CAPACITY, COMPETENCY & CONSENT
supporting adults with intellectual and developmental disabilities (IDD)
WELCOME
SCHEDULE

• Session 1 – 75 minutes
• Break
• Session 2 – 75 minutes
SESSION ONE
People with intellectual and developmental disabilities (IDD)
LEARNING OBJECTIVES:

- Understand intellectual and developmental disabilities
- Understand communication challenges
- Identify and use communication support tools
AT-RISK ADULT
AT RISK ≠ DISABILITY

In Colorado, persons shall not be considered “at-risk” solely because of age and/or disability – What does your state say?
Understanding your State’s definition of what is a intellectual and Developmental Disability (IDD) is the key to assuring access to services.

*Colorado = INTELLECTUAL AND DEVELOPMENTAL DISABILITY – IDD*

Section 25.5-10-202(26), C.R.S.

- Manifests before the person reaches 22 years of age;
- Constitutes a substantial disability to the affected individual; and
- Is attributable to an intellectual or developmental disability or related condition (e.g., cerebral palsy, epilepsy, autism, or other neurological conditions that result in impairment of general intellectual functioning or adaptive behavior similar to that of a person with an intellectual disability).
INTELLECTUAL DISABILITY
INTELLECTUAL DISABILITY
is a below-average cognitive ability with three characteristics:

1. Intelligence quotient (or I.Q.) is between 70-75 or below
2. Significant limitations in adaptive behaviors
3. The onset of the disability occurs before age 18.
INCIDENCE AND PREVALENCE

• Between one (1) percent and three (3) percent of Americans have intellectual disability.

• The most common syndromes associated with intellectual disability are autism, Down syndrome, Fragile X syndrome and Fetal Alcohol Spectrum Disorder (FASD).
OVERCOMING COMMUNICATION CHALLENGES

• Pay attention to verbal and non-verbal communication
• Match the communication and questions to functioning level
• Use Proper names
• Do not use lists
• Ask questions 2 or 3 different ways
• Do not praise
• Use activities of daily living for references
AUTISM SPECTRUM DISORDER
AUTISM SPECTRUM DISORDER (ASD)

- is a developmental disability that can cause significant social, communication and behavioral challenges.
- A person with ASD may NOT have an ID.
INCIDENCE AND PREVALENCE

• About 1 in 59 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC’s Autism and Developmental Disabilities Monitoring (ADDM) Network.
• ASD is reported to occur in all racial, ethnic, and socioeconomic groups.
• ASD is about 4 times more common among boys than among girls.
OVERCOMING COMMUNICATION CHALLENGES

- Be calm, literal and concrete
- Avoid sarcasm
- Recognize pragmatic communication challenges
- Echolalia
- Monotone or overly excited verbalizations
- Distractible
OTHER
DEVELOPMENTAL
DISABILITIES
DEVELOPMENTAL DISABILITIES are

• a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime.

• DDs could include ID, ASD, Cerebral Palsy, Epilepsy, etc.
INCIDENCE AND PREVALENCE

• One in six, or about 15%, of children aged 3 through 17 years have a one or more developmental disabilities.
OVERCOMING COMMUNICATION CHALLENGES

• Receptive may not reflect expressive
• Language may be hard to understand
• Ask for clarification if you are unsure
• Ask if there is a communication device
DIAGNOSIS AND DIAGNOSTIC TOOLS
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Intellectual Disability
• standardized tests of intelligence (testing a person's I.Q.) and adaptive behavior (the ability of a person to function and perform everyday life activities).

Autism Spectrum Disorder
• Developmental Screening and Comprehensive Diagnostic Evaluation

Developmental Disability
• Intelligence/IQ Wechsler or Stanford-Binet
• Adaptive Behavior Impairments
• Vineland-II
MENTAL ILLNESS refers to a wide range of mental health conditions diagnosed by a medical professional.

LEARNING DISABILITIES are neurologically-based processing problems that are diagnosed by a medical professional.

CO-OCCURRING DISABILITIES

• IDD, MI and LD’s are not the same.
• Co-occurring disabilities are when there are two diagnosis that reflect different types of disabilities, ie: MI/IDD, MI/LD
LANGUAGE MATTERS
PEOPLE-FIRST LANGUAGE

- Type of language that avoids marginalization or dehumanization (either conscious or subconscious) when discussing people with a health issue or disability.
- Person with developmental disability as opposed to developmentally disabled person.
- **SEE THE PERSON FIRST.**
ADAPTIVE FUNCTIONING
ADAPTIVE FUNCTIONING OR ADAPTIVE BEHAVIOR

- Identifies skills (conceptual, social, and practical)
- Indicates how independent as compared to others of a similar age and level of intellectual functioning.
- Helps in the identification of types and intensity of supports.
PRE-AND-NON-VERBAL COMMUNICATION
PRE-COMMUNICATION

• Communication used before speech is acquired.
• Consider infants who may or may not understand all of the words presented to her/him, may be unable to produce spoken words. There is a great deal of agreement that they do communicate, and some quite effectively through their behavior but no words.
NON-VERBAL COMMUNICATION

- Communication done without words and not using a communication device or alternative.
- Could include:
  - Eye contact
  - Gestures (pointing, showing using one’s hands, facial expressions)
  - Non-word vocalizations
  - Showing through acting out a role using oneself or
  - Implements such as dolls, objects used as people.
  - Showing through acting out
COMMUNICATION SUPPORT TOOLS
COMMUNICATION ALTERNATIVES

• Facilitated Communication – assisted typing on a keyboard or communication board
• Sign language: ASL, Signed English, Finger Spelling
• Bliss Symbolics – a reading system using symbols rather than words
• Computer Assisted Technologies
• Voiced Communications
• Pictographs
• Gestures, non-word vocalizations, eye blinking, head movement, showing through enactment or re-enactment.
COMMUNICATION DEVICES
• A communication device is a hardware device capable of transmitting an analog or digital signal over the telephone, other communication wire, or wirelessly.

COMMUNICATION TOOLS
• Tools can be alternatives, devices or accommodations.
• Accommodations includes could include more time to respond, spotting echolalia, etc.
TOOLS
VIDEOS
Q&A
WHAT WE HAVE LEARNED
SESSION TWO
Capacity, competency, consent and tools to help determine
LEARNING OBJECTIVES
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• Understand capacity, competency and consent
• Identify tools to help determine
APS, CAPACITY AND COMPETENCY
KNOW THE RULES IN YOUR STATE. IN COLORADO:

• If an at-risk adult is suspected to not have capacity APS has defined steps to be taken to assure safety and formalize capacity determination.
• Any intervention must done ethically and in the least restrictive intervention to ensure the client’s safety.
RIGHT OR PRIVILEGE
A **PRIVILEGE** is a certain entitlement to immunity granted by the state or another authority to a restricted group, either by birth or on a conditional basis.

A **RIGHT** is an inherent, irrevocable entitlement held by all citizens or all human beings from the moment of birth.
HUMAN RIGHTS
HUMAN RIGHTS are rights inherent to all human beings, regardless of race, sex, nationality, ethnicity, language, religion, or any other status. Human rights include the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression, the right to work and education, and many more.
CIVIL RIGHTS
CIVIL AND POLITICAL RIGHTS are a class of rights that protect individuals' freedom from infringement by governments, social organizations, and private individuals. They ensure one's ability to participate in the civil and political life of the society and state without discrimination or repression.
LEGAL RIGHTS
LEGAL RIGHTS refers to rights according to law. It exists under the rules of some particular legal system.

- Bill of Rights
AGE OF CONSENT
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FEDERAL
• Defined age at which a person is deemed legally competent to consent to sexual activity.

COLORADO
• The Colorado Age of Consent is 17 years old. Individuals aged 16 or younger in Colorado are not legally able to consent to sexual activity, and such activity may result in prosecution for statutory rape.
AGE OF MAJORITY
AGE OF MAJORITY
FEDERAL
• This age varies from state to state and ranges between 18 through 21.
• Age of majority pertains solely to the acquisition of the legal control over one's person, decisions and actions.

COLORADO
• As of 2018, Colorado statutes or laws assign different ages of majority or consent for different activities.
• The legal age of majority is 21, unless another law permits that action to be taken earlier.
COMPETENCY
COMPETENCY refers to the mental ability and cognitive capabilities required to execute a legally recognized act rationally.

Competency encompasses activities, such as:
• the ability to enter into a contract,
• to prepare a will,
• to stand trial, and
• to make medical decisions.
WHO DETERMINES AND HOW

• The determination of incompetence is a judicial ruling, i.e., decided by the court.
• Because an adjudication of incompetency effectively denies an individual autonomy to make decisions, such court cases become labor intensive.
• An individual is presumed to be competent unless demonstrated to be otherwise.
INCOMPETENCY BY STATE
In Colorado, an adult deemed INCOMPETENT is a person who is unable to effectively receive or evaluate information or both or make or communicate decisions to such an extent that he or she lacks the ability to satisfy essential requirements for physical health, safety, or self-care, even with appropriate and reasonably available technological assistance.
CAPACITY BY STATE
In Colorado, **CAPACITY** refers to an assessment by a medical professional regarding an individual's psychological abilities to form rational decisions, specifically the individual's ability to:

- understand,
- appreciate, and
- manipulate information and form rational decisions.

**Capacity IS NOT determined by a court of law.**
WHO DETERMINES AND HOW

• A medical professional or psychologist will need to investigate the referral to determine if he or she has the professional competence to address the referral question based on education, training, supervised experience, consultation, or study as required by the Ethical Principles.

• Capacity assessments are formal and can come from a variety of sources and occur in a variety of settings that influence the approach taken to evaluation, and the professional competencies needed.
CAPACITY CONTINUUM
There are very few clear lines that define what **CAPACITY** is and what constitutes incapacity generally, but there are many useful contextual and functional definitions of capacity to assist.

- Medical Decisions
- Drive a Car
- Make a Will
CAPACITY HICCUPS
CULTURAL CONSIDERATIONS

• Language
• Immigration status
• Economic status
• Perceptions of institutions
• Perceptions of disability
• Test bias, test fairness, and cultural equivalence
FAMILY AND SYSTEMIC BARRIERS
Factors in a person’s environment that, through their absence or presence, limit functioning and create disability. These include
• a physical environment that is not accessible,
• lack of relevant assistive technology (assistive, adaptive, and rehabilitative devices),
• negative attitudes of people towards disability,
• services, systems and policies that are either nonexistent or that hinder the involvement of all people with a health condition in all areas of life.
COMMUNICATION CHALLENGES

• Use of small print or no large-print versions of material.
• No Braille or versions for people who use screen readers.
• Auditory health messages may be inaccessible to people with hearing impairments.
• Oral communications without accompanying manual interpretation (such as, American Sign Language).
• The use of technical language, long sentences, and words with many syllables may be significant barriers to understanding for people with cognitive impairments.
BIAS, COMPETENCY AND CAPACITY
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- Attitudinal barriers
- Stereotyping
- Stigma, prejudice, and discrimination
INCAPACITY BY STATE
In Colorado, **INCAPACITY**

Person temporarily or permanently impaired by mental and/or physical deficiency, disability, illness, or by the use of drugs to the extent he or she lacks sufficient understanding to make rational decisions or engage in responsible actions.

Incapacity can be situational & permanent.
BUILDING CAPACITY
**CAPACITY BUILDING** includes focusing on the strengths of the individual and providing opportunities through coaching and feedback to learn to or regain control.

Capacity building is not about regaining competency.
CONSENT & APS IN COLORADO
REMINDER - CONSENT AND ADULT PROTECTIVE SERVICES

- Consent is not required for the county department to investigate or assess allegations of mistreatment or self-neglect.
- The final decision as to acceptance of protective services shall rest with the client unless the client has been adjudicated incapacitated by the court or as outlined in Section 30.600.
IMPLIED CONSENT
IMPLIED CONSENT refers to situations in which it is assumed a person consented to something by his actions. This means that, although the person has not given verbal or written consent, circumstances exist that would cause a reasonable person to believe the other had consented. Questions of implied consent arise in a variety of situations, including medical care, contracts, and even actions that may be considered criminal if no consent is given, such as rape.
WHO DETERMINES AND HOW

• Implied consent laws exist in all jurisdictions, covers a broad variety of circumstances and is intended to provide protection.
• Implied consent may be assumed in medical situations, legal representation, contract issues, and others.
• Implied consent should not to be confused with Informed consent
EXPRESSED CONSENT
EXPRESSED CONSENT

• Expressed consent is communicated either verbally, non-verbally or in written form.
CONSENT FACTORS
CONSENT is:

- informed,
- freely and actively given,
- mutually understandable via words or actions that indicate willingness to participate in mutually agreed upon activity
CONSENT is NOT given if it results from the use of:

• physical force,
• threats,
• intimidation, or
• coercion.
INFORMED CONSENT
INFORMED CONSENT is a written agreement that is freely given and signed after the individual is provided specific information that speaks to risks, benefits, alternatives and an assurance that withholding or withdrawal of consent shall not prejudice future opportunities.
INFORMED CONSENT must be knowledgeable.

- The person obtaining consent should be knowledgeable and well-informed about the condition or proposed intervention/plan.
- The person obtaining consent must understand and articulate the risk/benefit of the situation causes the need for informed consent.
INFORMED CONSENT must be specific.

• Time limited and specific points should be included, as opposed to forever and vague agreements.
INFORMED CONSENT must be voluntary.

• Consent must not be obtained through fraud, coercion or misrepresentation. The person should not be under any duress or pain.
• Allow sufficient time for the person to understand, consider the information, and ask questions. If additional information is requested, provide a timely response.
• It is important to be familiar with how the individual usually communicates (e.g., normal or unique pain responses), which may affect decisions.
INFORMED CONSENT must be given by a person who is competent to make the decision.

- Having an intellectual disability does not automatically preclude an individual from being able to give informed consent, nor does the lack of a guardian or conservator automatically mean an individual is capable of giving consent.
REFUSING CONSENT
REFUSING CONSENT

• Decline or reject agreement with the proposed treatment, decision or action.

• Consent would be completely pointless if it did not protect a person’s right to refuse. Overriding a refusal must be thoughtful and not simply because of a person’s decision is considered foolish or illogical.
THE BIG DEALS
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• Sex – Consensual versus assault
• Financial – Gift versus exploitation
• Medical – Capacity to consent to treatment
• Long Term Services – Informed consent or coercion
TOOLS
SCENARIOS
Q&A
Providing advocacy support for people in Aurora of all ages who have an intellectual or other developmental disability

720.213.1420
www.thearcofaurora.org
A program of The Arc of Aurora providing training and education to help improve the lives of people with disabilities

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