Volunteers of America®

Medicaid Long Term Care:
Serving People with Developmental Disabilities

Statement to the Medicaid Commission
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Irving, Texas

My name is Angela King, Director of Program Development for Volunteers of America, a national, nonprofit, faith-based organization dedicated to helping those in need reach their full potential. Since, 1896, our ministry of services has supported and empowered America's most vulnerable groups, including at-risk youth, the frail elderly, men and women returning from prison, homeless individuals and families, people with disabilities and those recovering from addictions.

We provide individualized services to people with developmental disabilities in 14 states and we are expanding these services throughout the country. Guided by a philosophy of self-determination, as well as the individual and their family's wishes, we empower people with disabilities to achieve their dreams of community involvement and increasing independence. Our comprehensive array of services to people with mental retardation and other developmental disabilities includes; in-home support services, specialized residential services, case management, day programs and supportive employment.

I have worked in the field of mental retardation for over 25 years and have seen vast improvement in services for people with disabilities, almost entirely funded by Medicaid. I understand the necessity of Medicaid funding in ensuring supports for people with disabilities and I commend the Medicaid Commission for focusing on improvements to long term care options for people with disabilities I would like to address three main areas in my statement today: 1) Separate funding for long-term care and acute care in the Medicaid system 2) adequate pay and benefits for direct support staff and 3) the importance of community-based care vs. institutional care.

1. **Separate Funding for Long Term Care and Acute Care in the Medicaid System**

Medicaid beneficiaries with developmental disabilities often have diverse and complex health care needs. In addition these individuals may need life long support

services, which will change over time. We have already seen reform proposals at the state level to design benefit packages that are tailored to specific beneficiary groups, such as families, children, the elderly, and people with disabilities. In a similar fashion, given the rising demand for long-term care and supports for the elderly and people with disabilities, we should explore a tailored approach for funding long-term care apart from acute health care services. Long-term care should have its own dedicated means of financing-that should include both private and public sources of funding. This means of financing should allow funds to move with the individual's needs and preferences to the most appropriate and preferred setting as the individual's life changes.

When I think of Medicaid and people with disabilities, I do not think of physician's visits, hospital stays, or medical procedures, instead I think of the life the person has in the community. A life that is available because of Medicaid funding. Transportation to work, a staff person to get you out of bed in the morning, assistance with meal preparation and eating, mental health treatment, nursing care and assistance with all the activities of daily living are all services provided by Medicaid. In my experience, many of the consumers we support do not have family support, and they are dependent on Medicaid funding to pay for all their activities of life. Without Medicaid they would not have the supervision and assistance they need to live. Literally, a staff person who is paid through Medicaid's Home and Community Based Services provides every glass of water some of our consumers receive. These services are not optional for people with disabilities, they are necessary for survival. When considering options for Medicaid's long-term care funding, we must recognize the life long dependence some people have on this system and not make changes that will disrupt the array of supports received by thousand of people with disabilities across the country.

2. Adequate Pay for Direct Support Staff

Direct support professionals are the backbone of our programs serving people with developmental disabilities. As a national service provider we are challenged in our mission to effectively provide high quality long-term care and supports when Medicaid reimbursement, which is 100% of our funding, is simply inadequate to recruit and retain these vital workers. It is typical for direct care staff wages and benefits to constitute 60-70% of many of our MR/DD (mental retardation/developmental disabilities) program budgets.

We are going to see a huge increase in demand for direct support staff in the next five years and without adequate reimbursement to pay a living wage, we will not be able to attract workers to this field. In some parts of the country our overtime typically runs 25-30%, as we cannot fill staff vacancies in our mental retardation programs. Last year, I was involved in the evacuation of our consumers from ICF-MR group homes in New Orleans; the dedication of direct support staff in supporting people with significant disabilities, regardless of the trauma in their own personnel lives as a result of Hurricane Katrina, was amazing to me. We trust direct support staff to

provide the most personal services, to insure that people are safe, to provide access to community activities, to provide some level of medical assistance, and to really care for people who are disabled or elderly. Yet, we don't value these caring staff enough to insure them a wage that is even reaches federal poverty standards. There is something very wrong with this scenario, and it needs to be addressed before our system collapses from high turnover and lack of staff. We endorse ANCOR's legislation, H.R. 1264 The Direct Support Professional Fairness and Security Act, which would provide incentives to states to increase direct support professional wages through enhanced federal Medicaid funding for a period of five years. This would begin to address the wage increases that we need to attract workers to this field.

3. The Importance of Community-Based Care for Persons with Disabilities

Institutional care is no longer the preferred option for people with disabilities or the elderly. Community services are preferred and appropriate for the vast majority of people and in most cases these services are less costly then institutional care. The Home and Community Based Services (HCBS) Waiver is the principal Medicaid funding source for MR/DD long-term care. Although the number of people served by HCBS has been steadily increasing over the last two decades, the majority of Medicaid's long-term care dollars still go toward institutional care. Further efforts must be undertaken to encourage states to rebalance their long-term care systems with greater emphasis on home and community based services such as in-home supports and supportive living services. The correlation between Medicaid supports and affordable accessible housing must also be addressed to insure that there are community options for people who want to leave institutions.

Conclusion

I want to thank the Commission for your consideration of my remarks. I want to assure you that Medicaid is working for tens of thousands of people with disabilities across the country. Others are waiting for this vital service while living with aging parents or in institutional settings. Medicaid has allowed people to move out of institutions and enjoy vibrant lives in their communities. We don't want to lose the momentum we have worked so hard to gain over the last 20 years.

People with significant disabilities now live and work in their communities because of the supports they receive from Medicaid. While some changes need to be made, increased flexibility for supports across the life span, adequate reimbursement for direct support staff wages and benefits, and a continued focus on community options, Medicaid long-term care funding is essential for people with disabilities to obtain the individualized supports they need. Please consider the successes of HCBS programs and services when considering re-design options for Medicaid long-term care and determine ways to continue to expand these vital supports.