

Supporting Patients with Intellectual and Developmental Disabilities (I/DD) & Sensory Needs

Case Facilitation Guide

Case focus: individual with IDD who presents with complex communication and sensory needs seeking treatment for unresolved physiological symptoms in emergency setting.

Learning Objectives:

1. Recognize the challenges adults with IDD and sensory needs experience in accessing healthcare in emergency settings
2. Identify ways that providers can better support and treat adult patients with IDD and sensory needs.

Areas of focus throughout discussion

1. **Assessment:** address issues that may be underlying or contributing causes of visit to ED. Observable agitation may indicate discomfort with environment and unfamiliar interactions. Symptoms are often expressed in atypical and uncommon ways in people with IDD.
2. **Treatment:** individualize treatment and care: Consider strategies for positive, person-centered communication (verbal techniques, visual aids; treat patients in a manner that is least restrictive)
 - Sensitivity to sound, light, touch, smell, taste, crowds, proximity, waiting times, unfamiliar people and things.
 - Difficulty with changes/new surroundings, routines, or caretakers
 - Likelihood of secondary psychiatric diagnosis (anxiety) as contributing factor

Case Presentation:

A man arrives at the Emergency Department. He is accompanied by a woman who is holding his coat and a folder with some sheets of paper. Since arriving in the emergency department several hours ago, he has been chewing on the collar of his shirt and pacing the hallway. When the woman talks to him or asks him to return to his seat, he begins to yell and walk away from the area. At one point, a security guard at the doorway escorts him back to his seat when he gets as far as the ED entrance. The waiting room is busy and crowded.

1. ***What modifications to the environment can be made to address sensory needs and potential anxiety?***

Discussion prompt: what does the patient’s behavior “chewing on the collar of his shirt and pacing the hallway, he begins to yell and walk away from the area” tell you?

- Increase availability of activities in waiting spaces
- Address lighting, textures or smells, or ambient noise
- Use natural light, or turn off fluorescent lights if possible, or make the lighting dim
- Provide updates and validation to the patient and caregivers about wait times
- Invite patient to wait outside and contact him when it is time to enter the exam room
- If possible, provide an area of quiet that limits proximity to others and reduces stimulation
- Rather than escorting him back to his seat, explore letting him wait outside until it is time for him to be seen

The patient is called back to a treatment room from the waiting room and we learn initial information: Jorge is a 43-year-old man with Autism Spectrum Disorder (ASD). He lives in a group home that he shares with two roommates and the woman with him is Karla, a direct support professional (DSP) who works there. Karla tells you Jorge seems to have pain in his stomach. Jorge communicates using a small vocabulary of specific words and short phrases, but primarily uses an iPad to express what he wants to say.

2. What other information do you need? How do you plan to get that information?

- Jorge is using the pillow to cover his face. This may indicate that he is responding to uncomfortable light or sounds. Reduce the lights and noise if possible.
- Use clear, precise language to ask questions.
- Ask very specific, concrete questions and avoid very broad questions.
- Read any written notes or information Jorge has brought with him.
- Try to minimize other noises when asking for information.
- To help him answer, be direct about symptoms he may be experiencing.
- Give Jorge extra time to process things he needs to see, hear, or feel before he responds.
- Use visual aids, such as pictures, diagrams, or models.
- Involve Karla as a support and source of information.
- Ask if he would like to call his sister or someone else.

You ask Jorge how he is feeling and he says “bad” and “hurts.” You ask what is hurting him and he gestures towards the left side of his body. Although he is able to answer some questions about his condition, he does not have an iPad or other communication device with him. You ask Jorge how long he has been in pain and he replies, “leave.” He is rocking back and forth and

covering his eyes. When you ask if he takes any medications, Jorge begins to punch himself on the on the left side of his body. He then grabs a pillow which he uses to cover his face.

3. What may be causing Jorge to become more agitated? What are some immediate things you can do for Jorge?

Discussion prompt: How can you be proactive about safety concerns given Jorge's escalating behaviors?

- Jorge is in pain and uncomfortable.
- Jorge may experience additional discomfort from the added uncertainty from moving from one environment to another. His behaviors may be in response to uncomfortable environmental stimuli in the exam room. He may lack social skills and familiarity navigating social situations. Jorge may have a past history of trauma related to previous unpleasant experiences with health care settings or professionals.
- Look for and address signs of mental health symptoms: signs of anxiety may be temporary due to the situation or an indicator of an underlying condition.
- He has difficulty in understanding verbal language and does not have his communication device/tool with him. He is also accompanied by someone who does not know him very well. This is frustrating.
- Manage your proximity to Jorge. Tell him what is going to happen during the exam. Explain what you are going to do before you do it with each step, ask for permission and wait for a response. Ask him if there is something he needs to be more comfortable. Show him equipment before using it. Warn him before touching him.

Karla identifies that she only began working with Jorge a few weeks ago and she does not know him very well. Jorge works part time in a warehouse for a paper company loading delivery trucks. He has a sister who lives two hours away who visits about once a month.

Karla reads to you from a paper she is carrying that Jorge has been “refusing to eat, screaming a lot and occasionally hitting or punching himself in his torso area. He missed work today and yesterday.”

He has experienced recent weight loss: 12 pounds in the past month.

She has a list of his medications: Nexium 40mg, Zoloft 100mg. He experiences anxiety.

You need to examine Jorge to gather further information. You explain to Jorge what you will be doing. As you go to touch him, he starts yelling “want to go home” and punches his side harder. He gets up and moves towards the exit of the room, knocking over a chair.

4. How can you de-escalate Jorge's behavior and help make him more comfortable in order to proceed with a physical examination?

Discussion Prompt: What are effective (verbal and nonverbal) communication strategies that can prepare Jorge, minimize uncertainty, clarify expectations, and provide choice and support?

- Establish rapport. Ask Jorge about himself and his interests. Use a calm tone of voice and reflective listening. Provide choice and control.
- Avoid methods that may increase trauma or agitation such as crowding the person, threatening the person with consequences, yelling, panicking, demanding, dismissing the person's concerns, touching or blocking the person from movement.
- Environmental modifications can include removal of unnecessary furniture or equipment. Limit traffic in the exam room to essential personnel and distance from the patient if he is agitated but still in a safe area. Give Jorge breaks as necessary.
- Next steps may include transition: If Jorge has to have any tests or procedures, give him a detailed explanation of what will happen. Let him know if it will involve an additional place or person. Anticipate the patient's behavior when moving from one environment to another.

By implementing strategies for a positive encounter, Jorge's anxiety has decreased and you are able to proceed. After your exam, you are able to make recommendations for assessment and treatment.

5. How can you continue to support Jorge's needs during discharge and follow up?

- Medical: provide Jorge with discharge and follow up instructions. Review information and confirm comprehension.
- Schedule longer appointments, if possible with providers Jorge knows or has met before.
- Provide information about the sequence of events that are likely to occur before and during the next exams and appointments.
- Support Jorge and his team (Karla and Jorge's sister) in preparation of techniques to promote relaxation such as social stories and desensitization.
- Consider use of a tool for successful Emergency Room visits for future use which includes information about patient's preferences for individualized care.

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