

# Decision Making Case

## IPE Facilitator Guide

### Color key for using this guide:

Black ink- general information, background and/or directions

Red color- Important information

Red color with yellow highlight: The answers to the questions

*Dear Volunteer Faculty,*

*Thank you for participating in our IPE small group discussion. Your role as the small group facilitator is to 1) lead the learners through an interdisciplinary patient case, 2) promote discussion among the group, and 3) obtain student evaluations at the end of the case.*

### **IPEC Core Competencies:**

VE 2: Advocate for social justice and health equity of persons and populations across the life span.

VE 5: Value the expertise of health professionals and its impacts on team functions and health outcomes

RR 3: Incorporate complementary expertise to meet health needs including the determinants of health.

RR 4: Differentiate each team member's role, scope of practice, and responsibility in promoting health outcomes.

C5: Practice active listening that encourages ideas and opinions of other team members.

TT3: Practice team reasoning, problem-solving, and decision-making.

TT2: Appreciate team members' diverse experiences, expertise, cultures, positions, power, and roles towards improving team function.

### **Medical Knowledge Objectives:**

Understand common comorbidities in individuals with Down syndrome

Explore different types of decision-making supports.

Consider long term planning options for individuals who need physical and/or decision-making supports.

### **Administrative:**

At each session we may have a variety of healthcare learners present. This may include medical students, residents, fellows, PA students, nursing students, medical assistant students, social work students.

### **Agenda:**

10 mins Intro and Icebreaker

35 mins Case discussion

10 Evaluation, attendance and wrap up and dismiss.

### I. **Introduction and Icebreaker: Approximate time 10 minutes**

1. Introduce yourselves and the overall goal of the session. You can read the statement below or state in your own words.

*The overarching goal is to prepare learners to work as a team in a clinical encounter with a patient that needs some decision-making support and whose caregivers/supporters are aging.*

2. Ask students to introduce themselves to the group by sharing the following:  
a. Name and school (type of training), where they grew up, and why they chose their field.

## **II. Case Discussion: Approximate time for case 35 minutes**

**A. Facilitators may read this case, or they may ask a student to volunteer to read the following paragraphs:**

Juan is a 45 yo male with Down syndrome, mild intellectual disability (IQ 60), hypothyroidism, obesity (BMI 38), and obstructive sleep apnea (OSA) who comes to the doctor with his parents. This is a new visit as they have just moved to your town after Juan's parents recently retired. The medical assistant rooms Juan and asks what medications he currently takes. Juan can tell the medical assistant all his medications, their doses, and why he takes them. Next the medical assistant gets his vital signs and notes that his heart rate is 58 and his blood pressure is 92/56. He comes out to report this to the provider as this is lower than most patients he sees in clinic.

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***Discussion: Before moving to the discussion, invite students to ask questions if they have questions about anything. Encourage students to answer any of the questions that arise, but if no one responds, provide the answers.***

### ***Questions for Discussion with answers highlighted in yellow:***

1. *How do you feel after hearing the initial part of this case? What stood out to you?*
  - a. *Multiple answers possible including how well Juan knows his diagnoses, medical conditions, and medications.*
  - b. *Heart rate and blood pressure seem low*
  - c. *Just moved to your town, parent retired*
2. *What are some common medical comorbidities in individuals with Down syndrome?*
  - a. *Autoimmune conditions are more common: hypothyroidism, celiac disease, Type 1 DM*
  - b. *Vision problems, hearing problems, hypotonia, autism (16-18%), seizures (bimodal distribution)*
  - c. *Obstructive sleep apnea, atlanto-axial instability, obesity, feeding difficulties as infants*
  - d. *Leukemia*
  - e. *Congenital heart defects, arrhythmias in adult patients with a history of congenital heart defects*
  - f. *Constipation*
  - g. *Early onset Alzheimer's like dementia, premature aging*

The provider goes into the room and asks about Juan's medical history. Juan tells the provider his surgical history, what his medical conditions are, and how he uses a CPAP machine to treat his OSA. In the city they used to live in, Juan worked part time at his local gym and volunteered at the food bank. He

also had some friends that went bowling with once a week. He is eager to find new friends here. You ask Juan if he needs any help with his daily living activities and he tells you that his mom helps him with more complicated cooking at home, laundry, and sometimes with hygiene if he asks her. His parents put money on a debit card for him to use as he has difficulty using cash and making change when at the store. His parents speak up that when they moved to your state, they were surprised that some agencies assumed that they had legal guardianship over Juan.

3. *How do you feel after hearing this part of this case?*
  - a. *Depends on learners' prior knowledge of guardianship/conservatorship: some may assume everyone with intellectual disability needs guardianship, others may note that he is quite independent and that guardianship/conservatorship doesn't seem right for him*
  - b. *Note that he has a job and volunteers and has friends in his old town --> wondering or worried about what that looks like in moving to a new place*
4. *What is legal guardianship/conservatorship?*
  - a. *Definition: "Guardianship, also, referred to as conservatorship, is a legal process, utilized when a person can no longer make or communicate safe or sound decisions about his/her person and/or property or has become susceptible to fraud or undue influence. Because establishing guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable." From the National Guardianship Association*
5. *What are other decision-making supports that are alternatives to guardianship?*
  - a. *Supportive decision making is a notarized, legal document outlining who the patient wants to have supporters in different aspects of their lives.*
  - b. *<https://www.aclu.org/documents/supported-decision-making-resource-library>*

His parents step out of the room for his exam and any other questions you may want to ask Juan privately. Juan is currently not using any alcohol, tobacco, or drugs. He is not currently sexually active and does not report any history of sexual abuse. Juan states that he feels safe living with his parents. He worries what will happen if his parents need help as they age, and he isn't able to help enough. He also worries about what would happen if his parents died. The provider brings Juan's parents back into the room and asks the social work team to go in and meet the family.

6. *How do you feel after hearing this part of the case?*
  - a. *Understanding why Juan is worried as having aging caregivers is a complicated situation*
  - b. *Glad that the provider had the parents step out of the room*
7. *What makes long-term planning particularly challenging for the parents of adults with IDD?*
  - a. *Parents don't want to burden others, even their only family members, with taking over the caregiving of their adult child with IDD. Parents often don't want to think about what would happen if they died.*
  - b. *As adults with IDD unfortunately still have a life expectancy lower than that of the general population, adults with IDD are often meeting the challenges of aging at the same time as their parents.*
  - c. *There are significant mental health challenges for adults with IDD as their caregivers become ill or pass away. Moving to a new living situation as an adult with IDD is also challenging.*
8. *What are some next steps for Juan and his family as they think about their future?*

- a. *Setting up a supportive decision-making agreement*
- b. *Talking together about who would support Juan if they were no longer able to*
- c. *Considering financial planning such as a special needs trust*
- d. *Discuss long-term living situation: with or near other family, in a group home, in a residential setting larger than a group home, etc. Including the funding for long term living.*

Invite any additional questions or comments from students.

### **III. Evaluation, Attendance and Wrap-Up Approximate time 10 minutes**

\*When the session is over (please end promptly), before leaving, ask the students to complete the online evaluations. The student QR code is included in the screen share document.

#### **Student Survey of the IPE Activity**

\*\*\*\* link and QR code

During that time, please finalize the attendance by noting who came late, left early, or had any other concerns. Also please complete the faculty assessment of the activity using the URL or QR Code below. You will need to enter the student's names and disciplines into the form so keep that information handy.

**Facilitators should complete this form and submit it.**

\*\*\* link and QR code