

Testimony for the HHS Medicaid Commission  
Jane Knox-Voina, Legal Guardian and Mother of Medicaid Client Robert Ray Knox  
July 11, 2006

Good Afternoon. My name is Jane Knox-Voina. I have come here today to speak to you on behalf of my adopted son, Robert Ray Knox and wish to take just a few minutes of your time to shed light on the severity of problems and the nature of his dependency on Medicaid and Assistive Technology.

Robert is a 37 year old adult who has moderate mental retardation and is profoundly deaf who, because of extreme abuse of various state and private caregivers, (including his biological father) has suffered from some psychological problems. Robert has had four different categories of residences: home (with me until he was 16), institutions, semi-independent apartment residence and community homes. The most negative of these was institutional living because it was in institutional settings where the most horrific, inhumane physical, psychological and sexual abuse occurred. All three of these institutions were state-run:

Austin State Mental Ward of Autistic Children, Austin, Texas  
Baxter School for the Deaf, Falmouth, Maine  
Hartford School for the Deaf, Hartford, Connecticut

Two years ago Robert was awarded \$100,000 from the State of Maine in a case brought before the Maine Baxter Compensation Board which found that Robert, among many other deaf children over the past 60 years, had been subjected to severe sexual, physical and psychological abuse by members of the Baxter community: teachers, the principal, boy scout master, house parents, community volunteers, and fellow students. Robert enrolled at Baxter School for the Deaf in December 1976 and graduated in June 1989. From 1982 until 1987 Robert was removed from the school because of the severity of the ongoing abuse. During that time he attended Beverley School for the Deaf, The American School of the Deaf, Hartford, Connecticut, and the American Embassy School in Moscow where I was working as an IREX Scholar with Assistive Technology and Handicapped Children in several Research Institutes.

The semi-independent living apartment on State and Congress Streets in Portland, Maine did not work out because, although there was a deaf services program nearby and staff that checked in on him occasionally, he tended to trust anyone and soon became prey to those who would take advantage of him sexually and psychologically. For fear that he would come to real harm, not to mention the threat of AIDS, it was decided that he should return to a residential community home in which he would have the advantage of supervision from signing staff who worked with other deaf adult residents. There, he could continue to live as a high functioning deaf adult, working in the community and receiving high praises from his various employers. In the community home, there was also a more normal sense of community and family which deaf adults need as much as hearing adults do. However, they are often unable to find the means to have their own home and cannot find suitable life mates to share them with.



What works?

In all of his living various environments, technology has been absolutely essential to Robert's safety, well-being and ability to communicate with the hearing world: special lights to replace fire or other alert alarms, special alarm clocks to wake him for work, TTY in place of regular telephone, video relay machines to allow him to see the person with whom he is communicating (since he can't hear the person). While at the American Embassy School for the children of American diplomats and scholars Robert took a computer course and with intensive instruction from one Russian computer teacher acquired basic math schools.

During this 6 month period in Russia he made more academic progress than during the rest of all his school education. Most recently, the personal computer has allowed Robert access to the internet where he can easily communicate with me anywhere in the world. Just as important as the issue of the quality of life for my son is also the quality of life of my husband and myself.

Major Problems:

One of the major financial problems for assuring the provision and ongoing use of this technologically rich environment is that Medicaid does not assist in this costly technological support because he does not own his own home, a catch-22 situation since very few deaf adults with developmental disabilities would be in a situation to own their own home.

It is also important to remind the Commission that quality of life is not always guaranteed by technology. Technology in an institution will not prevent the abuse that seems so prevalent in institutions. We all need to dismiss the concept that an institution with technology is an option.

Though email has been an excellent source of communication for my son, the fact remains that there is high vulnerability from email. The same people who prey on people who are deaf with developmental disabilities in the community find them easy prey over the internet. Moreover, because of his mild retardation and lower functioning math skills he would be sucked into all the on-line sales pitches. Therefore, my son could not have totally independent unsupervised internet access. It is important that we do not feel that replacing staff completely is an option. The staff supervisory component to assistive technology is absolutely essential.

Thank you for your time this afternoon and for your ongoing and important work. Your topic today is "Quality and Technology". My son has specific needs that many other adults do not have. If you allow Medicaid to fund his needs, he can utilize the technology available to live a quality life. Ultimately, the most important thing you could ever do on this Commission is to ensure that the quality of services provided with Medicaid funds keeps people like my son free from harm and supported in his community.