How to Handle a Disclosure

How Should a Victim of Sexual Violence Act?

Hysterical?	Angry?	Crying?	Tired?
Joking Around?	Nervous?	Laughing?	Isolated?
Flippant?	Irate?	Agitated?	Empty?

- There is no **one way** that a victim of sexual violence behaves.
- We all have different coping mechanisms & we all respond to trauma differently.
- Just because someone does not act the way that "a rape victim should," do not disregard their disclosure as attention seeking behavior.

Disclosures

Be an excellent listener. Try not to interrupt the victim or ask too many questions because it may make the victim feel like they are being interrogated.

Tell he/she that you believe them. People rarely make up stories of sexual abuse or rape. It is very important that you acknowledge & support the victim's disclosure because the first contact can significantly help or hurt the victim's healing process.

Contain your own feelings. Try to remain professional. Emotional reactions can make the victim feel guilty for disclosing or cause more feelings of shame.

Acknowledge their trust in disclosing to you. Highlight their courage & strength in taking action in their healing process.

Offer them the appropriate referrals for professional support- Provide them with information about local DV/SA providers & other counseling options.

Be familiar with you organization's policies regarding disclosure of abuse. If your organization does not have one, RCC would be happy to help you develop one.

Dos & Don'ts

Do tell the person that you believe them.

Do offer privacy to disclose. They may approach you in a group setting, so offer to move to a more private area.

Do tell the person that they were right to tell you & that it was brave.

Do tell the person that they are not the only one & that sexual violence happens to others.

Do tell them they are not responsible for what happened & it's not their fault.

Do make necessary referrals such as DSS & RCC.

Do consult your RCC staff members who are available 24/7.

Don't make promises that you can't keep; especially if they ask you to keep the disclosure a secret.

Don't panic or show that you are shocked; remain calm for the victim's sake.

Don't give the impression that you might believe the victim is somehow at fault, e.g. don't ask: "How much had you had to drink?" or "Why did you go over to his/her house?" or "This happened 2 months ago! Why didn't you tell me sooner?"

Don't ask intrusive questions.

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Your Words, Our Image

- Use **person-first language**. You are in a unique position to shape the public image of people with disabilities. Your words can create insensitive, negative images or a straightforward, positive view of people with disabilities.

Don't Say	Do Say
Differently abled, challenged	**Disability**
The disabled	**People with disabilities**
Slow learner	**Person with a learning disability**
Quad	**Person with quadriplegia**
Autistic	**Person with autism**
Mongoloid	**Person with Down syndrome**
Midget	**Person of short stature**
Burn victim	**Burn survivor**
Handicapped parking	**Accessible parking**
Blind	**Visually impaired**
Alcoholic	**Alcohol dependent**
Brain damaged	**Brain injury**
Polio	**Post-polio syndrome**
Confined to a wheelchair	**Uses a wheelchair**
Hare lip	**Cleft lip**
Fit, attack	**Seizure**
Mute, dumb	**Speech disorder**
Birth defect	**Congenital disability**
Mental retardation	**Intellectual disability**
Normal, able-bodied	**Nondisabled**
Deaf-mute, the hearing impaired	**Deaf, hard of hearing**

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THE MOST APPROPRIATE LABEL IS USUALLY THE ONE PEOPLE'S PARENTS HAVE GIVEN THEM.

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North Carolina Council on Developmental Disabilities
Building Bridges to Community

The Rape Crisis Center of COASTAL HORIZONS CENTER, INC.

This handout was developed based on input and/or direct experiences of individuals with atypical speech. Adapted with permission from Disability Services ASAP of SafePlace, Austin, Texas

How to Communicate with People with Atypical Speech

Attitudes:

- Assume that the person with whom you are speaking will be able to understand you, and that you will be able to understand them. The first assumption of many people who have limited experience with those whose speech is atypical is that there will be a problem communicating. Often, this is not the case. Sometimes it depends on what you expect.

- Assume that the person with atypical speech has typical intelligence. Just because a person's articulation is different from what you are accustomed to does not mean that the person has any intellectual difficulty/disability.

- Remember that communication is a partnership. Communicating means that both people are encouraged to express what is on their minds and that both individuals listen and take in what is being said and respond appropriately. Communication between two people is an exercise in turn-taking: each person learns to absorb what is said and then takes a turn being the speaker again. This turn-taking process is usually conducted unconsciously, and is only exposed as a process when one or both individuals have difficulty with their turn. To make this process conscious when first interacting with someone who has atypical speech, remind yourself to speak, wait and listen, and then take your turn again.

- Miscommunication between two people constitutes a communication "breakdown." In a communication breakdown, one person does not understand what the other is saying and the expected ease of the conversation is disrupted. In that moment, both people become aware that there is work to do. The appropriate response to a communication breakdown is an attempt to repair the breech. It is a partnership, so both parties share the work of repairing the communication breakdown. It may be helpful to identify the breakdown out loud to the person and say, "I'm so sorry, but I feel like we're missing each other. Can we start over?"

- Do not speak for someone else even if you are familiar with his or her speech patterns unless you have been asked to do so, or you have an agreement about it. People who are having difficulty understanding may turn to someone they think is easiest to communicate with and literally pass over the person whose speech is difficult to understand. This kind of "speaking for" infantilizes the speaker and it puts a third person into what was intended to be a two-person conversation. It is intrusive. To be a conscious communicator, you may have to say no to someone who is asking you to speak on behalf of a person with atypical speech. They have to do the work themselves. Rather than automatically answering, you might say, "I don't know, ask her."

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Actions:

- If you do not understand what someone has said, be honest about it. If you pretend to understand but do not, there is a noticeable shift in the equality of the interaction, and it signals a certain level of disconnection. People who have lived many years with atypical speech usually know when someone is pretending to understand, primarily because it changes the nature of the interaction by reducing the intelligibility of the conversation and creating emotional distance. Pretending to understand can result in the other person feeling embarrassed, angry, frustrated, and/or alienated.

- Tell the individual you have not understood what has been said. There is no "fault" in these situations, and there is no "right" way to feel about any communication breakdown. The focus needs to be on repairing the breakdown, and the first step is to acknowledge that you did not understand.

- Once you have admitted that you do not understand, wait for the individual to attempt to repair the breakdown. Most people who have atypical speech patterns have years of experience repairing communication breakdowns and they will employ any number of strategies to help you understand. You may not need to do anything more than admit you have not understood

Strategies for Effective Communication in Priority Order:

For those situations where effective communication requires more than a simple repetition, you and the person with atypical speech can employ any of the following strategies:

- **Wait:** Communicating with an individual who has difficulty with speech is complicated, so take your time. Decoding speech patterns that your ears are not trained for can take a little time. Listen to the whole sentence or phrase. Wait for a second and try to relax. Let the conversational context help you.

- **Repeat:** Simply repeating the sentence or thought may be enough. There are times, though, when repeating is not going to help because the speaker is not going to be able to change the way a specific word is pronounced. If repeating does not work, move on to another strategy.

- **Rephrase:** Ask the individual to try and express the same thought using various words. Often, the misunderstanding hinges on one or two words in a sentence.

- Identify which part of the sentence or thought was misunderstood: If you know most of the phrase or sentence that has been spoken and can identify which part(s) are unclear, you might try repeating back to the individual what you know has been said, and asking him/her to focus on finding a way to understand just the part you did not get. This has two functions: it lets the person with atypical speech know that you are still actively participating in the conversation and that you want to understand, and it also reduces the amount of repair that has to happen.

If the previously-mentioned strategies are not effective, consider the following:

- **Spelling:** Once you have located the word(s) you do not understand, ask the individual to spell for you. It usually just takes the first few letters of the word to clear up the confusion.

- **Writing:** You can ask him or her to write it down, or you can write down what you thought they said, and you can give each other feedback.

- **Guess:** Ask what the topic is and/or ask for a context in which you might better understand or "guess" – this can be really funny! And it can break the tension as long as the person with atypical speech knows that you are trying.

Other Accommodations

- Speech to Speech Relay (STS) is a service mandated by the Federal Communications Commission that enables people with a speech disability to use their own voice, voice prosthesis, or communication device to make a phone call. In an STS call, the speech of one person is relayed to the other by a communication assistant in a three-way call environment. Call 7-1-1 and request "Speech-to-Speech" to place a call or visit www.speechtospeech.org for a list of toll free numbers throughout the United States.

- Assistive or Adaptive Technology: The individual may use assistive or adaptive technology such as a communication board or electronic device with speech output. If this is the case, ask the person which mode of communication he/she prefers to use. Some individuals will prefer to use their own speech. Keep questions and responses short and simple. The person may have to spend more energy using the device to communicate. Ask the person with atypical speech if he/she prefers both parties to communicate in written form. The person may want to read your responses rather than hearing them. Be patient and wait. The person with atypical speech using assistive technology may require several minutes to communicate.

- Keep in mind that augmentative communication devices may be withheld and/or broken by perpetrators in an attempt to silence the individual who relies on them. In addition, some perpetrators may attempt to "speak for" the individual in an attempt to prevent a survivor from speaking out. Other perpetrators may refuse to program augmentative communication devices to further prevent disclosure. When interacting with individuals who may use these types of communication supports, be aware of this dynamic and include it in any safety planning that you may offer. In addition, discuss checking in periodically just to make sure that the communication device is being used to relay the person's intended message, not that of a perpetrator.

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Adapted from Identifiers of Caregiver Abuse by the Disability Services of ASAP of SafePlace, Austin, Texas.

Identifiers of Caregiver Abuse

Some forms of abuse may be subtle, but are still hurtful and disrespectful. The following is a list of possible identifiers of abuse inflicted by a caregiver or a person with a disability. The listing and the examples provided are not all-inclusive as there are many other specific forms of abuse.

Coercion and Threats

- Threatening to: hurt the individual, their child(ren), pet, or service animal; withhold basic support and rights; terminate relationship and leave the person unattended; report noncompliance with a service program; use more intrusive equipment; institutionalize the individual; take children away; or medicate the person
- Coercing the person to have sex without consent
- Using consequences and punishments to gain compliant behavior
- Pressuring the person to engage in fraud or other crimes

Intimidation:

- Raising a hand or using other looks, actions, gestures to create fear
- Destroying property
- Mistreating service animal(s) and/or abusing pet(s)
- Displaying weapons
- Providing personal care in a rough manner
- Driving recklessly

Emotional Abuse:

- Punishing or swearing at the person
- Refusing to speak and ignoring requests

- Ridiculing the person's disability, culture, traditions, religion, size, and/or personal tastes

- Enforcing a negative reinforcement program or any behavior program to which the person does not consent

- Keeping the individual awake

- Treating the person like a child or servant

Isolation:

- Controlling access to friends, family, neighbors, telephone, television and/or other forms of media

- Limiting employment or educational opportunities

- Discouraging contact with a case manager, advocate, or other service providers

- Determining living arrangements
- Locking the person in a room

Minimize, Justify, and Blame

- Denying or making light of abuse

- Denying physical and/or emotional pain of people with disabilities

- Justifying rules that limit autonomy, dignity, and relationships

- Excusing abuse as behavior management or caregiver stress

- Blaming the disability for the abuse

- Saying that the person is not credible

- Justifying that no one else would want to have sex with the individual or be willing to take care of the individual

Withhold, Misuse, or Delay Needed Supports

- Using medication to sedate the person for convenience

- Ignoring equipment safety requirements

- Breaking or not fixing adaptive equipment
- Refusing to use or destroying communication devices
- Using equipment to torture an individual

Economic Abuse

- Using a person's property and money without their permission
- Stealing money or personal items
- Using property and/or money as a reward or punishment program
- Making financial decisions for the person without their consent or permission
- Limiting access to financial information and resources

Caregiver Privilege

- Taking action without the individual's consent
- Making unilateral decisions
- Defining narrow, limiting roles and responsibilities
- Providing care in a way to accentuate the person's dependence and vulnerability
- Giving an opinion for the person as if it were that person's opinion
- Denying the right to privacy
- Ignoring, discouraging, or prohibiting the exercise of full capabilities

Non-Profits and the Americans with Disabilities Act of 1990

The Americans with Disabilities Act (ADA) of 1990 prohibits discrimination and ensures equal opportunity for persons with disabilities in non-profit facilities, State and local government services, and public accommodations. The 2010 Amendments to ADA includes detailed guidance to help nonprofits fulfill their obligation to offer full and equal access to persons with disabilities. Specifically, ADA states that:

- Nonprofits cannot discriminate against individuals on the basis of disability in the full and equal enjoyment and benefit of goods and services offered to the public.
- If your organization's goods and services cannot be accessed by individuals with disabilities as they are by the general public, then you must provide ways that are separate and/or different and just as effective as those provided to others.
- Nonprofits must ensure effective communication with people who have disabilities relating to vision, hearing, and speech as long as it does not impose an undue burden on their organization. You may need assistive communication devices, vision or hearing aids, large-print brochures, and/or qualified interpreters to be available. Each individual should make a request and your organization can determine if it's appropriate.
- Communication accommodations must be accessible, timely, and protective of the privacy and independence of the individual requesting the accommodation. There can be no extra charge imposed on individuals with disabilities to cover the cost of these measures.
- If providing an accommodation imposes an undue burden on your organization, you must seek alternatives that ensure effective communication to the maximum extent feasible.
- Accommodations must be provided to individuals in the most integrated setting appropriate to their needs. Accommodations cannot be excluded through false safety regulations or eligibility screening restrictions.
- To improve communication with individuals having cognitive disabilities, train your staff to rephrase and simplify concepts with demonstrations, providing information clearly, one topic at a time, keeping remarks short, and reducing distractions and noise.
- Nonprofits must remove architectural barriers when it is "readily achievable" to ensure access from approach points such as parking into the building, to the areas where services are offered, and to restrooms. When such access is not readily achievable, nonprofits must provide alternative methods (e.g., having personnel available to assist such individuals) until barrier removal is achieved.

For details of these regulations, see: www.ada.gov
The ADA Information Line is (voice) 800-514-0301 and 800-514-0383 (TTY)

Under the ADA, a disability is a physical or mental limitation that substantially impairs a major life activity such as seeing, hearing, walking, breathing, thinking, and/or performing activities of daily living. Trauma stemming from PTSD often qualifies as a disability. Persons with disabilities are encouraged to pursue personal, social, employment and/or family responsibilities to the extent their limitations interact with social and environmental factors.

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Mandated Reporting

NC Department of Social Services Reporting Law

Statute

North Carolina N.C. Gen. Stat. § 108A–102(a) – (b)

(a) Any person having reasonable cause to believe that a disabled adult is in need of protective services shall report such information to the director.

(b) The report may be made orally or in writing. The report shall include the name and address of the disabled adult; the name and address of the disabled adult's caretaker; the age of the disabled adult; the nature and extent of the disabled adult's injury or condition resulting from abuse or neglect; and other pertinent information.

Reporting to DSS-Reporting Law

- WHO MUST REPORT?
  Any person who has reasonable cause to believe that a person with a disability is in need of protective services.
- WHAT DOES THAT MEAN?
  If there is **suspicion** that someone is being abused (sexually, physically, financially, or verbally), neglected, or exploited.
- WHAT IS ABUSE?
  "Willful infliction of physical pain, injury, or mental anguish: unreasonable confinement; willful deprivation by a caretaker or services necessary for mental or physical health."
- WHAT IS NEGLECT?
  "Living alone and being unable to provided necessary care for physical and mental health; failure of caretaker to provided necessary services."
- In situations of stranger assault, DSS will usually not screen these reports in, unless there is a supervision issue.

Making a Report

- WHAT MUST BE INCLUDED IN THE REPORT?

  Information given by the reporter ideally including name, address, age of the individual with a disability; name and address of the caretaker; extent of injury, abuse, neglect, exploitation; or any other pertinent information.

  Reporting can be done anonymously but professionals **should not** report anonymously. If someone reports anonymously, their information will not be shared with the alleged perpetrator or the victim. A letter will be sent to the reporter stating how DSS will proceed with the report.

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Power & Control Wheel

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Adapted from the National Center on Domestic and Sexual Violence

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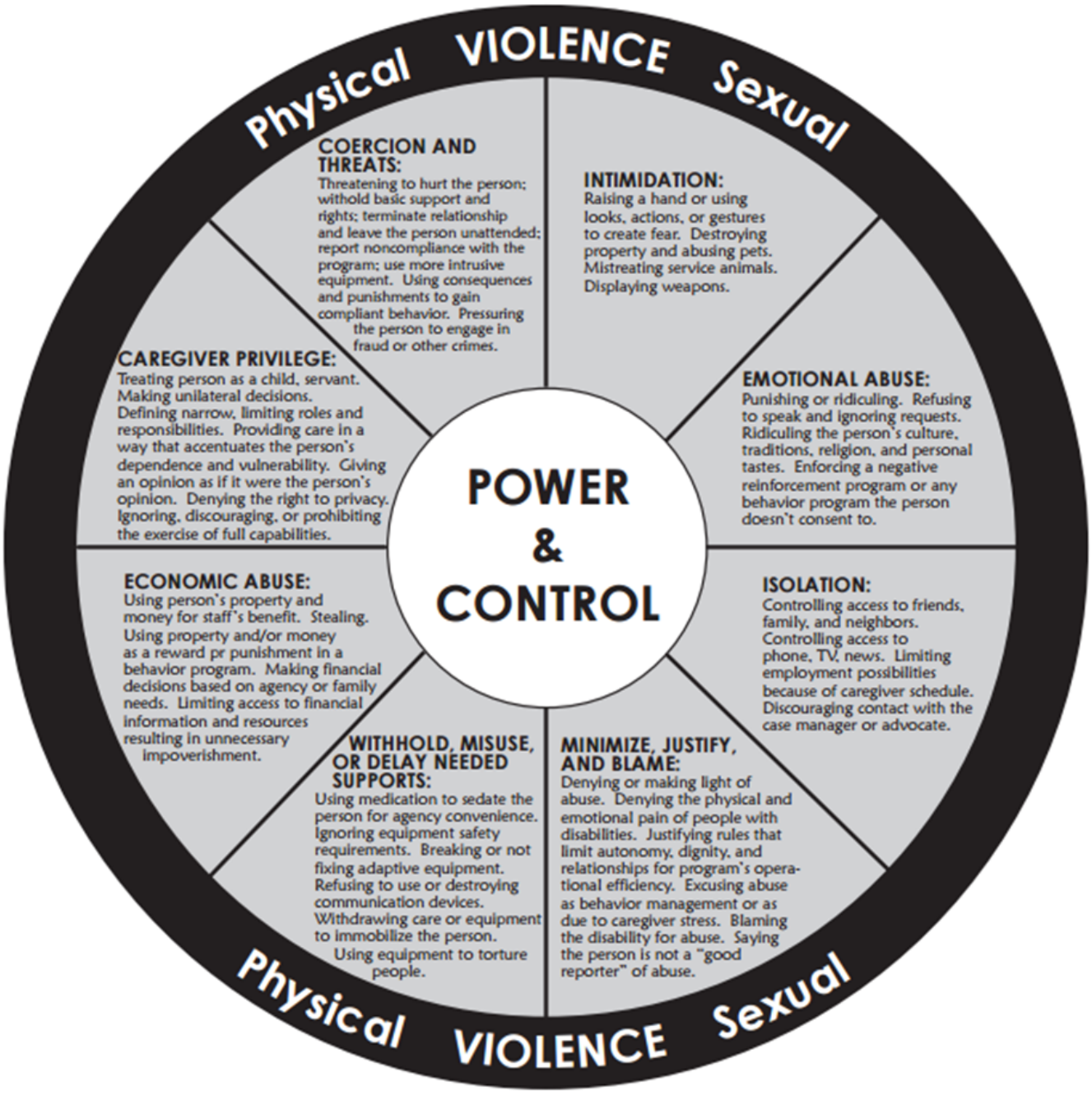
Power & Control Wheel: Individuals with Disabilities and Their Caregivers



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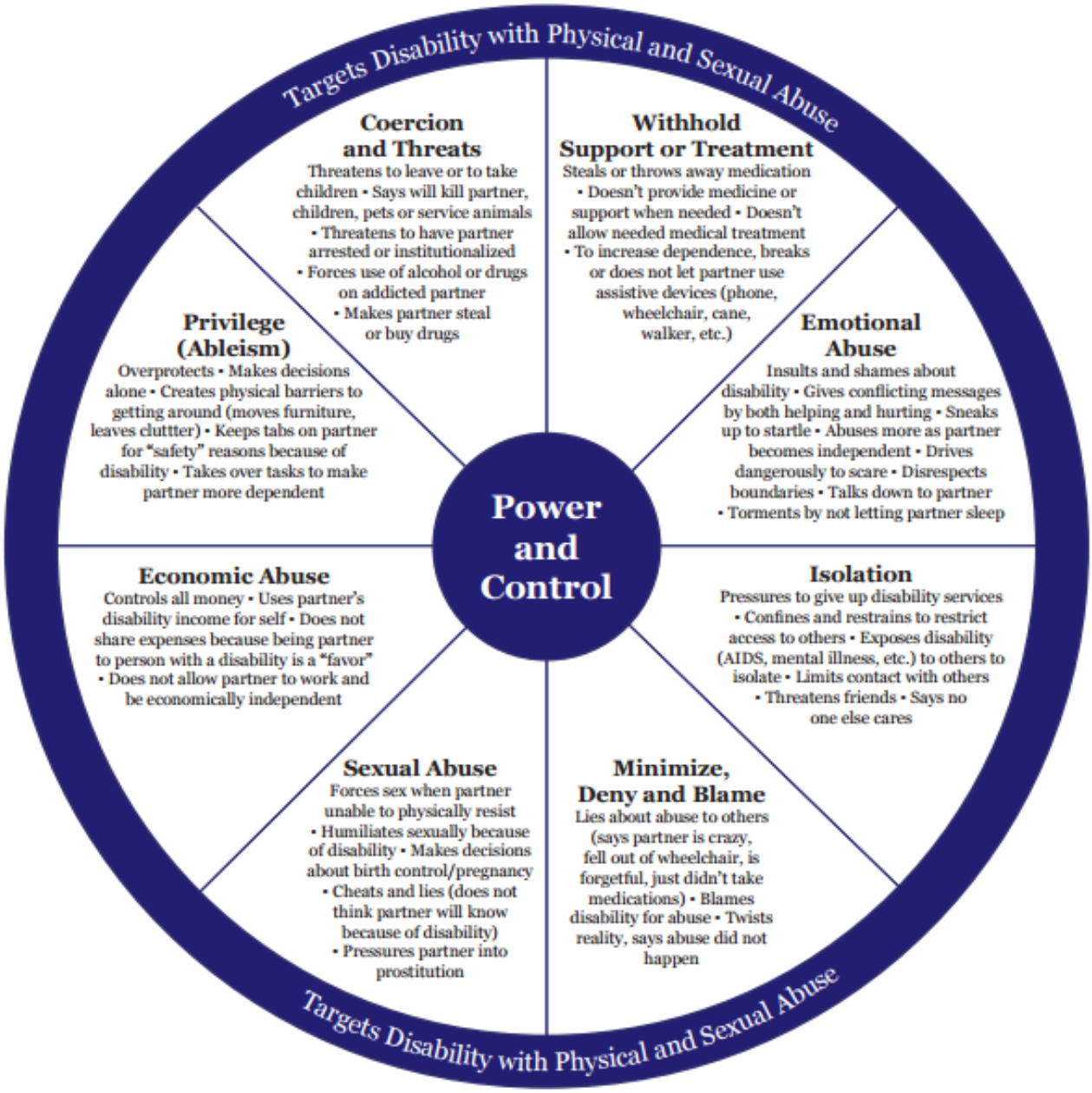
Power & Control Wheel:

Individuals with Disabilities in Partner Relationships



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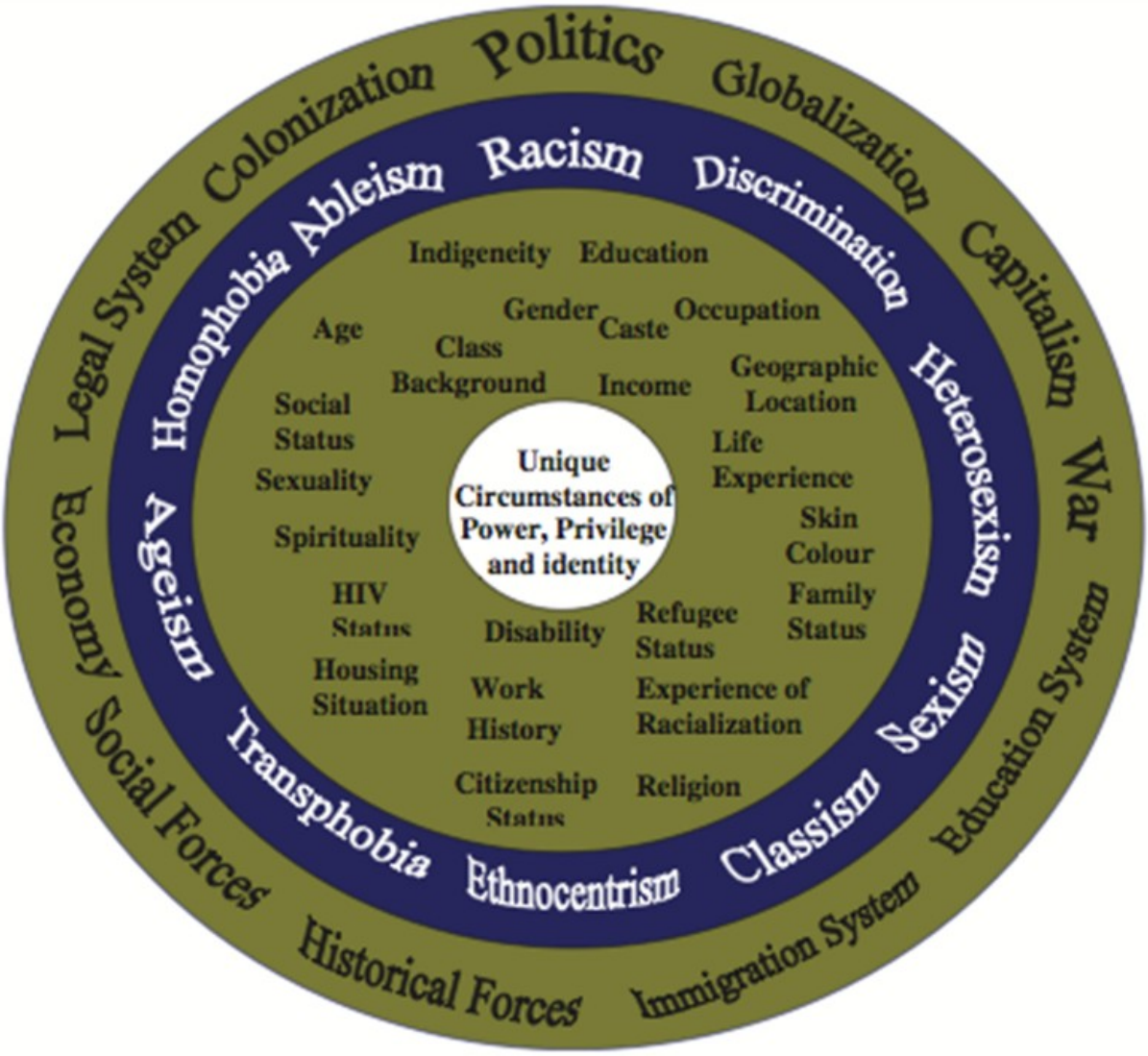
Intersectionality of Oppression



- Innermost circle represents a person's unique circumstances.
- Second circle from inside represents aspects of identity.
- Third circle from the inside represents different types of discrimination/isms/ attitudes that impact identity.
- Outermost circle represents larger forces and structures that work together to reinforce exclusion.

Note it is impossible to name every discrimination, identity, or structure. These are just examples to help give you a sense of what intersectionality is.

From A Toolkit for Applying Intersectionality by Joanna Simpson, CRIAW/ICREF

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Sexual Violence and People with Intellectual/Developmental Disabilities

A fact sheet with helpful information for respecting and supporting individuals with Intellectual /Developmental Disabilities (IDD).

What do we know about violence and individuals with disabilities?

- Persons with disabilities in NC experience sexual assault at a rate five (5) times higher than persons without disabilities.
- 80% of women and 60% of men with developmental disabilities have been sexually abused.
- Sexual violence can be prevented.
- No two people with disabilities are the same.

Common Questions About Intellectual and Developmental Disabilities

Q - What is a developmental disability (DD)?

A - DD means someone has limitations in three or more of the following areas: self-care, language, movement, self-direction, capacity for independent living, or economic self-sufficiency. The onset of DD is before age 22 and often includes intellectual disability. Examples are: Down syndrome, fragile X syndrome, cerebral palsy, or spina bifida. In North Carolina, DD includes disability caused by a traumatic brain injury at any age.

Q - What is an intellectual disability (ID)?

A - ID means someone has limitations in intellectual functioning (reasoning, learning, solving problems) and in adaptive behavior (the range of everyday social and practical skills). This type of disability usually originates before the age of 18.

Q - What is Autism Spectrum Disorder (ASD)?

A - ASD is considered a developmental brain disorder. Individuals with ASD may have difficulty understanding verbal/nonverbal communication and relating to people, objects, and events. It is often found in combination with other disabilities. ASD affects individuals differently.

1. Centers for Disease Control and Prevention (2010). Behavioral Risk Factor Surveillance System.
2. Hingsburger, D. (2001). *Sexuality and People with Developmental Disabilities*. Mountville: Vida Publishing.

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Values Embraced by the Disability Community

Self-Advocacy — To speak up and assert one's interests, desires, needs, and rights; to make informed decisions and take responsibility for them.

Inclusion — Individuals fully participate in communities, rather than live separated from mainstream society.

Self-Determination — People with disabilities make their own life decisions. The self-determination motto is "Nothing about us without us."

Diversity — The concept of diversity includes acceptance and respect for others. This means understanding that each individual is unique. Diversity involves moving beyond tolernce to celebrating differences.

Using Person-First Language

- Put the person first. *Person with a disability* instead of *disabled person.*
- Say *wheelchair user*, rather than *wheelchair bound*. The wheelchair enables the person to get around and participate in society; it's liberating, not confining.
- It's okay to use idiomatic expressions when talking to people with disabilities. *See you later*, to a person who is blind is acceptable.
- Avoid disempowering words: *victim, sufferer*.
- Avoid outdated terms like *handicapped*, *crippled* and *retarded*.

***Spread the Word to End the Word* is a National Movement (*www.r-word.org)*. Some people still use "mental retardation*",* but most people are offended by the "r" word, even if the person does not intend to be offensive.**

When you are supporting a sexual violence survivor with IDD…

- Acknowledge the individual's emotional state. *You seem upset today...You must be proud...That must be frightening.* Such statements validate the individual's experience, and help to build trust.
- Behavior is one way of communicating. Pay attention to non-verbal cues, over-compliance, resistance, and body language.
- Use more than one way to give information. Include stories, graphics, icons, and other tools.
- Be aware of your environment. Some individuals may feel comfortable pacing, need a small space, or prefer a quiet place away from distractions.
- Use verbal or visual cues when changing topics. If the individual is having difficulty understanding a question, try asking it in a different way.

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General Communication Tips

- **Speak in clear sentences.** Use simple words and concepts. Break a complex idea down into smaller parts**.**
- **Use precise language with simple words.** When possible, use words that relate to things you both can see. Avoid directional terms—*right/left, east/west*. Ask *who, what,* or *where* questions. *When* and *how* questions may be difficult to answer.
- **Speak directly; make eye contact** if possible before speaking. Say the person's name often.
- **Don't use "baby-talk" or talk down to the person.** Remember that adults—unless you are informed otherwise—can make their own decisions. Be aware of your voice tone and inflection.
- **Be prepared to use a variety of questions**: yes/no, either/or and open-ended questions. Individuals may be eager to please and tell you what they think you *want* to hear.
- **Be patient; allow the person to take time as needed.** It can be difficult for individuals to make quick decisions. Be encouraging, rather than correcting; don't speak for the person.
- **Signs with visual cues** can help individuals find their way around a facility or answer questions.
- **Use hand gestures and notes,** if helpful.
- **Don't pretend to understand** if you're having difficulty doing so.

Tips for Communicating with People on the Autism Spectrum

- **Use a calm, even voice tone.** Visual supports and gestures are helpful**,** especially in times of stress.
- **Be careful not to startle people.** Approach the individual slowly and quietly.
- **Avoid physically touching** the person if possible**.**
- **Use short, direct instructions.** *Tell me two places you go to feel safe.* Narrow choices to two or three.
- **Give the individual enough time** to respond before you repeat instructions.
- **Do not try to stop an individual's repetitive behaviors,** such as flapping hands or pacing, as these behaviors may be the person's way of calming him/herself.
- **Offer a break,** which can be helpful to reduce anxiety.
- **Remember not to take behaviors personally.** If the person has a lack of eye contact or speech, this may not mean disrespect.

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THIS FACT SHEET IS PROVIDED BY:

North Carolina Council on Developmental Disabilities

North Carolina Coalition Against Sexual Assault (NC CASA)

Carolina Institute for Developmental Disabilities (CIDD), UNC

It's time ... to talk about it! Talk early, talk often. Prevent sexual violence.

An overview of healthy childhood sexual development

Understanding healthy childhood sexual development plays a key role in child sexual abuse prevention. Many adults are never taught what to expect as children develop sexually, which can make it hard to tell the difference between healthy and unhealthy behaviors.

When adults understand the difference between healthy and unhealthy behaviors, they are better able to support healthy attitudes and behaviors and react to teachable moments. Rather than interpret a child's actions with an adult perspective of sex and sexuality, adults can promote healthy development when they understand what behaviors are developmentally expected at different stages of childhood. They are also better equipped to intervene when there are concerns related to behavior or abuse.

Understanding childhood sexual development

Sexuality is much more than sex – it's our values, attitudes, feelings, interactions and behaviors. Sexuality is emotional, social, cultural, and physical. Sexual development is one part of sexuality, and it begins much earlier in life than puberty. Infants and children may not think about sexuality in same way as adults, but they learn and interpret messages related to sexuality that will shape their future actions and attitudes. For example, when a three year old removes their clothes in front of others, a parent may tell him or her that "*being naked is okay at bath time, or in your room, but not while your cousins are here.*" The child is learning that there are times when it is OK to be naked and times when it is not.

Sexuality is emotional, social, cultural, and physical. Sexual development is one part of sexuality, and it begins much earlier in life than puberty.

Children are constantly learning social norms and what is expected or appropriate in interactions and relationships. There are healthy and common expressions of sexuality that children are likely to show at different developmental stages. Often adults want to know which behaviors are appropriate and indicate healthy childhood sexual development. The information below addresses common behaviors that represent healthy childhood sexual development as well as what knowledge and skills are appropriate for children at each stage (National Child Traumatic Stress Network, 2009; The Society of Obstetricians and Gynaecologists of Canada, 2012).

It's time ... to talk about it! Talk early, talk often. Prevent sexual violence.

Healthy childhood sexual development		
Stage of development	Common behaviors	Encouraging healthy development
Infancy (Ages 0-2)	• Curiosity about their body, including genitals • Touching their genitals, including masturbation, in public and in private • No inhibitions around nudity	• Teach correct names of body parts, such as penis and vagina • Explain basic information about the differences between male and female anatomy • Help children begin to understand how to interact respectfully with peers of the same age • Provide very simple answers to questions about the body and bodily functions
Early Childhood (Ages 2-5)	• Occasional masturbation. This usually occurs as a soothing behavior rather than for sexual pleasure. It may occur publicly or privately. • Consensual and playful exploration with children of the same age. This could include "playing house" or "playing doctor." • May ask questions about sexuality or reproduction, such as, "Where do babies come from?" • May show curiosity in regard to adult bodies (e.g., wanting to go to into the bathroom with parents, touching women's breasts, etc.) • Continued lack of inhibition around nudity. May take-off their diaper or clothes off • Uses slang terms for body parts and bodily functions	• Provide basic information about reproduction (e.g., babies grow in the uterus of a woman) • Encourage a basic understanding of privacy and when things are appropriate and inappropriate • Explain the difference between wanted and unwanted touch. For example, a hug that is welcome and positive versus one that is unwelcome and uncomfortable. • Teach children about boundaries. Let children know that their body belongs to them and that they can say no to unwanted touch.

It's time ... to talk about it! Talk early, talk often. Prevent sexual violence.

Healthy childhood sexual development		
Stage of development	Common behaviors	Encouraging healthy development
Middle childhood (Ages 5-8)	• Continued use of slang words, "potty humor" or jokes to describe body parts and functions • Deeper understanding of gender roles. May act in a more "gendered" manner as expected behaviors and norms associated with gender are learned (e.g., girls may want to wear dresses). • Sex play or activities that explore sexuality and bodies may occur with same- and opposite-sex friends • Masturbation. Some children may touch their genitals for the purpose of pleasure. This happens more often privately rather than in public.	• Promote a solid understanding of gender and how children experience their gender identity. Children who identify as transgender or gender non-conforming will experience this also, but can face confusion and may need increased support from adults. • Explain the basics of human reproduction, including the role of vaginal intercourse. • Talk about the physical changes that will occur during puberty. • Explain that there are different sexual orientations such as heterosexual, homosexual, and bisexual. • Teach that masturbation is something that occurs in private. • Educate on personal rights (e.g., "your body belongs to you") and responsibilities (e.g., treat boys and girls equally) related to sexuality.

Healthy childhood sexual development		
Stage of development	Common behaviors	Encouraging healthy development
Late childhood (Ages 9-12)	• As puberty begins an increased need for privacy and independence is often expressed. • Interest in relationships. May want to have a girlfriend or boyfriend. • May express curiosity about adult bodies. This could involve the child trying to see people naked or undressing or involve looking for media (such as TV, movies, websites, and magazines) with sexual content. • As social norms around masturbation become clearer. Masturbation will likely occur in private.	• Provide ongoing information about the physical aspects of puberty and changes in their body. • Educate children on the social and emotional aspects of puberty. Help to normalize the new emotions and needs that they may be experiencing. • Provide age-appropriate sexuality information and basic information about sexual behaviors and sexually transmitted infections, etc. • Encourage critical thinking and build the skills to differentiate fact from fiction in media images and representations of sexuality. • Support them in understanding they have both rights and responsibilities in their friendships and relationships. Encourage characteristics of healthy friendships and relationships.

Adolescence and ongoing development

As children progress into adolescence, signs of development become more pronounced and the need for accurate information about sexuality and sex continues. In addition to more detailed questions about sexuality and sexual health, young adults are often in need of support in finding accurate sources of information and resources. Additionally, adults can support youth as they navigate cultural and social messages about sexuality and gender shared though media and often reinforced by peers.

It's time ... to talk about it! Talk early, talk often. Prevent sexual violence.

Healthy childhood sexual development and child sexual abuse prevention

Discussing sexual development within the context of child sexual abuse prevention can cause discomfort and raise tough questions. Conversations about children and sexuality are often seen as taboo. Thus, education, including accurate information about childhood sexual development, is rare. This leaves the media and pop culture, which often hyper-sexualize or exploit children, as the primary information source for both adults and children.

It is important to recognize that many adults had little or no sexuality education growing up, and may have been given negative messages as children about their own sexual development. This can cause adults to see behaviors that are typical and developmentally expected of childhood sexual development as a problem. Discomfort can also occur for adults if they interpret a child's behaviors through an adult perspective. For example, a four-year-old who wants to shower with a parent may simply be curious about different bodies, while a parent may interpret this curiosity as overly sexual.

Childhood sexual development is a challenging topic. With more knowledge, comfort and skills, adults can better understand and support healthy development and recognize signs of unhealthy or abusive behaviors in both youth and adults. For parents, community members and persons working in sexual violence prevention, assessing one's comfort level is a great first step in determining what information and skill are necessary for a stronger understanding of healthy childhood sexual development. All adults in the community can be powerful allies and advocates in preventing child sexual abuse.

When is behavior a concern?

Remember that behavior falling within healthy childhood sexual development should exhibit the following characteristics (National Child Traumatic Stress Network, 2009):

- Children are being playful and/or curious, not aggressive or angry.
- Play involving sexuality (i.e. playing Doctor, "Show me yours/I'll show you mine") should be with a child of a similar age and developmental level, not with a much older or younger child.
- When adults ask children to stop or set limits around inappropriate behaviors they listen.
- The behavior does not cause physical or emotional harm to the child or others.

It's time ... to talk about it! Talk early, talk often. Prevent sexual violence.

Parents & caregivers can:

Develop positive and open communication around topics of sexuality. Create a dynamic where your children know they can come to you for accurate information and guidance that reflects your values without shaming.

Model respectful boundaries when it comes to touch and affection. Don't coerce children to give hugs or other displays of affection when they don't want to. Teach them that they have a right to have boundaries around their personal space and body from a young age and that they have a responsibility to respect the boundaries of others. Empower children to seek help when something feels uncomfortable to them.

All adults & community members can:

Challenge unhealthy norms. When you see or hear an unhealthy norm in either children or adults, in action, say something. Explain what is concerning about the norm and share a healthy alternative. Emphasizing safety, equality and respect as the standard is key to ending oppression and violence.

Be an engaged bystander. If you perceive it to be safe and you see something that is of concern, trust your instincts, and do or say something about it. Everyone has a responsibility to protect children from sexual violence. Active bystanders make an impact, and it's critical to speak up so institutions, policies, and laws can be changed to prevent harm.

Advocates, educators & professionals can:

Engage adults in addressing the issue. Help adults in the community better understand their roles in preventing child sexual abuse. Create opportunities in outreach and programming for dialogue and skill-building on this issue.

Act as resource. Parents and other community members need support and information on topics of childhood sexual development and child sexual abuse prevention. Provide connections to books, curricula and other resources that may help expand knowledge and comfort.

References

National Child Traumatic Stress Network. (2009). *Sexual development and behavior in children: Information for parents and caregivers.* Retrieved from the Alaska Department of Health and Social Services, Office of Children's Services: http://hss.state.ak.us/ocs/Publications/pdf/sexualdevelop-children.pdf

The Society of Obstetricians and Gynaecologists of Canada. *Sexuality and childhood development* (n.d.). Retrieved 8/19/2012 from http://www.sexualityandu.ca/parents/sexuality-child-development

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Autism Spectrum Disorder (ASD) Fact Sheet

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. People with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder.

People with ASD often have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things. Signs of ASD begin during early childhood and typically last throughout a person's life.

Children or adults with ASD might:

- not point at objects to show interest (for example, not point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled, or might cuddle only when they want to
- appear to be unaware when people talk to them, but respond to other sounds
- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- have trouble expressing their needs using typical words or motions
- not play "pretend" games (for example, not pretend to "feed" a doll)
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound

http://www.cdc.gov/ncbddd/autism/facts.html

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES · National Institutes of Health

National Institute on Deafness and Other Communication Disorders

NIDCD Fact Sheet | **Hearing and Balance**

American Sign Language

What is American Sign Language?

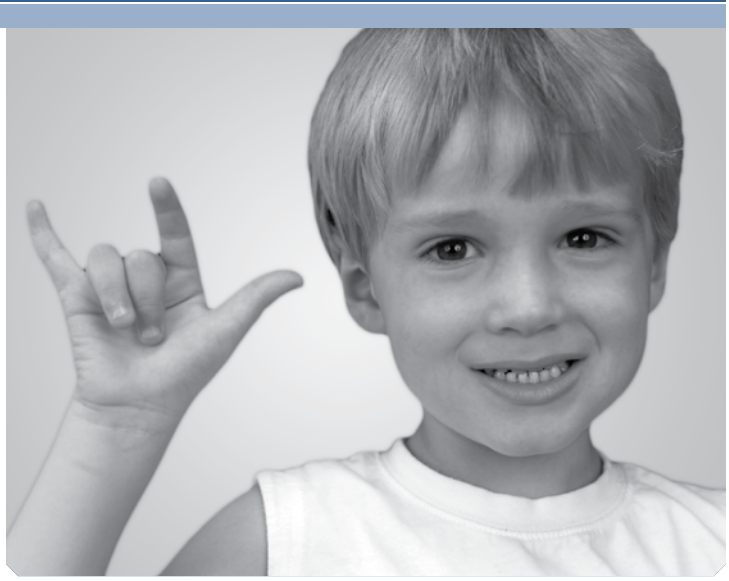
American Sign Language (ASL) is a complete, complex language that employs signs made by moving the hands combined with facial expressions and postures of the body. It is the primary language of many North Americans who are deaf and is one of several communication options used by people who are deaf or hard-of-hearing.

Is sign language the same in other countries?

No one form of sign language is universal. Different sign languages are used in different countries or regions. For example, British Sign Language (BSL) is a different language from ASL, and Americans who know ASL may not understand BSL.

Where did ASL originate?

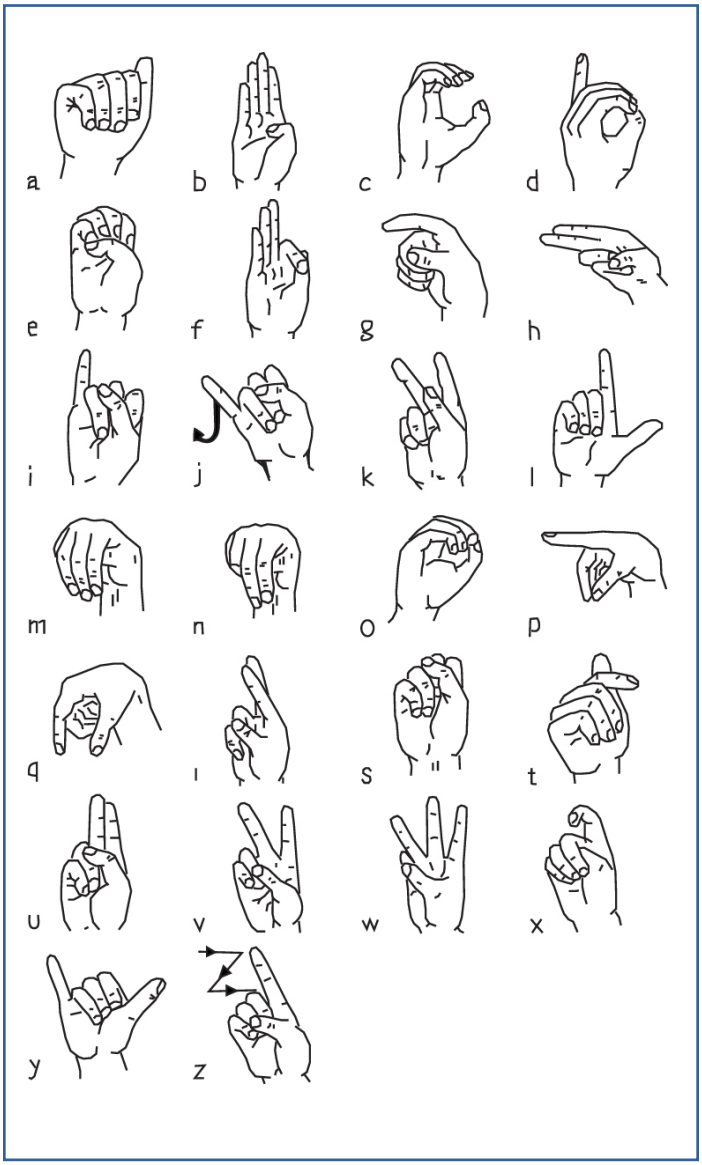
The exact beginnings of ASL are not clear, but some suggest that it arose more than 200 years ago from the intermixing of local sign languages and French Sign Language (LSF, or Langue des Signes Française). Today's ASL includes some elements of LSF plus the original local sign languages, which over the years have melded and changed into a rich, complex, and mature language. Modern ASL and modern LSF are distinct languages and, while they still contain some similar signs, can no longer be understood by each other's users.



A young boy signs "I love you."

How does ASL compare with spoken language?

In spoken language, words are produced by using the mouth and voice to make sounds. But for people who are deaf (particularly those who are profoundly deaf), the sounds of speech are often not heard, and only a fraction of speech sounds can be seen on the lips. Sign languages are based on the idea that vision is the most useful tool a deaf person has to communicate and receive information.



ASL is a language completely separate and distinct from English. It contains all the fundamental features of language—it has its own rules for pronunciation, word order, and complex grammar. While every language has ways of signaling different functions, such as asking a question rather than making a statement, languages differ in how this is done. For example, English speakers ask a question by raising the pitch of their voice; ASL users ask a question by raising their eyebrows, widening their eyes, and tilting their bodies forward.

Just as with other languages, specific ways of expressing ideas in ASL vary as much as ASL users do. In addition to individual differences in expression, ASL has regional accents and dialects. Just as certain English words are spoken differently in different parts of the country, ASL has regional variations in the rhythm of signing, form, and pronunciation. Ethnicity and age are a few more factors that affect ASL usage and contribute to its variety.

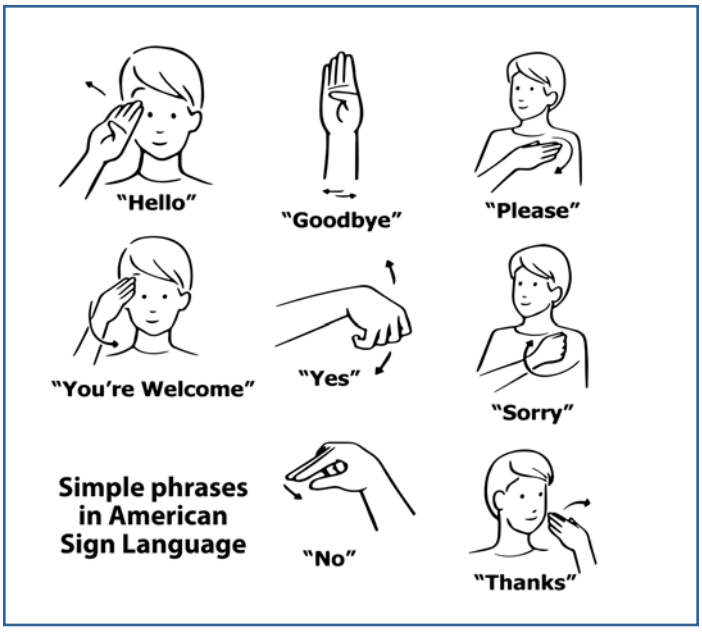
How do most children learn ASL?

Parents are often the source of a child's early acquisition of language, but for children who are deaf, additional people may be models for language acquisition. A deaf child born to parents who are deaf and who already use ASL will begin to acquire ASL as naturally as a hearing child picks up spoken language from hearing parents. However, for a deaf child with hearing parents who have no prior experience with ASL, language may be acquired differently. In fact, nine out of 10 children who are born deaf are born to parents who hear. Some hearing parents choose to introduce sign language to their deaf children. Hearing parents who choose to learn sign language often learn it along with their child. Surprisingly, children who are deaf can learn to sign quite fluently from their parents, even when their parents might not be perfectly fluent themselves.

Why emphasize early language learning?

Parents should introduce a child who is deaf or hard-of-hearing to language as soon as possible. The earlier any child is exposed to and begins to acquire language, the better that child's communication skills will become. Research suggests that the first few years of life are the most crucial to a child's development of language skills, and even the early months of life can be important for establishing successful communication. Thanks to screening programs in place at almost all hospitals in the United States and its territories, newborn babies are tested for hearing before they leave the hospital.

If a baby has hearing loss, this screening gives parents an opportunity to learn about communication options. Parents can then start their child's language learning process during this important early stage of development. For more information, see National Institute on Deafness and Other Communication Disorders (NIDCD) fact sheet "Communication Considerations for Parents of Deaf and Hard-of-Hearing Children" at *http://www.nidcd.nih.gov/health/hearing/pages/commopt.aspx.*



What research is being done on ASL and other sign languages?

The NIDCD supports research looking at whether children with cochlear implants become bilingual in spoken language and sign language in the same way that (or in different ways from how) hearing children become bilingual in both languages. This research will tell us more about how language development in children with cochlear implants might differ between hearing and nonhearing families and could offer important insights to help guide educational decisions and parent counseling.

An NIDCD-funded researcher is studying Al-Sayyid Bedouin Sign Language (ABSL), a sign language used over the past 75 years by both hearing and nonhearing people in an isolated Bedouin village in Israel. Because it was developed among a small group of people with little to no outside influence and no direct linguistic input, ABSL offers researchers the opportunity to document a new language as it develops and evolves. It can also be used to model the essential elements and organization of natural language.

Another NIDCD-funded research team is also looking at sign language systems that develop in isolation. The research team is learning more about how grammar is built and expanded in situations where there is little linguistic input. In one setting, they are observing "home sign" systems used by deaf children who live in isolation. In another, they are studying a family sign language that has been used and handed down over several generations on a remote fishing island.

National Institute on Deafness and Other Communication Disorders

Where can I find additional information about American Sign Language?

The NIDCD maintains a directory of organizations that provide information on the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language. Visit the NIDCD website at *http://www.nidcd.nih.gov* to search the directory.

Use the following keywords to help you find organizations that can answer questions and provide printed or electronic information on American Sign Language:

- American Sign Language
- Cued speech
- Deaf culture

More NIDCD fact sheets on Hearing and Balance:

- Assistive Devices for People with Hearing, Voice, Speech, or Language Disorders
- Cochlear Implants
- Hearing Aids
- It's Important to Have Your Baby's Hearing Screened
- What Are the Communication Considerations for Parents of Deaf and Hard-of-Hearing Children

Visit the NIDCD website at *http://www.nidcd.nih.gov* to read, print, or download fact sheets.

For more information, additional addresses and phone numbers, or a printed list of organizations, contact us at:

The NIDCD Information Clearinghouse
1 Communication Avenue
Bethesda, MD 20892-3456
Toll-free Voice: (800) 241-1044
Toll-free TTY: (800) 241-1055
Fax: (301) 770-8977
Email: nidcdinfo@nidcd.nih.gov

http://www.nidcd.nih.gov

Follow the NIDCD on Twitter at @NIDCD

The NIDCD supports and conducts research and research training on the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language and provides health information, based upon scientific discovery, to the public.

American Sign Language
NIH Publication No. 13-4756
Updated February 2014

ADHD
FACT SHEET

What is ADHD?

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common neurobehavioral disorders of childhood. It is sometimes referred to as Attention Deficit Disorder (ADD). It is usually first diagnosed in childhood and often lasts into adulthood. Children with ADHD may have trouble paying attention, controlling impulsive behaviors (may act without thinking about what the result will be), or be overly active.

What are some of the signs of ADHD?

Many children have trouble focusing and behaving at one time or another. However, children with ADHD do not just grow out of these behaviors. The symptoms continue and can cause difficulty at school, at home, or with friends.

A child with ADHD might:

- daydream a lot
- forget or loose things
- squirm or fidget
- talk too much
- make careless mistakes or take unnecessary risks
- have a hard time resisting temptation
- have trouble taking turns
- have difficulty getting along with others

Deciding if a child has ADHD is a several step process. There is no single test to diagnose ADHD, and many other disorders, like anxiety, depression, and certain types of learning disabilities, can have similar symptoms. One step of the process involves having a medical exam, including hearing and vision tests, to rule out other problems with symptoms like ADHD. Another part of the process may include a checklist for rating ADHD symptoms and taking a history of the child from parents, teachers, and sometimes, the child.

What can I do if I think my child may have ADHD?

Talk with your child's doctor or nurse. If you or your doctor has concerns about ADHD, you can take your child to a specialist such as a child psychologist or developmental pediatrician, or you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older).

CDC sponsors the National Resource Center, a program of CHADD – Children and Adults with Attention-Deficit/ Hyperactivity Disorder. Their website has links to information for people with ADHD and their families (www.help4adhd.org). The National Resource Center operates a call center with trained staff to answer questions about ADHD. The number is 1-800-233-4050.

To find out who to speak to in your area, you can contact the National Dissemination Center for Children with Disabilities by logging on to http://www.nichcy.org/ or calling 1-800-695-0285.

In order to make sure your child reaches his or her full potential, it is very important to get help for ADHD as early as possible

Additional Information:

www.cdc.gov/adhd
800-CDC-INFO, TTY: 888-232-6348; **cdcinfo@cdc.gov**

National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disability

alzheimer's association®

factsheet

MARCH 2014

alz.org

2014 Alzheimer's Disease Facts and Figures

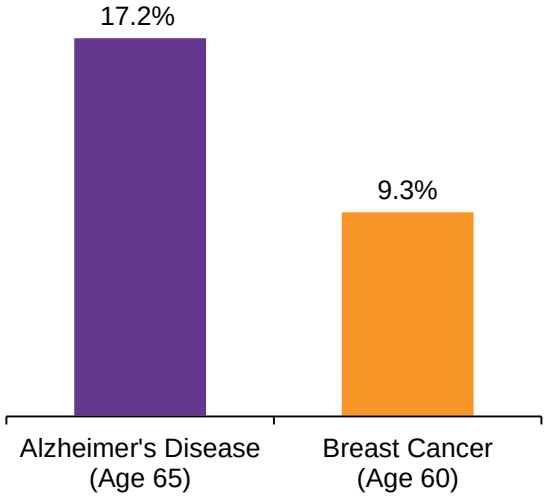
Women are at the epicenter of the Alzheimer's crisis.

- Nearly two-thirds of those with Alzheimer's disease – 3.2 million – are women.
- Women in their 60s are about twice as likely to develop Alzheimer's disease over the rest of their lives as they are to develop breast cancer.
- More than 3 in 5 unpaid Alzheimer's caregivers are women – and there are 2.5 more women than men who provide on-duty care 24-hours a day for someone with Alzheimer's.
- Among women caregivers who also work, 20 percent have gone from working full time to part time because of their caregiving duties.

All caregivers of people with Alzheimer's – both women and men – face a devastating toll.

- In 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at $220.2 billion.
- Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; more than one-third report symptoms of depression.
- Due to the physical and emotional toll of caregiving, Alzheimer's and dementia caregivers had $9.3 billion in additional health care costs of their own in 2013.

Remaining Lifetime Risk of Women Developing Alzheimer's Disease and Breast Cancer



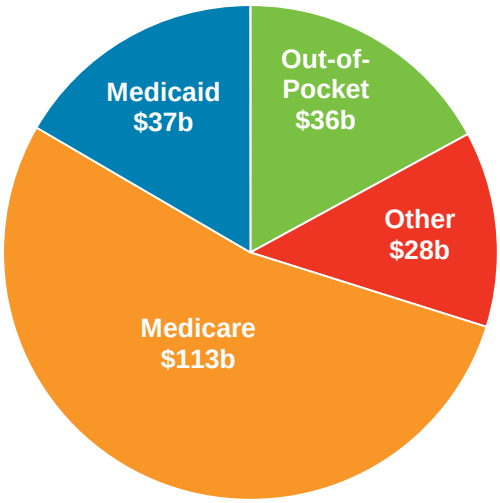
The number of Americans with Alzheimer's disease is growing – and growing fast.

- Today, over 5 million Americans are living with Alzheimer's disease, including an estimated 200,000 under the age of 65. By 2050, up to 16 million will have the disease.
- Of Americans aged 65 and older, 1 in 9 has Alzheimer's; 1 in 3 people aged 85 and older has the disease.
- Another American develops Alzheimer's disease every 67 seconds. In 2050, an American will develop the disease every 33 seconds.

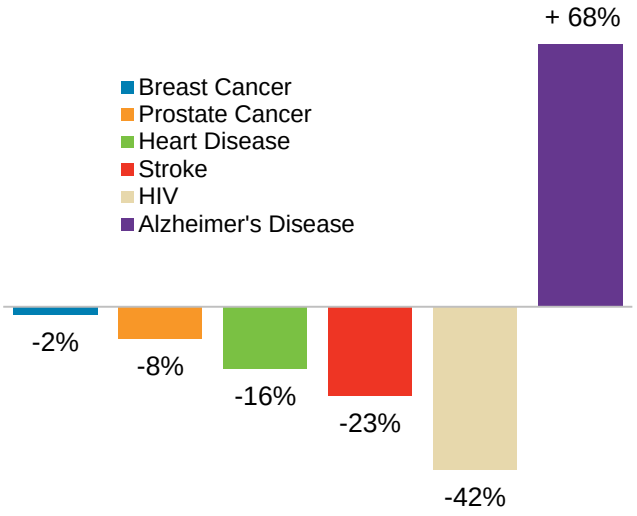
The growing Alzheimer's crisis is helping to bankrupt America.

- In 2014, the direct costs to American society of caring for those with Alzheimer's will total an estimated $214 billion, including $150 billion in costs to Medicare and Medicaid.
- Nearly one in every five dollars of Medicare spending is spent on people with Alzheimer's and other dementias.
- Average per-person Medicare spending for those with Alzheimer's and other dementias is three times higher than for those without these conditions.
- Average per-person Medicaid spending for seniors with Alzheimer's and other dementias is 19 times higher than average per-person Medicaid spending for all other seniors.
- Unless something is done, Alzheimer's will cost an estimated $1.2 trillion (in today's dollars) in 2050. Costs to Medicare and Medicaid will increase nearly 500 percent.

2014 Costs of Alzheimer's = $214 Billion



Change in Number of Deaths
Between 2000 and 2010



Alzheimer's is not just memory loss – Alzheimer's kills.

- In 2010, 83,494 Americans died from Alzheimer's, according to the official cause of death listed on death certificates. This makes Alzheimer's disease the 6th leading cause of death in the United States.
- In addition, in 2010, Alzheimer's played some role in the deaths of 500,000 Americans. And, in 2014, an estimated 700,000 people will die *with* the disease, meaning they will die after having developed it.
- Deaths from Alzheimer's increased 68 percent between 2000 and 2010, while deaths from other major diseases decreased.

Facts in Your State

The *2014 Alzheimer's Disease Facts and Figures* report also contains data on the impact of the disease in every state across the nation. Find the full report and information on your state at www.alz.org/facts.

Cerebral Palsy
FACT SHEET

What is cerebral palsy?

Cerebral means having to do with the brain. *Palsy* means weakness or problems with using the muscles. Cerebral palsy is a group of disorders that affect a person's ability to move and keep their balance and posture as a result of an injury to parts of the brain, or as a result of a problem with development. Often the problem happens before birth or soon after being born. Cerebral palsy causes different types of disabilities in each child. A child may simply be a little clumsy or awkward, or unable to walk at all.

What are some of the signs of cerebral palsy?

The signs of cerebral palsy vary greatly because there are many different types and levels of disability. The main sign that your child might have cerebral palsy is a delay reaching the motor or movement milestones. If you see any of these signs, call your child's doctor or nurse.

A child over 2 months with cerebral palsy might:
- have difficulty controlling head when picked up
- have stiff legs that cross or "scissor" when picked up

A child over 6 months with cerebral palsy might:
- continue to have a hard time controlling head when picked up
- reach with only one hand while keeping the other in a fist

A child over 10 months with cerebral palsy might:
- crawl by pushing off with one hand and leg while dragging the opposite hand and leg
- not sit by himself or herself

A child over 12 months with cerebral palsy might:
- not crawl
- not be able to stand with support

A child over 24 months with cerebral palsy might:
- not be able to walk
- not be able to push a toy with wheels

What causes cerebral palsy?

Cerebral palsy is caused by a problem in the brain that affects a child's ability to control his or her muscles. Problems in different parts of the brain cause problems in different parts of the body. There are many possible causes of problems, such as genetic conditions, problems with the blood supply to the brain before birth, infections, bleeding in the brain, lack of oxygen, severe jaundice, and head injury.

What can I do if I think my child might have cerebral palsy?

Talk with your child's doctor or nurse. If you or your doctor have concerns about cerebral palsy, you can seek the help of a specialist such as a developmental pediatrician or child neurologist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out who to speak to in your area, you can contact the National Dissemination Center for Children with Disabilities by logging on to **www.nichcy.org/states.htm**. In addition, the Centers for Disease Control and Prevention (CDC) has links to information for families (**www.cdc.gov/ncbddd**).

To help your child reach his or her full potential, it is very important to get help for him or her as early as possible!

www.cdc.gov/actearly

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

CDC
SAFER · HEALTHIER · PEOPLE™

Learn the Signs. Act Early.

Hoja informativa sobre la parálisis cerebral

¿Qué es la parálisis cerebral?

Cerebral significa que tiene relación con el cerebro. Parálisis (Palsy en inglés) significa debilidad o problemas al usar los músculos. La parálisis cerebral es un grupo de trastornos que afectan la capacidad de la persona para moverse, mantener el equilibrio y la postura, como resultado de una lesión en partes del cerebro o problemas del desarrollo. A menudo ocurre antes del nacimiento o poco después. La parálisis cerebral causa diferentes tipos de discapacidades en cada niño. Es posible que unos niños se tropiecen mucho y se les dificulte caminar, mientras que otros simplemente no pueden caminar.

¿Cuáles son algunos de los síntomas de la parálisis cerebral?

Los síntomas de la parálisis cerebral varían considerablemente ya que existen muchos tipos y niveles diferentes. El primer síntoma de que su hijo tiene parálisis cerebral es un retraso en alcanzar los indicadores importantes en el área motora o del movimiento. Si observa alguno de estos síntomas, llame al doctor o enfermera de su hijo.

Un niño de más de 2 meses con parálisis cerebral puede:

- tener dificultad para controlar la cabeza cuando es levantado
- tener piernas rígidas que se cruzan como tijeras cuando es levantado

Un niño de más de 6 meses con parálisis cerebral puede:

- seguir teniendo dificultad para controlar la cabeza cuando es levantado
- tratar de alcanzar las cosas con una sola mano mientras que la otra permanece empuñada

Un niño de más de 10 meses con parálisis cerebral puede:

- gatear empujándose con una pierna y un brazo mientras que arrastra la pierna y el brazo opuestos
- ser incapaz de sentarse por sí solo

Un niño de más de 12 meses con parálisis cerebral puede:

- no gatear
- ser incapaz de pararse con apoyo

Un niño de más de 24 meses con parálisis cerebral puede:

- no caminar
- ser incapaz de empujar juguetes con ruedas

¿Qué causa la parálisis cerebral?

La causa de la parálisis cerebral es un problema en el cerebro que afecta la capacidad del niño para controlar los músculos. Problemas en diferentes partes del cerebro causan problemas en diferentes partes del cuerpo. Existen muchas causas posibles como: condiciones genéticas, problemas con el suministro de sangre al cerebro antes del nacimiento, infecciones, hemorragias cerebrales, falta de oxígeno, ictericia aguda y lesiones en la cabeza.

¿Qué puedo hacer si creo que mi hijo puede tener parálisis cerebral?

Por favor hable con el médico o enfermera de su hijo. Si usted o su doctor temen que su hijo tenga parálisis cerebral, puede buscar la ayuda de un especialista tal como un pediatra especializado en el desarrollo o neurólogo infantil y puede llamar a su agencia local de intervención temprana (para niños menores de 3 años) o su escuela pública (para niños de 3 años o mayores). Para averiguar con quién hablar en su área, puede comunicarse con el Centro Nacional de Información sobre Niños y Jóvenes con Discapacidades (NICHCY por sus siglas en inglés) ya sea en la página de Internet **www.nichcy.org/states.htm**. Los Centros para el Control y la Prevención de Enfermedades (CDC por sus siglas en inglés) también tienen enlaces con información para las familias en el sitio electrónico **www.cdc.gov/ncbddd**.

¡Para que su hijo alcance su máximo potencial es de suma importancia conseguirle ayuda lo más pronto posible!

1-800-CDC-INFO www.cdc.gov/pronto

DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

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Aprenda los Signos. Reaccione Pronto.

Fetal Alcohol Spectrum Disorders
FACT SHEET

What are fetal alcohol spectrum disorders?

Fetal alcohol spectrum disorders (FASDs) is the name given to a group of conditions that a person can have if that person's mother drank alcohol while she was pregnant. These conditions include physical and intellectual disabilities, as well as problems with behavior and learning. Often, a person has a mix of these problems. FASDs are a leading known cause of intellectual disability and birth defects.

What causes FASDs and how can they be prevented?

FASDs are caused by a woman's drinking alcohol while she is pregnant. There is no known amount of alcohol that is safe to drink while pregnant. All drinks that contain alcohol can harm an unborn baby. There is no safe time to drink during pregnancy. Alcohol can harm a baby at any time during pregnancy. So, to prevent FASDs, a woman should not drink alcohol while she is pregnant, or even when she might get pregnant. FASDs are 100% preventable. If a woman doesn't drink alcohol while she is pregnant, her child will not have an FASD.

What are some signs of FASDs?

Signs of FASDs can be physical or intellectual. That means they can affect the mind or the body, or both. Because FASDs make up a group of disorders, people with FASDs can show a wide range and mix of signs.

Physical signs of FASDs can include abnormal facial features such as narrow eye openings and a smooth philtrum (the ridge between the upper lip and nose), small head size, short stature, and low body weight. Rarely, problems with the heart, kidneys, bones, or hearing might be present.

Intellectual and behavioral signs of FASDs might include problems with memory, judgment or impulse control, motor skills, academics (especially in math), paying attention, and low IQ. Specific learning disabilities are also possible.

What can I do if I think my child has an FASD?

Talk to your child's doctor or nurse. If you or the doctor thinks there could be a problem, ask to see a specialist (someone who knows about FASDs) such as a developmental pediatrician, child psychologist, or clinical geneticist. In some cities, there are clinics whose staffs have special training in recognizing and dealing with children with FASDs. Also contact your local early intervention agency (for children younger than 3 years of age) or local public school (for children 3 years of age or older). To find out who to call, contact the National Information Center for Children and Youth with Disabilities at **www.nichcy.org/states.htm** or by calling **1-800-695-0285**.

To learn more about FASDs, go to the Centers for Disease Control and Prevention (CDC) website at **www.cdc.gov/ncbddd/fas**, or the National Organization on Fetal Alcohol Syndrome at **www.nofas.org**.

To help your child reach his or her full potential, it is very important to get help for FASDs as early as possible!

www.cdc.gov/actearly

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Learn the Signs. Act Early.

Hoja informativa sobre los trastornos del espectro alcohólico fetal

¿Qué son los trastornos del espectro alcohólico fetal?

Trastornos del espectro alcohólico fetal (FASD, por sus siglas en inglés) es el nombre que se da a una serie de afecciones que una persona puede tener si su madre bebió alcohol mientras estuvo embarazada. Estas afecciones abarcan discapacidades tanto físicas como intelectuales, así como problemas de conducta y aprendizaje. Con frecuencia se presentan varios de estos problemas a la vez. Se sabe que los FASD constituyen una causa principal de discapacidad intelectual y de defectos congénitos.

¿Cuáles son las causas de los FASD y cómo se pueden prevenir?

Los FASD se presentan si la mujer toma alcohol mientras está embarazada. No se sabe de ninguna cantidad de alcohol que la madre pueda ingerir durante el embarazo sin que corra ningún riesgo. Cualquier bebida que contiene alcohol puede afectar al bebé que se está formando. No hay ningún momento en el embarazo en el cual se pueda beber sin correr riesgos, el alcohol puede perjudicar al bebé en cualquier etapa del embarazo. Por lo tanto, para prevenir los FASD, la mujer no debe beber alcohol ni durante el embarazo ni si piensa que podría quedar embarazada. Los FASD son totalmente prevenibles. Si la mujer no bebe alcohol mientras está embarazada, su bebé no tendrá ningún FASD.

¿Cuáles son los signos de los FASD?

Los signos de FASD pueden ser físicos o intelectuales, es decir, pueden afectar tanto la mente como el cuerpo, o ambos. Debido a que los FASD abarcan una serie de trastornos, las personas que los padecen pueden presentar una amplia variedad y combinación de signos.

Entre los signos físicos de los FASD pueden encontrarse rasgos faciales anormales, tales como una apertura pequeña de los ojos o surco nasolabial liso (espacio sin marca entre el labio superior y la nariz), cabeza pequeña, estatura baja y bajo peso corporal. En contados casos pueden presentarse problemas cardíacos, renales, óseos o auditivos.

Entre los signos intelectuales y de conducta que puede presentar una persona con FASD se encuentran problemas de memoria, de control de sus emociones e impulsos, de sus destrezas motoras y académicas (especialmente relacionadas con las matemáticas) y de atención así como un bajo coeficiente intelectual (CI). También es posible que se presenten problemas de aprendizaje.

¿Qué puedo hacer si creo que mi hijo tiene un FASD?

Hable con el médico o la enfermera de su hijo. Si usted o el médico sospechan que existe algún problema, pida una cita con un especialista (alguien que conozca a fondo de FASD), como un pediatra especializado en desarrollo, un psicólogo infantil o un genetista. En algunas ciudades, existen centros médicos que cuentan con personal especialmente capacitado para reconocer y tratar a niños con FASD. Además comuníquese con la agencia de intervención temprana (para niños de menos de tres años de edad) más cercana a su casa o con la escuela pública local (para niños de tres años de edad en adelante). Para saber a quién llamar, comuníquese con el *National Information Center for Children and Youth with Disabilities* (centro nacional de información sobre niños y jóvenes con discapacidades) a través de su sitio web **www.nichcy.org/states.htm** o llame al **1-800-695-0285**.

Para obtener más información sobre los FASD, visite el sitio web de los Centros para el Control y la Prevención de Enfermedades (CDC) **www.cdc.gov/ncbddd/fas** o el sitio web de la *National Organization on Fetal Alcohol Syndrome* (organización nacional sobre el síndrome alcohólico fetal) **www.nofas.org**.

Para ayudar a su hijo a alcanzar su potencial máximo, es importante que busque ayuda para tratar los FASD lo más pronto posible.

www.cdc.gov/pronto

Aprenda los signos. Reaccione pronto.

SPINA BIFIDA ASSOCIATION

SPINA BIFIDA

What is Spina Bifida?

Spina Bifida literally means "split spine." Spina Bifida happens when a baby is in the womb and the spinal column does not close all of the way. Spina Bifida is the most common birth defect that disables people for life. Every day, about eight babies born in the United States have Spina Bifida or a similar birth defect of the brain and spine.

What causes Spina Bifida?

No one knows for sure. Scientists believe that genetic and environmental factors act together to cause the condition.

Are there different types of Spina Bifida?

Yes. They are:

Occult Spinal Dysraphism (OSD)

Infants with this have a dimple in their lower back. Because most babies with dimples do not have OSD, a doctor has to check using special tools and tests to be sure. Other signs are red marks, tufts of hair or small lumps. In OSD, the spinal cord may not grow the right way and can cause serious problems as a child grows up. Infants who might have OSD should be seen by a doctor, who will recommend tests.

Spina Bifida Occulta

It is often called "hidden Spina Bifida" because about 15 percent of healthy people have it and do not know it. Spina Bifida occulta does not cause harm, has no signs and the spinal cord and nerves are fine. People usually find out they have it after having an X-ray of their back.

Meningocele

It causes part of the spinal cord to come through the spine like a sac that is pushed out. Nerve fluid is in the sac, and there is usually no nerve damage. Individuals with this condition may have minor disabilities.

Myelomeningocele (Meningomyelocele)

This is the most severe form of Spina Bifida. It happens when parts of the spinal cord and nerves come through the open part of the spine. It causes nerve damage and other disabilities. Seventy to ninety percent of children with this condition also have too much fluid on their brains. This happens because fluid that protects the brain and spinal cord is unable to drain like it should. The

fluid builds up, causing pressure and swelling. Without treatment, a person's head grows too big, and may have brain damage. Children who do not have Spina Bifida can also have this problem, so parents need to check with a doctor.

How is Spina Bifida Treated?

A child with meningomyelocele usually is operated on within two to three days of birth. This prevents infections and helps save the spinal cord from more damage.

A child with meningocele usually has it treated with surgery, and more often than not, the child is not paralyzed. Most children with this condition grow up fine, but they should be checked by a doctor because they could have other serious problems, too.

A child with OSD should see a surgeon. Most experts think that surgery is needed early to keep nerves and the brain from becoming more damaged as the child grows.

Spina Bifida occulta does not need to be treated.

What Can You Do to Prevent Spina Bifida?

Women who are old enough to have babies should take folic acid before and during the first three months of pregnancy. Because half of the pregnancies in the United States are unplanned, the Spina Bifida Association asks women to take a vitamin with 400 mcg (0.4 mg) of folic acid each day during the years of their lives when they are possibly able to have children. Women who have a child or sibling with Spina Bifida, have had an affected pregnancy or have Spina Bifida themselves should take 4000 mcg (4.0 mg) of folic acid for one to three months before and during the first three months of pregnancy.

What is Folic Acid?

Folic acid is a vitamin that the body needs to grow and be healthy. It is found in many foods, but the man-made or synthetic form in pills is actually better absorbed by our bodies.

What Conditions are Associated with Spina Bifida?

Children and young adults with Spina Bifida can have mental and social problems. They also can have problems with walking and getting around or going to the bathroom, latex allergy, obesity, skin breakdown, gastrointestinal disorders, learning disabilities, depression, tendonitis and sexual issues.

What Physical Limitations Exist?

People with Spina Bifida must learn how to get around on their own without help, by using things like crutches, braces or wheelchairs. With help, it also is possible for children to learn how to go to the bathroom on their own. Doctors, nurses, teachers and parents should know what a child can and cannot do so they can help the child (within the limits of safety and health) be independent, play with kids that are not disabled and to take care of him or herself.

Can Spina Bifida be Detected Before Birth?

Yes. There are three tests.

1. A blood test during the 16th to 18th weeks of pregnancy. This is called the alpha-fetoprotein (AFP screening test). This test is higher in about 75–80 % of women who have a fetus with Spina Bifida.

2. An ultrasound of the fetus. This is also called a sonogram and can show signs of Spina Bifida such as the open spine.

3. A test where a small amount of the fluid from the womb is taken through a thin needle. This is called maternal amniocentesis and can be used to look at protein levels.

Parents should know that no medical test is perfect, and these tests are not always right.

Can Children with Spina Bifida Grow Up and Live a Full Life?

Yes. With help, children with Spina Bifida can lead full lives. Most do well in school, and many play in sports. Because of today's medicine, about 90 percent of babies born with Spina Bifida now live to be adults, about 80 percent have normal intelligence and about 75 percent play sports and do other fun activities.

Fact Sheet Contributor:
Gregory S. Liptak, MD, MPH

Questions?
Call 800-621-3141
Web: *www.spinabifidaassociation.org*

This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.

Revised June 2008

Facts About Intellectual Disability

What is intellectual disability?

Intellectual disability, also known as mental retardation, is a term used when there are limits to a person's ability to learn at an expected level and function in daily life. Levels of intellectual disability vary greatly in children – from a very slight problem to a very severe problem. Children with intellectual disability might have a hard time letting others know their wants and needs, and taking care of themselves. Intellectual disability could cause a child to learn and develop more slowly than other children of the same age. It could take longer for a child with intellectual disability to learn to speak, walk, dress, or eat without help, and they could have trouble learning in school.

Intellectual disability can be caused by a problem that starts any time before a child turns 18 years old – even before birth. It can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual disability is not known. Some of the most common known causes of intellectual disability – like Down syndrome, fetal alcohol syndrome, fragile X syndrome, genetic conditions, birth defects, and infections – happen before birth. Others happen while a baby is being born or soon after birth. Still other causes of intellectual disability do not occur until a child is older; these might include serious head injury, stroke, or certain infections.

What are some of the signs of intellectual disability?

Usually, the more severe the degree of intellectual disability, the earlier the signs can be noticed. However, it might still be hard to tell how young children will be affected later in life.

There are many signs of intellectual disability. For example, children with intellectual disability may:

- sit up, crawl, or walk later than other children
- learn to talk later, or have trouble speaking
- find it hard to remember things
- have trouble understanding social rules
- have trouble seeing the results of their actions
- have trouble solving problems

What can I do if I think my child may have intellectual disability?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, you can take your child to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out who to speak to in your area, you can contact the National Dissemination Center for Children with Disabilities by logging on to www.nichcy.org/states.htm.

To help your child reach his or her full potential, it is very important to get help for him or her as early as possible!

1-800-CDC-INFO | www.cdc.gov/ncbddd

Hoja informativa sobre Discapacidad Intelectual

¿Qué es el discapacidad intelectual?

Discapacidad intelectual, también conocido como retraso mental, es un término utilizado cuando una persona no tiene la capacidad de aprender a niveles esperados y funcionar normalmente en la vida cotidiana. En los niños, los niveles de discapacidad intelectual varían ampliamente, desde problemas muy leves hasta problemas muy graves. Los niños con discapacidad intelectual puede que tengan dificultad para comunicar a otros lo que quieren o necesitan, así como para valerse por sí mismos. El discapacidad intelectual podría hacer que el niño aprenda y se desarrolle de una forma más lenta que otros niños de la misma edad. Estos niños podrían necesitar más tiempo para aprender a hablar, caminar, vestirse o comer sin ayuda y también podrían tener problemas de aprendizaje en la escuela.

El discapacidad intelectual puede ser la consecuencia de un problema que comienza antes de que el niño nazca hasta que llegue a los 18 años de edad. La causa puede ser una lesión, enfermedad o un problema en el cerebro. En muchos niños no se conoce la causa del discapacidad intelectual. Algunas de las causas más frecuentes del discapacidad intelectual, como el síndrome de Down, el síndrome alcohólico fetal, el síndrome X frágil, afecciones genéticas, defectos congénitos e infecciones, ocurren antes del nacimiento. Otras causas ocurren durante el parto o poco después del nacimiento. En otros casos, las causas del discapacidad intelectual no se presentan sino hasta cuando el niño es mayor, tales como lesiones graves de la cabeza, accidentes cerebro-vasculares o ciertas infecciones.

¿Cuáles son algunos signos del discapacidad intelectual?

Por lo general, mientras más grave sea el grado de discapacidad intelectual, más temprano se identificarán los síntomas. Sin embargo, podría ser difícil indicar la manera como el discapacidad intelectual afectará a los niños más tarde en la vida. Hay muchos síntomas de discapacidad intelectual. Por ejemplo, los niños con discapacidad intelectual puede que:

- se sienten, gateen o caminen más tarde que otros niños
- aprendan a hablar más tarde o tener problemas para hablar
- tengan dificultad para recordar cosas
- tengan problemas para entender las reglas sociales
- tengan dificultad para ver las consecuencias de sus acciones
- tengan dificultad para resolver problemas

¿Qué puedo hacer si creo que mi hijo tiene discapacidad intelectual?

Por favor hable con el médico o enfermera de su hijo. Si usted o su doctor piensan que podría existir algún problema, puede llevar a su hijo a un pediatra especializado en desarrollo u otro especialista; también puede llamar a su agencia local de intervención temprana (para niños menores de 3 años) o su escuela pública (para niños de 3 años o más). Para averiguar con quién hablar en su área, puede comunicarse con el Centro Nacional de Diseminación de Información para Niños con Discapacidades (NICHCY, por sus siglas en inglés) ya sea a través de su sitio web **www.nichcy.org/states.htm**.

¡Para ayudar a su hijo a alcanzar su máximo potencial, es de suma importancia conseguirle ayuda lo más pronto posible!

1-800-CDC-INFO | www.cdc.gov/ncbddd/defaultspan.htm

Facts About Fragile X Syndrome

What is fragile X syndrome?

Fragile X syndrome (FXS) is the most common known cause of intellectual disability (formerly referred to as mental retardation) that can be inherited, that is passed from parent to child. It is estimated that FXS affects about 1 in 4,000 boys and 1 in 6,000 to 8,000 girls. Both boys and girls can have FXS, but girls usually are more mildly affected.

What causes FXS?

The cause of FXS is genetic. FXS occurs when there is a change in a gene on the X chromosome called FMR1. The FMR1 gene makes a protein needed for normal brain development. In FXS, the FMR1 gene does not work properly. The protein is not made, and the brain does not develop as it should. The lack of this protein causes FXS. Other Fragile X-associated Disorders (FXDs) can be present in the extended family, even if not currently evident. Talk with a genetic counselor for more information.

What are some signs of FXS?

Children with FXS might:

- Sit up, crawl, or walk later than other children
- Have trouble with learning and solving problems
- Learn to talk later, or have trouble speaking
- Become very anxious in crowds and new situations
- Be sensitive about someone touching them
- Bite or flap their hands
- Have trouble making eye contact
- Have a short attention span
- Be in constant motion and unable to sit still
- Have seizures

Some children with FXS have certain physical features such as:

- A large head
- A long face
- Prominent ears, chin, and forehead
- Flexible joints
- Flat feet
- Macroorchidism (enlarged testicles in males; more obvious after puberty)

These physical features tend to become more noticeable as the child gets older.

What conditions are common among children with FXS?

Children with FXS might have learning disabilities, speech and language delays, and behavioral problems such as attention-deficit/hyperactivity disorder (ADHD) and anxiety. Some boys can develop aggressive behavior. Depression can also occur. Boys with FXS usually have a mild to severe intellectual disability. Many girls with FXS have normal intelligence. Others have some degree of intellectual disability, with or without learning disabilities. Autism spectrum disorder (ASD) occurs more often among children with FXS.

What can I do if I think my child has FXS?

Talk with your child's doctor or nurse. If you or your doctor thinks there could be a problem, the doctor can order a blood test for FXS or refer you to a developmental specialist or geneticist, or both. Also, contact your local early intervention agency (for children younger than 3 years of age) or public school (for children 3 years of age or older) to find out if your child qualifies for intervention services. To find out whom to call in your area, contact the Center for Parent Information and Resources at **www.parentcenterhub.org/find-your-center/**.

In addition, CDC has links to information for families at **www.cdc.gov/fragilex**.

Additional resources include the National Fragile X Foundation **(www.fragilex.org)** and the FRAXA Research Foundation **(www.FRAXA.org)**. CDC also supports the efforts of the Fragile X Clinical & Research Consortium **(www.FXCRC.org)** which can be reached through the National Fragile X Foundation.

While there is no cure for fragile X syndrome, therapies and interventions can improve the lives of those affected and of their families. It is **very** important to begin these therapies and

Interventions as early as possible to help your child reach his or her full potential. Acting early can make a real difference!

1-800-CDC-INFO | www.cdc.gov/fragilex

National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disability

Hoja informativa sobre el síndrome del cromosoma X frágil

¿Qué es el síndrome del cromosoma X frágil?

El síndrome del cromosoma X frágil (FXS) es la causa hereditaria, es decir que se pasa de padres a hijos, más frecuente de discapacidad intelectual (conocida previamente como retraso mental). Se estima que el síndrome del cromosoma X frágil afecta a aproximadamente 1 de 4,000 niños y 1 de 6,000 a 8,000 niñas. Tanto los niños como las niñas pueden presentar este síndrome pero por lo general afecta un poco más a las niñas.

¿Qué causa el síndrome del cromosoma X frágil?

La causa del síndrome del cromosoma X frágil es genética. Ocurre cuando hay un cambio en un gen en el cromosoma X llamado FMR1. El gen FMR1 produce una proteína necesaria para el desarrollo normal del cerebro. Con el síndrome del cromosoma X frágil, el gen FMR1 no funciona de manera adecuada y al no producir esta proteína, el cerebro no funciona como debería. La falta de esta proteína causa el síndrome del cromosoma X frágil.Aunque en el presente no se note, otros trastornos asociados con el síndrome del cromosoma X-frágil pueden estar presentes en miembros de la familia extendida. Hable con un consejero genético para obtener más información.

¿Cuáles son algunos de los signos del síndrome del cromosoma X frágil?

Los niños con el síndrome del cromosoma X frágil podrían:

- Sentarse, gatear o caminar más tarde que otros niños
- Tener problemas de aprendizaje o al resolver problemas
- Aprender a hablar más tarde o tener dificultad en el habla
- Sentirse ansiosos en las multitudes y frente a nuevas situaciones
- Ponerse muy sensibles cuando alguien los toca
- Morderse o aletear las manos
- Tener dificultad para hacer contacto visual
- Tener un periodo de atención corto
- Estar en constante movimiento y no poder sentarse quietos
- Tener convulsiones

Algunos niños con el síndrome del cromosoma X frágil tienen ciertas características físicas tales como:

- cabeza grande
- cara larga
- orejas, mentón y frente prominentes
- articulaciones flexibles
- pie plano
- macroorquidismo (aumento del tamaño de los testículos en los varones; más evidente después de la pubertad)

Estas características físicas tienden a ser más visibles conforme el niño va creciendo.

¿Qué afecciones son más comunes entre los niños con síndrome del cromosoma X frágil?

Los niños con el síndrome del cromosoma X frágil pueden tener problemas de aprendizaje, retrasos en el habla y el lenguaje y problemas de comportamiento como el trastorno de déficit de atención e hiperactividad (ADHD, por sus siglas en inglés) y ansiedad. Algunos niños pueden exhibir conductas agresivas. También pueden presentar depresión. Los niños con el síndrome del cromosoma X frágil por lo general padecen de discapacidad intelectual que oscila entre leve y grave. Muchas niñas con este síndrome tienen una inteligencia normal. Otras tienen un cierto grado de discapacidad intelectual con o sin problemas de aprendizaje. Los trastornos del espectro autista (TEA) ocurren con más frecuencia en niños que tienen el síndrome del cromosoma X frágil.

¿Qué puedo hacer si creo que mi hijo tiene el síndrome del cromosoma X frágil?

Hable con el médico o la enfermera de su hijo. Si usted o su médico cree que puede haber un problema, el médico puede ordenar un análisis de sangre para determinar si tiene el síndrome del cromosoma X frágil o puede remitirlo a un especialista en el desarrollo o genetista o a ambos. Además, comuníquese con la agencia de intervención temprana (para niños menores de tres años de edad) local o con la escuela pública (para niños de tres años de edad o más) para averiguar si su hijo reúne los requisitos para recibir servicios de intervención. Para saber a quién puede llamar en su localidad, comuníquese con el Centro Nacional de Información sobre Niños y Jóvenes con Discapacidades (National Information Center for Children and Youth with Disabilities) a través de su sitio web **www.nichcy.org/states.htm** o en el teléfono **1-800-695-0285**.

También, los Centros para el Control y la Prevención de Enfermedades (CDC) tienen enlaces a páginas con información para las familias en **www.cdc.gov/ncbddd/single_gene/fragilex.htm**.

Otros recursos disponibles incluyen la Fundación Nacional del Síndrome del Cromosoma X Frágil (National Fragile X Foundation [**www.fragilex.org**]) y la Fundación para la Investigación del Síndrome del Cromosoma X Frágil (FRAXA Research Foundation [**www.FRAXA.org**]). Los CDC también apoyan los esfuerzos del Consorcio de Clínicas e Investigación del Síndrome del Cromosoma X Frágil (Fragile X Clinical & Research Consortium [**www.FXCRC.org**]) que se puede contactar a través de la Fundación Nacional del Síndrome del Cromosoma X Frágil.

Aunque no hay cura para el síndrome del cromosoma X frágil, las terapias y las intervenciones pueden mejorar la vida de los niños afectados por este síndrome y la de sus familias. Es **muy** importante empezar estas terapias e intervenciones tan pronto sea posible para ayudar al niño a alcanzar su máximo potencial. ¡Actuar rápido puede hacer una gran diferencia!

1-800-CDC-INFO | www.cdc.gov/ncbddd/spanish/fxs/index

Victimization of Persons with Traumatic Brain Injury or Other Disabilities:

A Fact Sheet for Professionals

What is victimization?

According to the U.S. Department of Justice (2004), victimization occurs when "…a person suffers direct or threatened physical, emotional, and/or financial harm." Victimization can include physical violence, sexual violence, psychological or emotional abuse, and neglect. The Centers for Disease Control and Prevention (CDC) acknowledges such victimization as a serious and preventable public health problem.

- **Physical violence** is "the intentional use of physical force with the potential for causing death, disability, injury, or harm."(Rosenberg and Mercy 1991; CDC 2006) It includes, but is not limited to, "scratching, pushing, shoving, throwing, grabbing, biting choking, shaking, slapping, punching, burning, use of a weapon, and use of restraints or one's body, size, or strength against another person."(CDC 2006)

- **Sexual violence** is "the use of physical force to compel a person to engage in a sexual act against his or her will, whether or not the act is completed; an attempted or completed sex act involving a person who is unable to understand the nature or condition of the act, to decline participation, or to communicate unwillingness to engage in the sexual act; and abusive sexual contact." (CDC 2004)

- **Emotional abuse** occurs when a person is "threatened, terrorized, or severely rejected, ignored, or verbally attacked."(Nosek et al. 2001) It includes, but is not limited to, "episodes of yelling, threats, or acts meant to humiliate or hurt feelings." (Curry et al. 2003)

- **Neglect** is a "situation in which the basic needs of a person (such as food, clothing, hygiene, protection, or medical care) are temporarily or permanently not met."(Verdugo and Bermejo 1997) It includes, but is not limited to, "preventing a person with disabilities from using a wheelchair, cane, respirator, or other assistive devices as well as failure to address basic needs for food, clothing, shelter, or hygiene."(McFarlane et al. 2001)

What is the extent of the problem?

Current knowledge about victimization of persons with disabilities is based on a small number of studies, and little is known about victimization of important groups such as persons with traumatic brain injury (TBI) (Marge 2003).

- Persons with disabilities are 4 to 10 times more likely to become a victim of violence, abuse, or neglect than persons without disabilities (Petersilia 2001).
- Children with disabilities are more than twice as likely to be physically or sexually abused as children without disabilities (Petersilia 2001; Sobsey and Mansell 1994).
- Similar proportions of women with and without disabilities report having experienced episodes of physical violence, sexual violence, or emotional abuse (Sobsey and Mansell 1994). Women with disabilities, however, report greater numbers of perpetrators and longer time periods of individual episodes than women without disabilities (Young et al. 1997).

Where does victimization occur?

- Victimization can occur anywhere; however, it usually happens in isolated locations where a person with disabilities has little or no control of the environment (Sobsey and Mansell 1994), and the setting is away from the view of law enforcement (Verdugo and Mermejo 1997).
- Institutional settings are risk locations for persons with disabilities because multiple episodes of physical and sexual violence, emotional abuse, neglect, or violence may be committed against them by staff or other residents and yet go undetected or unreported (Sobsey and Mansell 1994; Brown and Turk 1994; Turk and Brown 1993).

Who commits acts of victimization?

- More men than women, either as intimate partners or as health care workers (Brown and Turk 1994; Marley and Buila 2001), are reported to commit acts of physical violence, sexual violence, emotional abuse, or neglect against persons with disabilities.
- Family members have been reported to commit crimes of victimization while caring for a relative with disabilities (Milberger et al. 2003; Stromsness 1993).
- Personal home care attendants (Oktay and Tompkins 2004; Saxton et al. 2001) or health care workers at institutions (Brown and Turk 1994; Sequeira and Halstead 2001) have been reported to perpetrate emotional abuse and sexual violence against persons with disabilities.
- In institutional settings, persons with disabilities may commit acts of physical violence or sexual violence against other persons with disabilities (Sobsey and Doe 1991).

What factors make a person with disabilities susceptible to victimization?

Societal Factors:

- Misperceptions about disability include “having a disability protects a person from victimization”; the risks to a person with disabilities are thought to be less than the risks to a person who has none (Young et al. 1997).
- Unemployment or underemployment of persons with disabilities restricts their income and limits their choices for caregivers, leading to an increased risk of physical and sexual violence, emotional abuse, or neglect (Stromsness 1993).
- Lack of money often causes persons with disabilities to live in areas where crime rates are high and the potential for physical and sexual violence is greater than in wealthier neighborhoods (Curry et al. 2001).

Community Factors:

- Community resources for victims of physical and sexual violence, emotional abuse, or neglect are usually designed to assist people without disabilities (Swedlund and Nosek 2000; Chang et al. 2003; Cramer et al. 2003). Organizations that provide such resources do not routinely collaborate with organizations that assist persons with disabilities (Curry et al. 2001; Swedlund and Nosek 2000; Chang et al. 2003).
- Frequently, health care (Swedlund and Nosek 2000; Chang et al. 2003; Cramer et al. 2003) and law enforcement (DOJ 1998) professionals are uninformed about victimization of persons with disabilities. Thus, they may not have the specialized knowledge or skills to identify and assist these individuals when victimized.

What factors make a person with a traumatic brain injury, or TBI, susceptible to victimization?

Relationship Factors:

- Persons living with a TBI often have difficulty with anger management, which may prompt others to use undue physical force or inappropriate medication (Kim 2002).
- Misperceptions about TBI and its effects may lead to treatment that is demeaning or abusive (Sequeira and Halsted 2001).
- TBI outcomes affect others' perceptions of a person's ability to honestly and accurately report an incident of victimization (DOJ 1998).
- Persons with TBI or other disabilities may experience physical and sexual violence, emotional abuse, or neglect by a caregiver in return for access to medication, adaptive equipment, or assistance with activities of daily life (Oktay and Tompkins 2004).

Individual Factors:

- A TBI can cause cognitive problems that reduce one's ability to perceive, remember, or understand risky situations that could lead to an incident of physical or sexual violence (Kim 2002; Levin 1999).
- Persons with a TBI may engage in at-risk drinking or drug use that place them in situations or relationships that lead to episodes of victimization (Kwasnica and Heinemann 1994; Li et al. 2000).
- In some persons, a TBI causes uninhibited behaviors that lead to risky sexual engagement, exposing them to HIV/AIDS or other sexually transmitted diseases (Jaffe et al. 2000; Kramer et al. 1993).

Information and Support

Brain Injury Association of America At the national and state level, the Association serves as a clearinghouse for community service information for persons with TBI, their families, and sponsors of educational programs.	800-444-6443	www.biausa.org
Defense and Veterans Brain Injury Center Serves active-duty military personnel and veterans who acquired TBI in the line of duty; provides medical care and educational programs for them and their dependents.	800-870-9244 662-6345 (DSN)	www.dvbic.org
National Disability Rights Network Voluntary association of protection and advocacy systems and client-assistance programs. Promotes rigorous enforcement of laws protecting the civil and human rights of persons with disabilities, including those with TBI.	202-408-9514 202-408-9521 (TTY)	www.ndm.org
National Domestic Violence Hotline Provides information and advice about domestic violence; makes referrals to local resources and shelters.	800-799-SAFE 800-787-3224 (TTY)	www.ndvh.org

References

1. Brown H, Turk V. Sexual abuse in adulthood: ongoing risks for people with learning disabilities. *Child Abuse Review* 1994;3(1):26–35.

2. Chang JC, Martin SL, Moracco KE, Dulli L, Scandlin D, Loucks-Sorrel MB, et al. Helping women with disabilities and domestic violence: strategies, limitations, and challenges of domestic violence programs and services. *Journal of Women's Health* 2003;12(7):699–708.

3. Cramer EP, Gilson SF, DePoy E. Women with disabilities and experiences of abuse. *Journal of Human Behavior in the Social Environment* 2003;7(3–4):183–199.

4. Curry MAA, Hassouneh-Phillips D, Johnston-Silverberg A. Abuse of women with disabilities: an ecological model and review. *Violence Against Women* 2001;7(1):60–79.

5. Curry MA, Powers LE, Oschwald M. Development of an abuse screening tool for women with disabilities. *Journal of Aggression, Maltreatment & Trauma* 2003;8(4):123–41.

6. Department of Health and Human Services (US), Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Intimate partner violence: overview [online]. 2006 [cited 2006 Apr 19]. Available from: URL: www.cdc.gov/ncipc/factsheets/ipvoverview.htm.

7. Department of Health and Human Services (US), Centers for Disease Control and Prevention, National Center for Injury Prevention and Control. Uniform definitions for sexual violence [online]. 2004 [cited 2006 Apr 18]. Available from: URL: www.cdc.gov/ncipc/pubres/sv_surveillance/04_uniform_definitions.htm.

8. Department of Justice (DOJ) (US) , Office of Justice Programs, Office of Victims of Crime. Overview of victimology [online]. 2004 [cited 2005 Nov 9]. Available from: URL: from www.ojp.usdoj.gov/ovc/assist/nvaa/ch03.htm.

9. Department of Justice (DOJ) (US), Office of Justice Programs, Office for Victims of Crime. Working with victims of crime and disabilities. Washington (DC): Government Printing Office; 1998. OVC Bulletin No.:1. p. 1–15.

10. Jaffe MP, O'Neill J, Vandergoot D, Gordon WA, Small B. The unveiling of traumatic brain injury in an HIV/AIDS population. *Brain Injury* 2000;14(1):35–44.

11. Kim E. Agitation, aggression, and disinhibition syndromes after traumatic brain injury. *Neurorehabilitation* 2002;17(4):297–310.

12. Kramer TH, Nelson DF, Li PW. AIDS knowledge and risk behaviors among traumatic brain injury survivors with coexisting substance abuse. *Brain Injury* 1993;7(3):209–17.

13. Kwasnica CM, Heinemann A. Coping with traumatic brain injury: representative case studies. *Archives of Physical Medicine & Rehabilitation* 1994;75(4):384–9.

14. Levin HS. Neurocognitive/behavioral outcomes in children and adults. In: Ragnarsson KT, editor. Report of the NIH consensus development conference on the rehabilitation of persons with traumatic brain injury. Washington (DC): Department of Health and Human Services (US), Public Health Service, National Institutes of Health; 1999. p. 49–54.

15. Li L, Ford JA, Moore D. An exploratory study of violence, substance abuse, disability, and gender. *Social Behavior & Personality* 2000;28(1):61–71.

16. Marge K. Introduction to violence and disability. In: Marge K, editor. A call to action: Ending crimes of violence against children and adults with disabilities, a report to the nation. Syracuse: State University of New York, Upstate Medical University; 2003. p. 1-16.

17. Marley JA, Buila S. Crimes against people with mental illness: types, perpetrators, and influencing factors. *Social Work* 2001;46(2):115–24.

18. McFarlane J, Hughes RB, Nosek MA, Groff JY, Swedlend N, Dolan Mullen P. Abuse assessment screen-disability (AAS-D): measuring frequency, type, and perpetrator of abuse toward women with physical disabilities. *Journal of Womens Health & Gender-Based Medicine* 2001;10(9):861–6.

19. Milberger S, Israel N, LeRoy B, Martin A. Violence against women with physical disabilities. *Violence and Victims* 2003;18(5):581–91.

20. Nosek MA, Howland CA, Hughes RB. The investigation of abuse and women with disabilities: going beyond assumptions. *Violence Against Women* 2001;7(4):477–99.

21. Oktay JS, Tompkins CJ. Personal assistance providers' mistreatment of disabled adults. *Health & Social Work* 2004;29(3):177–88.

22. Petersilia JR. Crime victims with developmental disabilities: a review essay. *Criminal Justice & Behavior* 2001;28(6):655–94.

23. Rosenberg, ML, Mercy JA. Assaultive violence. In: Rosenberg ML, Fenley MA, editors. Violence in America. New York and Oxford: Oxford University Press; 1991. p. 14–50.

24. Saxton M, Curry MA, Powers LE, Maley S, Eckels K, Gross J. "Bring my scooter so I can leave you": a study of disabled women handling abuse by personal assistance providers. *Violence Against Women* 2001;7(4):393–417.

25. Sequeira H, Halstead S. "Is it meant to hurt, is it?": management of violence in women with developmental disabilities. *Violence Against Women* 2001;7(4):462–76.

26. Sobsey D, Doe T. Patterns of sexual abuse and assault. *Sexuality & Disability* 1991;9(3):243–59.

27. Sobsey D, Mansell S. An international perspective on patterns of sexual assault and abuse of people with disabilities. *International Journal of Adolescent Medicine & Health* 1994;7(2):153–78.

28. Swedlund NP, Nosek MA. An exploratory study on the work of independent living centers to address abuse of women with disabilities. *Journal of Rehabilitation* 2000;66(4):57–64.

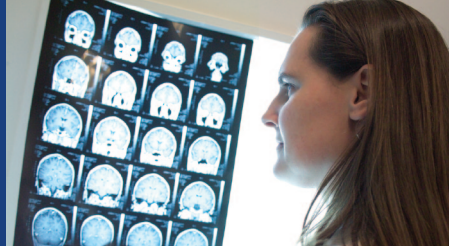
29. Stromsness MM. Sexually abused women with mental retardation: hidden victims, absent resources. *Women & Therapy* 1993;14(3–4):139–52.

30. Turk V, Brown H. The sexual abuse of adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research* 1993;6(3):193–216.

31. Verdugo M, Bermejo B. The mentally retarded person as a victim of maltreatment. *Aggression & Violent Behavior* 1997;2(2):143–65.

32. Young ME, Nosek MA, Howland C, Chanpong G, Rintala DH. Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine & Rehabilitation* 1997;78(12 Suppl 5):S34–8.

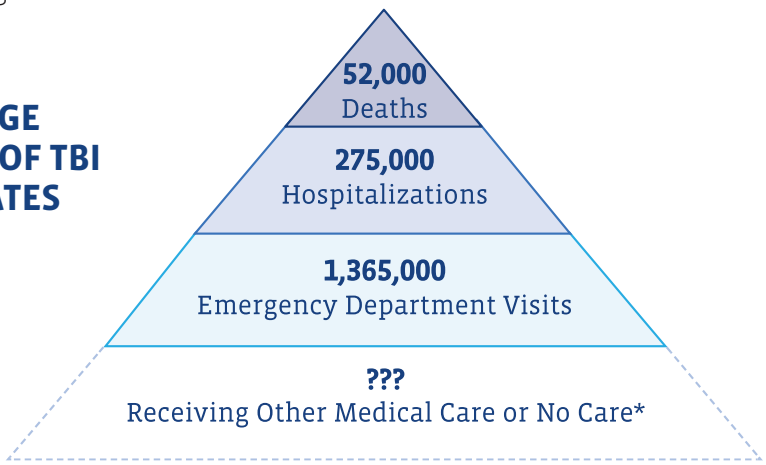
Get the Stats on Traumatic Brain Injury in the United States



Each year, traumatic brain injuries (TBI) contribute to a substantial number of deaths and cases of permanent disability. A TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. The severity of a TBI may range from "mild" to "severe".

Data are critical to understanding the impact of this important public health problem. This information can help inform TBI prevention strategies, identify research and education priorities, and support the need for services among those living with a TBI.

ESTIMATED AVERAGE ANNUAL NUMBER OF TBI IN THE UNITED STATES 2002–2006[1]



* There is no estimate for the number of people with non-fatal TBI seen outside of an emergency department or hospital or who receive no care at all.

TBI in the United States

- An estimated 1.7 million people sustain a TBI annually.[1] Of them:
  - 52,000 die,
  - 275,000 are hospitalized, and
  - 1.365 million, nearly 80%, are treated and released from an emergency department.
- TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States.[1]
- About 75% of TBIs that occur each year are concussions or other forms of mild traumatic brain injury (MTBI).[2]
- Direct medical costs and indirect costs of TBI, such as lost productivity, totaled an estimated $60 billion in the United States in 2000.[3]

TBI by Age[1]

- Children aged 0 to 4 years, older adolescents aged 15 to 19 years, and adults aged 65 years and older are most likely to sustain a TBI.
- Almost half a million (473,947) emergency department visits for TBI are made annually by children aged 0 to 14 years.
- Adults aged 75 years and older have the highest rates of TBI-related hospitalization and death.

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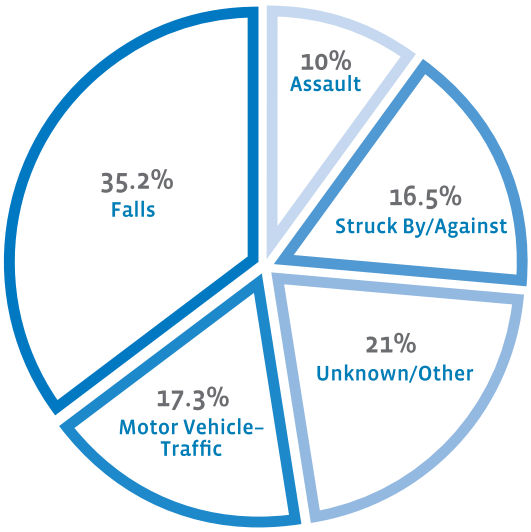
TBI by Sex[1]

- In every age group, TBI rates are higher for males than for females.
- Males aged 0 to 4 years have the highest rates of TBI-related emergency department visits, hospitalizations, and deaths combined.

TBI by External Cause[1]

- Falls are the leading cause of TBI. Rates are highest for children aged 0 to 4 years and for adults aged 75 years and older.
- Falls result in the greatest number of TBI-related emergency department visits (523,043) and hospitalizations (62,334).
- Motor vehicle–traffic injury is the leading cause of TBI-related death. Rates are highest for adults aged 20 to 24 years.

ESTIMATED AVERAGE PERCENTAGE OF ANNUAL TBI BY EXTERNAL CAUSE IN THE UNITED STATES 2002–2006[1]



Additional TBI Findings[1,*]

- There was an increase in TBI-related emergency department visits (14.4%) and hospitalizations (19.5%) from 2002 to 2006.
- There was a 62% increase in fall-related TBI seen in emergency departments among children aged 14 years and younger from 2002 to 2006.
- There was an increase in fall-related TBI among adults aged 65 and older; 46% increase in emergency department visits, 34% increase in hospitalizations, and 27% increase in TBI-related deaths from 2002 to 2006.

* Estimates based on one year of data can produce varied results.

CDC analyzed existing national data sets for its report, *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002–2006*. CDC's National Center for Injury Prevention and Control funds 30 states to conduct TBI surveillance through the CORE State Injury Program. TBI-related death and hospitalization data submitted by participating CORE states are published in CDC's *State Injury Indicators Report*.

References

[1] Faul M, Xu L, Wald MM, Coronado VG. *Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002–2006*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2010.

[2] *Report to Congress on Mild Traumatic Brain Injury in the United States: Steps to Prevent a Serious Public Health Problem*. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2003.

[3] Finkelstein E, Corso P, Miller T and Associates. *The Incidence and Economic Burden of Injuries in the United States*. New York (NY): Oxford University Press; 2006.

Get More Information on TBI in the United States

For more on TBI research, programs, and educational initiatives please visit: www.cdc.gov/TraumaticBrainInjury

Facts about Concussion and Brain Injury

About Concussion

A concussion is a type of traumatic brain injury (TBI) caused by a bump, blow, or jolt to the head. Concussions can also occur from a fall or a blow to the body that causes the head and brain to move quickly back and forth. Doctors may describe a concussion as a "mild" brain injury because concussions are usually not life-threatening. Even so, their effects can be serious.

Concussion Signs and Symptoms

Most people with a concussion recover quickly and fully. But for some people, symptoms can last for days, weeks, or longer. In general, recovery may be slower among older adults, young children, and teens. Those who have had a concussion in the past are also at risk of having another one and may find that it takes longer to recover if they have another concussion. Symptoms of concussion usually fall into four categories:

Thinking/Remembering	Difficulty thinking clearly	Feeling slowed down	Difficulty concentrating	Difficulty remembering new information
Physical	Headache Fuzzy or blurry vision	Nausea or vomiting (early on) Dizziness	Sensitivity to noise or light Balance problems	Feeling tired, having no energy
Emotional/Mood	Irritability	Sadness	More emotional	Nervousness or anxiety
Sleep	Sleeping more than usual	Sleep less than usual	Trouble falling asleep	

Getting Better

Rest is very important after a concussion because it helps the brain to heal. Ignoring your symptoms and trying to "tough it out" often makes symptoms worse. Be patient because healing takes time. Only when your symptoms have reduced significantly, in consultation with your doctor, should you slowly and gradually return to your daily activities, such as work or school. If your symptoms come back or you get new symptoms as you become more active, this is a sign that you are pushing yourself too hard. Stop these activities and take more time to rest and recover. As the days go by, you can expect to gradually feel better.

Tips to help you get better:

- Get plenty of sleep at night, and rest during the day.
- Avoid activities that are physically demanding (e.g., sports, heavy housecleaning, working-out) or require a lot of concentration (e.g., sustained computer use, video games).
- Ask your doctor when you can safely drive a car, ride a bike, or operate heavy equipment.
- Do not drink alcohol. Alcohol and other drugs may slow your recovery and put you at risk of further injury.

There are many people who can help you and your family as you recover from a concussion. You do not have to do it alone. Keep talking with your doctor, family members, and loved ones about how you are feeling, both physically and emotionally. If you do not think you are getting better, tell your doctor.

For more information and resources, please visit CDC on the Web at: www.cdc.gov/Concussion.

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Traumatic Brain Injury in Prisons and Jails:

An Unrecognized Problem

Many people in prisons and jails are living with traumatic brain injury (TBI)-related problems that complicate their management and treatment while they are incarcerated. Because most prisoners will be released, these problems will also pose challenges when they return to the community. The Centers for Disease Control and Prevention (CDC) recognizes TBI in prisons and jails as an important public health problem.

What is known about TBI and related problems in prisons and jails?

General:

- More than two million people currently reside in U.S. prisons and jails.[1]
- According to jail and prison studies, 25-87% of inmates report having experienced a head injury or TBI [2-4] as compared to 8.5% in a general population reporting a history of TBI.[5]
- Prisoners who have had head injuries may also experience mental health problems such as severe depression and anxiety,[3] substance use disorders,[6-8] difficulty controlling anger,[6] or suicidal thoughts and/or attempts.[6,9]

Women:

- Although women are outnumbered by men in U.S. prisons and jails, their numbers more than doubled from 1990 to 2000.[1,10] As of June 2005, more than 200,000 women were incarcerated.[1] Women now represent 7% of the total U.S. prison population and 12% of the total U.S. jail population.[10]
- Women inmates who are convicted of a violent crime are more likely to have sustained a pre-crime TBI and/or some other form of physical abuse.[11]
- Women with substance use disorders have an increased risk for TBI compared with other women in the general U.S. population.[12]
- Preliminary results from one study suggest that TBI among women in prison is very common.[13]

Substance abuse, violence, and homelessness:

- Studies of prisoners' self-reported health indicate that those with one or more head injuries have significantly higher levels of alcohol and/or drug use during the year preceding their current incarceration.[6]
- The U.S. Department of Justice has reported that 52% of female offenders and 41% of male offenders are under the influence of drugs, alcohol, or both at the

time of their arrest,[14] and that 64% of male arrestees tested positive for at least one of five illicit drugs [cocaine, opioids, marijuana, methamphetamines, or PCP].[15]

- Among male prisoners, a history of TBI is strongly associated with perpetration of domestic and other kinds of violence.[16]
- Children and teenagers who have been convicted of a crime are more likely to have had a pre-crime TBI[17,18] and/or some other kind of physical abuse.[17,19,20]
- Homelessness has been found to be related to both head injury[21] and prior imprisonment.[22]

How do TBI-related problems affect prisoners with TBI and others during their incarceration?

A TBI may cause many different problems:

- Attention deficits may make it difficult for the prisoner with TBI to focus on a required task or respond to directions given by a correctional officer. Either situation may be misinterpreted, thus leading to an impression of deliberate defiance on the part of the prisoner.[2,23]
- Memory deficits can make it difficult to understand or remember rules or directions, which can lead to disciplinary actions by jail or prison staff.[24]
- Irritability or anger might be difficult to control and can lead to an incident with another prisoner or correctional officer and to further injury for the person and others.[23,25]
- Slowed verbal and physical responses may be interpreted by correctional officers as uncooperative behavior.[23]
- Uninhibited or impulsive behavior, including problems controlling anger[6] and unacceptable sexual behavior, may provoke other prisoners or result in disciplinary action by jail or prison staff.[23,26]

What is needed to address the problem of TBI in jails and prisons?

A recent report from the Commission on Safety and Abuse in America's Prisons recommends increased health screenings, evaluations, and treatment for inmates.[27]

In addition, TBI experts and some prison officials have suggested:

- Routine screening of jail and prison inmates to identify a history of TBI.[28,29]
- Screening inmates with TBI for possible alcohol and/or substance abuse and appropriate treatment for these co-occurring conditions.[15,30,31]
- Additional evaluations to identify specific TBI-related problems and determine how they should be managed.[28] Special attention should be given to impulsive behavior, including violence,[2,26] sexual behavior[23] and suicide risk if the inmate is depressed.[32]

What is needed to address TBI-related problems after release from jails and prisons?

Lack of treatment and rehabilitation for persons with mental health and substance abuse problems while incarcerated increases the probability that they will again abuse alcohol and/or drugs when released.[15,31] Persistent substance problems can lead to homelessness,[33] return to illegal drug activities,[34,35] re-arrest,[36] and increased risk of death[37] after release. As a result, criminal justice professionals and TBI experts have suggested the following:

- Community re-entry staff should be trained to identify a history of TBI and have access to appropriate consultation with other professionals with expertise in TBI.[17,29,30]
- Transition services for released persons returning to communities should accommodate the problems resulting from a TBI.[17,28,29]
- Released persons with mental health and/or substance abuse problems should receive case management services and assistance with placement into community treatment programs.[27,30,37]

CDC supports new research to develop better methods for identifying inmates with a history of TBI and related problems and for determining how many of them are living with such injury.

Further information is available from these websites:

Traumatic Brain Injury (TBI):

CDC, National Center for Injury Prevention and Control
www.cdc.gov/ncipc/tbi/TBI.htm

This site provides information for professionals and the general public regarding TBI. Topics include prevention, causes, outcomes, and research. Data reports regarding TBI in the United States and many free publications and fact sheets can be downloaded. Materials are available in English and Spanish.

Health Issues in Correctional Settings:

CDC, National Center for HIV, STD, and TB Prevention
www.cdc.gov/nchstp/od/cccwg/default.htm

This site provides information for public health and criminal justice professionals about health topics with an emphasis on infectious diseases in the correctional setting. It also has materials for the general public with links to related organizations.

Intimate Partner Violence (IPV):

CDC, National Center for Injury Prevention and Control
www.cdc.gov/ncipc/factsheets/ipvfacts.htm

The site provides information for professionals and the general public regarding IPV. The site contains an overview and fact sheet about IPV, prevention strategies, links to other IPV prevention organizations, and a list of current CDC publications.

Legal Issues of Persons with TBI within Correctional Settings:

National Disability Rights Network
www.ndrn.org/aboutus/consumer.htm

This site provides information about the laws protecting the civil and human rights of persons with disabilities, including TBI. Incarcerated persons with disabilities, or their families, can receive help from the Network regarding prisoners' legal rights, access to mental health services and/or medication, and restoration of benefits upon release.

Substance Abuse:

Substance Abuse & Mental Health Services Administration
www.samhsa.gov

This site provides information about treatment resources for persons with, or at risk for, mental and/or substance abuse problems. Also, the site provides information for professionals regarding alcohol and other drug-related disorders. The site has materials for specific populations and age groups and hotline numbers for support organizations.

References

1. Department of Justice (US), Office of Justice Programs, Bureau of Justice Statistics. Prison and jail inmates at midyear 2005 [online] 2006 [cited 2006 May 22]. Available from URL: www.ojp.usdoj.gov/bjs/pub/pdf/pjim05.pdf.

2. Schofield PW, Butler TG, Hollis SJ, Smith NE, Lee SJ, Kelso WM. Traumatic brain injury among Australian prisoners: rates, recurrence and sequelae. *Brain Injury* 2006;20(5):499-506.

3. Slaughter B, Fann JR, Ehde D. Traumatic brain injury in a county jail population: prevalence, neuropsychological functioning and psychiatric disorders. *Brain Injury* 2003;17(9):731-41.

4. Morrell RF, Merbitz CT, Jain S, Jain, S. Traumatic brain injury in prisoners. *Journal of Offender Rehabilitation* 1998;27(3-4):1-8.

5. Silver JM, Kramer R, Greenwald S, Weissman M. The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study. *Brain Injury* 2001;15:935-45

6. Walker R, Hiller M, Staton M, Leukefeld CG. Head injury among drug abusers: an indicator of co-occurring problems. *Journal of Psychoactive Drugs* 2003;35(3):343-53.

7. Barnfield TV, Leathem JM. Neuropsychological outcomes of traumatic brain injury and substance abuse in a New Zealand prison population. *Brain Injury* 1998;12(11):951-62.

8. Barnfield TV, Leathem JM. Incidence and outcomes of traumatic brain injury and substance abuse in a New Zealand prison population. *Brain Injury* 1998;12(6):455-66.

9. Blaauw E, Arensman E, Kraaij V, Winkel FW, Bout R. Traumatic life events and suicide risk among jail inmates: the influence of types of events, time period and significant others. *Journal of Traumatic Stress* 2002;15(1):9-16.

10. Womens' Prisons Association. Hard hit: the growth in the imprisonment of women, 1977-2004. Greene J, Pranis K, editors; New York; Women's Prison Association, [online]. 2006 [cited 2006 Aug 3]. Available from URL: www.wpaonline.org/institute/hardhit/part1.htm#np.

11. Brewer Smyth K, Burgess AW, Shults J. Physical and sexual abuse, salivary cortical, and neurologic correlates of violent criminal behavior in female prison inmates. *Biological Psychiatry* 2004;55(1):21-31.

12. Felde AB, Westermeyer J, Thuras P. Co-morbid traumatic brain injury and substance use disorder: childhood predictors and adult correlates. *Brain Injury* 2006;20(1):41-9.

13. Diamond P, Magaletta P. TBI in the Federal prison: assessing history of traumatic brain injury in a prison population. A lecture given at the National Center for Injury Prevention and Control. Centers for Disease Control and Prevention; February 17, 2006; Atlanta, GA.

14. Department of Justice (US), Office of Justice Programs, Bureau of Justice Statistics. Substance abuse and treatment, state and federal prisoners, 1997 [online]. 2001 [cited 2006 Nov 8]. Available from URL: www.ojp.usdoj.gov/bjs/pub/pdf/satsfp97.pdf.

15. Department of Health and Human Services (US), Substance Abuse and Mental Health Services Administration. Put prevention into practice. Rockville (MD): Department of Health and Human Services; 1998. Treatment Improvement Protocol (TIP) Series 44, DHHS Publication No. (SMA) 98-3249. [cited 2006 Aug 3]. Available from URL: www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat5.chapter.80044.

16. Cohen RA, Rosenbaum A, Kane RL, Warnken WJ, Benjamin S. Neuropsychological correlates of domestic violence. *Violence and Victims* 1999;14(4):397-411.

17. Leon-Carrion J, Ramos FJ. Blows to the head during development can predispose to violent criminal behaviour: rehabilitation of consequences of head injury is a measure for crime prevention. *Brain Injury* 2003;17(3):207-16.

18. Timonen M, Miettunen J, Hakko H, Zitting H, Veijola J, von Wendt LRP. The association of preceding traumatic brain injury with mental disorders, alcoholism and criminality: the Northern Finland 1966 Birth Cohort Study. *Psychiatry Research* 2002;113(3):217-26.

19. Department of Justice (US), Office of Justice Programs, Bureau of Justice Statistics. Women offenders [online]. 2000 [cited 2006 May 15]. Available from URL: www.ojp.usdoj.gov/bjs/abstract/wo.htm.

20. Yeager CA, Lewis DO. Mental illness, neuropsychologic deficits, child abuse, and violence. *Child & Adolescent Psychiatric Clinics of North America* 2000;9(4):793-813.

21. Bremner AJ, Duke PJ, Nelson HE, Pantelis C, Barnes TR. Cognitive function and duration of rooflessness in entrants to a hostel for homeless men. *British Journal of Psychiatry* 1996;169(4):434-439.

22. Kushel MB, Hahn JA, Evans JL, Bangsberg DR, Moss AR. Revolving doors: imprisonment among the homeless and marginally housed population. *American Journal of Public Health* 2005;95(10):1747-52.

23. Kaufman CW. Handbook for correction officers and other institutional staff to identify and manage inmates with traumatic brain injuries [dissertation]. Miami (FL): Carlos Albizu University 2001. Available from: University Microfilms, Ann Arbor, MI. (UMI No. AAT3040762).

24. Merbitz C, Jain S, Good GL, Jain A. Reported head injury and disciplinary rule infractions in prison. *Journal of Offender Rehabilitation* 1995;22(3-4):11-19.

25. Department of Justice (US), Office of Justice Programs, Bureau of Justice Statistics. Medical problems of inmates, 1997 [online]. 2001 [cited 2006 May 15]. Available from URL: www.ojp.usdoj.gov/bjs/abstract/mpi97.htm.

26. Young MH, Justice JV, Erdberg P. Assault in prison and assault in prison psychiatric treatment. *Journal of Forensic Science* 2004;49(1):1-9.

27. Commission on Safety and Abuse in America's Prisons. Gibbons JJ , Katzenbach NB, co-chairs. Confronting confinement [online]. 2006 [cited 2006 Jun 8]. Available from URL: www.prisoncommission.org.

28. Sarapata M, Herrmann D, Johnson T, Aycock R. The role of head injury in cognitive functioning, emotional adjustment and criminal behaviour. *Brain Injury* 1998;12(10):821-42.

29. Fowles GP. Neuropsychologically impaired offenders: considerations for assessment and treatment. *Psychiatric Annals* 1988;18(12):692-7.

30. Department of Health and Human Services (US), National Institutes of Health, National Institute on Drug Abuse. Principles of drug abuse treatment for criminal justice populations. Rockville (MD): National Institutes of Health; 2006.

31. Department of Health and Human Services (US), Substance Abuse and Mental Health Services Administration. Substance use disorder treatment for people with physical and cognitive disabilities. Rockville (MD): Department of Health and Human Services; 1998. Treatment Improvement Protocol (TIP) Series 29, DHHS Publication No. (SMA) 98-3249. [cited 2006 August 3]. Available from URL: www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat5.chapter.52487.

32. Cauffman E. A statewide screening of mental health symptoms among juvenile offenders in detention. *Journal of the American Academy of Child & Adolescent Psychiatry* 2004;43(4):430-9.

33. Department of Justice (US), Office of Justice Programs, National Institute of Justice. When prisoners return to the community: political, economic, and social consequences. Petersilia J, editor. Washington (DC): Department of Justice; 2000. Sentencing & Corrections. No 9, NCIJ 180775 [online] [cited 2006 Aug 3]. Available from URL: www.ncjrs.gov/pdffiles1/nij/184253.pdf.

34. Burdon WM, Messina NP, Prendergast ML. The California treatment expansion initiative: aftercare participation, recidivism, and predictors of outcomes. *Prison Journal* 2004;84(1):61-80.

35. Prendergast ML, Campos M, Farabee D, Evans WK, Martinez J. Reducing substance abuse in prison: the California Department of Corrections. *Prison Journal* 2004;84(2):265-80.

36. Coid J. Correctional populations: criminal careers and recidivism. Oldham JM, Skodol AE, Bender DS, editors. Textbook of Personality Disorders. Washington (DC): American Psychiatric Publishing; 2005. p. 579-606.

37. Binswanger IA, Stern MF, Deyo RA, Heagerty PJ, Cheadle A, Elmore JG, et al. Release from prison—a high risk of death for former inmates. *New England Journal of Medicine* 2007;356(2):157-65.

Down Syndrome Fact Sheet

national down syndrome society
ndss

• Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.

• Down syndrome is the most commonly occurring chromosomal condition; one in every 691 babies in the United States is born with Down syndrome.

• There are more than 400,000 people living with Down syndrome in the United States.

• Down syndrome occurs in people of all races and economic levels.

• The incidence of births of children with Down syndrome increases with the age of the mother, but due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.

• People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.

• A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all.

• Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.

• People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many ways.

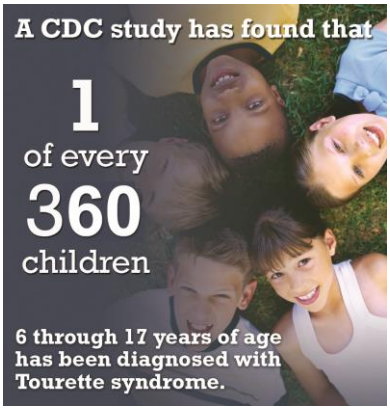
• All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.

• Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to realize their life aspirations and lead fulfilling lives.

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

For more information on Down syndrome and NDSS, visit *www.ndss.org* or call *800-221-4602.*

Tourette Syndrome Overview



Tourette Syndrome (TS) is a neurobehavioral disorder that begins in childhood. It often co-occurs with other neurobehavioral disorders and can impact educational outcomes, relationships and health. Learn about TS and what the Centers for Disease Control and Prevention (CDC) are doing about it.

What is TS?

TS is a condition of the nervous system. It causes people to have "tics." Tics are sudden twitches, movements, or sounds that people do repeatedly. People who have tics cannot stop their body from doing these things. People with TS have two forms of tics: motor tics, involving movements of the body, like blinking; and vocal tics, involving sounds made with the voice, like grunting. The tics occur many times a day, nearly every day, for at least a year. Symptoms usually begin when a child is 5 to 10 years of age. The media often portray people with TS as involuntarily shouting out swear words (coprolalia), or repeating the words of other people (echolalia). However, these symptoms are rare, and are not required for a diagnosis of TS.

What conditions are associated with TS?

TS often occurs with other related conditions. Among children diagnosed with TS, more than 80% also have been diagnosed with at least one additional mental health, behavioral, or developmental condition. The two most common conditions are attention-deficit/hyperactivity disorder (50% to 70%) and obsessive-compulsive disorder (30% to 50%). People with TS also have higher rates of depression, anxiety, and learning disabilities.

How many people are affected by TS?

The exact number of people with TS is unknown. Centers for Disease Control and Prevention (CDC) scientists recently used data from 2011-12 to estimate that 1 out of every 360 U.S. children (about 138,000) 6 through 17 years of age had been diagnosed with TS. Since estimates from community studies are often higher, it likely means that there are a significant number of individuals who have TS, but who have not been diagnosed. TS is three to four times more common among boys than girls.

How is TS managed?

Management of TS should include timely and accurate diagnosis, education, and behavioral or medication treatment, if needed. Related conditions must be considered and also might require treatment.

What is CDC doing about TS?

- CDC funds and partners with the Tourette Syndrome Association (TSA) to provide health education and training to physicians, nurses, social workers, and educators on the standard diagnostic and treatment practices for TS and related disorders.
- CDC assisted in developing a module on TS for inclusion in the 2007 and 2011 National Survey of Child Health, a nationally representative survey. The 2007 data provided the first ever U.S. prevalence of TS among youth 6 through 17 years of age, including data on racial and ethnic disparities, severity, and related conditions.
- CDC supported research at the University of Oklahoma to conduct an epidemiology study of tics and TS among school-aged children to better understand the prevalence, associated behaviors, and related conditions among children with TS.
- CDC sponsored the University of Rochester and the University of South Florida in studying the impact of tic disorders, including TS, among youth, on individuals, families, and communities.
- CDC supports the University of South Carolina and the University of Colorado Denver for a new, community-based study of children's mental health that includes TS and tic disorders

For more information about TS, please visit the CDC website: http://www.cdc.gov/tourette

National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disability