

Communication and Care Management for People with Intellectual and/or Developmental Disability: Jason Case Study

Overview of Teaching Strategy

Care management for people with an intellectual and/or developmental disability (IDD) requires intentional communication skills by health care professionals. This teaching strategy uses a case study approach to serve a variety of health care professionals in skill development for communicating with a child with an IDD, including gathering information and planning for the provision of appropriate person-centered care. The case study can be used with a specific set of health care providers or as an interprofessional experience with multiple types of health care providers. The case study features Jason, a 4-year-old male who is deaf, has a moderate intellectual disability, and is unable to communicate through verbal speech.

Learning Objectives

Students will:

1. Discuss the impact that serious physical illness, intellectual disability and/or hearing loss can create on a child's physical, cognitive, social, and emotional development.
2. Discuss how to interact appropriately with a 4-year-old child who is deaf, has a moderate intellectual disability, and is unable to communicate through verbal speech.
3. Using a family-centered approach, discuss how to involve a parent and the child in the process of completing an assessment of a child with an intellectual disability and hearing loss.
4. Develop a plan to conduct an initial assessment, using appropriate techniques in approaching and communicating with the child with an intellectual disability and hearing loss and the child's parent.
5. If a simulation lab experience is provided, students will, using a family-centered approach, interact appropriately with the parent of a 4-year-old child who is deaf, has a moderate intellectual disability, and is unable to communicate through verbal speech.

Learner Prework

Read the following sections of [*Intellectual and Developmental Disability: A Toolkit to Enhance Education of Health Care Professionals to Provide Quality Health Care to Persons with IDD*](#):

1. Module 1: Communicating with People with Intellectual and Developmental Disability
2. Module 4: Intellectual and Developmental Disability – Part I: What It Is

3. Module 5: Intellectual and Developmental Disability – Part II: Select Health-Related Issues

Suggested Readings:

1. Module 2: Attitudes, Bias, Ableism, and Stereotyping
2. Module 3: Social Determinants of Health, Intersectionality, and Models of Disability

Optional:

Watch video: The Silent Child <https://www.youtube.com/watch?v=2GbxFIVQv8c> (*This is a moving brief video set in rural England and inspired by real-life events. The story centers around a profoundly deaf 4-year-old girl named Libby who is born into a middle-class family and lives in a world of silence until a caring social worker teaches her the gift of communication.*)

Hearing Loss. Boston Children’s Hospital

<https://www.childrenshospital.org/conditions/hearing-loss> (*This website explains hearing loss, possible treatments, and resources.*)

Suggested Learning Activities

The Jason case study below can be used in a variety of different learning activities. This case can be assigned as a homework assignment or read aloud in class. Discussion prompts are listed to facilitate classroom discussion. The case study, which reflects a real-life situation, can be used as an interprofessional experience with groups working separately and/or jointly and coming together to discuss issues from varied perspectives. Alternatively, the case can be used as a simulation lab experience with a manikin simulating Jason who has moderate intellectual disability and hearing loss. Another standardized patient would portray Jason’s parent.

Jason Case Study

Jason is a 4-year-old (weight: 14 kg) who was born with numerous severe genetic abnormalities requiring multiple specialists to diagnose, begin to provide care, and maintain management of care. According to his parent, he has several developmental delays, including moderate intellectual disability, due to his genetic abnormalities. Among other issues, he had cardiac surgery soon after birth and a tracheostomy at four months of age (now decannulated). He also had a tethered spinal cord and hypospadias, and has profound sensorineural hearing loss. Because he has a congenital absence of auditory nerves, he is permanently deaf. He does not walk independently and does not speak verbally. Jason is learning American Sign Language and attends a school for students who are deaf and hard of hearing; the school is close to his home. His family is also learning to communicate with Jason using sign language.

Jason had a bowel perforation at 11 weeks of age with resection of 12 cm of his small intestine and half of his colon. As a result, he has been diagnosed with short gut syndrome and is dependent on total parenteral nutrition (TPN). Jason's family has been managing his care at home on their own, due to his parents' comfort level with his care and lack of availability of trained home health aides. The school nurse manages his care when he is at school; however, his parents are exploring resources that are available to Jason and his family for the future.

Jason's Current Medications:

Bowel regimen:

Loperamide - 0.1 mg/kg by mouth twice daily

Polyethylene glycol 3350 - 17 g powder packet by mouth once daily PRN for no bowel movements >24 hours

Gastric reflux management:

Famotidine - 0.5 mg/kg by mouth twice daily

Respiratory management:

Glycopyrrolate - 50 mcg/kg by mouth three times daily

Albuterol - 2.5 mg nebulization inhaled every four hours PRN shortness of breath

Budesonide - 0.5 mg inhaled twice daily

For spasticity:

Baclofen - 25 mg by mouth three times daily

For centrally infused TPN:

- Run at 50 ml/hr x 24 hours
- Dextrose 18%
- Amino acid 2.5 g/kg/day
- Lipid emulsion 20% at 2.5 kg/day
- Sodium Chloride 4 mEq/kg/day
- Sodium Phosphate 2 mEq/kg/day
- Potassium Chloride 3 mEq/kg/day
- Calcium Gluconate 2 mEq/kg/day
- Magnesium 0.5 mEq/kg/day
- Tralement 0.2 ml/day
- Pediatric multivitamins

Case Study Discussion Prompts

In a classroom discussion, ask students to plan how they would address the following issues during a health care visit with Jason and his parents. Remind students to use principles of communication, interprofessional collaboration, informed consent, and supported decision-making for children with intellectual or developmental disabilities.

- The impact of significant physical disability, moderate intellectual disability, and hearing loss on a child's physical, cognitive, social, and emotional development.
- How would you address the following issues?
 - The need for an effective way to communicate with Jason.
 - Anticipated changes in the home/family environment resulting in family's plans to change how care is provided to Jason (consider: additional siblings, finances, parents' work, and conflicts with child management).
- Are there relevant issues related to medications that Jason is taking as well as the TPN that he receives via central line?
- In an interprofessional scenario, identify the role of clinicians from your profession and what might you do?
- How would you assess the parents and their immediate and long-term needs? Discuss their means of support, including self-care practices.
- What community resources would be relevant to Jason and his family (including respite care)?

While facilitating the classroom discussion, encourage students to consider the following:

- Determine how Jason communicates and how you can communicate with him.
- Identify priorities that Jason and his family have for his short-term and long-term health care and goals for psychological and social development.
- Identify how you would assess Jason's developmental levels now and in the future.
- Explore strategies to promote Jason's health and developmental needs while meeting the needs of his family related to his immediate and long-term care.
- Identify strategies that acknowledge Jason's parents' long-term care of their son while promoting his independence and autonomy to the extent possible.
- Explore family members' readiness to share care responsibilities with others.
- Identify additional resources that could help Jason and his parents as he grows up.
- Identify any physical issues of concern given the complexity of his medical and health care needs.
- Identify additional members of the health care team who could assist in identifying resources now and in the future to support Jason's and his family members' needs.

Planning Jason's Initial Assessment

In small groups, ask learners to review all available data and plan an initial assessment for Jason.

Optional Activity: Simulation Lab Experience

If the case study is used as a simulation lab experience, a manikin for the child would be appropriate with a standardized patient for the parent. When using this case with SPs, adjust the situation to read the case, review the medication list, and “interview” the manikin used to portray Jason and the SP portraying Jason’s parent. Then discuss the potential issues noted and how they could be approached and managed.

Suggested Reading

U.S. Department of Justice, Civil Rights Division, *Disability Rights Section (2005)*. ADA Business BRIEF: Communicating with People Who Are Deaf or Hard of Hearing in Hospital Settings <https://www.ada.gov/hospcombr.htm> (This website provides information about the ways that communication can occur in health care settings based on the ADA principles.)

Centers for Disease Control and Prevention (2024). Communicating With and About People with Disabilities. <https://www.cdc.gov/disability-and-health/articles-documents/communicating-with-and-about-people-with-disabilities.html> (This website provides an overview and specific tips on what to say and not to say when referring to persons with disability.)

Centers for Disease Control and Prevention (2021). Guiding Principles for Inclusive Communication. <https://stacks.cdc.gov/view/cdc/112847> (This website provides key points to use when describing disability.)

Centers for Disease Control and Prevention (2021). Hearing Loss in Children: Treatment and Intervention Services. <https://www.cdc.gov/ncbddd/hearingloss/treatment.html> (This is a comprehensive website that focuses on hearing loss in children: causes, types, treatment and intervention, recommendations, and guidelines.)

Hearing loss in children (2024). CDC Resources for parents with children with hearing loss, <https://www.cdc.gov/hearing-loss-children-guide/parents-guide/index.html> (This section of the website addresses brief descriptions for organizations, agencies, and corporations that provide information related to children with hearing loss and their families as well as contact information.)

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