

Aidan's Story

Aiden is a 10-year-old boy who has a medical diagnosis of spina bifida. He is in fifth grade. His parents are recently divorced and share custody. He is their only child. Aiden spends more time at his mother's home, which was adapted in the past to make things more accessible for him. His father would like to see Aiden spending more time at his home but knows Aiden is frustrated in the new space. Aiden enjoys school and is able to participate in school clubs. He is particularly fond of games and storytelling. His teacher recently challenged his class to develop their own game. Aiden is liked by his peers; they consider him a friend, and the feeling is mutual. Although they like to be helpful when needed, they also enjoy hanging out with Aiden.

Aiden's parents first became aware of his diagnosis during a prenatal ultrasound. Because of his need for specialized care, Aiden has experienced regular medical appointments with a multidisciplinary team at a spina bifida clinic. His parents have found the parent group sponsored by the clinic helpful.

Aiden has hydrocephalus, a common occurrence with spina bifida, which required placement and revision of a shunt. He has had orthopedic surgery for alignment of his ankle, and the orthopedist continues to monitor muscle contractions. Nutrition, neuropsychology, urology, neurosurgery, physical therapy, occupational therapy, and social work follow him through the spina bifida clinic. Aiden was introduced to a wheelchair for mobility as a preschooler, and he uses it at school and in the community. With the use of braces, he can walk short distances, but this has become increasingly harder this past year.

When Aiden began school, a 504 plan provided accommodations for his limited mobility, his need for regular bowel and bladder care, and guidance to eat a healthy diet to avoid weight gain. In second grade, his teacher had concerns about his comprehension skills and memory abilities. An individualized education program (IEP) was developed, which added speech and language therapy and time with a special education teacher in a small group to support his learning. Testing at that time revealed an average IQ (94 on the *WISC-III*), but with a split between his Verbal and Performance IQ scores. His Receptive Language score (77) was significantly below Expressive Language (86) score on the *Clinical Evaluation of Language Fundamentals*.

Currently in fifth grade, Aiden is demonstrating a larger gap in academic skills than was noted in past years. Abilities in language arts, math, and spelling are particularly concerning. With adaptive seating, his handwriting is good for short assignments, but longer tests are often not completed in the time available. The school nurse works with Aiden with bladder catheterization and has him assist with a goal of Aiden managing his care independently in the future. Remaining on a consistent schedule has helped to decrease occurrence of bladder infections. Because of a potential latex allergy due to the daily urinary catheterization, all staff are aware of a need to eliminate latex in classroom activities.

Orthopedic surgery is scheduled for Aiden this school year to address muscle contractions in his hips and knees. His mother is concerned that he will get further behind while missing school, and she is concerned that she may not have enough sick leave to cover his recovery. She is also concerned that his diet is no longer ideal, and a recent gain in weight has been seen. Although Aiden can do some of his dressing tasks, getting on his pants takes an increasingly longer amount of time with current muscle contractures. His parents previously shared assisting Aiden in the morning.

Summary

Aiden is a 10-year-old with spina bifida, who is experiencing new challenges with learning and is adjusting to his parents' divorce. He has gained weight recently, has greater difficulty with walking, and will have surgery for muscle contractions this year. He needs assistance with daily activities and monitoring of his health.

Aiden's parents are adjusting to sharing custody of a child with ongoing medical needs. His mother is concerned about his challenges with learning, the upcoming surgery, and missing school. They are pleased that he has friends and interests outside of school. They are concerned that their divorce is causing additional challenges for Aiden with the emotional stress it has introduced into his world.

Follow-Up Suggestions and Recommendations

- 1. Further evaluation of learning style by neuropsychologist at the Spina Bifida Clinic or school psychologist with recommendations for programming.*
- 2. Reconvene IEP meeting to revise plan to support his learning needs. Consider evaluation of alternatives to lengthy written work, possible use of verbal reports and tests, adaptations for writing, e.g., use of computer programs for note-taking/written work.*
- 3. Use of homebound teaching after surgery. Inclusion of active physical therapy services at school after surgery.*
- 4. Outpatient physical therapy after surgery.*
- 5. Possible counseling for Aiden related to divorce.*
- 6. Seek out resources to help evaluate and prioritize home adaptations needed at father's home.*
- 7. Consultation with spina bifida clinic staff or community resources for weight gain.*
- 8. Parents may benefit from connecting with members of the parent group or another group for divorced parents.*

