



Tuesday, March 7, 2017

Ways and Means Committee

Testimony in support of SB 173 by Deb Voth, President

My name is Deb Voth and I am President of Rainbows United, Inc. in Wichita, Kansas. We provide services annually to more than 3,500 children and youth with special needs ages birth to 21 years and their families. **I am here today in support of SB 173.**

SB 173 impacts services to **13 year old Janna who is non-verbal, cannot stay by herself and needs one-on-one individualized care** to help with every bodily function. Her wheelchair provides her some independence as she goes from home to school and other places in the community. **Janna is dearly loved by her family**, including her parents and 2 brothers.

The I/DD Medicaid Waiver service that Rainbows provides and Janna uses is **Personal Care Services (PCS) for children and youth between the ages of 6 and 21 years**. This service is best described as In-Home Care which occurs in the family home or other location in the community, After School and All Day Latchkey, plus Weekend care in one of our centers. And an 8 week Summer Day Camp.

Children and youth who qualify for I/DD under the State's eligibility criteria require care or supervision beyond what is needed for typically developing children. For these children and youth, quality specialized care is needed to meet the individual's basic needs, ensure his or her safety, and prevent physical self-injury or injury to others. **Parents need a safe environment and knowledgeable caregivers for their child with special needs to have quality of life.**

Parents of children with special needs often experience isolation, stress, and exhaustion when they do not have regularly scheduled care for their child provided by others. In response to a recent survey to families we serve, of the 52 parents who provided data, **49 (94%) rated their stress lower now that they have Personal Care Services**. Twenty-eight (28) parents (or 54%) reported their stress level would go even higher than it was before they received care if care was not available.

This **chronic stress on parents impacts the family and leaves parents susceptible** to inconsistent work attendance, depression, anxiety, insomnia, and poor sleep quality. The family may become dysfunctional, creating other challenges for the community.

One example of a youth who benefits from PCS is Gage a high school sophomore who has ADHD, autism and developmental delays and has frequent outbursts when he becomes anxious. He needs a place to go where staff understand his needs and are ready to redirect his challenging behaviors before they get out of hand. Last Summer attentive staff at our Summer Day Camp figured out that by having a “pretend phone conversation” Gage is more likely to express his feelings rather than act out his aggression and cause disruption to those around him or hurt himself. **PCS helps this young man be successful and safe.**

In 2016, Rainbows provided **55,767 hours** of Personal Care Services for an unduplicated number of **151 individuals** between the ages of 6 and 21 years. For each hour of PCS care provided by Rainbows through the I/DD Medicaid Waiver, we receive \$12.24/hour. However, the cost of the care is \$16 an hour. That equals a **loss of \$209,684 last year in this one service area alone.**

So why do we continue providing this service? Rainbows provides PCS because we know parents depend on it to work, go to school, attend an activity of another child or just have a break from the 24/7 demand of caring for a child with significant disabilities. For the families we serve, **85% use this service so they can work.** Without Personal Care Services, many parents say they would not be able to keep the job they have and provide an income for their family. Some would have to work fewer hours or be in lower-paying jobs or even stop working all together.

In Sedgwick County, there are **only two providers of Personal Care Services left** including Rainbows. Two providers dropped out at the first of the year due to low reimbursement rate and difficulty finding staff.

Rainbows estimates **165 hours of care go unmet each week** for those seeking services from us. It typically takes 4 staff members to meet the care needs of one individual served. We cannot find quality staff at the rate we are able to pay. **Candidates must pass eleven required background checks** as well as have a desire to take care of the multiple needs of the children.

On behalf of 6 year old Jesse who needs extra medical attention, is fed through a tube and takes medications to keep him alive; and 17 year old Tina who grows socially by going on field trips and participating in community activities; **I ask you to strongly consider the important impact of SB 173 on individuals across the State who are depending on others to act in their best interests and say YES.**

Thank you.