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TESTIMONY FOR TEXAS SENATE HEARING
MEDICALLY FRAGILE CHILDREN

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Yesterday I attended the tenth birthday party for a boy named Rusty. Ten years ago I worked with Rusty's mother to try to find an alternative to placing her son in a pediatric nursing home. Ten years ago we were trying to close the last pediatric nursing home in the state by finding alternatives for the children who lived there. Rusty was ready for discharge from the hospital. He had Vater's Syndrome which left him with a tracheostomy, a gastrostomy, a colostomy, an amputated leg, and recurrent apnea. His single mom had no home, no car, no friends, no insurance, and no plan to care for Rusty except her will. We provided Rusty's mother with enough support to enable her to take him home, including sixteen hrs a day of in home nursing. The whole package amounted to \$145,000 the first year he was home. He still has the same medical condition, but his support now is \$10,000 per year. How and why we did that for Rusty and his family is what I would like to share with you today.

As a point of reference, let me describe the Michigan system. The Department of Mental Health, where I work, is responsible for services for people with developmental disabilities. The Department of Social Services is responsible for child welfare and protective services. The Department of Public Health is responsible for licensing and regulation of health care facilities. Ten years ago, children with significant health care problems were served, and sometimes not served, by this fragmented system, much like what I've heard described as a problem here in Texas.

By way of historical perspective, the Department of Mental Health had eleven institutions in 1972 with 12000 residents. Eight of those have closed and the population of those remaining is under 400 and falling. The Department of Mental Health also had developed seven specialized nursing homes exclusively for people with mental retardation which served over 1000 people. Six of those are closed with the last one to close in March of this year. The Department of Public Health licensed 3 children's pediatric nursing homes serving 300 children which have since closed. A small number of children had also found their way into geriatric nursing homes.

My experience has been as a staff with the Department of Mental health for the past 19 years at the Macomb Oakland Regional Center. I worked there on a pilot project to provide support to birth families, including a cash subsidy. The project was the precursor to Michigan's Family Support Subsidy Legislation which provides a cash subsidy to all families in the state with a taxable

income under \$60,000 who have a child at home who is severely disabled. Of most significance to the hearing today is my experience in heading a project which closed the last pediatric nursing home in the state between 1984 to 1986. Of the 150 children who lived in the nursing home, 50% moved to specialized foster care at an average of \$44 per day, 25% went home to their birth families and 20% (those age 17 and over) went to specialized group homes of six or fewer residents. 5% died, an indication of the severity of their health care conditions. In addition to the 150 children living in the nursing home, we also worked with another 100 families who were referred to, but diverted from the nursing home over the two years during the phase out.

We found, as I believe you now face, six major reasons to make the transition from facility support to family support.

(1) The anonymity is gone. You have now met these children and their families through the hearings today and through the Gamino coverage that brought about the hearings. You will find as we did, that once we met real families and real children we could no longer avoid the need to develop a viable family support system.

(2) We found that children were healthier growing up in families than they were growing up in the best of nursing homes. Human development requires nurture of a primary caregiver with an emotional bond. Studies have shown that failure to provide that bond of attachment impedes development.

(3) The deficits in institutional care are inherent in the very nature of the institution. Deficits are not due to evilness of the staff of the institutions. Their very nature precludes a nurturing environment. The lack of consistency of caregivers, and the lack of individual time and attention in group care define the institution. The number of staff who rotate through a child's life, between shift changes, days off, vacation coverage, and daily routine prevents a primary caregiver. The idea that care is given by specialists, is belied by a time analysis of the number of minutes of each day a particular child spends with the physician or nurse.

(4) You think you cannot afford to move to family support. In fact you cannot afford not to. The cost of facility care is rising rapidly and will certainly continue to do so as a result of the attention to this issue your hearing is bringing. In addition there is a public cost in families that collapse after falling apart for lack of support. Not to mention the threat of lost federal funding or litigation.

(5) It is do-able. Supporting families to care for very severely disabled children is do-able. Our experience closing pediatric nursing homes for children shows this. Our experience of a waiting list of foster families, because there are not enough disabled children in need of homes demonstrates this.

(6) Its right. The issue is not about quality of care. It is about quality of life. Its not about good feeding, bathing, and medicating. Its about playing, and hugging and holding and being tucked into bed at night by your mom.

I would like to share with you seven problems that we encountered in trying to take on this issue that I expect you have and are experiencing. The issue involves a large cast of people including the legislature, the various state departments, the long term care industry, the health care professionals, and of course the families and their children. They each had issues which contributed in some way. We found seven major problems with which we had to come to terms.

(1) Multiple state departments. In our case the Department of Social Services knew a lot about children but not about these children. The Department of Mental Health knew a lot about these children, but was not historically very good about working with their families. The Department of Public Health knew a lot about monitoring facilities, but not about family dynamics and community organizing. And of course the Departments did not communicate very well with each other. From the testimony I've heard this is a familiar scenario to you.

(2) Nursing home industry. We had to come to terms with the fact that the nursing homes were not the villains. In most cases they were just doing what we had asked of them, or more accurately had asked and then abandoned them to do.

(3) Health care professionals. We had to recognized that health care professionals were very good at health care, but not necessarily good at finding family supports, sorting out community resources, dealing with family dynamics, and recruitment and development of needed options.

(4) Families and children. We had to face that we in the system, were not often viewed as helpers by families. Too frequently we could not offer what they needed, offered what they didn't need, or agreed with what they needed but had no funding. And when a family expressed a complaint, we frequently attributed it to "guilt" over having a handicapped child. The children with their many diagnoses and resulting conditions, were foreign to many in the system. Gastrostomies, tracheostomies, ventilators, seizures, and apnea were more frightening to us than to the frightened families.

(5) Budgets. We had to recognize that "what you see is what you got". It was clear that there would not be additional dollars to solve the problem.

(6) Plot. We had to face the fact that the system hadn't decided what was OK for children, or at least it had not articulated its position. By default, the fact that there was a special place for special children, which was licensed and funded

and monitored by the system, seemed to endorse that as the way to serve children.

(7) Answer NOT in better facilities. We came to realize that the answer for medically involved children was not in making better facilities. We had developed specialized pediatric facilities, exclusively for these children. They were specially licensed, more heavily funded, regulated by pediatric based standards, and monitored regularly. Full day school programs were provided. As a casemanager, I was responsible for a pediatric nursing home and I visited daily. Despite this attention, the pediatric nursing home did not meet the children's needs. It could not by its very nature, despite the most rigorous efforts. The children did not thrive there.

Facing all of these issues, that seem very similar to the issues in Texas brought out in the hearings today, we managed to find solutions that resulted in the elimination of pediatric nursing home care. I would like to share thirteen of the elements which contributed to the shift in Michigan from facility care to family support for children who had formerly been cared for or at risk of referral to our nursing homes.

(1) We got the Governor to announce in his State of the State address of 1984 the goal that no child with a developmental disability live in an institution by 1986. This, in effect, set the plot.

(2) We got the legislature to compel interdepartmental interaction by providing conditions in each of the departmental appropriations that required referral to the Department of Mental Health before payment of pediatric nursing home costs by the Department of Social Services (the Medicaid agency), with prior authorization by Department of Public Health (the licensing agency).

(3) We worked with the nursing home industry, not as adversaries, but in a mutually planned phase out which included provisions to assure the nursing home was not financially penalized in the process.

(4) We had in place (prior to the plans to phase out) a specialized foster care recruitment system that had become successful enough to have available waiting foster families. The success of the recruitment efforts is born out in the waiting list of foster families. The success was connected to three elements: (a) an exclusive staff whose sole responsibility is finding good foster families; (b) paying those families reasonably which averages \$44 per day, and (c) supporting those families with whatever they need including casemangement, interdisciplinary team expertise, equipment, respite, transportation, or anything else that will help them succeed in raising a disabled child. In our two counties we have developed over 400 foster families.

(5) We learned from foster families how to support any family. Because we were "forced" to listen to foster families or risk losing them, we learned what it takes for families to thrive and enjoy the handicapped child who shares their lives. We learned that families are willing, capable, and conservative. They will lovingly accept children with very significant disabilities. They become experts in their care. And they don't ask for more than they need. In fact they don't want the system's intrusion in their lives unless they really need it. We learned to provide what families need on their terms, as what is most successful is their perception of being supported. We learned to change our perspective from focusing on the child's disability to focusing on the family's needs. When we began to apply what we had learned from foster families to birth families, we began to be more successful in adequately supporting birth families to enable them to keep their children at home.

(6) We learned that we should expect resistance by families whose children were already in placement. We learned that we could not dictate what we would do for their children, even if we felt it best. We found that we had to convince them of the merits of our beliefs and bring them to share them. Facing the issue of another family caring for a child by the birth family who could not was an especially difficult process. But we were successful. None of the foster care placements were made over birth family objection. Birth families retain all legal rights, and make the placement voluntarily. They approve the particular foster family. In doing so the situation becomes one of shared parenting.

(7) We learned that we had to de-mystify the term "nursing care". We learned it was possible to teach many health care procedures to non-licensed people, including parents and family members and staff. With adequate training and follow up support, the ability of families to care for children was increased and the cost of care was significantly decreased. It became very important for us to sort out which procedures truly required a licensed person to implement and which could be delegated safely.

(8) We were successful in closing the 150 bed nursing home, in part because we gave it the focus of a special project. A small team of three people (a nurse, a social worker, and an administrative leader) were identified to coordinate the alternative plans for each of the children and their families. The team had direct access to the department heads to remove barriers and endorse decisions. But most importantly, the team worked with each individual child and his or her family, in their living room on a very personal level.

(9) We found that we had to inject ourselves at the referral sources to the nursing homes. This most frequently was the neonatal intensive care units of hospitals. Prior to the interdepartmental legislative referral requirement, we initially gained entry in a very informal way by literally "planting" a nun on a neonatal unit. Her acceptance created an entre to talking

with families who were struggling with discharge plans that might have included only a nursing home. Her contact helped steer them to some other choices.

(10) We learned that we had to distinguish the health care professionals expertise from the placement development expertise. We learned that a team with a variety of expertise, rather than only medical expertise, was essential to sorting out what it would take to support a family or assist a family in considering placement with a foster family.

(11) We learned, and made mistakes, I believe, in making interim plans in the phase out stage of closing nursing homes. In one situation, we closed the home by moving all of the children in a short period of time to a number of smaller "transitional units" in hospitals. In other closures we opted for a slow phase out, with an arrangement to pay for vacant beds as units were closing. The first method resulted in unnecessary dangers incurred in transfer trauma. I would strongly encourage you to avoid that method.

(12) Finally we had to wrestle with the budgetary implications. What became apparent, was that the number of children whose support needs were very expensive (\$400 to \$600 per day) represented a very small proportion of the children in nursing homes. Far more of the children could be supported in less expensive ways. Of the 150 children in the pediatric home which closed, 50% went to foster homes at an average per diem of \$44 per day. 13% went home with no extraordinary expenses. A 1989 study done by The Center on Human Policy at Syracuse University evaluated the total public costs of our children who had been in institutional settings for more than a year and subsequently were placed in family settings. The study compared the total public costs of each kind of placement for each child. The average institutional cost for the last year of institutional placement for this group of medically involved children was \$88 per day. The average first year for the same children in subsequent family placements was \$48 per day. The 1986/87 fiscal year cost for this same group of children was \$45 per day. What we learned was that we were making good investments over time. Rusty, who I mentioned in my opening remarks is a good example. His first year of life in his family home required supports of \$145,000 (adjusted for inflation). The current cost of supports to his family is \$10,000 per year and by next year will be less. Had he remained in the nursing home, the cost of his care would continue without reduction. What we found was that we could reconfigure the supports to more closely fit the needs of individual families and children. By supports costing less than the nursing home for some children, others which cost more could be accommodated.

(13) Finally we learned the importance of celebrating these children and their families and the successes of their supports. We came to see that these children were not tragedies. Sometimes the circumstances that led to their disabilities were. And

sometimes what we did to them were. But they were not.

In closure, I commend your efforts today to take on these very challenging issues. We have come to see that family support is the best deal going. It is good public policy. It is better use of public resources and it is doing what's right.