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ABSTRACT

In this paper, by an educator who is also the parent of a son with mental retardation, the urgent needs of families whose children have chronic medical needs in addition to disabilities are discussed. One family's efforts to maintain their severely retarded and disabled son at home are described as an illustration not only of the unsurpassed quality of care that families can provide but also of the need for respite care and other help to such families from outside sources. Among points made in the paper are that quality of health care and quality of life is enhanced when parents are empowered to be primary health care providers; that parents can assume this role cost effectively; that parents need financial support to undertake the effort; that the quality of life for the community is improved as people with disabilities interact with people without disabilities; and that people with extensive health needs as children can grow to become tax-contributing citizens and economic assets to their states. (CL)

# The Parent's Role in Health Care:
# Children with Disabilities and Chronic Illness

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It is indeed a pleasure to participate in this timely conference, addressing the issues facing children and families during the first 60 months. I want to commend Governor Castle for his dynamic leadership. I am also grateful to Mrs. Alexander for including on this panel the perspectives of parents as providers, coordinators, and advocates for the health care of their children.

Allow me to share with you both good news and bad news. The good news focuses on the Lisbon family from Lawrence, Kansas. I wish that you could know the Lisbons personally. They have four children, the youngest of whom, Kevin, is 15 years old. Kevin experiences some very complicated health problems. In addition to the fact that he has severe mental retardation, Kevin receives kidney dialyses four times per day, is tube-fed six times per day, and receives 19 medications per day. There are some special challenges involved in caring for Kevin due to self-injurious behavior such as head-banging and hair-pulling. Kevin literally needs to be attended to <u>every</u> second, since even one jerk of his dialyses tube would result in a crisis.

Despite the complexity of Kevin's health needs, his parents and siblings, particularly Jan (his mother), provide a quality of care unsurpassed at any hospital in this country. They provide the kind of care characterized by love that only a family can generate. Jan has the most intimate knowledge of the very subtle cues indicating Kevin's needs--the sparkle of his eyes or the tinge of his lips can give her critical information to help monitor his bodily functions. Jan reads his needs like a book, needs that Kevin cannot communicate verbally. I can assure you that watching the synchrony with which Jan and Kevin work together to meet Kevin's health needs makes a believer out of any person who doubts the parents' capability to be their child's primary health care provider. That's the good news.

Now, it's time to share the bad news with you. That news is that meeting Kevin's health needs at home is placing an emotional and financial strain on the Lisbons that is almost shattering. When they have gone through periods of providing almost all of Kevin's care themselves, they have become so exhausted physically and emotionally that they have desperately needed a break from responsibility. But when this break was experienced and they faced major financial demands in paying nurses to take over the health care, the financial demands were overwhelming.

Kevin could be institutionalized at the state's expense (which would be exorbitant) or he could be hospitalized in an intensive care unit at the insurance company's expense. The intensive care unit costs for Kevin is over $600 per day. Yet, Medicaid and the insurance coverage to care for Kevin <u>at home</u> is frightfully scant. The need to have respite services and nurses to assist with his health care in the home is a foreboding financial threat to his family.

What can you do? There is a great deal that you can do to help the Lisbons and other families in their situations. Here are some suggestions for your consideration:

*You can reverse the trend of supporting institutions rather than families to take care of children. In 1977 through 1984, 13 billion government dollars were spent on accredited public residential facilities. Of this 13 billion dollars, 82% went to state institutions and only 18% to community facilities. Of the money that went to community facilities, the amount that actually went to pay natural families was negligible. You can reverse this emphasis. If state leaders would put funds now going in institutions into community services and family support, I wager that there is not a single person that is now in an institution that could not be served in a more qualitative and cost-efficient way in the community. Institutions are financial black holes. No amount of money will make them home-like and family-like.

*You can support national legislation now pending in Congress to phase-down institutional support by 85% over the next fifteen years.

*You can provide family subsidy programs which give cash allotments to families such as the Lisbons to help them cover excess costs. Currently, at least 18 states have model programs underway. An evaluation of the program in Minnesota revealed that 97% of the families reported that the program was of "great or very great help". Families use the funds to purchase respite care, health services, special equipment, and services for the child.

*You can work with insurance companies to change their policies to provide incentives rather than discentives for family care.

*You can support the development of family-like alternatives, such as adoptive and foster care, for the families unable to assume a major health care role with their child. All families are not able to do what the Lisbons are doing, even with financial support.

I want to emphasize that supporting families to take care of their own children has a long-range economic benefit for states. As I have indicated, families rather than institutions can enhance the quality of health care that children with disabilities and chronic illness receive. Additionally, family care in community settings provides the opportunity for <u>personal relationships</u> between people with and without disabilities. There can be magic in the personal relationships in terms of spill-over to economic implications for the states. I want to illustrate this point for you by sharing a very meaningful experience that is happening in our community with my son, Jay, who is 18 years old and has mental retardation. Because Jay lives at home with his family and experiences life in the neighborhood and community, he has had an opportunity to get to know many people who do not have disabilities and they, in turn, have had an opportunity to get to know him.

One of Jay's best friends is our neightbor, David Schwartzburg, who is the co-owner and manager of Packer Plastics, a large plastic company in Lawrence. Because David and Jay have had a great deal of time to interact informally and to develop the kind of relationship where they truly care about each other, David became very interested in Jay's employment potential and the opportunities he would have to be a productive worker. This interest led David to seek out opportunities to provide employment to the adults with disabilities who work in the same vocational training program as Jay, who is part-time there and at the local high school.

David was very pleasantly surprised when he discovered that the workers with disabilities did such an excellent job in terms of quality and promptness of work in Packer's shipping department that he decided to expand their role and give them increasing amounts of work opportunities. This experience evolved into one in which David and his brother, the co-manager of the company, made the decision to expand their physical facility by 50,000 square feet and to employ over 20 workers with mental retardation. David and his brother negotiated a contract with the vocational training program in which these workers are now enrolled. Just prior to the signing of the contract, they expressed to the director of the vocational training program that they had one final issue to raise prior to closing the contract. They then posed the question, "Will Jay Turnbull be a client whom you will prepare to work with us? We want to make it clear to you that in our neighborhood we have a belief that we take care of our own. Jay is our friend and we want to make sure that he has the fullest opportunity to engage in productive employment." The truth of the matter is that in the "pecking order" of clients moving out of the vocational training program into industry, Jay was not at the top of the group that would be ready to take on the Packer Plastics jobs. However, the advocacy displayed in his behalf by his friends resulted in employment opportunities that he may have never had otherwise.

This is exactly what can happen in communities across this country as persons with disabilities and chronic illness are supported to live with their families. Families live in neighborhoods, and they have social support networks that can provide opportunities that state dollars can never buy. When these children have an opportunity to live in the mainstream of society, they will build the kinds of personal relationships that will open doors for them to contribute to society in many ways, including the critical role of being a tax-paying citizen.

In summary, I would like to reinterate my major points.

*The quality of health care and the quality of life for children with disabilities and chronic illness is enhanced when parents are empowered to be primary healthcare providers.

*It is cost-effective for parents to assume this role.

*Parents need financial support from Medicaid, other state substidies, and insurance.

*The quality of life for community citizens is enhanced when personal relationships between people with and without disabilities occur.

*Persons who require even extensive health resources as children can grow up to be tax-contributing citizens and economic assets to their states.

Because practically all of our policy options are trade-offs, it is rare to be in a position to support an option in which everyone benefits. Supporting parents to be primary health care providers of children with disabilities and chronic illness, however, is one of those rare options. I urge you to insure that families with children having special needs not only endure, but, indeed, prevail. I cannot emphasize strongly enough how very much the Lisbons, the Turnbulls, and other families across this land need your help!