



A Book Study on *When Down Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals, 2nd edition*

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Chapter 1

1. The author of this book shares the family's personal journey of raising a son with Down Syndrome and Autism. Discuss the challenges and strengths they faced in both the school and community settings.

2. Many strategies were put in place for Brennan that proved to be successful. Choose 2-3 strategies mentioned in the chapter. Discuss reasons why you believe these certain strategies were helpful for an individual like Brennan.

3. The author often referenced priming as a strategy that was implemented for her son. In OCALI's Many Faces of Autism 90-minute video, one of the simple strategies mentioned is "Prepare for What's Coming Up Next." View Chapter 6 "Simple Strategies" and discuss ideas you can use with your student or family member. <https://autismcertificationcenter.org/>.



Chapter 2

1. Reflecting on your prior knowledge about autism, how does the information presented in this chapter expand upon your understanding? Discuss specific examples or insights from the chapter that reshaped your perception of autism, its history, and its impact on individuals and society.

2. Reflect on the co-occurring conditions associated with autism described in this chapter. Identify which ones you have observed in the individuals you live with or work with. Discuss challenges that manifest in addressing the complex needs of individuals with multiple diagnoses.

Chapter 3

1. In the "what to notice" part of the case studies, what were some key observations made by the author that can help families and educators better support children with both Down syndrome and autism?



2. Section 3 focuses on adding the diagnosis of autism for teens and adults. Why do you think the author included this section? Why would it be important for families to have the dual diagnosis?

Chapter 4

1. On page 120 the authors point to four categories that most impact children with DS-ASD. Choose one and describe a resource or strategy that you could use to help alleviate the challenge in that area.

2. In what ways can you help to promote self-advocacy and independence for a DS-ASD adult who is transitioning into adult primary and specialty care?

Chapter 5

1. Challenges were identified throughout the chapter in gaining a dual diagnosis. Which did you find could be the most challenging for families and why?



2. As mentioned, there are no diagnostic tools to identify both DS-ASD together. What areas do you believe need further research to better diagnose individuals with Down syndrome and autism?

Chapter 6

1. The authors state that parents seek medication at the point of “whatever may help” or as a last resort. What have been your experiences with this and how can you support families who may be struggling with the decision to use medication?

2. The authors listed several co-occurring psychiatric conditions that could prompt the use of medication. Which of these conditions would you consider your primary concern for someone you currently work with or might work with in the future? Please explain why you chose this condition.



Chapter 7

1. The author gave examples of several strategies to use both in the dental office and at home around sensory challenges. Choose one sensory challenge and the strategy you would use. Get more ideas from our [Autism Center Grab and Go Resource Gallery of Interventions](#)

2. The author presented several resources for professionals and families to access. OCALI has a video: [OCALI | Special Care Dental Presentation: Smile, the Dentist is in!](#) which provides more information on dental care. What other resources have you found?

Chapter 8

1. Review the various intervention strategies presented in the chapter. Which interventions seem most promising and why?

2. How can improved sleep positively affect other areas of life for individuals with Down syndrome and autism? Consider aspects such as behavior, cognitive function, and overall health.

Chapter 9

1. Dr. Patel lists many strategies to use to help alleviate stress for individuals when going to a medical appointment. Many of these strategies take planning. Which one would you consider using or recommending to others who have DS-ASD and why?

2. Virtual medical visits were mentioned several times throughout the chapter. What are the benefits and challenges of these types of visits for individuals with down syndrome and autism?

Chapter 10

1. The authors make a distinction between nonverbal vs. nonspeaking. Describe what the implications for each term are for how individuals are viewed when describing their communication this way.

2. What assessments are you/your organization using when determining communication challenges and strengths? Who is part of this team? For more information on communication assessments for communication visit: [Assistive Technology Internet Modules](#)



3. When reading about behavior strategies the authors stress that you must first determine the underlying function. Page 283 lists the most common underlying behavioral triggers. When you think of someone you know or have worked with who has complex behaviors, what was the function and how do you know (what were the antecedents and/or setting events).

4. How might you work with an occupational therapist in your home or organization to meet an individual's sensory challenges?

Chapter 11

1. How can families and schools collaborate to cultivate an empathy-based approach to understanding different perspectives? Discuss specific strategies that could be implemented to encourage this kind of environment and the potential challenges that may arise.

2. The author states “when communication is lacking between a parent and educator, misunderstandings are certain to occur, which can only impede the educational goals for the student.” How do you communicate to ensure success of your child/students?



3. What do you do to ensure an effective IEP meeting? What suggestions from this chapter may help to improve these meetings?

Chapter 12

1. Discuss some of the primary reasons for delays in diagnosing autism in minority populations. Reflect on systemic, cultural, and socio-economic factors that contribute to diagnostic delays.
2. Examine the differences in access to services among different ethnic groups. What barriers do minority families face in accessing appropriate and timely interventions for individuals with DS-ASD?
3. Review the considerations of values, beliefs, life ways and intervention tips in working with multicultural families listed on pp. 342-346. Provide examples of how understanding and integrating cultural elements can enhance the effectiveness of interventions for individuals with DS-ASD.



Chapter 13

1. Share a personal story or an anecdote about a family's journey upon receiving a diagnosis of autism and/or Down Syndrome. How did the family react to receiving the diagnosis? Discuss the type of support the family had at the time of the diagnosis.

2. In what ways can professionals and community members effectively support families navigating both Down Syndrome and Autism Spectrum Disorder? Consider strategies related to emotional support, practical resources, and advocacy.

3. How can understanding the unique challenges and strengths associated with DS-ASD inform the development of more inclusive and effective support systems?

Chapter 14

1. In this chapter, we explored anecdotes from different family members that offer insights into the experiences of raising and/or being around a loved one with DS-ASD. Reflect on which of these stories resonated with you the most and how they influenced or altered your perspective on the challenges and rewards of this journey.



2. As shared in this chapter, family members talked about the crucial role of routines and patterns for their loved one with DS-ASD. To see how these ideas and methods connect with the families' experiences, check out [OCALI's Autism Internet Modules](#) on Rules and Routines.

Chapter 15

1. In what ways do the experiences shared by parents and caregivers in this chapter illustrate the impact of finding a supportive community on their well-being and effectiveness as caregivers? How did their connections with others experiencing similar challenges influence their approach to supporting their children or loved ones with DS-ASD?

2. The book discusses the feelings of grief and loss that family members often experience following a diagnosis of DS-ASD. How can we effectively support and encourage family members grappling with these emotions? What strategies or approaches from the book can be used to help them navigate their feelings and find a path toward acceptance and hope?

