

To ; The HHS Medicaid Commission

July 11, 2006

In 1972 a motorcycle driven by a teenager hit our healthy, active 10-year-old daughter, Becky. She survived but as a result has severe brain damage. She spent 9 months in two hospitals before coming home in 1973. At home we had a nurse for 6 hours, five days a week. Carolyn was her primary caregiver and mother of two younger children. Wayne met with government officials to see if a longer-term solution could be created. After one year at home our fund for at-home nursing was depleted.

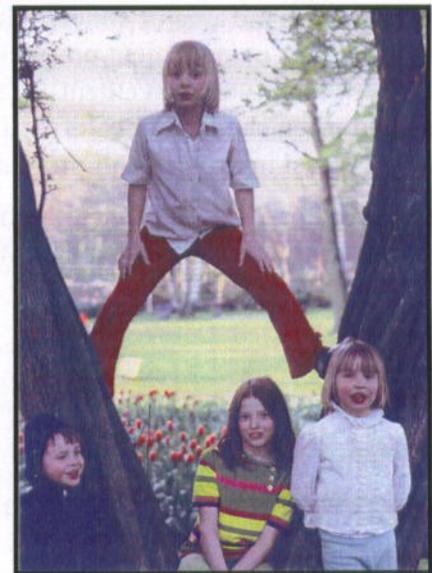
In 1972 to 1973 there was no program to help with support for kids like Becky. Medicaid didn't really start until 1975 with ICF/MR community programs in Minnesota. Our only choice was a state hospital, which we visited and the conditions were not good. People were on gurneys with sheets over them and it was all two staff could do for 50 to keep them clean. People with developmental disabilities had no choice.

Local support systems, neighbors, family and our faith enabled us to get through those early days and keep our family together. The odds weren't great but we and other parents started Homeward Bound, a non-profit ICF/MR program for medically involved children. A federal insured loan for a building and bipartisan support of fundraising for start-up costs enabled us to qualify for Medicaid funding in 1975. Becky qualified for Medicaid because her disability occurred before age 18.

We have been married for 45 years. Becky has three siblings and seven nieces and nephews. She now lives in a four-bedroom home in Eden Prairie, Minnesota with three other women who all receive supports from paid staff under waived services. Becky still requires total support in daily living, is non-verbal and non-ambulatory but goes to a workshop daily. She expresses emotions, we get bear hugs and she participates in family gatherings. She is limited in her ability to communicate but is able to choose her activities and which caregiver works with her. Medicaid has allowed her to have a more normal life over the past 30 years, her life has more positive outcomes compared to the gurney and sheets that the state hospital had to offer. Medicaid has made a real difference in her life.

Medicaid also allowed us to have a family life and provide a secure environment for our other children, while being the primary advocate for Becky in her daily life. We continue to be involved as advocates for Becky and others with Developmental disabilities. That original program in 1975, Homeward Bound, supported 16 children and now serves over 100 children and adults in 20 locations in Minnesota. We both have continued the connection to that program. However, we have also been involved with the ARC and kept a life with our family, church, and friends.

Wayne's work today is Executive Director of Mount Olivet Rolling Acres, a church affiliated non-profit organization that serves over 700 people with disabilities with 375 staff providing: in-home, respite care, foster homes, waivers, ICF/MR and supports to people in Crisis. We also are implementing



a pilot project with an HMO that combines Medicare and Medicaid funds to provide case management, acute/primary medical care, prescription drugs, residential living, and employment services to adults with a developmental disability in the Twin Cities area. CMS and the State of Minnesota have been partners in this initiative.

Our experience as parents and as a provider these past 34 years since Becky's accident has given us the perspective that stability with Medicaid for vulnerable people with disabilities is critical. Flexibility and creativity is also essential so that quality and affordability are not overcome by regulation and funding changes. A real choice of providers and the ability to take the entitlement elsewhere are powerful options to ensure quality.

Technology and Quality are basic to services in today's environment at Mount Olivet Rolling Acres. A web based Information System allows all involved staff and guardians to view client files. With guardian approval the county social worker, work program staff and medical providers can also view files. Examples of what this means in real life are: families can see results of medical appointments to ask questions and be informed; the work program can see a calendar of medical appointments to coordinate schedules; a Common file system exists with Risk Management Plans.

We encourage the use of Quality Improvement systems so providers don't focus on minimum standards or whatever is the area of concern this year by the federal survey system. This past year a survey focus was on money management programs for all. What is more important to us is a dedication to reduce turnover (Quality Improvement) so workers know our daughter and can then bring her to church or understand when she is not healthy. The national turnover rate is over 50% for direct support professionals. This must improve so all programs can have a quality workforce that is valued by society.

Thank you for this opportunity to share our experience with you. Medicaid has been important to Becky and to thousands of Americans in Minnesota and throughout our Nation.



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