

WHAT IS A DEVELOPMENTAL DISABILITY?

Developmental disabilities represent a disability acknowledged in childhood and impacts an individual during his/her developmental growth. Type of developmental disabilities includes, but is not limited to:

- Autism spectrum disorder,
- Cerebral palsy,
- Epilepsy,
- Down syndrome,
- Fragile X,
- Fetal alcohol syndrome\Fetal alcohol effect.

Intellectual Disability is a developmental disability, and includes limitation in intellectual function and adaptive behavior. Having an intellectual disability impairs an individual's capacity BUT it should not immediately be presumed that a person is incapacitated.

Autism Spectrum Disorder (ASD) is a developmental disability that primarily affects communication and social interaction. A person with a diagnosis MAY or MAY NOT have an intellectual disability. The term Autism is now referred to Autism Spectrum Disorder. Many people with Autism Spectrum Disorder also have behaviors that may be confused with having a mental illness.

HOW DO I KNOW IF A PERSON HAS A DEVELOPMENTAL DISABILITY?

Diagnosing a developmental disability is done through assessments that are conducted by a medical or psychology professional. So, if you suspect a person may have a developmental disability - Ask, and be prepared that a person may or may not answer directly. As a follow up if you are given a confusing answer, consider asking, "Do you have a support person that helps you?"

WHAT IF I SUSPECT THAT A PERSON HAS A DEVELOPMENTAL DISABILITY BUT HE/SHE WON'T DISCLOSE?

Many people with developmental disabilities are reluctant to share that they have a developmental disability because of the associated stigma. Observational Cues and Clues, with that assumption that your expertise in understanding the culture of the person you are serving, may be helpful

OBSERVATIONAL CUES AND CLUES INCLUDE:

Overly dependent on others for activities of daily living

Unable to satisfactorily complete those activities either independently or at all. Activities like:

- self care,
- receptive and expressive language,
- learning,
- mobility,
- self-direction,
- capacity for independent living, and
- economic self-sufficiency

Difficult time communicating

Not understanding what you are saying -- resulting in confusing answers or answering "Yes" to everything asked.

Struggle with understanding what types of supports he/she may need.

Not understanding the importance, depth and long term implications of their needs.

COMMUNICATING WITH A PERSON WITH DEVELOPMENTAL DISABILITIES

- Speak in a way that matches the person's – if a person responds in 2 or 3 word sentences, then ask questions in short sentences.
- Use plain language – simple and concrete statements and questions
- Try not to use jargon, acronyms, etc.
- Ask person to repeat his/her understanding of questions you asked or statements you said to help you determine his/her understanding of the conversation (i.e. "Can you explain to me what I just said?" or "Can you explain what _____ means?")
- Ask clarifying questions (i.e. "I heard you say..., is that correct?")
- It's ok to say you don't understand. If you do not understand the individual, do not pretend you do. Ask for clarification. A then ask a different way.
- Keep your body language neutral because many people with developmental disabilities are taught to comply. Specifically avoid nodding or shaking your head during responses indicating approval or disapproval.
- Pay attention to the individual's body language and verbal cues including if the person is getting uncomfortable or tired and watch for signs of stress (withdrawal, distraction, fidgeting, humming, rocking, groaning, etc.). If you see these signs announce a break (i.e. "I would like a break, would you like to take one as well?")

-Sometimes people with developmental disabilities cannot listen to another person until they are able to communicate something they are focused on. Consider asking is there something you need to share?

- Ask one question at a time. Do not fire questions one after another. Many people with developmental disabilities have processing issues. So waiting doesn't create awkward silences and allowing for few moments to process will help get a more accurate response.
- Do not use compound questions (embedding two or more questions or topics into one sentence)
- Do not ask questions in list form (i.e. "Was it Dave, Tom or Harry?"), but ask a general "who" question or ask who it was individually (i.e. "Was it Dave?").
- Be patient and let the individual take his/her time answering questions.

COMMUNICATING WITH A PERSON WITH AUTISM

- People with Autism Spectrum Disorder often think literally and in concrete ways.
- Keep calm and help the person with Autism Spectrum Disorder work through his/her crisis. Remember restating a question when you get an unexpected response is important.
- Don't use sarcasm, many people with Autism Spectrum Disorder don't get it because sarcasm is understood through tone of voice, inflection, content and facial cues.
- As the opposite of person with an intellectual disability who may not be able say words clearly or use long, complex sentences with correct grammar, many people with Autism Spectrum Disorder may be able to have tremendously complex conversation **BUT** still have a communication challenges.

TYPES OF COLORADO SUPPORTED AND SURROGATE DECISION MAKERS AIDING A PERSON WITH DEVELOPMENTAL DISABILITIES

AUTHORIZED REPRESENTATIVE means an individual designated by the person receiving services, or by the parent (child) or guardian of the person receiving services, if appropriate, to assist the person receiving services in acquiring or utilizing services and supports pursuant to section 25.5-10, C.R.S

- The authorized representative **DOES NOT** have the power to speak or act for the individual or family.
- The authorized representative **CANNOT** sign for the individual or family.

REPRESENTATIVE PAYEE is a person appointed by the Social Security Administration (SSA) to receive and

manage benefits administered provided through the SSA.

REPRESENTATIVE PAYEE CANNOT sign legal documents, other than Social Security documents, on behalf of a beneficiary.

MEDICAL/HEALTH CARE PROXY gives authority specific to medical/health treatment **ONLY**.

- In Colorado, no one is given automatic authority to make decisions for another adult, and healthcare providers cannot simply make decisions for patients except in an emergency.
- If a person has not appointed a healthcare agent (see Medical Durable Power of Attorney), and if a person is unable to make or express decisions for a "proxy" is needed.

MEDICAL/HEALTH CARE PROXY cannot refuse artificial nutrition and hydration, unless two doctors agree that such treatment would not help the person get well but would only prolong dying.

A **GUARDIAN** is a person lawfully vested with the power and charged with the duty of taking care of and being accountable for acting in the best interest of the incapacitated under guardianship.

GUARDIANSHIP duties include:

- Being the Ward's personal representative
- Having access to the Ward's records and information to the same extent that the Ward is entitled.
- Arranging for care and protection including deciding on living arrangements.
- To the extent possible, encouraging the Ward to participate in decision-making, including when making decisions for the Ward, consider his or her expressed desires and personal values.

WHO SHOULD I CALL IF A PERSON WITH DEVELOPMENTAL DISABILITIES NEEDS HELP?

Colorado Department of Health Care Policy and Financing oversees Community Centered Boards - (800) 221-3943

Colorado Community Centered Boards are federally and state funded to oversee case management and direct supports - 303.832.1618

The Arcs in Colorado are private non-profits that provide advocacy support, but do not offer or manage direct care - 303.864.9334

