



November 16, 2006

Statement to the HHS Bipartisan Commission on Medicaid Reform

Mrs. Andrina Fiene Campbell, Lutheran Services in America Disability Network

Good afternoon. My name is Andrina Fiene Campbell and I am the LSA Disability Network Public Policy Liaison for Lutheran Services in America. Many of you have met my members as we have attended every HHS Medicaid Commission meeting since your inception. I have had the pleasure of getting to know many of you at the meetings and am pleased to speak to you today.

LSA-DN knows that your work will strongly influence the lives of people with developmental disabilities who rely on Medicaid to meet their basic human needs. Your work is a priority for LSA-DN. We have brought CEOs, program administrators, self advocates, direct care staff, and parents to speak to you to give you their perspective of how Medicaid reform would impact their lives and the people they serve. We hope that our work has helped in the task that is set before you. LSA-DN wishes to remain a helpful partner in the work of the Commission.

LSA-DN supports a recurring recommendation that has been mentioned more than a few times in your meetings - the reversal of the institutional bias. LSA-DN supports providing choice for consumers with developmental disabilities, choices that best meet the individual's needs. Evidence has shown the effectiveness of providing services in the least restrictive setting. However, community life is not possible without needed supports such as affordable housing, transportation and social services.

If you recommend that the institutional bias is to be reversed in favor of a home and community services bias, we ask that you include a recommendation that services such as transportation, affordable and accessible housing and other supports and services be provided and coordinated with Medicaid services. Without these important community services, services that fall outside of the Medicaid program's jurisdiction, community living is not a viable option.

Many people with developmental disabilities live with their parents for the first part of their lives but wish to live with friends or on their own, as do their peers, when they become adults. We know that many adults with developmental disabilities are living with aging parents and receiving no services from Medicaid.

Waiting lists have developed in many states that allow people with developmental disabilities to wait to receive Medicaid waiver Home and Community Based Services so that they do not have

to go to an institution. These individuals are not receiving any services, and many of them are indeed living with aging parents. Accurate waiting lists should be developed in every state so that appropriate economical systems capacity is realized and crisis management is avoided.

Below are LSA-DN recommendations that have been presented to you over the past year. We hope that you will continue to consider our recommendations as you vote on your final recommendations.

- ❖ Medicaid Policy should provide adequate and equitable reimbursement for services provided on the basis of individual needs. People with developmental disabilities deserve fair and appropriate supports and services that are adequately and equitably funded.
- ❖ Medicaid policy should encourage more flexible supports and more flexible regulations that are necessary in integrated community living and are valued by the consumer. People with developmental disabilities have various needs that do not always warrant costly and highly regulated supports.

Medicaid policy should allow all eligible individuals with developmental disabilities access to Medicaid supports as needed. Millions of people with developmental disabilities are not receiving any Medicaid funded supports.

- ❖ Medicaid policy should support reforms that coordinate the provision of skilled support staff services and affordable and accessible housing and transportation services for people with developmental disabilities. People with developmental disabilities should be enabled to live in their communities.
- ❖ Medicaid policy should not diminish eligibility for people with developmental disabilities as Medicaid reform proceeds.
- ❖ Medicaid policy should require the coordination of the delivery of health care and long-term supports and services. People with developmental disabilities who depend upon Medicaid for both their daily supports and their medical supports should be allowed to access a coordinated system.
- ❖ Medicaid policy must ensure that families have support in their efforts to achieve independence and community inclusion for their sons and daughters with disabilities.
- ❖ Medicaid policy should continue to move away from its institutional bias, and should normalize the funding of home and community based services to persons with developmental disabilities now permitted through state waiver programs.
- ❖ Medicaid policy should continue to support the growing ability of the Medicaid program to allow supports and services to individuals through a variety of “waivers”. Flexibility in service definitions, tailored supports and services, and the funding of the supports and services is very important.

- ❖ Medicaid policy should encourage initiatives such as the Money Follows the Person Initiative that provide valuable steps for persons with developmental disabilities to live in the community. One size cannot fit all and thus we support proposals that support funding following the person.
- ❖ Medicaid policy should promote comprehensive and high quality care for persons with severe medical needs for those who need that level of care but only within an institutional setting as a last resort.

Thank you, once again, for your work on this Commission. We know that your recommendations will have a significant impact on the future of the Medicaid program and on the future of the many people with developmental disabilities that we serve. Your policy recommendations will make a difference in the life of Chris Hunnicut as well as others in Atlanta who were unable to communicate verbally but their stories were told to you by their guardians and direct care staff. They and millions of other people in need of Medicaid are looking forward to an improved Medicaid program that enables them to live in the least restrictive setting of their choice.

The LSA Disability Network looks forward to being helpful to the Commission in the final days of your work on this important issue. I am leaving LSA-DN at the end of the year but Andrew Morris, an expert on Medicaid from Oregon, will be taking my place.

We also invite you to join us on a site visit to our organizations to learn more about the quality services that we provide to people with developmental disabilities. We know that seeing the services provided with Medicaid funding, hearing the stories of those receiving the services and meeting the caring staff who provide for our consumers is always a very valuable experience.

Below are the names and contact information for the staff and members of the LSA Disability Network public policy team. We have enjoyed working with you. Please don't hesitate to contact us if we can be of further assistance.

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