developmental disabilities (i.e. Mental Retardation, Cerebral Palsy, Epilepsy, and Autism).

3b. recognize some of the support needs of people with developmental disabilities.

3c. understand the concept of Dual Diagnosis and the stereotypes and stigma often attached to mental health diagnoses.

3d. understand that labeling people can be harmful.
Each individual you will be working with is a unique, one-of-a-kind person. Each person will have his/her own likes and dislikes and personality. All people with developmental disabilities must have the opportunity for independence and full inclusion in our society. People with developmental disabilities go to school, have jobs, have relationships, get married, raise families, and live in homes of their own. The descriptions found in this section will introduce you to some of the more common disabilities of the people who will receive your support and assistance.

As these disabilities are discussed, keep in mind that they are labels that are useful in diagnosis and in determining eligibility for supports and services. These labels are not how the person should be referred to or described.

Remember the people you provide supports to are people first.

Not all people with the same diagnosis require the same supports. Supports are individualized based on what a person needs and wants for his/her life. The supports a person receives may also depend on family involvement, social connections, where the person lives, and funding, etc...
Mental Retardation

The American Association on Intellectual and Developmental Disabilities (AAIDD) [formerly American Association of Mental Retardation (AAMR)] Definition of Mental Retardation (2002):

“Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18.”

Adaptive skills are daily living skills needed to live, work, and play in the community. The adaptive skills are: communication, self-care, home living, social skills, leisure, health and safety, self-direction, fundamental academics, community use, and work.

Other terms used for mental retardation include intellectual disability and cognitive disability.
It is important to note that the current preferred practice is to eliminate the use of the term Mental Retardation and replace it with Intellectual Disability.

This slide should be used to give examples as to what adaptive behavior skills are. Let participants know that they shouldn’t assume that because a person has an intellectual disability they won’t be able to do all the activities listed. Some people with intellectual disabilities will be able to do some of the activities on their own; others may need support.

Here are skills that staff may be assisting or supporting the individual to learn.

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<th>Social Skills</th>
<th>Practical Skills</th>
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<td>Relationships</td>
<td>Eating</td>
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<td>Reading and writing</td>
<td>Responsibility</td>
<td>Dressing</td>
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<td>Money concepts</td>
<td>Self-esteem</td>
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<td>Self-direction</td>
<td>Understanding social rules</td>
<td>Toileting</td>
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<td></td>
<td>Obeying laws</td>
<td>Taking medication</td>
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<td></td>
<td>Avoiding victimization (e.g. being taken advantage of)</td>
<td>Preparing meals</td>
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<td></td>
<td></td>
<td>Using the phone</td>
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<td>Using transportation</td>
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<td></td>
<td>Managing money</td>
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<td></td>
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<td>Housekeeping</td>
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<td>Job skills</td>
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Supports should be individualized and may focus on: skill building, independence, community inclusion, and personal well-being.
General Information:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age, peers, and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Limitations often coexist with strengths. (e.g. knows how to ride the bus, but needs to be reminded to take a shower; takes medication independently, but needs support to count change, etc...).
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate individualized supports over a sustained period, the life functioning of the person an intellectual disability generally will improve.
What are supports?

Supports are defined as the resources and individual strategies necessary to promote the development, education, interests, and personal well-being of a person with mental retardation. Supports can be provided by a family member, friend, teacher, psychologist, doctor or by any appropriate person or agency.

Why are supports important?

Providing individualized supports can improve personal functioning, promote self-determination and inclusion, and improve personal well-being of a person with intellectual disabilities.

Supports include:
Being patient
Allowing for repetition
Developing adaptations

Encourage Independence!
Encourage people with intellectual disabilities to be as independent as possible. Some people may take longer to rip the lettuce, but it will be his/her salad s/he is eating. People should pick out the curtains for their own homes. People should choose the job of their liking.

http://www.aamr.org/Policies/faq_mental_retardation.shtml
Cerebral Palsy

- Affects body movement and muscle coordination

- Common types of Cerebral Palsy
  - Spastic, Athetoid, Ataxic, and Combined

- Common characteristics:
  - Muscle tightness or spasticity
  - Involuntary movement
  - Disturbance in gait or mobility
  - Difficulty swallowing
  - Problems with speech

www.ucp.org

Cerebral Palsy

What is cerebral palsy (CP)?

“Cerebral palsy, also referred to as CP, is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during, or shortly after birth; or during infancy.” - United Cerebral Palsy (UCP)

23-44% of people with CP will have some type of cognitive impairment.

Spastic cerebral palsy: (affects 70% - 80% of people with CP) primary characteristic is stiffly and permanently contracted muscles.

Athetoid, or dyskinetic cerebral palsy: (affects about 10% to 20% of people with CP) characteristics include uncontrolled, slow, writhing movements typically affecting the hands, feet, arms, or legs and, in some cases, the muscles of the face and tongue, causing grimacing or drooling. The movements often increase during periods of emotional stress and disappear during sleep. People with this form of CP may also have problems coordinating the muscle movements needed for speech, a condition known as dysarthria.

Ataxic cerebral palsy: A rare form of CP (affects an estimated 5% to 10% of people with CP) that affects the sense of balance and depth perception. Characteristics may include poor coordination; unsteady walking with a wide-based gait (feet unusually far apart). A person with this form of CP may experience difficulty when attempting quick or precise movements, such as writing or buttoning a shirt. They may also have intention tremor. An intention tremor begins as a voluntary movement, such as reaching for a book, causing a trembling that affects the body part being used and that worsens as the individual gets nearer to the desired object.
**Combined forms:** It is not unusual for people with CP to have symptoms of more than one of the previous three forms. The most common mixed form includes spasticity and athetoid movements but other combinations are also possible.
Support for People with Cerebral Palsy

In order to lead the lives they want some people with CP need support services such as personal assistance services, therapy, educational and vocational training, independent living services, transportation, recreation/leisure programs, and employment opportunities.

Supports may include:

1. Wheelchair use
2. Therapies (Speech, Occupational, Physical, etc…)
3. Support with various activities (e.g. eating, personal care, positioning, etc…)
4. Assistive Technology (e.g. communication devices, etc…)
5. Medication (e.g. Botox, Baclofen pump, etc…)

http://www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447
Epilepsy

Epilepsy is a neurological condition that involves seizures. A seizure is a change in sensation, awareness, or behavior brought about by a brief electrical disturbance in the brain.

Seizures vary from a momentary disruption of the senses, to short periods of unconsciousness or staring spells, to convulsions. Some people have just one type of seizure. Others have more than one type.

Although they look different, all seizures are caused by the same thing: a sudden change in how the cells of the brain send electrical signals to each other.

[http://www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) and [www.epilepsy.com](http://www.epilepsy.com)
Epilepsy
3 Common Types of Seizures

• **Absence Seizure**  
  (formerly “petit mal”)  
  – Brief lapse in awareness  
  – Staring, eye blinking, upward eye rolls

• **Complex-Partial Seizure**  
  (formerly “temporal lobe” or “psychomotor”)  
  – Activity stops  
  – Dazed, staring expression  
  – Automatic, repetitious and purposeless behavior

• **Tonic-Clonic Seizure**  
  (formerly “grand mal”)  
  – Convulsions (body stiffens)  
  – Person falls to the ground (body jerks, temporary loss of consciousness)

Type of Seizures

**Absence Seizure**: (formerly known as “petit mal”) mild type of seizure that often passes for daydreaming. Characteristics include:
- Brief lapses of awareness.
- Staring, eye blinking or upward eye rolls are often observed.

**Complex-Partial Seizure**: (formerly known as “temporal lobe” or “psychomotor”) most common partial seizure consisting of three brief phases:
- Activity stops, displays a dazed staring expression.
- Begins a pattern of automatic, repetitious, and purposeless behavior (lip smacking, picking at clothes, buttoning and unbuckling, finger pulling).
- Upon consciousness the person will be disoriented and confused for a brief time.

**Tonic-Clonic Seizure**: (formerly known as “grand mal”) the most common generalized seizure. Characteristics include:
- Convulsions: body stiffens, arms flex, legs, head and neck extend and jaws clamp shut (tonic phase).
- Person falls to the ground, the body jerks with a temporary loss of consciousness (clonic phase).
- Incontinence may occur as a result of the seizure. The tongue or inside of the mouth may be bitten during the episode; breathing afterwards may be noisy and appear to be labored.
Support for Seizures

• Keep the person safe.
• Reassure the person.
• Document the time, length and outcome of all seizures.

Support during all seizures:
1. Keep the person safe (for example, block hazards such as stairs, doors, traffic).
2. Remove any nearby objects that might cause injury.
3. Do not restrain the person.
4. Stay with the person until the seizure ends.
5. Be reassuring and supportive.
6. Document the seizure (e.g. seizure record, individual logs, medical notes, etc…).

Support during tonic-clonic seizures (Do all of the above and…):
1. Safely help the person to the floor.
2. Cushion the person’s head using a small pillow or folded clothing.
3. Loosen tight clothing.
4. Do not place anything in the person’s mouth or between the person’s teeth.
5. When the seizure ends, if needed, place the person on their side, with the face toward the floor (to allow secretions to drain).
6. If the person does not resume breathing after the seizure, call 911 and start CPR.
7. Let the person rest until fully awake.

Call 911 if:
1. First seizure.
2. Multiple seizures.
3. Over 5 minutes.
4. Injured during a seizure.
5. Pregnant.
6. Diabetic.
7. Not part of normal seizure history.
8. You are not sure.

Do Not Call 911 if the seizure is part of the person’s normal seizure history.
Medical Support for People with Epilepsy

- 80% of epileptic seizures can be at least partially controlled by medication.

- Although seizure medications are not a cure, they control seizures in the majority of people with epilepsy.

- Vagus nerve stimulation therapy is another form of treatment that may be tried when medications fail to stop seizures. The therapy prevents seizures by sending pulses of electrical energy to the brain via the vagus nerve, a large nerve in the neck.

Medical Support for People with Epilepsy

Epilepsy is not a disease. Most people with epilepsy lead active and productive lives when properly treated.

Although seizure medications are not a cure, they control seizures in the majority of people with epilepsy. 80% of epileptic seizures can at least partially be controlled by medication.

Vagus nerve stimulation therapy is another form of treatment that may be tried when medications fail to stop seizures. It is currently approved for use in adults and children over the age of 12 who have partial seizures that resist control by other methods. The therapy is designed to prevent seizures by sending regular small pulses of electrical energy to the brain via the vagus nerve, a large nerve in the neck.

As with surgery and the Ketogenic/Ketonic diet (see glossary), it will almost always be necessary to continue anti-epileptic medication although the person should be able to take less medication than in the past.

If the person you are supporting is being treated with antiepileptic drugs, s/he may need blood tests from time to time. It is important to remember that drug levels cannot tell how the person feels or how many seizures s/he’s had. Achieving the best seizure control possible depends on the person taking the same amount of the medicine every day in the manner prescribed by the person's doctor.
Autism

Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD) (also known as Autism Spectrum) which include:

1. Autism
2. Asperger’s syndrome
3. Childhood Disintegrative Disorder (CDD)
4. Rett’s syndrome
5. PDD – Not Otherwise Specified (PDD-NOS)

According to NJ’s Center for Outreach and Service for the Autism Community (COSAC) “children and adults with autism exhibit atypical, repetitive behaviors and deficits in social and communication skills. Autism is usually diagnosed during the first three years of life and is four to five times more prevalent in boys than in girls. It knows no racial, ethnic or social boundaries.”

1. Autism is defined and diagnosed behaviorally.
2. The cause of autism is not known; however, there is much support that autism is a biologically based disorder.
3. No known factors in the psychological environment of a child have been shown to cause autism.
4. Although autism is a lifelong developmental disability it is treatable. Early diagnosis and appropriate intervention are extremely important.
5. Developmental and symptomatic patterns among individuals with autism can vary greatly.
6. Not all people with diagnoses of autism have an intellectual disability.
7. About 25% of all individuals with autism develop seizures.

http://www.njcosac.org/cosac2/aboutautism
Characteristics of Autism

1. Some individuals with autism do not spontaneously reach out to others to share information or feelings and often do not know how to engage in simple social interactions.

2. There is often a delay in or a lack of development of spoken language. Many individuals with autism do develop speech. People with autism may have difficulty understanding non-verbal communication (e.g. body language, facial expressions, and frequent eye contact).

3. People with autism could have a restricted range of interest, periods of sustained activity (i.e. rocking, picking, flapping, etc…), resistance to changes in routine, or unusual attachment to objects.


Autism

Dispelling Myths and Misconceptions

• People with autism do make eye contact.
• Many people with autism communicate.
• Not all people with autism display exceptional skills.
• People do not “outgrow” autism.
• People with autism can show affection.

Myths and Misconceptions

There are many myths and misconceptions about autism. Contrary to popular belief, many people with autism do make eye contact; it just may be less often or different from people without autism.

Many people with autism also have good functional language and others can develop communication skills, such as sign language or use of pictures.

Although some people with autism exhibit specific exceptional skills, most do not. (i.e. “Rainman” is not an accurate reflection of most people with autism.)

One of the most devastating myths about people with autism is that they cannot show affection. While sensory stimulation is processed differently in some people, most can and do give affection. However, it may require patience to accept and give affection in a way that makes sense to the person.

www.autism-society.org
Supporting People with Autism

People with diagnoses of autism must have the opportunity for independence and full inclusion in society.

Get to know the person, know his/her likes/dislikes, review his/her plans, and know his/her routine and how to maintain it.

Give people a lot of time to answer. Don’t assume that people are being disrespectful based on their method of communication. Be clear, concrete, and consistent with instructions.

For many people with autism, computers, sign language, picture boards, and other augmentative devices may be useful in communication.

A person with autism’s senses may be over or under active. People with autism may be sensitive to sound and may need TV’s, radios, and other sound devices to be turned down or off. People with autism may also be sensitive to touch, taste and textures. Some people with autism engage in “self-stimulating” behavior such as rocking, hand flapping, etc…

www.autism-society.org
Pica

An eating disorder involving a compulsive craving to eat non-food items, lasting more than one month.

Know the warning signs of Pica:
- Repetitive consumption of non-food items.
- The eating behavior is considered inappropriate for the individual’s age or developmental stage (older than 18 to 24 months).
- The eating behavior is not a part of a cultural, ethnic, or religious practice.

Support:
Pica can be life threatening. Close supervision and removal of items that the person might eat may be necessary for safety.

Pica

Some people have an eating disorder involving a compulsive craving to eat non-food items, lasting more than one month. This is known as Pica.

Know the warning signs of pica:
- Repetitive consumption of non-food items.
- The eating behavior is considered inappropriate for the individual’s age or developmental stage (older than 18 to 24 months).
- The eating behavior is not a part of a cultural, ethnic, or religious practice.

Supporting People with Pica

Pica can be life threatening. Close supervision of the person is required and all potential items that s/he might eat must be removed from his/her environment. Collaboration with a doctor is important in the management and prevention of pica as s/he can provide useful information and may prescribe medication. More information regarding pica can be found in the 10/6/06 DDD Bulletin (see Resource Appendix).

Each individual who receives services from a residential or day program sponsored by DDD must get approval from Licensing to lock kitchens, cabinets, and/or refrigerators.
Dual Diagnosis

People are labeled as having a dual diagnosis when they have both a developmental disability and a mental health diagnosis.

Some Common mental health diagnoses:
- Anxiety Disorder
- Depression
- Bipolar Disorder
- Schizophrenia
- Dementia

Dual Diagnosis

Dual Diagnosis is when an individual has both a developmental disability and a mental health diagnosis. Often if the mental health needs of the individual are addressed, the individual's quality of life and their overall ability to function will improve.

Some common mental health diagnoses that exist are:

1. Anxiety Disorders

   Anxiety is characterized by unpleasant and over-riding tension with no “reasonable” cause (in comparison to anxiety that is typical in most people). According to the National Institute of Mental Health (NIMH) approximately 18% of the population over 18 years of age will have an anxiety disorder in a given year. The anxiety disorder frequently occurs with another disorder or substance abuse. Some sub-types of anxiety disorder are:

   a. Panic Disorder: Feeling of moderate to extreme panic, heart is pounding, can't breathe, feels like you are going to die. These feelings are also known as panic attacks.
   b. Obsessive-Compulsive Disorder (OCD): Anxious thoughts, rituals, and obsessions a person feels they can't control. Common triggers include dirtiness, contamination, religion, sexuality, and doubts/worries (ie: did I lock the door?).
   c. Post-Traumatic Stress Disorder (PTSD): This can develop after a terrifying event. Reliving the trauma includes frightening thoughts, memories of the ordeal, and flashbacks. The person may try to avoid situations that remind him/her of the event. The person may also have an exaggerated startle response, unrealistic fright, and other changes in mood.
   e. Specific Phobias: Irrational fears such as fear of flying, heights, tunnels, water, highway driving, etc…
f. **Generalized Anxiety Disorder:** Chronic anxiety that fills one’s day with exaggerated worry and tension.

2. **Depression**
   Symptoms can include feeling sad, anxious, hopeless, helpless, irritable, difficulty concentrating. Eating and sleeping patterns may change. Many people who suffer from depression also complain of headaches, stomach disorders, back pain, and other chronic pain. People who suffer from depression may display risk taking behaviors and may think about and/or attempt suicide.

3. **Bi-Polar Disorder**
   The person goes through alternating times of mania and depression. Examples of mania can include being excessively irritable, having a decreased need for sleep, increased levels of energy, grandiose or extravagant ideas, racing thoughts, excessive talking, increased sexual energy, binge drinking and drugging, unpredictable rage attacks, impulsivity, poor judgment, and inappropriate social behavior. Times of mania and depression may last as little as a few hours or last for months or years.

4. **Schizophrenia**
   Person may display distorted perceptions of reality. Examples can include hallucinations/illusions, delusions of persecution, disordered thinking, severe reduction in emotional expressiveness. Medications may cause significant side effects.
Supporting People with Mental Health Diagnoses

- First make sure the behavior isn’t related to a medical condition.
- Follow treatment plans.
- Get to know the person and be aware of support needs.
- Having a mental health diagnosis is personal and can be stigmatizing.

Supporting People with Dual Diagnosis

When working with someone who displays behaviors that might be signs of a mental health issue, it is important to always rule out medical illness first. Some medical diseases have a psychiatric component also, such as a brain tumor, cancer, etc... Once a medical illness is ruled out by a physician, consult with a behavioral support team or mental health professional to begin the process of understanding the problem and formulating the diagnosis. A referral to a psychiatrist may be needed to confirm the diagnosis and develop a treatment plan. The individual (when possible) and all who spend time with her/him (staff, family, sponsors, DDD case managers, etc...) should be educated about the treatment plan and confidentiality.

Treatment plans are usually a combination of drug therapy and psychotherapy/counseling (family therapy, group therapy, individual therapy, etc...).

When working with a person with a dual diagnosis, the challenge exists in supporting an individual’s needs resulting from the developmental disability while still recognizing and being sensitive to the supports needed resulting from the psychiatric disorder. For example: Don’t tell a person with OCD to stop washing his/her hands.
- Don’t whisper in front of someone who is paranoid.
- Don’t tell a person with depression to “cheer up”.

It is important to get to know the person and to understand that sometimes environmental factors may trigger symptoms related to their mental health diagnosis. For example: Don’t take a person with a phobia of loud noises to see fireworks.
- Do provide extra supports for a person who has social phobia at large gatherings.
Having a mental health diagnosis is personal. Comments such as “he’s psycho” or “she’s crazy” are not only disrespectful and incorrect, they perpetuate the stigma attached to having a mental health diagnosis. If a person exhibits symptoms of a mental illness, that does not mean that there is a diagnosis. People should never be referred to by their diagnosis, even if there is one.

According to National Institute of Mental Health, most people with a mental health diagnosis, such as schizophrenia, are not violent. Another common myth associated with people with a mental health diagnosis is that they are dangerous and commit crimes. This is not true. People with a mental health diagnosis are no more likely to commit a crime than anyone else.

- Portions Adapted from Dan Baker, Ph.D. -- Good Shepard Communities Workbook (2001)

Additional information can be found at [www.webmd.com](http://www.webmd.com)
Dementia

- Alzheimer’s Type
  - Cause of 50%-60% of all dementia
  - Risk of Alzheimer's increases with a diagnosis of Down syndrome

Dementia

Dementia is significant loss of intellectual abilities such as memory capacity, severe enough to interfere with social or occupational functioning. Dementia is not temporary confusion or forgetfulness that might result from a self-limited infection, underlying illness, or side effects of medications. Dementia typically progresses to become worse over time.

Alzheimer’s Type Dementia: Alzheimer’s disease causes 50-60% of all dementias. Alzheimer’s disease is a condition in which nerve cells in the brain die, making it difficult for the brain’s signals to be transmitted properly. A person with Alzheimer’s disease has problems with memory, judgment, and thinking, which makes it hard for the person to work or take part in day-to-day life. Symptoms of Alzheimer’s disease include:

1. Impaired memory and thinking
2. Disorientation and confusion
3. Misplacing things
4. Difficulty with abstract thinking
5. Trouble performing familiar tasks
6. Changes in personality and behavior (angry, irritable, restless, quiet, confused, paranoid, fearful)
7. Poor or decreased judgment
8. Inability to follow directions
9. Problems with language and communication (recall or understanding meaning)
10. Impaired visual and spatial skills
11. Loss of motivation or initiative and loss of normal sleep patterns
Supporting people with Alzheimer’s disease:
1. Approach people with Alzheimer’s from the front. Don’t speak to them suddenly from behind or you might startle them.
2. Ask one “yes” or “no” question at a time. Repeat the question using the same words if the person doesn’t answer you.
3. Be sure to let people with Alzheimer’s know what you are doing, one step at a time.
4. Don’t scold, criticize or abuse people with Alzheimer’s for not cooperating with you.

(Adapted from a Disease Process Module: Understanding Alzheimer’s Disease, 2005)

Alzheimer’s and Down syndrome: The risk of Alzheimer’s disease increases with a diagnosis of Down syndrome. Adults with Down syndrome often are in their mid to late 40s or early 50s when Alzheimer’s symptoms first appear.
Some of the people you support may have the following disabilities:

- Fragile X Syndrome
- Prader-Willi Syndrome
- Rett’s Syndrome
- Spina Bifida
- Traumatic & Acquired Brain Injuries
- Tourette Syndrome

…and many others

This is not an exhaustive list. There are many others. If you have any questions about these other disabilities, please ask the trainer. The instructor has a manual that has information in the resource section.
People with Disabilities are People First

- Labels focus attention on a person’s deficits rather than strengths.
- Labels dehumanize.
- Labels can lower others’ expectations.
- Labels can lower self-esteem and self-confidence.
- Labels often lead to a loss of individuality.

Individuals with Disabilities are People First

Individuals with disabilities are people first. They are persons with diverse skills, dreams, aptitudes, and life experiences. A disability label does not tell us about a person’s skills or capabilities. It does not tell us about different personality characteristics. Ultimately it is your personal and professional relationship with each person, his/her friends and family, and your knowledge of his/her community that will enhance his/her personal growth.

1. Labels focus attention on a person’s deficits rather than strengths.
2. Labels dehumanize.
3. Labels can lower others’ expectations.
4. Labels can lower self-esteem and self-confidence.
5. Labels often lead to a loss of individuality.
Objectives:
The staff member will be able to…

4a. understand the different stages of life in relation to the service system.

4b. recognize the different programs that are available to people with developmental disabilities based on their age.
Birth to Twenty-one

- Birth to 3:
  - Early Intervention Services
  - Individualized Family Service Plan (IFSP)

- 3 through 21 (School Age):
  - Individuals with Disabilities Education Act (IDEA)
  - The Individualized Education Program (IEP)
  
  www.state.nj.us/njded/specialed

Birth to 3:

1. Children with developmental disabilities or delays are eligible for Early Intervention Services. These are a partnership between the family, community, providers, schools, and child care programs.
2. The plan during Early Intervention is called an Individualized Family Service Plan (IFSP) and is formulated by a multidisciplinary team, including the parents.
3. Most supports are provided in natural settings – at the home or child care center – and consist of therapies (physical, occupational, and speech), educational evaluation, and other needs (such as adaptive or medical equipment).

School Age (3 –21 Years):

1. The Individuals with Disabilities Education Act (IDEA) guarantees children with disabilities the right to a free and appropriate education delivered in the least restrictive environment.
2. The child study team (of each local Board of Education), with the consent of the child’s parents, evaluates the child for special education services. The team includes a school psychologist, learning disabilities teacher-consultant, school social worker, and therapists (physical, occupational or speech), if applicable.
3. An Individualized Education Program (IEP) is developed. This document states the goals, objectives, and supports needed for the child’s education. The IEP should be written with the participation of the family, student, teachers, counselors, social workers, and other school staff that provide support for the student.
4. In addition to educational services, other services should be available, such as special pre-schools, therapy programs, after-school programs, and recreation.

For more information about Early Intervention in NJ, go to http://www.state.nj.us/health/fhs/eis/index.shtml
For more information about NJ Special Education Programs, go to http://www.state.nj.us/njded/specialed/
Transition

Note - The term “transition” is also used when discussing people moving out of the institutions/developmental centers and into the community.

More frequently staff will use the word “transition” on an informal basis in discussing when a person they are supporting moves from one activity to the next.

Transition is the term commonly used for the act of preparing for and moving from school to work and community life for students receiving special education services. Work contributes to defining a person’s self-concept and sense of participation in society.

The Individuals with Disabilities Education Act requires schools to prepare students for the transition to adult life by including a description of needed transition services in the student's Individualized Education Program (IEP). This must occur by the age of 14.

For more information http://www.thearc.org/faqs/qa-idea-transition.html

The transition from school services to adult services can be difficult. People are moving from an entitlement program (education) to adult services where resources may not be readily available and must be sought.

Adult services can be obtained through the Division of Developmental Disabilities (DDD), Medicaid and Supplemental Security Income (SSI), and/or the Division of Vocational Rehabilitation Services (DVRS).

For information on what’s happening in NJ: http://www.state.nj.us/humanservices/ddd/transition.htm
Guardianship

Many people with developmental disabilities don't need a guardian.

Guardianship is:

• Designed to protect the rights of people with disabilities and ensure appropriate care.

• Provided if it has been legally determined that the person is not able to act on his/her own behalf because s/he don't have the capacity to make informed decisions.

Types include general, limited, etc…

Guardianship

Many people with disabilities are their own guardian. Appointing legal guardianship to someone other than the individual is a removal of the person's fundamental right to self-determination. Therefore, this should be a last resort. A conclusion that a legal guardian is required should be based upon sound clinical data and be regularly reviewed.

If a person has been legally determined to not have the capacity to make informed decisions in certain areas of his/her life (i.e. health, safety, finances, etc…) and it becomes necessary to act on his/her behalf, legal guardianship services are provided for those specific areas.

In some instances an individual might have someone appointed to them by the court to be his/her guardian. This person's family/friend/advocate or Bureau of Guardianship Services' (BGS) role is to protect the individual's rights and to make sure that all supports and services are appropriate.

The most common types of guardianship include:

• **General guardian** - an individual or agency appointed by a court of competent jurisdiction to make all major decisions in a person's life.

• **Limited guardian** - The court may appoint a limited guardian of the person, a limited guardian of the property or a limited guardian of both the person and property. A limited guardian would only be allowed to make decisions in the area that the person has been judged unable to by a court (i.e. legal contracts, medical decisions, etc…)
Adulthood - Living Arrangements

The following is a list of some of the more common types of living situations. It is not a comprehensive list because there are as many choices of living as there are people.

1. **The majority of people with developmental disabilities live with their families.** Some people receive an individual budget from the Division of Developmental Disabilities so that they are able to purchase their own supports and hire their own staff. They are typically enrolled in self-directed programs like “Real Life Choices” and “Self-Determination.”

2. **Sponsor Families** provide the person 24-hour support while living as part of the family of a trained worker.

3. **Group Homes** provide on-site, 24-hour staffing. Typically they are homes in the community in which 4-6 people live.

4. **Supervised Apartments** provide 24-hour support from staff; however the staff work out of an office that may be in another apartment. Typically individuals live with 1 or 2 roommates.

5. **Supportive Living Programs** provide 24-hour access to staff through an on-call number. Assistance is provided on an as-needed basis, usually for no less than 2 hours per week and often in the areas of budgeting and managing government-entitled assistance (Social Security, Medicaid, etc…).
6. **Independent Living** is another option. By combining personal and Division funds, and/or by pooling funds with other residents, individuals can purchase or rent a house or condo. Supports may be available if needed.

7. **Full home ownership** is an option for individuals and/or families with sufficient resources. They can apply for funding from the state Housing and Mortgage Finance Agency to purchase a home. Supports may be available if needed.

8. **Institutions – Developmental Centers** are large housing facilities with 24-hour supervision.
Adulthood
Living Arrangements

- Homes should fit in with the surrounding neighborhood.
- A home should feel and look warm and be decorated thoughtfully, according to what those who live there prefer.

"Think of where you would want to live."

Homes should fit in with their surrounding neighborhoods as much as possible. Signs on the door of the home, logos on van, etc… only point out differences.

A home should feel and look warm, be decorated thoughtfully, according to the preferences of those who live there.
Adulthood
Work

- Adult Training Services
- Sheltered Workshops
- Supported Employment Services
- Competitive Employment

Work

Work is the glue that holds our society together. Even prior to the days of community integration, there was a philosophy that those who could work, should work. Working helps individuals build a personal sense of self-esteem, motivation, and accomplishment. The following are some basic models of employment:

1. **Adult training services** help individuals with basic vocational skills, such as those needed to develop social skills, manage money, and take care of their homes.

2. **Sheltered workshops** provide extended employment where individuals receive work-related training, such as learning how to package and assemble products, as well as job counseling and job referrals.

3. **Supported employment services** include on-site job coaches; crew work, in which an individual works as part of a group; and arrangements in which a person can sample different jobs to find a good "fit."

4. **Competitive Employment** is regular work at regular wages. People may work in competitive employment with or without supports. Often they have the support of a job coach that is eventually phased out. Sometimes people keep a job coach throughout employment.

- Instead of preparing an individual for the environment, the environment is chosen based on the individual’s wants, needs, and abilities.

- Assistive technology and behavioral technologies have given us tools to support the dreams of regular employment for many people with disabilities.

- The Americans with Disabilities Act (1991) provides federal guidelines and legal support for individuals who are willing and able but are physically barred from a particular job.
Volunteering is another way for people to get to know their community, make a contribution, and find places they enjoy spending their time. Volunteer opportunities can occur at places such as a community food bank, Society for Prevention of Cruelty to Animals (SPCA), county parks, Meals on Wheels, thrift shops, etc...

Community Resource Centers provide community based training. Participants choose from activities such as volunteer work, job sampling, swimming, and museum trips. Classes are also provided on subjects like art and cooking.

Recreational activities are another way to become involved in the community. People often need the support of staff to help locate and arrange activities in which they would like to participate. Examples include joining a sports team, attending craft classes, volunteering with the local youth organization, joining Special Olympics, attending local bingo, participating in karaoke, going to a local bar, joining a local gym or swim club, attending theatre productions, using the nature trails at county parks, etc... The local newspaper is a good resource for town activities (i.e. fire department fundraisers, church, movies or concerts in the park, fireworks displays, craft fairs, community days, parades, etc…). Radio announcements, local cable channels, and the local news are other good resources.

Supports:
- Staff may need to go with and participate in the activity the person chooses.
- Staff need to follow through with transportation plans to make sure that people reach the activities they choose to attend.
- Staff need to be aware of the transportation options in the community. Some transportation options include agency vehicles, Access Link, public transportation, car-pooling, etc…
- Staff may need to help make appointments, assist with exact change, pre-plan travel routes, and help the individual prepare for the activity they are going to (i.e. money, medication, etc…)
- Staff need to make sure that the person has an updated ID, knows how to contact someone in case of emergency and has important phone numbers with them.
There is so much more in life than work and home. When we think of what gives our lives meaning, many people look first to the relationships in their lives as well as how they interact with people in the community. We value the roles we have such as child, sibling, parent, volunteer worker, faith community member, etc.... We treasure the times when we experience joy through planned activities, such as going to a play, or just having a good laugh with a friend over something simple. It is extremely important that we provide support in these areas so that every individual has the opportunity to find and experience what is most valued in his or her life. What follows are some examples of relationships and community inclusion that may be important to the people you support.

Relationships

Men and women who have a developmental disability should be given the opportunity to meet socially and express their feelings. How that happens and what form that will take is as unique as the individual. The support we provide could range from providing transportation to teaching how to be a friend to teaching important health tips. Relationships can come in many forms and may include:

1. **Acquaintances**
   These are people we like to communicate with when we see them. We usually do not share deeply personal information with them and don’t necessarily make plans to see them. They do, however, provide pleasant experiences by giving us a sense of being connected to others. An example would be going to a neighborhood store regularly so that the cashier knows you and always gives you an extra smile or makes sure to ask how you are.

   Support can include assisting individuals with visiting local establishments and interacting with people in the community by providing transportation, suggesting places and times to go, and teaching social skills.
2. **Friendships**

These are people who help to fill our lives with meaning. We make plans to communicate with them and spend time with them. We share the good and bad events in our lives with our friends and rely on them for support. Friends can be people we interact with once in awhile or even daily. It is important for us to assist the individuals we support to develop a network of friends that are not paid staff. Many individuals who receive staff support will meet literally hundreds of staff people in their lives. A network of support should be in place that does not rely heavily on people who are a fleeting part of the individuals’ lives.

Support can include assisting people with developing and maintaining friendships by providing transportation, suggesting activities and companions, assisting with invitations, and teaching friendship skills.

3. **Romantic Relationships**

These are the relationships that help connect us with another person in a significant way that includes friendship along with romantic feelings. These relationships span a wide range of involvement. It could include someone “saying” s/he has a partner (or partners) but they do not spend much time together, they just enjoy thinking of each other in these terms. It may also be more intense feelings and experiences, including actively going on dates and communicating with each other regularly. These relationships can also involve physical intimacy, including hugging, kissing, oral sex, sexual intercourse, etc... Romantic relationships for individuals with developmental disabilities, like any human being, will vary greatly depending upon the individuals involved.

Support can include assisting people with developing and maintaining romantic relationships, if desired, by teaching relationships skills, teaching life skills such as how to stay healthy emotionally and physically, suggesting and assisting with planning activities, and providing transportation.

4. **Family Relationships**

Many individuals that you support will have family that they have contact with. Family members play an important role in our lives. They have a shared history, provide support, and offer an opportunity to develop the skill of being concerned about people other than ourselves in a significant way. Being a good daughter/son, aunt/uncle, sister/brother, and/or parent is a role that many of us value. As staff members come and go through the individual’s life, the family is often the only thing that is constant. Some individuals may not have any family that is related by blood. For those individuals it is important for us to teach that many people develop family relationships with those who are not blood relations. That could include roommates or friends who are like brothers or sisters. Even people who have family may develop this type of “family by choice” if the family they have is not particularly involved in their lives or is not a healthy influence.

Support can include assisting individuals with maintaining family relationships by providing transportation, assisting with communication with family for important days such as birthdays, teaching skills needed to be a good daughter/son, sister/brother, aunt/uncle, and/or parent.
Community Inclusion

We interact with our community in many ways. Sometimes it is more formal, through volunteer work or attending a faith-based activity. Often it is informal, through going to a favorite restaurant or watching the local high school football game. Of the many ways that individuals can be a part of their communities, and of the supports that we can provide to ensure this, the following are a few examples:

1. **Having Fun**
   Having fun is a very important part of life. Laughter is clinically proven to improve our health. Planned recreational activities are fun, can reduce stress, connect people to others, and teach valuable skills. Having fun can also occur through unplanned moments. It could be a sing-along started on a van run to day program, a spur-of-the-moment decision to go out for ice cream, or working on a puzzle together at home. Life should be filled with more than work and watching television at home.

   Support can include providing transportation, suggesting activities, sharing your sense of humor, being creative in making daily tasks more enjoyable, and teaching skills that would enable the individual to participate in fun activities.

2. **Faith-based Activities**
   Many people find that religion, or some type of belief system, is an important part of their lives. This can include a belief in a “higher power”, prayer, attending a place of worship, and/or being actively involved in a faith-based community. It is important for us to support a person if they choose to participate in faith-based activities and to be sure that the activities are ones they have chosen. At no time should we be attempting to force people into faith-based activities, such as meal-time prayers or attending a place of worship. We should always support the individuals in the faith of their choice, not the faith of the “group” or of the staff currently working.

   Support can include assisting people with expressing their faith by providing transportation to places of worship, providing religious materials pertaining to the faith.
of their choice, and teaching social skills to interact with members of the faith community.

3. Civic Responsibilities
Being an active member of our community is often a role that people value. This could include voting, going to town meetings, volunteer work, etc...

Support can include assisting people with learning about the views of the candidates, providing transportation, educating individuals about town issues/concerns, and suggesting places to share their skills and interests through volunteer work.

4. Personal Interests
We all have specific interests that are important to us. This can include hobbies (doing puzzles, arts and crafts, dancing, etc...), traveling, going out, playing sports, etc...

Support can include assisting people in developing and maintaining interests that are important to them by providing transportation, suggesting activities, and teaching the skills needed to participate in the activities of their choice.
Retirement

Some options for retirement are:

- Participating in typical retirement activities that focus on personal interests.
- Reducing their schedule (i.e. 2 or 3 days per week)
- Retirement Day Programs are created with more relaxing social events
- Accessing an already existing senior day program
- Doing volunteer work (e.g. delivering Meals on Wheels)

Retirement

Retirement is part of the natural aging process. Individuals may request retirement from community jobs or training centers. Physicians may determine that it is medically necessary, or staff may notice a general “slowing down.” Retirement decisions should be based on the individual’s wishes or needs.

People with disabilities should be given the opportunity to retire. If a person chooses to retire s/he may need help to advocate for this. It is the responsibility of the provider agency and case manager to facilitate the individual’s choice to retire.

Those supporting people who are aging need to use creative ideas to maintain relationships and activities during retirement. Some people may choose not to retire and prefer to continue working regardless of chronological age.

Some options for retirement are:

1. Taking part in typical retirement activities or focus on personal interests (e.g., travel, bingo, hobbies, faith-based activities, card clubs, etc…)
2. Reducing their schedule (i.e. 2 or 3 days per week)
3. Attending a Retirement Day Program with more relaxing social events
4. Accessing an already existing senior day program
5. Doing volunteer work (e.g. delivering Meals on Wheels)
6. Staying home with the necessary supports
7. A combination of the above
Like the rest of the population, more adults with developmental disabilities are living into old age. Life expectancy and age-related medical conditions of adults with developmental disabilities are similar to that of the general population.

However some persons with certain disabilities (Down syndrome, Cerebral Palsy, severe levels of cognitive impairment, multiple disabilities) may experience age-related changes (sensory, cognitive, and adaptive skill losses) earlier than the general population.

Specifically individuals who have Down syndrome show physical changes related to aging about 20 to 30 years earlier than people of the same age in the general population.

Alzheimer’s disease is more common in people with Down syndrome than in the general population. Alzheimer’s symptoms often first appear in adults with Down syndrome in their mid to late 40’s or early 50’s. Extra genetic material found among persons with Down syndrome may lead to abnormalities in the immune system and a higher susceptibility to certain illnesses besides Alzheimer’s, such as: leukemia, seizures, cataracts, breathing problems and heart conditions.

For adults with Down syndrome, symptoms of dementia may often be caused by other conditions that are treatable such as hypo/hyperthyroidism, depression, and hearing and vision impairments.
1. **Dementia**
   Dementia is significant loss of intellectual abilities such as memory capacity, which is severe enough to interfere with social or occupational functioning. Vascular dementia is a decline in a person's mental abilities that results from a series of strokes (when blood flow to part of the brain is blocked, cutting off the blood supply to the brain).

   Staff are responsible for noticing and reporting symptoms immediately to their supervisor both verbally and in writing.

2. **Mental Health**
   Aging people with developmental disabilities may experience higher rates of mental health problems.

3. **Menopause**
   The term menopause is commonly used to describe any of the changes a woman experiences either just before or after she stops menstruating, marking the end of her reproductive period. Menopause occurs 3 to 5 years earlier in women with intellectual disabilities compared with women in the general population. Women with Down syndrome and women with Fragile X syndrome appear to have especially early onset of menopause.

4. **Osteoporosis**
   Osteoporosis is bone density loss that typically increases after menopause and is due to estrogen loss. In addition, long-term use of anti-convulsants is a risk factor for osteoporosis. Osteoporosis, which causes an increased risk for fractures, was also found in younger women with intellectual disabilities who had hypogonadism, a small body size, or Down syndrome.

5. **Long-term Medication Effects**
   Persons with a lifelong history of certain medications (e.g., psychotropics, anti-seizure) are at a higher risk of developing secondary conditions (e.g., osteoporosis, tardive dyskinesia, swallowing problems).

**Providing Supports**
When supporting a person with a severe illness it is important to be positive and encouraging. It is also important to support the person's wishes in discussing the realities of the illness.

It's very important to know the person you work for. Even what appears to be the smallest change in behavior or health should be documented. This documentation will help the individual receive the appropriate supports necessary for both good physical and mental health. Once the best ways to support the person's health needs are determined, they should be documented and followed.
Aging/End of Life

- Opportunities for support, counseling, and memorial events should be developed and provided.
- Grief and other feelings of loss can be expressed verbally and through non-verbal behavior.
- Everyone needs supportive relationships and opportunities to express and share their grief, to remember and to celebrate the lives of others.
- End of life experiences should be seen and planned for as a normal part of life.

People with developmental disabilities experience the same feelings of grief and loss as everyone else. Loss can include: severe illness, staff leaving, roommates relocating, family members moving, and death of friends, family, or staff. This will generate feelings which may include the common stages of grief - denial, anger, bargaining, depression, acceptance, fear (Elizabeth Kubler-Ross, *On Death and Dying*, 1969). People may also express feelings of guilt, uncertainty, doubt, confusion, sadness, loss, etc... Staff who work with people with developmental disabilities who are dying will also have their own feelings of grief and loss.

**Supporting Grief and Loss:**

1. Opportunities for support, counseling, sharing of feelings, and memorial events need to be developed and provided.
2. Grief and other feelings of loss can be expressed verbally and through non-verbal behavior.
3. Adults with disabilities need supportive relationships and opportunities to express and share their grief, to remember, and to celebrate the lives of others.
4. End of life experiences should be seen and planned for as a normal part of life (i.e. living will, hospice care, do not resuscitate (DNR), funeral arrangements).
Tips for talking about death

- Don’t Delay
- Be truthful
- Use simple words
- Let the individual feel his/her own emotions, not yours

Tips
1. Don’t delay, the longer you wait the more likely the person will accidentally hear.
2. Go to a quiet, private place where the person can be comfortable.
3. Be truthful.
4. Carefully choose your first sentence, say something like “I have some sad news to tell you.”
5. Try to use simple words that you know the person will understand. For example use the word “die” or words like “heart stopped beating.” Avoid phrases that can have more than one meaning, for example, “passed away”, “lost”, “went to sleep”.
6. Give simple details that will help the person to understand. Remind her/him about details that may have been seen, such as the person’s condition the last time s/he saw the person.
7. Ask if the person has questions.
8. Ask questions such as “Do you know what happens at a funeral?” “Do you know what a grave is?” and/or “Are you sad (or angry) that (the person’s name) died?”
9. Encourage the person to attend services.
10. If a person does not have an opportunity to participate with family grief rituals (i.e. wake, funeral, Shiva), help the person to have their own ceremony. For example, the person might want to have a special dinner with a picture of the person’s loved one and invite people who are important to them.
11. Allow choice in how the person will deal with the problem.
12. Let the individual feel his/her own emotions, not yours.
13. Let the individual express him/herself in any way that is comfortable for him/her.
14. Reassure the person that you and/or others will be available to help.
15. Don’t try to “push” someone through the stages of grief.
16. Even those individuals who speak may not want to talk about their grief.
17. Try using photos or assist the person to draw pictures.
18. Do not avoid mention of the religious beliefs of the individual (not your own beliefs if different from the individual's!) if they are ways of coping.
19. Remember that most people have some notion of death. Assume the person will experience stages of grief: shock or disbelief, denial, anger, bargaining, guilt, depression, acceptance and hope.

20. Remember that one person’s loss may remind others of their own loss. Be prepared for others to experience grief as well.

21. Show genuine concern.

22. If you are grieving too, do not try to hide your grief, share it. Share your thoughts and feelings. Grieve together. Be careful that your grief is not being forced on the person.

23. Advise people honestly about how you are handling the grief.

24. It’s the staff person’s responsibility to help the individual get through their grief.

25. Be with the person; spend more time with them than usual.

26. Talk about the death and the person.

27. If other losses/changes are scheduled (moving homes, changing jobs) try to evaluate if this is the best time for that change.

- Portions of the above text were adapted from *Mental Retardation and Grief Following a Death Loss*, published by The Arc of the United States
Objectives:
The staff will be able to…

5a. understand that people with disabilities are people first.

5b. understand that people with disabilities want the same things out of life that people without disabilities do.

5c. describe key concepts related to Person-Centered Supports.

5d. recognize how community inclusion is possible.

5e. describe key concepts related to self-advocacy.
People Value...

- Being respected
- Having relationships with family, friends, and neighbors
- Having opportunities to make choices and decisions
- Living where we want with people we care about
- Independence

Values

All people value…

1. being respected.
2. being recognized as individuals, separate from ANY label.
3. being accepted by friends, neighbors and family.
4. living with people we care about in a comfortable home in a safe community.
5. having the opportunity to make choices and not being limited to one job, one outfit, one TV show, or one meal.
6. having the opportunity to do things as independently as possible.
7. making decisions and knowing the joy of being right or even being wrong.
8. having friends who enjoy our company.

When we devalue others, we dehumanize them. When we see others as human, we cannot accept and condone inhumane treatment.

“The distinction between the terms different and devalued is important. Many individuals are different but not devalued. The late Howard Hughes or Hugh Heffner, for example may have acted or act very differently from most people. They have not, however, been devalued. Like the absentminded professor or the million-dollar athlete, some people can act very differently because they are valued. If you are valued and accepted by friends, you can deviate from the norm in certain ways and your friends will still tolerate you. However, people who have developmental disabilities and are devalued are not allowed to act differently.”

- James F. Gardner and Michael S. Chapman
  Staff Development in Mental Retardation Service
### You and I

<table>
<thead>
<tr>
<th>I am a resident.</th>
<th>You reside.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am admitted.</td>
<td>You move in.</td>
</tr>
<tr>
<td>I am aggressive.</td>
<td>You are assertive.</td>
</tr>
<tr>
<td>I have behavior problems.</td>
<td>You are rude.</td>
</tr>
<tr>
<td>I am noncompliant.</td>
<td>You don’t like being told what to do.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>When I ask someone out for dinner, it is an outing or a recreational activity.</th>
<th>When you ask someone out, it is a date.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wanted to talk to the nice-looking person behind us at the grocery store. I was told that it was inappropriate to talk to strangers.</td>
<td>You met your spouse in the produce department. They couldn’t find the bean sprouts.</td>
</tr>
<tr>
<td>I am on a special diet because I am ten pounds over your ideal body weight.</td>
<td>Your doctor gave up telling you.</td>
</tr>
<tr>
<td>I am learning household skills.</td>
<td>Your tee shirt proudly states you are a &quot;Couch Potato&quot;.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>After I work on my budgeting program today, I might have enough money to go to McDonald’s.</th>
<th>You are glad that the restaurant will take your charge card tonight.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t know how many people have read the progress notes people write about me. I don’t even know what is in there.</td>
<td>You didn’t speak to your sister for a month after she read your journal.</td>
</tr>
<tr>
<td>I make mistakes during my check-writing program. Someday the staff will decide if I am ready to get a real checking account.</td>
<td>You forgot to record some withdrawals from your account. Oh well, these things happen.</td>
</tr>
<tr>
<td>I celebrated my birthday yesterday with five other residents and two staff. Maybe next year my family can come.</td>
<td>You had a surprise party for 50. It sounded great.</td>
</tr>
<tr>
<td>My case manager sends a report every month to my guardian. It says everything I did wrong and some of the things I did right.</td>
<td>You are still mad at your brother for telling your mother that you got a speeding ticket.</td>
</tr>
<tr>
<td>My case manager, psychologist, psychiatrist, nurse, occupational therapist, physical therapist, nutritionist, behaviorist, job coach and every staff person from my program set goals for me for the next year.</td>
<td>You haven’t decided what you want out of life yet.</td>
</tr>
<tr>
<td>Someday, someone will decide if I am ready to be more independent.</td>
<td>You will always move onward and upward.</td>
</tr>
</tbody>
</table>

- Adapted from Elaine Popvich, Lutheran Social Services, Midland
Labels are used for funding and eligibility, but support needs determine what you do to help the person. Not everyone with the same diagnosis needs or wants the same supports.

<table>
<thead>
<tr>
<th>Examples of People First Language</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Now we say:</strong></td>
</tr>
<tr>
<td>People with disabilities.</td>
</tr>
<tr>
<td>Paul has an intellectual disability (diagnosis).</td>
</tr>
<tr>
<td>Kate has autism (or a diagnosis of...).</td>
</tr>
<tr>
<td>Ryan has Down syndrome (or a diagnosis of...).</td>
</tr>
<tr>
<td>Sarah has a learning disability (diagnosis).</td>
</tr>
<tr>
<td>Bob has a physical disability.</td>
</tr>
<tr>
<td>Mary is of short stature/she’s a little person.</td>
</tr>
<tr>
<td>Tom has a mental health diagnosis.</td>
</tr>
<tr>
<td>Nora uses a wheelchair/mobility chair.</td>
</tr>
<tr>
<td>People without disabilities.</td>
</tr>
<tr>
<td>Communicates with her eyes/device/etc…</td>
</tr>
<tr>
<td>Accessible parking, hotel room, etc…</td>
</tr>
<tr>
<td>She needs . . . or she uses . . .</td>
</tr>
<tr>
<td><strong>We used to say:</strong></td>
</tr>
<tr>
<td>The handicapped or disabled.</td>
</tr>
<tr>
<td>He’s mentally retarded.</td>
</tr>
<tr>
<td>She’s autistic.</td>
</tr>
<tr>
<td>He’s Down’s; a Down's person; mongoloid.</td>
</tr>
<tr>
<td>She’s learning disabled.</td>
</tr>
<tr>
<td>He is crippled/quadriplegic.</td>
</tr>
<tr>
<td>She’s a dwarf/midget.</td>
</tr>
<tr>
<td>He’s emotionally disturbed/mentally ill.</td>
</tr>
<tr>
<td>She’s confined to/is wheelchair bound.</td>
</tr>
<tr>
<td>Normal/healthy/typical people.</td>
</tr>
<tr>
<td>Is non-verbal.</td>
</tr>
<tr>
<td>Handicapped parking, hotel room, etc…</td>
</tr>
<tr>
<td>She has problems/special needs.</td>
</tr>
</tbody>
</table>

Keep thinking—there are many more descriptors we need to change!
Used with permission - 2006 Kathie Snow, www.disabilityisnatural.com; revised 09/06.
Person-Centered Supports

- Values each person as unique, with gifts and possibilities
- Assists individuals to discover and invent a personal dream for themselves
- Involves learning together in order to make meaningful change happen
- Builds relationships and community inclusion
- Helps us to develop plans that reflect strengths, needs and choices

Person-centered supports challenge us to...

1. value each person as unique, with gifts, and possibilities.
2. find ways to discover our common experiences and work together to build a life where these gifts can be shared with others.
3. assist individuals to discover and invent a personal dream for themselves.
4. craft a pattern of living that increases people’s participation and belonging in community life.
5. learn together how to solve problems over time and make meaningful change happen.
6. make dramatic changes in how we deliver services.
7. learn new ways to support the building of relationships, to find welcoming spaces in community life, and to present new forms of community experience.
8. develop Individual Habilitation Plans (IHP) and Essential Lifestyle Plans (ELP) which objectively reflect strengths, needs, and choices of the person.
Getting to Know You!

Take some time to get to know the people you are supporting.

Get to know:
• Preferences
• Routines
• Good Days & Bad Days
• What Works & Doesn’t Work
• Best Ways to Interact with Him/Her
• Celebrations
• Dreams, etc…

Get to know the person(s) you are working with:

Getting to know the person(s) on a friendly, personal level is the key to successful interactions:

1. What are the person’s preferences? Do they like a shower or a bath? Are they “morning” or “evening” people? What type of music do they prefer?
2. Their routines? Should you wake them or is the alarm the best way? Do they shower in the morning or in the evening? Do they always have a snack when they return from work?
3. What works/doesn’t work? Do they like reminders to stay on task or prefer to return on their own? Should you stay away from certain topics? (For example, holidays and birthdays cause happiness for some, depression for others.)
4. Best ways to interact? Will that pat on the back be pleasant or unpleasant to them? How does noise or volume affect them? Would they rather you “show them”, not “tell them”?
5. The person’s dream? Where do they see themselves one year, 5 years, and 10 years from now? What would they like to accomplish?
Service Plans – are tools for the planning and implementing of generic and specialized services designed to achieve personal outcomes that are appropriate to the individual’s interests, strengths, needs, and preferences.
**Individualized Habilitation Plan (IHP)**

- Everyone receiving services funded by DDD is required to have an IHP.
- The IHP allows the individual to set goals each year to increase skills and further independence.
- The IHP is developed by an Interdisciplinary Team (IDT) – a group consisting of the individual, their family, friends, support workers, and others involved in their lives.
- You may be included in an IDT. You play an important role in the development and implementation of the goals.

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**Individual Habilitation Plan (IHP)**

Each individual who receives services from a residential program or a day training program sponsored by the Division of Developmental Disabilities (DDD) is entitled and required by law to have an Individual Habilitation Plan. The IHP is a documented plan that assists the person in exploring their personal goals.

Here are the steps in the process:

1. The person must have an IHP meeting once per year. The date is determined by the month they entered into their first DDD-sponsored program.
2. A plan coordinator, which may be the individual if capable, is responsible for most of the process. The plan coordinator is often a supervisor in the residential or day program or a staff member designated by the provider agency.
3. The individual, plan coordinator and DDD case manager establish the meeting date. The individual then invites other participants. These may include relatives, friends, guardian (if applicable), support staff (may be direct support professionals), and others who are important to them (for example their job coach, speech therapist, psychologist, advocate). This group makes up the Interdisciplinary Team (IDT).
4. Assessments are done prior to the meeting. They may be conducted by any program staff with whom the individual is comfortable. Most agencies use standardized assessments, choosing specific documents which are most relevant to that individual. (For example, if the individual wishes to learn to take their own medication, there is a self-medication assessment.) The assessment should be summarized and that document should be ready prior to the meeting.
5. The plan coordinator (or designated staff) must complete sections 1-15 of the IHP before the meeting.
6. The plan coordinator should review the previous IHP and get input from the IDT members before the meeting.
7. The IHP meeting is held. The individual is the central focus of the meeting. The documents described in # 4-6 above should be reviewed, but briefly. The meeting should be a forward looking process – focusing on goals and objectives for the coming year. Goals are long-range outcomes and objectives are short-range outcomes that are observable, measurable, and have criteria for completion. Ideas for goals and objectives can be brought to the meeting, but are not finalized until discussion at the meeting. Consensus should be sought if there is disagreement among the IDT members.

8. After the meeting, the plan coordinator must document how each goal and objective will be implemented. Then direct support staff must be trained to work with the person to achieve his/her objectives. The individual’s progress must be tracked.

9. Monitoring takes place on a daily, weekly, or monthly basis. The report may also contain information about the individual’s medical status, social activities, and contact with family.

10. Remember that if at any time it becomes apparent that any new goal/objective is not a good fit, or if the individual clearly has lost interest in pursuing it, the team can meet (physically or through phone/fax/e-mail format) to make a modification to the plan. An IHP Modification Form would be completed.
Your role is to:

1. support the person with a disability to be as involved as possible in the process.
2. know each person’s IHP.
3. provide information about the person's needs and wants.
4. support the person to achieve his/her goals.
5. know which objectives should be worked on during your shift.
6. document progress.
Other Planning Documents: Essential Lifestyle Plan (ELP)

- Planning document developed to support the person in living the life s/he wants to live.
- Meant to be used regularly and allows for staff to record new learning.
- In NJ people who may have ELPs include those:
  - Self-directing services through “Real Life Choices"
  - Transitioning from school to adult life
  - Moving out of institutions and into the community
  - Receiving services from agencies using the ELP
  - Who request that an ELP be developed with them
- May be incorporated into the IHP

The Essential Lifestyle Plan (ELP) is another type of commonly used planning document. It is a written description of what is learned about a person and what is important to them which is incorporated into a plan for delivering services and supports. It is meant to be incorporated into the IHP. It allows for those supporting the person to record new learning, and therefore should be looked at regularly.

Some agencies in NJ are using the ELP. You may need to use an ELP if you are supporting people self-directing services through Real Life Choices as well as people transitioning out of high school and institutions.

The ELP is easy to use as it is free of clinical jargon and focuses on the person and what s/he wants and needs. All ELPs have several common components, but they have an open framework so additional important information may be added. Some common information found in an ELP includes:

1. Relationship Map – displaying those people who are close to the person
2. Great Things about the Person
3. Important To/Important For
   - Important to – what a person says with his/her words or behavior
   - Important for – health and safety issues and what others see as important to the person to be a valued member of society
4. Characteristics of people who support the person best
5. What others need to know or do to support the person
6. What other people need to know or do to help the person stay healthy and safe
7. Things to figure out – space for people to document things they don’t understand or need more information about
8. Communication Chart – records how a person communicates using behavior
9. What works/makes sense – What doesn’t work/doesn’t make sense in areas of the person’s life
10. Goals & Action Planning
Other planning documents that the people receiving services may have:

1. Individual Family Service Plan (IFSP) – Plan developed for children in early intervention (birth to 3)
2. Individualized Education Program (IEP) – school age children (3-21)
3. Individualized Support Plan (ISP) – People in the self-determination program
Video

Planning for Life: The Role of Direct Support Professionals in Self-Directed Supports
Self-Advocacy

Self-Advocacy is a way through which individuals stand up for their rights. It enables individuals to take charge of their own lives. Self-advocacy is the process of speaking up for oneself, knowing one’s rights and responsibilities, making decisions, solving problems, seeking assistance when necessary, and discovering ways in which one can contribute to the community. Self-advocacy can be speaking out to improve conditions for the individual, program, agency, community or even at a statewide or national level.

Self-Advocacy is about:

1. Self-determination
2. Taking risks
3. Knowing they can ask for help
4. Finding out what/who will support them
5. Empowerment
6. Making informed choices
7. Beginning to change the way things are
8. Speaking out on behalf of oneself
9. Taking charge of one’s life

There are several self-advocacy organizations which encourage individuals to stand up for their own rights. Many people belong to these self-advocacy groups where they coordinate voter registration drives, rally in Trenton, discuss issues with legislators, testify at legislative hearings, attend town meetings to increase community accessibility, etc… Some of the organizations in New Jersey are Monday Morning [www.njcdd.org](http://www.njcdd.org), New Jersey United Self-Advocates (NJUSA) [http://www.njselfadvocacyproject.org/](http://www.njselfadvocacyproject.org/), etc…
Lesson 6:

Direct Support Professional Roles

Objectives:
The staff member will be able to…

6a. understand the DSP Code of Ethics set forth by the National Association of Direct Support Professional.

6b. understand the role of a DSP.
What is a Direct Support Professional (DSP)?

Direct Support Professionals (DSPs) are people who work directly with individuals with developmental, physical and/or mental health disabilities. DSPs support people with disabilities to lead the life they want to lead. This includes supporting them to complete daily activities and participate in and contribute to the community. DSPs provide supports to people with disabilities at home, work, school, places of worship and other areas throughout the community. DSPs advocate for the person they support by helping them to communicate their needs, feelings and goals.

Regardless of the job titles individual agencies use, Direct Support Professionals are staff that support people with disabilities in their day to day lives.

The following slide has been adapted from the National Alliance of Direct Support Professional’s Code of Ethics. [www.nadsp.org](http://www.nadsp.org)
Staffs’ Role

• Person-Centered Supports
• Physical and Emotional Well-Being
• Integrity and Responsibility
• Confidentiality
• Justice, Fairness, & Equity
• Respect
• Relationships
• Self-Determination
• Advocacy

1. Person Centered Supports
   • Provide supports based on the person’s wants and needs

2. Promoting Physical and Emotional Well-Being
   • Foster the well-being of those supported
   • Encourage growth and individuality while being attentive to reducing risk of harm

3. Integrity and Responsibility
   • Work in partnership with those being supported, other professionals, and the community.

4. Confidentiality
   • Protect and respect the confidentiality and privacy of those being supported.

5. Justice, Fairness, and Equity
   • Promote and practice justice, fairness, civil rights, and equality for those being supported.

6. Respect
   • Respect and value the human dignity and uniqueness of those being supported.

7. Relationships
   • Assist when needed in the development and maintenance of relationships.

8. Self-Determination
   • Assist those supported in living their lives according to their own plan.

9. Advocacy
   • Advocate with those supported to ensure justice, inclusion, and full community participation
Staffs’ Role

To make sure that...

- Lives are organized based on the preferences, choices and desires of the people who live them balanced with health and safety.
- Lives are enriched with good work, good jobs, good food, meaningful ways to contribute in community life, and the increased ability of people to manage their lives.
- Lives are filled with experiences and relationships.
- Lives are rich in relationships in which one feels appreciated, loved, and comforted by people who care.

It is staffs’ role to make sure that...

1. Lives are organized based on the preferences, choices and desires of the people who live them balanced with health and safety.

2. Lives are enriched with good work, good jobs, good food, meaningful ways to contribute in community life, and the increased ability of people to manage their lives.

3. Lives are filled with experiences and relationships.

4. Lives are rich in relationships in which one feels appreciated, loved, and comforted by people who care.
Overview of Developmental Disabilities

Challenge

• Use the information and tools you have learned when you are on the job.
• Don’t let others tell you “That is just training, you don’t have to do it.”
• Remember the Golden Rule: Treat others the way you want to be treated
• Use this opportunity to do more than a “job” and look to change lives, both yours and the people you support

1. You should use the information that you have received and also look into further resources that relate specifically to those you support.

2. You should not let veteran staff tell you things like “That is just training” or “That is not how we do it here” and discourage you from doing what you know is right.

3. You should think how you would want to be treated, not just if you ever needed assistance but also in general, as a human being. If you are speaking to someone in a tone of voice you would never tolerate being used on you or asking someone to do something you would never want asked of you, then you should stop it.

4. You should take the opportunity that is being presented to you to significantly improve the quality of someone’s life. In doing so you will find your own life may change as you see the positive effect you can have on others.
We know that ideas are more than just dreams. We must all believe and focus on the person, the vision, the dream – not the disability.