

# Communication and Care Management for People with Intellectual and/or Developmental Disability: Sandy 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 enhance provider skills for communicating with people with an IDD, including gathering information and planning for the provision of appropriate person-centered care. The case study features Sandy, a 17-year-old female with Down Syndrome.

## Learning Objectives

Students will:

1. Apply principles of informed consent and supportive decision making for adults with intellectual or developmental disabilities in communicating with people with an IDD.
2. Develop a potential health promotion plan to be discussed with Sandy and her mother during a health care visit.

If optional simulation lab experience is completed, students will:

3. Conduct an information gathering assessment with Sandy and her mother using appropriate communication techniques.

## 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\*](#):

- Module 1: Communicating with People with an Intellectual and Developmental Disability
- Module 4: Intellectual and Developmental Disability – Part I: What It Is
- Module 5: Intellectual and Developmental Disability – Part II: Select Health-Related Issues

Suggested Readings:

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

## Suggested Learning Activities

The Sandy 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 can be used as an interprofessional experience where groups could work separately and/or jointly and come together to discuss issues from varied perspectives. Alternatively, the case can be used as a simulation lab experience with a standardized participant (SP) with an IDD to portray Sandy and another SP to portray Sandy's mother.

### Sandy Case Study

Sandy S. is a 17-year-old female who has Down syndrome. She lives at home with her mother and two older siblings. She received early intervention services beginning at a very young age and has done well in school with support from her mother, siblings, teachers, and educational assistants. She is currently enrolled in a life-skills program and plans to remain in the program until she is 21 years of age.

Sandy has been receiving her health care from a pediatric primary care practice, but her mother has discussed with Sandy the need for her to begin to see a health care provider for adults. Sandy is very comfortable with the providers in the pediatric practice and has been reluctant to make a change. Although Sandy usually follows recommendations from her mother and her health care professionals, she is not willing to participate in health promotion activities, including exercise and healthy eating. Recently she seems to have lost interest in the social activities that she usually enjoys.

Of concern to Sandy and her mother is her 35-lb weight gain in the last 6-8 months. She has irregular menstrual periods about four times per year but has otherwise generally been in good health other than the recent weight gain. She has never had a gynecologic exam and her mother thinks one is indicated because of Sandy's irregular menstrual periods. Sandy tends to rely on her mother to make most decisions for her although her mother would like Sandy to become more independent and less dependent on her.

Sandy was recently diagnosed with hypothyroidism, has started levothyroxine, and her dosage is being adjusted according to her bloodwork. Sandy's recent blood work was showing signs of early insulin resistance with a repeated A1C at 6.0-6.2. Her primary care provider recently prescribed her metformin 500 mg once per day. Sandy has a history of mild Vitamin D deficiency.

**Sandy's Current Medications:**

*Vitamin supplements:*

Multivitamin - 1 tablet by mouth daily

Vitamin D – 1,000 iu by mouth daily

*For Hypothyroidism:*

Levothyroxine - 50 mcg by mouth daily - take on an empty stomach

*For Pre-Diabetes/Insulin Resistance:*

Metformin - 500 mg by mouth daily in AM

*For Constipation:*

Polyethylene glycol 3,350 - 1 capful by mouth once daily; mix with 4 oz of water/ juice

**Case Study Discussion Prompts**

In a classroom discussion, ask students to plan how they would address the following issues during a follow-up health care visit in which Sandy's mother has accompanied her to the visit. Remind students to use the principles of interprofessional collaboration, informed consent and supportive decision making for adults with intellectual or developmental disabilities.

- Transitioning Sandy from a pediatric practice setting for primary health care to adult primary care practice? (Give consideration to transition issues, women's health issues, health promotion [exercise/eating], and risk for depression)
- Sandy's reluctance to participate in health promotion activities
- Recent weight gain of 35 pounds in the last 6-8 months
- Need for gyn visit and exam to evaluate Sandy's irregular menstrual periods
- Sandy's plans after high school and goal for her to be less dependent on her mother
- Sandy's sexuality needs and education regarding establishing safe and healthy relationships
- Future care of Sandy (considering aging parent)
- Based on your profession, what is your role/or what might you do?
- A number of health care professionals are likely involved in Sandy's care (e.g., primary care physician, nurse and nurse practitioner, or physician assistant; dietician, endocrinologist; pharmacist; physical therapist; gynecologist or women's health nurse practitioner); how would you communicate your concerns and plans to the other health care professionals?

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

- Determine how Sandy best communicates and how she would like health care providers to communicate with her
- Consider Sandy's preferences; evaluate her ability to make independent decisions without relying on her mother to make decisions for her
- Identify Sandy's short- and longer-term health goals

- Explore Sandy's views about recent weight gain and reluctance to participate in health promotion activities
- Explore Sandy's responses to new medications prescribed for her, her adherence to new medication schedule, and her understanding of why the medications were prescribed
- Explore Sandy's plans and acceptance of recommendations for transitioning to adult practice and her mother's goal for her to become more independent

### **Developing Sandy's Plan of Care**

In small groups, ask learners to review all available data and draft a plan of care for Sandy.

### **Optional Activity: Simulation Lab Experience**

If the case study is used as a simulation lab experience, hire a person with Down Syndrome to portray Sandy if possible. When using this case with SPs, adjust the situation to read the case, review the medication list, and interview the SP portraying Sandy and the SP portraying Sandy's mother. Then discuss the potential issues noted and how they could be approached and managed.

### **Suggested Reading**

General issues: Healthcare for adults with intellectual and developmental disabilities: Toolkit for primary care providers. (2022). World Press and VKC Live Wire  
<https://iddtoolkit.vkcsites.org/> (This website provides many resources to be used by health care practitioners to provide additional information and support in the care of adults with intellectual and other developmental disabilities).

Reppermund S, Weise J, Cvejic R and Trollor J (2019) How Can We Provide Better Healthcare for People With An Intellectual Disability?. Front. Young Minds. 7:124.  
<https://kids.frontiersin.org/articles/10.3389/frym.2019.00124> (This article describes intellectual disability, the levels and causes of it, as well as associated medical problems and what healthcare professionals can do to support care).

Six Core Elements of Healthcare Transition. 2023. Got Transition  
<https://www.gottransition.org/six-core-elements/> (This website focuses on helping to create smooth transitions from health care for a child to that of an adult).

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