Providing Medical Care to Individuals with Intellectual and Developmental Disabilities (I/DD) who have Sensory or Behavioral/Mental Health Needs

Panel Description and Discussion Questions

**Learning Objectives:**

1. Understand the challenges adults with I/DD who have sensory or behavioral/mental health needs experience in accessing healthcare
2. Learn about ways that adults with I/DD who have sensory or behavioral/mental health needs prefer to be accommodated when accessing healthcare
3. Recognize ways that providers can better meet the needs of adult patients with I/DD who have sensory or behavioral/mental health needs

**Panel composition:**

- **Person with IDD and sensory needs:** someone who is verbal, comfortable speaking in front of a crowd, comfortable talking about his/her own disability, and has sensory needs that may make doctor’s visits challenging, can speak to good and bad experiences
- **Person with IDD and behavioral/mental health needs:** someone who is verbal, comfortable speaking in front of a crowd, comfortable talking about his/her own disability, and has behavioral/mental health needs that may make doctor’s visits challenging, can speak to good and bad experiences
- **Direct Support Professionals (DSPs):** comfortable speaking in front of a crowd, is experienced and, ideally, knows a person with I/DD and sensory needs well, has accompanied persons with I/DD to medical appointments, can speak to ways that sensory or behavioral/mental health needs create challenges in accessing medical care
- **Family member:** comfortable speaking in front of a crowd, has accompanied a family member with I/DD to medical appointments, can speak to ways that sensory or behavioral/mental health needs interfere in seeking medical treatment

**Note:** These are suggestions for creating a robust and effective panel, but are flexible based on availability of panelists who meet these criteria and are willing to share their experiences.

**People may have had negative experiences with health care professionals in the past. This panel presentation offers a means to use those experiences to educate other professionals and provide clear examples. Panelists should be able to share such negative experiences without hostility or accusation.
Panel Description and Discussion Questions:

**Moderator:**

- **Healthcare provider with experience caring for adults with I/DD:** can share the healthcare providers’ perspective about what is challenging and what is helpful when providing care to adults with I/DD

**Questions for Panelists:**

1. Please tell us about yourself.
   - For family and DSPs, please share what your role is when supporting the patient during a healthcare visit?
2. What are the most important things for health care providers to know about you and your needs/the needs of the person you support?
3. Can you describe a time when sensory or behavioral/mental health needs prevented you from getting the healthcare you needed?
   - What might have helped things go better?
4. Can you describe a time when you got the healthcare you needed and your sensory or behavioral/mental health needs were accommodated well?
   - What was so helpful about this experience?
5. What types of things can health care providers do to make people with I/DD who have sensory or behavioral/mental health needs feel included and comfortable?
6. Anything else you’d like to share?

**Note:** Questions should be shared with panelists in advance to allow time for them to prepare their responses. If you know someone well, feel free to request that they include specific experiences or information in their responses.

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