

## Jayla's Story

Jayla is a 16-year-old girl who is a member of the Chippewa Tribe. She lives with her maternal grandmother, Leighanne, on an Indian reservation in northern Wisconsin. Leighanne works as a legal assistant for the tribe. Jayla has been in her grandmother's care since she was a baby. Jayla's mother, Bree, has a cognitive disability. Bree became pregnant when she was 15 years old. The whereabouts of Jayla's father is unknown.

Jayla was diagnosed with Prader-Willi syndrome (PWS) as a baby. As a newborn, she had lots of difficulty feeding and had very low muscle tone that prevented her from getting enough nourishment. She was diagnosed with failure to thrive as an infant and had a g-tube for about 10 months until she was able to feed on her own. As a preschooler, Jayla developed an intense interest in food and began to put on weight. She was eventually diagnosed when she was 3 years old, through an outreach genetics clinic, with Prader-Willi syndrome. Bree and her mother were counseled about how to structure their home to limit Jayla's access to food. They met with a dietitian to learn about the need for Jayla to have a low-calorie diet and exercise. Bree had lots of difficulty understanding Jayla's condition and providing the structure needed to limit her access to food. As Bree approached her 18<sup>th</sup> birthday, Leighanne made plans to retain guardianship of Bree and to become Jayla's legal guardian. Bree refused to have Leighanne be her guardian but agreed to have her become Jayla's legal custodial parent.

Bree graduated from high school and began working in the tribal daycare setting part time. Leighanne reduced her hours to stay home with Jayla. She had locks put on all of the cabinet doors as Jayla grew and became independent and her food seeking behavior increased. Leighanne put structure into every aspect of Jayla's day, picture schedules, planned activities, timers, anything to keep Jayla from food seeking. Jayla progressed through school with support from a special educator to address difficulties in learning and continued support of a dietitian and public health nurse. This life was not what Leighanne had imagined. The amount of structure and redirection required to raise a child with Prader-Willi seemed without boundaries.

At age 16, we see Jayla living alone with her grandmother. Bree left the home when Jayla was 7 years old and has had little contact with her mother. Jayla has moved into high school. Her obsessive food-seeking behavior has reached a new level of intensity. Leighanne has found Jayla in the neighbor's garbage can eating food that has been thrown away. The school has reported similar activity; Jayla has been found opening trash bags at school looking for food. This has caused some significant social rejection, and Jayla has been having behavioral outbursts at home, at school, and in the community. Leighanne is concerned about Jayla's disrespect, incessant talking, and constant picking at her skin. Leighanne longs for solitude.

### *Summary*

*Despite Leighanne's best efforts to provide rules, structure, and a healthy diet for Jayla, her symptoms of PWS are causing significant stress for Leighanne. Leighanne is*

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*concerned that she does not have what it takes to keep Jayla from eating garbage and that Jayla's behavior is pushing her to her own personal and spiritual limits. She is having difficulty seeing a positive future for herself and for Jayla.*

*Jayla is an adolescent girl with Prader-Willi syndrome who has excessive food-seeking behaviors and other emerging obsessive behaviors. She is showing behavioral challenges in the form of argumentativeness, disrespect, and outbursts in the community.*

*Follow-Up Suggestions and Recommendations*

- 1. Leighanne and Jayla may benefit from a referral to a behavioral and/or mental health specialist to address some of the obsessive behaviors.*
- 2. Leighanne could benefit from contact with other families who have teenagers with PWS for support and strategies.*
- 3. School staff should be working with Jayla and Leighanne around independent living skills as part of her transition plan in her IEP.*
- 4. Discuss respite options for Leighanne within the tribal community or outside the community.*

