



# DEVELOPING AN IDD TRAINING FOR FIRST RESPONDERS

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## INTRO:

- **Introduction: Yourself, role, length of work in the field etc.**
  - **Short intro about the agency you work for**
  - **Thanks for the invite**
- Liz Holle, Deputy Operations Officer
  - Emily Loudermilk, Development and Marketing Specialist
  - Big Lakes has been serving individuals with intellectual and developmental disabilities in Riley, Geary, Clay and Pottawatomie counties since 1973

## SESSION GOALS

- **Lay out the goals of the session so they know what you want the takeaways to be as they listen to your presentation.**
  - Provide a greater understanding of **cues to identify** a person with a developmental disability
  - A greater understanding of **experiences of individuals** with developmental disability
  - Knowledge of **available supports** for individuals with IDD and the limitations of available support options
  - Knowledge of **appropriate communication, language, and response tactics** for working with individuals with IDD

# VAST DEMOGRAPHICS OF THE IDD POPULATION

- **Goal: to understand there is a vast array of diagnoses and characteristics that fall under the umbrella of IDD. Sometimes it's easy to tell sometimes it isn't.**
- **Goal: Important to understand dual diagnosis: Co-occurring mental health disorder: depression, Bi-Polar disorder, schizophrenia etc.**
- Notes:
- Symptoms may not be readily apparent to an outside observer
- Dual Diagnosis: Co-Occurring mental health disorder
- Stats are for the state of Kansas as of 7/1/23
- Shared Living in the area –
- # of IDD in catchment area 368
- # of IDD in Kansas 8,939 receiving HCBS services in Kansas
- # on waiting list in our catchment area 131
- # on Kansas Waiting list 5,100 with an average wait time of 10 years

- Developmental Disability is an umbrella term including intellectual disability.
- Intellectual disabilities are not mutually exclusive to DD. A person with DD may have other disabilities
- Intellectual disability is characterized by significant limitations in both intellectual functioning and in adaptive behavior.
  - IQ below 70-75, significant limitations in two or more adaptive areas, before the age of 18
  - Down Syndrome
  - Williams Syndrome
  - Fetal Alcohol Syndrome
  - Fragile X Syndrome
  - Turner Syndrome
  - Cerebral Palsy
  - Autism Spectrum Disorders
  - Traumatic Brain Injury before the age of 18
  - Developmental Delay
- Dual Diagnosis Dementia – nearly all individuals with Down Syndrome will experience some symptoms before the age of 40
  - 50% of people with IDD have a mental illness (Substance Abuse and Mental Health Services, NCI, 2016)
  - Varying medical complications

# SENSORY PROCESSING DISORDER

## ■ Experiencing Sensory overload

- <https://www.bing.com/videos/search?view=detail&mid=689F21195211D9632A3C689F21195211D9632A3C&shetp=GetUrl&shid=7c91866f-5bd4-48db-8745-1080d91e6ee6&shk=YXV0aXNtIHNIbnNvcnk3ZlcmxvYWQgc2ltdWxhdGlvbG%3D%3D&shdk=d2FybmluZyBjYW4gY2F1c2Ugc2Vuc29yeSBvdmVybG9hZA%3D%3D&shk=IPxIzDLT9DojB69jcV9JzI3BQ4AZG%2FXidKjPn8D4vxI%3D&form=VDSHOT&shth=OSH.KzvB5%252BOq%252FMwRmhgVWGUt02w>

## ■ Meet Michelle

- <https://youtu.be/aID-Vdbcmkw>

- **Key Takeaway:** when you talking the person this may be what they are experiencing and they are not able to actually hear you or focus on their environment or actions

- May have sensitivity to:

- Sounds – may wear headphones (removing them may make things worse)
- Touch – may hit themselves to lower adrenaline level, may display violent behavior that they cannot control, may overreact to touch

- Experiencing Sensory overload

- Self-Stimulation or Stimming

- Flapping hands
- Flicking fingers
- Chewing on things
- Closing eyes
- Holding ears
- Lack of ability to control the volume of their voice

# SENSORY OVERLOAD EXERCISE

This activity received good feedback to understand how difficult and frustrating it was to think, to communicate, to remain calm, to understand, etc.

It provides good perspective

- Groups of 4
- Once through the questions, rotate

## Sensory Overload Practice

If you are asking the questions:

1. What are you doing this weekend?
2. Where was your last vacation?
3. What is one thing on your bucket list?
4. Tell me how to cook your favorite recipe.

If you are doing the reciting:

1. Say the Pledge of Allegiance
2. Sing/recite a nursery rhyme
3. Say the ABC's
4. Count by 5's

# AUTISM

- **Talking Points:**

- Notice the man offered his hand but didn't touch the person with IDD – let him be the one to grab his hand
- Explain what to expect
- Lack of eye contact

- Autism First Responder Training Video  
<https://www.youtube.com/watch?v=TNBV66MLGXc>
- Struggle to understand social norms, sarcasm, or figures of speech
- Difficulties with nonverbal communication: doesn't understand facial expressions
- May think in pictures and take each word literally
  - Best not to remember Chestnut like this  
<https://www.youtube.com/watch?v=6NmVUJTOJnQ>
- May answer the way they think you want them to instead of the truth if they are uncomfortable
- Emotion/Impulse Control – unable to stop something they know is wrong due to a strong desire for the outcome
- Some people believe that people with Autism Spectrum Disorder have high IQ's but that is not necessarily the case
- May repeat themselves or you (particularly the last thing you said) answers may be unreliable

# IDENTIFYING A POTENTIAL DEVELOPMENTAL DISABILITY

## ■ Talking Points:

■ Examples: Tall tales, examples of clients phrases or person specific behavior

■ Examples of TBI

Communication	Behavior	Interaction
<ul style="list-style-type: none"><li>• Limited vocabulary</li><li>• Speech Impairment</li><li>• Difficulty answering questions</li><li>• Short attention span</li></ul>	<ul style="list-style-type: none"><li>• Inappropriate actions</li><li>• Easily influenced</li><li>• Difficulty with directions</li><li>• Trouble with day-to-day tasks, such as making change or using a phone</li><li>• Repetitive motions or motor impairments</li></ul>	<ul style="list-style-type: none"><li>• Eagerness to please</li><li>• Communication through others</li><li>• Bluffing greater understanding than they have</li><li>• Over-engaged or under-engaged</li></ul>



# AVAILABLE SUPPORTS FROM COMMUNITY BASED SERVICES

- Quick over view of supports in Day Services and Supported Employment
  - Explanation of types of Residential Services
  - Case Management – all ages coordinator overseeing supports, finding resources, writing yearly support plans
  - Health Services explanation – Nursing Dept. (RN, LPN, Assistants)
  - Personal Services – In home supports
  - Shared story about clients with co-occurring mental health diagnosis that have required additional support from the mental health system and the police and discuss the gaps in care between IDD and mental health systems
- Day Services - 139
  - Supported Employment - 42
  - Residential Services - 106
  - Case Management - 194
  - Health Services – all 139
  - Personal Assistant Services
  - Shared Living

# CRISIS INTERVENTION TRAINING FOR DSPS

- Demonstrate physical skills for MANDT or whatever system you use to show the limitations of the supports we offer for someone in crisis.
- Guardianship Program
- Provide examples – escalated by police presence or by women of authority etc.

- DSPs or Direct Service Providers receive training in relational and physical support techniques
- Scope of supports in crisis
- MANDT and understanding it's limitations
  - When we call for assistance, we need it
  - When community members call it may be within the realm of our training
    - This can be confusing for you and for staff as to who takes the lead
- Nexus of supports with multiple diagnosis

# HELPFUL THINGS TO BE AWARE OF

- Quick over view to explain the responsibilities and limitations of each.
- Note: sometimes the guardians are appointed and may or may not have relationship with the client outside of their annual meeting.... How does she seem to be acting to you

- Wait List – over 10 years in Kansas
- Guardianship - A guardian is a person appointed by a court to act on behalf of a minor or impaired person, who is called a “ward.” A guardian manages a ward’s personal health, safety, and welfare.
- Payee - A representative payee is an individual or organization appointed by SSA that receives Social Security and/or SSI payments for someone who cannot manage or direct someone else to manage his/her money. Having power of attorney, being an authorized representative or having a joint bank account with the beneficiary is not the same as being a payee. These arrangements do not give you legal authority to negotiate and manage payments for someone receiving Social Security and/or SSI payments.
- Conservator - A conservator is a person appointed by a court to act on behalf of a minor or impaired person, who is called a “conservatee.” A conservator manages a conservatee’s property or “estate,” such as money, personal and real property

# IDD POPULATION AT RISK

- Individuals with disabilities are over four times as likely to be victims of crime as the nondisabled population (at least two times more likely for violent crimes and four to ten times for abuse and other crimes) (Sobsey, 1996).
- 64% of the children who were maltreated had a disability. The most common type of maltreatment was neglect. Children with mental retardation were the most severely abused. Children with communication disorders were more likely to be physically and sexually abused (Sullivan & Knutson, 1998).
- One of 30 cases of sexual abuse or assault of persons with developmental disabilities is reported as opposed to one of five in the nondisabled population (James, 1988).
- People with disabilities are isolated from resources to whom a report of abuse could be made
- For people with mild to moderate mental retardation sexual development and sexual interest occur at approximately the same age as the normal population (Tharinger, 1990), and precocious puberty is 20 times more likely to occur in persons with developmental disabilities than in the normal population (Siddigi, 1999);
- Frequently the abuser is known to the person with the disability so be conscious of a caregiver assisting in an interview or investigation no to influence or taint the investigation. Make sure you are well documented with the caretakers assistance in an investigation.

Yet their cases are rarely investigated or prosecuted because of discrimination, devaluation, prejudice that they are not worthy of protection, and mistaken stereotypes that none can be competent witnesses. Their victimization comes in many forms including violence, oppression, financial exploitation, sexual exploitation, and human trafficking;

# THINGS TO KEEP IN MIND

- Provide examples

- Easily manipulated by others
- Unaware of malice
- May accept blame without understanding
- Confused about responsibility
- Try to determine if they have a guardian
- May understand you though they may not be able to communicate to you in kind
- May not be able to recognize danger or have appropriate and realistic fear
- May be exceptionally excited, exceptionally scared, or exceptionally unaffected by the authority of First Responders
- May not understand who is legally an adult and who is not
- Caregivers
  - Burn Out
  - Grief Cycle

# QUICK TIPS

- Stimuli – lights, noises, canine
- Example: Story of individual being treated as a child due to their disability  
May drink lemonade not realize it's a hard lemonade
- I am going to put this cuff on your arm and it is going to squeeze your arm so I may check on your heart and then the EMT demonstrated on himself
- Communication
- Assume they have a trauma history
- As much as possible for safety give them space
- Remove stimuli if possible when it is causing stress, or lack of focus – sirens or lights for example
- Do not remove stimuli that is calming the person (headphones, stimming, harmless tactile object)
- Ensure you are there to help them and keep them safe
- Identify the desire or the frustration to aid in de-escalation
- Explain and demonstrate what you are going to do before you do it
- For people with physical disabilities always ask for what assistance they need and how to assist them before assuming
- Allow them time to process your questions or requests
- As much as possible gain consent to touch them
- May not be able to process, recognize, or communicate pain – check them for injuries

# COMMUNICATION TIPS

- Talk softly and use their name if possible
  - Be very direct, logical, literal and concrete in your requests and speech, Break steps into small parts
  - Be careful not to ask leading questions
    - May take what they heard to be what happened to something they don't understand
  - Objects or illustrations of your words can assist the person in remaining calm and understanding
  - Rephrase questions to check for accuracy. Don't assume confession, look for facts (Do you want an apple or an orange?... Orange. Do you want an orange or an apple?... Apple)
  - If they struggle with verbal communication it does not necessarily mean they cannot hear and you do not need to talk louder
  - Write questions or requests if they are able to read
  - May phrase it as a statement when it is a question or wanting verification
  - Sometimes client may not understand the meaning of the word but know how others will react to the word. Check for their understanding or meaning.
    - Rape – what does rape mean, tell me what happened first, then second etc.
    - Stating that a person was in a bad mood again when describing a violent sexual assault
- Use examples of unique ways your clients phrase things to
  - Demonstrate how to check an answer by asking it 3 times with two options changing order.

# INTERACTION TIPS

A person may be able to answer yes or no with a gesture or to touch something in order to make a choice (red one or blue one, thumbs up for yes or thumbs down for no, may use an iPad or other assistive device to aid in communication sometimes with an augmented voice or by showing you something on it.

I want to talk to you for a couple minutes. They may take things very literal.

- Example: Waive your right – eyes peeled

- Attempt to find a quiet area for the person especially to talk with them
- Keep your movements slow – not rapid
- Don't interrupt odd behavior if possible
- Do not remove an object from the individual unless harming themselves or others
- Pictures or illustrations may be a valuable aid in explaining or answering questions
- Do not tell them something is going to happen or when \_\_\_\_\_ then \_\_\_\_\_ unless that is in concrete.





# DOCUMENTATION AND FOLLOW-UP

- The point here is that individuals with disabilities should still be considered worthy of giving their perspective, account, or testimony and documentation is important to show that they were not being led to answer the way they did or that they were led if that were the case.

- Document every aspect of the interaction
- Be prepared that the interview process may require additional time and patience
- Identify yourself clearly to the person being interviewed
- Explain to the individual with a disability everyone's role and reason for being present at the interview
- Use your usual tone and volume of voice and make effort to keep your language simple and clear
- When asking follow-up questions, be aware of who is present for the questioning/interview
- The caregiver/other individual present could be a negative influence on the situation and influence the answers being given the opposite could be true as well
- Avoid leading questions
- Do not challenge or push an individual with I/DD to second guess their answer

# PERSON FIRST LANGUAGE

Words to Avoid	Words to Say
Brain damaged	Person with brain injury
Deaf person	Person who is deaf or person with a hearing impairment
Crippled; wheelchair-bound; wheelchair-confined	Person who uses a wheelchair
Disabled; Handicapped; Physically challenged	Person with a disability (or the name of the disability)
Able-bodied	Person without a disability
Suffers from...	Person who has...
Mentally retarded	Person with an intellectual disability
Stroke victim	Stroke survivor
Epileptic; diabetic	Person with epilepsy/diabetes

# DO'S AND DON'TS OF COMMUNICATION

DO	DON'T
<ul style="list-style-type: none"><li>• Gain the person's attention ('Sean, are you ready to answer some questions?')</li><li>• Give positive feedback about the process of the interview ('You're doing a great job of thinking about my questions.')</li><li>• Restate the focus of the interview ('I need to know some more about what happened in the parking lot.')</li><li>• Instruct the person to try to concentrate ('Take a pause and see if there's more you can remember about the activity in question.')</li><li>• Repeat the question calmly when the person does not answer</li><li>• Ask the individual to demonstrate or show what she/he meant ('Can you show me with your hands how you used the spray paint?')</li><li>• Ask the person to clarify something that was said ('I'm sorry, I didn't understand that, the lady wore a red what?')</li></ul>	<ul style="list-style-type: none"><li>• Tell the person there is more to tell ('I know that there is more to tell about the situation you haven't told me.')</li><li>• Use bribery ('If you remember one more thing, I'll buy you a soda.')</li><li>• Criticize the person if he/she does not provide an immediate response ('Hurry up, we don't have all day.')</li><li>• Ask if the person is sure about his/her response ('Are you sure the car was red and not black?')</li><li>• Dispute what the person says ('I think you're tricking me, I think the store was closed on that day.')</li></ul>

# RESOURCES AND SUPPORTS

- Explain the role of the CDDO and why they are the person that would most likely know the individual if they have had any contact with the IDD system outside of the school system.
- Giving the map of CDDO information allows officers from other catchment areas to know who to contact as well as the officers in the training may not all be from your catchment area.

- CDDO – Name your CDDO
- [cddo-map9acd5ea0172e66d690a7ff00009edf98.pdf \(ks.gov\)](#)
  - Initial Point of contact for individuals accessing developmental disability services and supports
  - Referral source to community agencies
  - Quality oversight and monitoring of services provided for providers
- Case Management Director
- Manager On Call (hours)
- Who is the manager or officer to contact during Day Services? (hours)