STATEMENT of CAROLE L. SHERMAN APPEARING BEFORE HOUSE AND SENATE HEALTH SERVICES SUBCOMMITTEES OF THE HOUSE AND SENATE PUBLIC HEALTH, WELFARE & LABOR COMMITTEES

August 28, 2014

Chairman Caldwell, Chairman Mayberry, Members of the Subcommittees, Members of the General Assembly and guests, I am Carole Sherman, of Little Rock.

My interest in the work of these subcommittees is as the mother and co-guardian of our son, age 45, whose severe brain injuries occurred at birth. John functions on the level of a young toddler; his care is beyond our family's capacities and for many years his safe home has been a public long-term care facility for people with cognitive and developmental disabilities, the Arkadelphia Human Development Center (HDC). I have over 45 years of first-hand experience with persons with cognitive-developmental disabilities and over 35 years' experience with long term-care facilities and their vulnerable residents.

There are five state-operated HDCs serving vulnerable individuals from every county. Over 65% of HDC residents function in the profound range of cognitive ability. Over three-quarters require a modified diet. Many have extreme medical and behavioral conditions in addition to cognitive deficits. We will forever be grateful for our HDCs.

I serve as Public Affairs chairman for Arkansas' statewide parent-guardian association, Families & Friends of Care Facility Residents (FF-CFR). FF-CFR is an all-volunteer organization; we employ no staff. Our members support public policies which reflect common sense and reality. We support a range of services for persons with disabilities — home, community and institutional. There is an absence of common sense and humanity in federal-DHHS policies when the agency uses generous amounts of discretionary public funds to entice States to stop providing a diverse system for choice of care which better reflects the realities of people with disabilities and their families.

Our five HDC programs are institutional programs which have historically been successful in assuring the health and safety of vulnerable individuals who cannot report their hurts and needs or who can do so with great effort and who require close twenty-four hour supervision. Under the federal Community First Choice Option (CFCO) grant, states are given extra funds for the care of persons who qualify for institutional care but the CFCO long-term care funded programs cannot be provided in long-term care facilities, like our HDCs.

In today's Exhibit C, page 1, three individuals who would benefit from CFCO are described. There is no mention of persons like my son or our family. Two persons with disabilities currently live with their family or in their own home. A third person is elderly, lives independently, needs attendant services and meals delivered 5 days a week. From the

information given, it does not appear that these individuals at present require round-the-clock, 24-hour long-term care. One asks: when families are unable to provide direct care and other needed services for family members with life-long disabilities, or when an elderly person is no longer safe living alone, what happens under CFCO?

Additionally, one asks:

- what is the future viability of our HDCs and other long-term care facilities if the State participates in a federal program which rewards the State for not admitting persons to HDCs and other long-term care facilities?
- Does DHS recognize the value of our HDCs? Does DHS consider them vital to the long-term care service system? If so, why has it not steadily requested general improvement funds for the needed replacements of HDC residential units and upgrades of facility equipment?

Conclusion

For the past several years, representatives of our HDC families have attended most of the public informational meetings of which we were aware offered by DHS regarding services and supports for persons with cognitive disabilities. We are still in the dark about the department's policy objectives. We do not have enough information to know how or if the new service delivery system will affect our family members with disabilities, their peers or the life-saving human development centers.

Thank you for your consideration of the many questions which I submitted separately; thank you for the opportunity to provide comments and ask additional questions today; and

Thank you for your public service.

Carole L. Sherman Mother and Co-Guardian of John (Arkadelphia HDC resident) Public Affairs Chair, Families & Friends of Care Facility Residents, Arkansas' statewide parentguardian association

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