

Case Example: William K, Age 8

Medical History

William K was born at 24 weeks gestation (born 16 weeks before his due date) with a birthweight of 475 grams (equivalent to 1.05 pounds) who had a variety of complications following birth. He experienced CLD, pPHTN, Hypotension, and SIP. He was intubated and required ventilation and then iNO for an extended period of time due to pulmonary hypertension. He required pressor support and has a Complex GI history with a SIP requiring removal of 3cm distal ileum with ostomy formation. He spent his first six months in hospital. Since hospital discharge, he has been reasonably medical stable, but the family has had difficulty returning for specialty appointments.

School History

William received early intervention and preschool special education. He then entered The Lovely Elementary School and was found eligible for special education with a disability of "Developmental Delay." The IEP team later established that William has a specific learning disability including a two-year delay in reading. **His current IEP includes 60 minutes per week of specialized instruction for reading skills and two 20-minute sessions of speech therapy** to work on articulation and processing of auditory information. He also has been encouraged to participate in an anger management class with the school counselor as he has resisted adult-directed activities and has had frequent altercations with children.

Family History

William has had multiple primary caregivers since six months old. His mother has been involved in his care, but she is currently living separately with her male partner. William's Grandmother has been his primary caregiver for the last four years. There are also three high school-aged aunts who reside with William. His Grandmother reports that one of the aunts has a close relationship with him and enjoys helping him with his homework.

It is important to note that his Grandmother is often unable to get time off from work for and does not have consistent access to a car. Bus rides take between 60 and 90 minutes each way for follow-up hospital visits which are attended inconsistently.

Hospital Evaluation

William's pediatric nurse practitioner recommended a comprehensive evaluation at the Major Children's Hospital because she did not think the school was adequately addressing William's need.

Following parental consent, an evaluation team consisting of a developmental pediatrician, speech and language pathologist, occupational therapist, educational diagnostician, social worker and psychologist evaluated William over the course of three days. The clinicians observed William in the Child Life playroom, conducted extensive assessments, reviewed school records and interviewed mother and grandmother.

They concluded that William had a variety of disorders as a result of his extreme prematurity and the complications that he experienced during his early months of life. They explained that children like William often have delays in language development, find it difficult to be in situations with loud noises, have problems focusing on activities and other learning concerns. His Grandmother said that nobody

had told them this before, and they just assumed that William would do fine because he had been a “miracle baby” in the hospital.

General Recommendations

The Hospital recommend that William be coded for Multiple Disabilities (Specific Learning Disorders in reading, writing; Emotional Disability). They suggested accommodations and interventions that support his cognitive, attentional, behavioral, social and emotional difficulties. They recommended an educational environment that included trauma-informed accommodations and interventions that are structured to allow him to learn at his own pace and address the needs of a child who has had exposure to adverse experiences and traumatic stress.

Specific Recommendations

- **10 hours a week of direct special education services (including 2 hours of consultation for his teachers and other service providers)**
- **5 hours a week of specialized reading intervention (e.g. Kurzweil program)**
- **45-minute sessions (3-5x a week) speech and language therapy**
- **30-minute sessions (2-3x a week) occupational therapy**
- **1-2 hours a week consultation with psychologist**
- **Weekly counseling to Grandmother and mother by school counselor**

Special Considerations

William’s problematic behaviors may be learned behaviors that were adaptive in a previous time or environment and may have been attempts to cope with or understand the upsetting and/or confusing, disturbing or painful events that he has experienced in his life thus far.

William’s symptoms may put a strain on positive parent-child interactions. His caregivers may desire ongoing support and education to maintain positive feelings toward him and prevent feelings of isolation and resentment.

William should be given alternative behaviors with a combination of stability, appropriate adult models, and unconditional positive regard from caregivers.

William should see in the home models of regulated responses to daily/minimal stressors. Adults can model such strategies as taking a walk, self-time-out, counting to ten, taking deep breaths, problem-solving, etc.

William’s grandmother said that she has been overwhelmed at previous meetings. She said that people talk too fast and that she doesn’t understand what they are telling her. To assist her in the IEP process, resources were provided to the family to enable them to invite an educational advocate to attend the IEP meeting