

Review: T1D + very low intelligence.

Problem: In the current waiver system there is an assessment given to evaluate the level of care needed for a mentally disabled person and then a formula determines the number of minutes that is required to provide that care. Today, this system has no mechanism in place that accounts for the need of a person that has the combination of Type 1 Diabetes + very low intelligence which creates a huge gap in the care that is needed vs. what is allocated.

Why is this a problem: A person who has Type 1 Diabetes (T1D) must manage their blood sugar 24 hours a day in order to live. If not managed properly then a range of bad outcomes follow. High blood sugars make you feel sick and over time will destroy your vascular system and cause blindness, loss of limbs and death. Low blood sugars starve the brain of fuel which causes confusion, seizures, and then death. An untreated extreme low blood sugar event can cause death in minutes.

When you mix this disease with a person who has very low intelligence, it requires another person to manage this disease for them 24 hours a day. This is certainly true for Kenzie who operates at between a four- to five-year-old intelligence level. Kenzie can not read, write, do math, understand the concept of time, etc. Without another person to manage her T1D, Kenzie would die very quickly.

Kenzie requires insulin dosing all throughout the day and night. The MN law says that providing insulin requires a nursing level adult or a parent to administer because over-dosing can cause death. That means that families on the CDCS waiver require the hourly wage of what the state of MN sets for nursing care in order to hire the required people. In fact, due to the current law, the county will not allow a caregiver to give Kenzie insulin. Anyone who is providing care for Kenzie – their first duty is to keep her alive. The county says that it has to be a nurse – but will not provide the funding to hire a nurse. Everywhere you turn, the current laws are preventing Kenzie from getting care.

Families on the CDCS waiver: Families on the CDCS waiver provide a portion of the care at no cost. That is part of being on the CDCS waiver. In cases like Kenzie's case – an equitable care disbursement would be 50-50. 12 hours of care funding provided from the waiver and 12 hours of care provided by family at no charge. The best way to do this is to have an exemption for 9 hours of care at the current nursing pay scale. This combined with minutes given for daily needs will amount to about 12 hours of care a day. There is never a day off from T1D so this care must be provided 365 days a year.

How many nursing level care minutes is the assessment currently providing people who have T1D + very low intelligence? Answer: Zero.

Kristi and I have been providing 24-hour care for Kenzie for 3 years now (since all school programming has stopped) without being provided with the funding that is required to hire providers for her. This situation requires families to have to quit their careers and provide most of the care unpaid which causes financial problems. Having Kenzie for a child has made us experts in what it takes to provide care for a person with T1D + very low intelligence. We can hire the right people and train them. Families shouldn't have to quit careers, lose homes and exhaust savings just to share the care needs of people with T1D+DD.

Everyone involved in this process agrees that the T1D+DD situation is a giant missing piece in the assessment. The problem is that the county needs the assessment to allocate the correct funding so that they can then allocate it to the family. If we can keep people like Kenzie in their home and split care coverage with families, it saves 70% of the cost it would take if the person was to be placed in a nursing home. Group homes cannot guarantee “no-gap” coverage, so the options are limited.

According to a google search, in 2015 Minnesota had approximately 950 people with T1D. It doesn't say how many of those people also were mentally disabled. But I would say that guessing that there may be 100 people with this DD+T1D would be a close guess. It is a small number so the overall cost would not be difficult. But the impact on these people would be life-changing and lifesaving.

Thank you.

Kristi and Shawn (Kenzie) OKeefe