

## Sam's Story, Age 14

Sam is a 14-year-old individual with Down syndrome. His parents, Jessica and Jon, have found support from the nearest Down syndrome clinic since he was an infant. We first met Sam when he was 4 months old. Before age 1, Sam underwent cardiac surgery and has had no further cardiac problems post-surgery. The family includes Sam in family activities with his older sister Emma, age 17, and he participates in Special Olympics held in a neighboring town.

This year Sam is a sixth grader in middle school. His individualized education program (IEP) includes support from a special education teacher to adapt educational materials because of his intellectual disability. On his last cognitive testing (*WISC-III*), he received a score of 49 (in the moderate range of intellectual disability). Academically, Sam demonstrates competency in sight-reading of common signs, his class schedule, and a chore list at home. He uses a digital watch along with a class schedule to keep track of upcoming transitions for his favorite classes. He understands and participates in simple games and follows two-step directions. Sam uses short sentences of three to five words and is understood much of the time by people familiar with him. Strangers may find it difficult to comprehend Sam if the context is out of sight. His fine motor dexterity skills are delayed, making it difficult for him to manage clothing fasteners, and his mother has adapted his clothing to make tasks easier for him. With these adaptations, he is independent in dressing, bathing, and toileting with some reminders. His parents are pleased with his mastery of daily living skills.

Several students in his classroom have known Sam since grade school due to the small size of the school district. Students have been supportive and included him in selected school activities. Outside of school he is not invited to participate in their activities. Sam considers others at Special Olympics as his friends, but due to distance he only sees them on event days. He does not talk on the phone or text, but he does send pictures of his dog and family activities to his grandmother with the help of his mother. He enjoys spending time with his grandmother and occasionally stays overnight at her home. The family often selects recreational activities that Sam enjoys, including camping, bowling, and shooting baskets. He likes to spend time outdoors and also enjoys participation in simple carpentry activities with his father. At home Sam has some chores that he does, including feeding his dog, clearing his dishes, and vacuuming.

Recently, Sam has been inappropriately masturbating in front of others at home and school. This has created a problem in the classroom and at home. His sister Emma is no longer inviting her friends to the house as a result and has been unwilling to have him join her in community activities, as she worries his behavior may be inappropriate. His parents have talked with him about restricting this behavior to his room, but to date he does not exhibit self-control. At school, the staff has tried redirecting him to computer or craft activities that require the use of both hands but with little success. On occasion, at school Sam has pulled up his shirt to show his scars from surgery to a substitute teacher. The school notified his parents and asked them to discuss this behavior with him. Jessica and Jon are concerned that this new behavior will jeopardize his previously good relationship with teachers and students. In addition, they have always appreciated Emma's caring attitude towards Sam and are worried that this is changing.

### Summary

*His parents have been pleased with Sam's school program and his progress. They have worked hard to develop his independence in daily living skills and primarily structure their free time with activities that Sam enjoys. Jessica and Jon wish he had close friends. He has recently been inappropriately masturbating at home and school, causing challenges for the school staff and parents. His sister who has often spent time including Sam in activities has started to withdraw.*

*Sam is now a 14-year-old boy with Down syndrome who is participating in a regular education classroom with support of a special education teacher. He is functioning in the moderate range of intellectual disability. He lacks friends and has developed socially inappropriate behavior in the form of masturbation and lifting his shirt to show his scars.*

### Follow-Up Suggestions and Recommendations:

- 1. Seek out a resource to provide support and guidance to the school and family in developing a plan to address inappropriate behaviors. Perhaps a school or community psychologist or staff at the Down syndrome clinic could be a resource. Include all staff at school who work with Sam in implementing a consistent behavior plan. Consider adding a nurse and occupational therapist to Sam's IEP team to help address socially appropriate behavior in a visual modality to help Sam understand these concepts. A specially designed sexuality curriculum for individuals with intellectual disabilities may be useful if not already in place. Occupational therapy (OT) consultation may be useful to address or replace behaviors that provide sensory inputs.*
- 2. Seek out additional resources for developing friendships and activities in which Sam could practice social skills, such as humane society volunteer programs.*