

Prepared by Lisa Thornton, president of the Utah Prader-Willi Syndrome Association

Questions presented during the appropriations committee meeting on January 30, 2008, regarding the proposal for the care manager for families affected by Prader-Willi syndrome in Utah.

1. Question by Representative Newbold: Is Prader-Willi syndrome considered a disability? What is its classification? It is covered under traditional Medicaid?

Answer: Prader-Willi syndrome is considered a disability. The syndrome is a genetic disorder occurring on the 15th chromosome. The syndrome is diagnosed through a blood test.

The World Health Organization International Classification of Diseases give Prader-Willi syndrome the code: Abbr. ICD 9 Code 759.81. This classification fits under the category of chromosomal abnormalities. This classification system is one of the two most common used in the United States and worldwide.

Medicaid covers people with Prader-Willi syndrome. For people 18 and over, SSI requires that to be eligible, the applicant must show: (1) a disability and (2) a specified asset and income criteria. In no case has an individual with Prader-Willi syndrome failed to show they have a “disability” under the SSI requirements. If the applicant is under 18, the only difference is that the parents’ income/assets are considered in the determination. Again, Prader-Willi syndrome is considered a disability for those applicants.

As a side note, this last December, the Social Security Administration heard testimony regarding listing Prader-Willi Syndrome (along with other rare syndromes) as an automatic qualifier. Based upon the risk of food seeking and behavioral issues (that make most of those with the syndrome unable to work in traditional employment settings), SSA officials indicated that Prader-Willi Syndrome will likely be added to the “List of Impairments” for which disability is automatically presumed. This change should occur this year.

2. Question: Would the intervention (care manager) help those who do not qualify for Medicaid? For those that do qualify for Medicaid, would they qualify for the intervention (care manager)? If they do not qualify for that, what do they qualify for, what kind of services?

Answer: All individuals affected by Prader-Willi syndrome in the state of Utah would be served by the proposed care manager, regardless of Medicaid status. The care manager would help those who do not qualify for Medicaid. Currently, the parents of a child with Prader-Willi syndrome completely organize the care for their children. Many are not getting the medical, behavioral, and educational interventions that are currently available in the state of Utah either because of lack of knowledge by the parents, physicians, or both. Many parents give up because of the complexity of care. Families are breaking

apart, with many of our children suffering devastating health consequences and early death. Often the state has fully paid for housing and medical care in the last few year of the child's life.

For the few children with Prader-Willi syndrome that currently qualify for Medicaid in Utah, this intervention (the care manager) would also serve them. Currently, none of these children on Medicaid has a Medicaid care manager that is managing their care. One child (in foster care) has a team helping him through DCFS. However, the team calls the parent group to organize the medical, educational, and behavioral care needed for this boy.

New Mexico currently has a full-time care manager in place who serves 58 families. The state allocates \$90,000 for this position. This model has proven highly effective, especially in saving medical costs and hospital expenses for the state and for keeping children with their families.

Summary:

The annual cost to support the proposed care manager would be more than recaptured by bringing a single individual into a well-managed condition or by preventing a single individual from losing control. The legislature could set important precedent for cost-effective management of rare conditions that have highly distributed medical and behavioral support needs by sponsoring a care manager to establish accountability and to advocate for families affected by Prader-Willi Syndrome.