

Facilitator Notes: Cerebral Palsy

We are preparing these lessons for individuals with a wide range of experience in providing training to their staff and co-workers. As a result, we have provided considerable structure and advice for those who would like it. Please feel free to change and improve on these lessons and make them your own. Our philosophy is that the best lesson is the one that reflects what you think is worth learning.

What to do before the session

- Read the lesson; decide if you want to make changes.
- Adjust the amount of materials covered by eliminating exercises or by deciding what to cover in greater detail.
- Make copies of handouts and exercises for each participant.
- Set up the presentation area to accommodate participants in groups of 2-5. It will be helpful but not critical if they have a surface to write upon.

Notes to the Facilitator

Notes to the facilitator of the lesson are written in blue and enclosed in []. They include background information, questions to ask the learners, points to emphasize, and answers to exercise questions. The "participant" versions of the handouts and exercises do not have them. Use them to orient yourself to the lesson, or simply ignore them if it is too much information.

Introducing the topic -- here are some points you might want to make

- Some of the individuals we serve experience cerebral palsy.
- Communication difficulties, physical limitations, cognitive limitations, and poor social skills can make these individuals difficult to serve.
- Having a basic understanding of cerebral palsy and how it impacts people can help us get to know the individuals we serve and to identify effective support strategies

30 Minute Lesson: Cerebral Palsy

Facilitator Version

Cerebral palsy (CP) is a term used to describe a group of chronic conditions affecting body movement and muscle coordination, caused by damage to one or more specific areas of the brain. This lesson focuses on building an understanding of cerebral palsy, particularly from an employment standpoint.

Learning Objectives

- < Build an understanding of cerebral palsy: causes, prevalence, management strategies, characteristics
- < Review information about the types of cerebral palsy
- < Review information about successful employment approaches for people with cerebral palsy

The Ideal Participant

- < Works with individuals with CP in an employment context

Prep activities and time required

10-20 minutes, including reading the lesson, making copies of handout exercises, and organizing.

Lesson length, other requirements

30-45 minutes. Can be adjusted by eliminating or modifying exercises

Does not require an overhead or LCD projector. A flip chart or whiteboard is handy but not necessary. All handouts are ready to use, or can be modified by user to meet specific needs.

Other related lessons

Developmental Disabilities and Intellectual Disability (Mental Retardation)

Epilepsy

Autism

Asperger Syndrome

Test Your Knowledge!

[About 5 minutes to take the quiz; 5 additional minutes at the end to review the correct answers. The point of this activity is to get your learners thinking about their CP knowledge, and to test some of their assumptions. Have them complete the questions individually, discuss the last question briefly with others in a small group, then hang on to their papers. At the end of your session, review the correct answers.]

What is the most common type of cerebral palsy?

70 to 80% of people with CP have spastic CP, where muscles are stiffly and permanently contracted.

True or False: Cerebral Palsy is caused by problems with muscles and nerves.

False: it's caused by brain damage

True or False: Cerebral Palsy always causes significant disabilities.

False: a person with mild cerebral palsy might be only slightly awkward and require no special assistance.

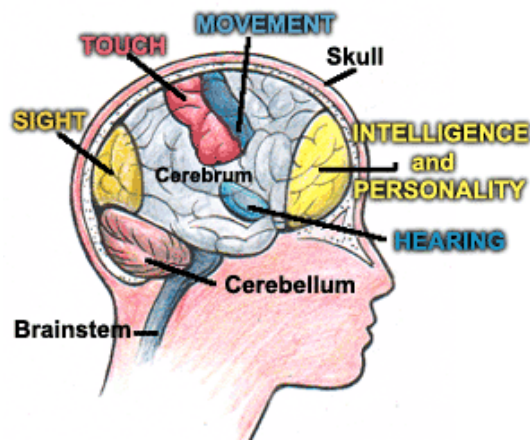


“Jenny has CP.” What characteristics come to mind when you hear that phrase? Write your list below, and then compare notes with the others in your small group.

Cerebral Palsy

[10 minutes. These three pages review information about CP. You can go through the material in lecture format, have participants read the sections to themselves, or take turns reading them out loud. You might have the group address the questions in blue type as you go along.]

What is Cerebral Palsy?



Cerebral palsy (CP) is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. CP is caused by damage to one or more specific areas of the brain.¹

In some cases, the cerebral motor cortex doesn't develop normally during fetal growth. In others, the damage is a result of injury to the brain either before, during, or after birth. In either case, the damage cannot be repaired and the disabilities that result are permanent.²

CP is not caused by problems in the muscles or nerves. It is the faulty development or damage to motor areas in the brain that disrupts the ability to adequately control movement and posture. The term *cerebral* refers to the motor area of the brain's outer layer (called the cerebral cortex), the part of the brain that directs muscle movement; *palsy* refers to the loss or impairment of motor function.

CP itself is not progressive (i.e. brain damage does not get worse); however, secondary conditions, such as muscle spasticity, can develop which may get better over time, get worse, or remain the same. CP is not communicable. It is not a disease and should not be referred to as such; it is a condition. Although CP is not "curable" in the accepted sense, training and therapy can help improve function.³

How Many People Have Cerebral Palsy?

The United Cerebral Palsy (UCP) Foundation estimates that nearly 800,000 children and adults in the United States have some type of cerebral palsy – about 3 out of every 1,000 people. According to the Centers for Disease Control and Prevention, each year about 10,000 babies born in the United States will develop cerebral palsy.⁴

1 <http://www.jan.wvu.edu/media/CP.html>

2 http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

3 http://www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447#what

4 http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm#99513104

Despite advances in preventing and treating certain causes of cerebral palsy, the percentage of babies who develop the condition has remained the same over the past 30 years – prevention and treatment efforts have been counterbalanced by higher survival rates for very low birth weight babies who have developmental defects in their nervous systems or suffer brain damage that will cause them to have cerebral palsy. ⁵



In the United States, about 10 % of children who have cerebral palsy acquire the disorder after birth. The figures are higher in underdeveloped countries. Acquired cerebral palsy results from brain damage in the first few months or years of life and can follow brain infections such as meningitis or encephalitis, or result from head injury -- most often from a motor vehicle accident, a fall, or child abuse.⁶

[How many of the people we support have some type of cerebral palsy? How many of these individuals also have other diagnosed disabilities, and what are they?]

⁵ http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm#99513104

⁶ <http://www.legalpointer.com/displaymonograph.php?MID=124>

What Are the Effects of Cerebral Palsy?

From http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

Depending on which areas of the brain have been damaged, one or more of the following may occur:

- lack of muscle coordination when performing voluntary movements (*ataxia*);
- stiff or tight muscles and exaggerated reflexes (*spasticity*);
- walking with one foot or leg dragging;
- walking on the toes, a crouched gait, or a “scissored” gait;
- variations in muscle tone, either too stiff or too floppy;
- excessive drooling or difficulties swallowing or speaking;
- shaking (*tremor*) or random involuntary movements; and
- difficulty with precise motions, such as writing or buttoning a shirt.

The effects of cerebral palsy differ in type and severity from one person to the next, and may even change in an individual over time. Some people with cerebral palsy also have other medical disorders, including mental retardation, seizures, impaired vision or hearing, and abnormal physical sensations or perceptions.

Cerebral palsy doesn't always cause profound disabilities. While one person with severe cerebral palsy might be unable to walk and need extensive, lifelong care, another with mild cerebral palsy might be only slightly awkward and require no special assistance.

(Photo of Matthew Huddleston from Disability Rights Center of Kansas; <http://drckansas.org>)

[Which of these characteristics are exhibited by the people with CP we're supporting? How does this list match the issues you identified in your quiz?]



Special Health Challenges among Adults with CP

http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm#71703104



Because of improvements in medical care, rehabilitation, and assistive technologies, people with cerebral palsy are living longer than ever. This increase in life expectancy is often accompanied by a rise in medical and functional problems including premature aging because of the extra stress and strain the condition puts upon their bodies.

Most adults with CP experience what is called *post-impairment syndrome*, a combination of pain, fatigue, and weakness due to muscle abnormalities, bone deformities, repetitive motion injuries, and arthritis. Fatigue is often a challenge, since individuals with cerebral palsy use three to five times the amount of energy that able-bodied people use when they walk and move about.

Mental health issues can also be of concern as someone with cerebral palsy grows older. The rate of depression is three to four times higher in people with disabilities such as cerebral palsy. It appears to be related not so much to the severity of their disabilities, but to how well they cope with them.

Acute and chronic pain is experienced by many adults with CP, and may go unrecognized by health care providers since individuals with cerebral palsy may not be able to describe the extent or location of their pain. Pain is experienced most commonly in the hips, knees, ankles, and the upper and lower back

[What are some of the employment implications of these health challenges?]

Types of Cerebral Palsy

[10 minutes. These two pages review the types of CP. You can go through the material in lecture format, have participants read the sections to themselves, or take turns reading them out loud. You can also omit this detailed information if your time is short, or pass it out as reference material.]

Spastic cerebral palsy: 70-80%. In this form of cerebral palsy the muscles are stiffly and permanently contracted. Specific labels are based on which limbs are affected, i.e spastic diplegia (both legs) or left hemi-paresis (the left side of the body). These names given combine a Latin description of affected limbs with the term plegia or paresis, meaning paralyzed or weak.

Spastic hemiplegia/hemiparesis. This type of cerebral palsy typically affects the arm and hand on one side of the body, but it can also include the leg. Children with spastic hemiplegia generally walk later and on tip-toe because of tight heel tendons. Depending on the location of the brain damage, a person with spastic hemiplegia may also have seizures. Speech will be delayed and may be impaired, but intelligence is usually average or above average.

Spastic diplegia/diparesis. In this type of cerebral palsy, muscle stiffness is predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. Tendon reflexes are hyperactive. Toes point up. Tightness in certain leg muscles makes the legs move like the arms of a scissor. People with this kind of cerebral palsy may require a walker or leg braces. Intelligence and language skills are usually within normal ranges.

Spastic quadriplegia/quadruparesis. This is the most severe form of cerebral palsy, often associated with moderate-to-severe mental retardation. It is caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck. They are rarely able to walk. Speaking and being understood are difficult. Seizures can be frequent and hard to control.

Athetoid, or dyskinetic cerebral palsy: 10-20%. This form of CP is characterized by uncontrolled, slow, writhing movements. These movements usually affect the hands, feet, arms, or legs and may also cause grimacing or drooling. The movements often increase during periods of emotional stress and disappear during sleep. A person may also have problems coordinating the muscle movements needed for speech. Intelligence is rarely affected in these forms of cerebral palsy.

Ataxic cerebral palsy: 5 to 10%. This rare form affects the sense of balance and depth perception. Affected persons often have poor coordination; walk unsteadily placing their feet unusually far apart; and experience difficulty when attempting quick or precise movements, such as writing or buttoning a shirt. They may also have intention tremor. In this form of tremor, beginning a voluntary movement, such as reaching for a book, causes a trembling that affects the body part being used and that worsens as the individual gets nearer to the desired object.

Mixed types. It is common for people to have symptoms that don't correspond to any single type of cerebral palsy. Their symptoms are a mix of types. For example, a person with mixed cerebral palsy may have some muscles that are too tight and others that are too relaxed, creating a mix of stiffness and floppiness.

Information from http://www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447#types and http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

Managing Cerebral Palsy

[5 minutes. This page reviews information about approaches to managing CP. You can go through the material in lecture format, have participants read the sections to themselves, or take turns reading them out loud.]

Managing cerebral palsy often involves services and equipment like these:

- ✓ Physical therapy to improve walking and gait, stretch spastic muscles, and prevent deformities
- ✓ Exercise programs to keep muscles that aren't normally used moving and active and less prone to wasting away, and to reduce the risk of contracture
- ✓ Occupational therapy to develop compensating tactics for everyday activities such as dressing, going to school, and participating in day-to-day activities
- ✓ Speech therapy to address swallowing disorders, speech impediments, and other obstacles to communication
- ✓ Recreational therapy, such as therapeutic horseback riding, to improve gross motor skills
- ✓ Counseling and behavioral therapy to address emotional and psychological needs and help people cope emotionally with their disabilities
- ✓ Medication to control seizures, relax muscle spasms, and alleviate pain
- ✓ Surgery to correct anatomical abnormalities or release tight muscles
- ✓ Braces and other orthotic devices to compensate for muscle imbalance, improve posture and walking, and increase independent mobility
- ✓ Mechanical aids such as wheelchairs and rolling walkers for individuals who are not independently mobile
- ✓ Communication aids such as computers, voice synthesizers, or symbol boards to allow people to communicate with others ⁷

[In your experience, which of these services do adults with CP have good access to? Which seem more unusual, or harder to access?]

Exercise: Job Placement Strategies (5 minutes to develop list)

The next page will offer some strategies for job placement success for people with CP. Before reviewing this section, ask the group to brainstorm strategies and approaches they've found successful in supporting individuals with CP. You may want to create a list on flip chart paper or a white board as you solicit ideas from the group. When you have developed your list, move on to review the suggestions on the next couple of pages and see how they compare.

⁷ http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

Going to Work – Potential Support Approaches⁸

Accessing the workspace

- Maintaining unobstructed hallways, aisles and other building egress
- Assigning workspace in close proximity to office machines
- Providing lightweight doors or automatic door openers
- Providing designated parking, accessible routes and entrances

Learning/organizing tasks

- Task lists in appropriate formats (Day Timer, large print, daily checklist, pictures)
- Job coaching

Motor challenges (physical limitations that may interfere with completing tasks)

- Modifying workstation design and/or height
- Using alternative computer input devices or software (e.g. voice recognition)
- Using telephone assistance devices
- Using writing aids and grips
- Building in jigs or fixtures
- Head pointers
- Computerized switches utilizing controllable muscles

Communicating (e.g. understanding instructions, asking for help or clarification)

- Natural communication techniques (e.g. gestures, vocalizations, facial expressions, nonverbal signals)
- Graphic and manual signs (e.g. ASL, pictures, symbol systems, letters, words)
- Communication aids (e.g. communication boards, communication notebooks, picture wallets, computer-based systems using pointers or switches)



Social integration (Most job failures of people with CP do not result from the person's physical limitations, but from an inability to get along with co-workers and supervisors)

- Co-worker mentoring
- Job coaching
- Education on CP and the accommodations that are being developed or provided

Personal care on the job

- Allow use of a personal attendant or service animal at work
- Move workstation closer to the restroom
- Allow longer breaks
- Develop a plan and providing equipment for safe evacuation in case of emergency

[How did this list compare to our ideas?]

⁸ <http://www.jan.wvu.edu/media/CP.html>

Handout: Two Accommodation Examples

(adapted from “Adaptive environments in the workplace” by JoAnn Sowers, in **Assistive Technology; A Resource For School, Work, And Community** by Karen Flippo, Katherine Inge, and Michael Barcus (Eds); Paul Brooks 1995; pages 180-181).

Low Tech

Roberta is a young woman with cerebral palsy and cognitive disabilities. She uses a power chair for traveling distances, but can use a manual chair which she propels with her one functional hand and her feet. She can speak but is somewhat difficult to understand.

Roberta works at a credit union, where her tasks include typing and laminating new membership cards, filing, cleaning up and stocking the customer area, destroying misprinted checks, and collating information packets for new members. Because Roberta uses only one hand, it was difficult for her to align the card on the plastic laminating sleeve and to fold it over for placement into the machine. A guide was built from plywood that held the sleeve and the card in place while she folded the sleeve. A wooden guide was also built for her to use in stabilizing papers to be stapled. To insert the informational papers into envelopes, she puts the envelope between her knees and then inserts the papers. The total cost for her adaptations was less than \$10.

High Tech

Tom has cerebral palsy, learning disabilities, and excellent spoken communication skills. He has no functional use of his hands and limited vision; his manual wheelchair is pushed by an attendant or other person.

Following high school, Tom started a meeting reminder business to remind members of committees and task forces of meeting times, dates, and locations. Tom uses a voice activated device, head switch, and customized computer software to call several hundred people monthly to remind them of scheduled meetings. The assistive technology allows Tom to independently place phone calls, read printed names and numbers, and keep track of who has been called and whether they would be attending the meeting.

Internet Resources on Cerebral Palsy

<http://www.cpconnection.com/>

<http://www.ucp.org>

http://www.ninds.nih.gov/disorders/cerebral_palsy/cerebral_palsy.htm

<http://www.nichcy.org/pubs/factshe/fs2txt.htm>

http://www.marchofdimes.com/professionals/681_1208.asp

<http://www.jan.wvu.edu/media/CP.html>

http://www.ucp.org/ucp_channelsub.cfm/1/17/11928 fact sheets

Wrapping up the Session

[It is important to spend a few minutes (5 minutes or so) bringing the lesson to a sensible close. Usually the focus will be on emphasizing the most important point(s), relating how the information could be integrated into current services. Here are some suggestions for wrap-up questions:]

- ❖ What did you learn today that surprised you?

- ❖ Was there a specific person or persons you had in mind as we reviewed the information about CP? How closely did their situation match the information that was presented?

- ❖ What else should we learn about this disability?

30 Minute Lesson: Feedback Form

Please let us know what you think of this product, so we can continue to better meet your training needs. Fax or mail to Laurie Ford at 6912 220th SW, Suite 105, Mountlake Terrace, WA 98043; Fax (425) 774-9303

Topic of Lesson _____

- Facilitator Version
- Participant Version
- Non-Facilitated Group Version
- Self-Study Version

1. On a scale of 1 to 5, please rate the relevancy of these materials to your job _____
(1 is worst, 5 is best)
2. On a scale of 1 to 5, please rate the positive impact of these materials on your professional skills, knowledge, and abilities (1 is worst, 5 is best) _____
3. On a scale of 1 to 5, please rate the positive impact of these materials on your organization (1 is worst, 5 is best) _____
4. What was the most useful part of the lesson?
5. What was the least useful part of the lesson?
6. How could this lesson be improved?
7. What additional topics would you like to see in a 30 Minute Lesson?