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Mr. Chairman and Members of this Committee,

Thank you for the opportunity to appear before you today and provide testimony regarding long-term care reform. This hearing, the third in a series of hearings dedicated to long-term care, is focused on: the need for reform of our current system for providing and financing long term care; the local, state, and national context within which that reform will occur; appropriate mechanisms for encouraging and facilitating the process of reform; and recommendations for both immediate and long range system changes. My role here today is to share with you a state's perspective on long term care reform, including the impact of Olmstead and Barthelemy, and the process of partnership-building and solution-sharing between the aging and disability communities in Louisiana.

The Impact of Olmstead on Louisiana

The 1999 U.S. Supreme Court decision, *Olmstead v. L.C.*, had a dual effect on the state of Louisiana. First, it became the legal basis for Louisiana's version of Olmstead, the *Barthelemy v. Department of Health and Hospitals* lawsuit. Second, it was central force that led to a partnership between the aging and disability communities in the state of Louisiana.

In April 2000 the Advocacy Center, the state's Protection and Advocacy System, filed a class action lawsuit, *L.B. et al. V. Department of Health and Hospitals*, referred to as "*Barthelemy*". This lawsuit was filed on behalf of persons in nursing homes or at imminent risk of being placed in nursing homes. This main provisions of the lawsuit (see attachment A) are designed to increase the options for community services, ensure that individuals are informed of their options, and professionals are trained regarding the availability of community services. The implementation of the provisions in this lawsuit will form some of the initial steps of long-term care reform in Louisiana.

During the time that the *Barthelemy* settlement was being negotiated, Olmstead was creating action both at the state department level and at the grassroots level. On July 26, 2000, at the request of the Office of Civil Rights, the Louisiana Department of Health and Hospitals (DHH) held a meeting between DHH officials, consumers, family members and advocates. Unsure as to whether DHH would proceed with the development of an Olmstead plan, aging and disability advocates held a meeting in August of 2000 to discuss common ground. It was there that Olmstead became the catalyst in forging a partnership between the aging and disability communities. Aging and disability advocates realized that they had similar needs, were "fighting for the same pots of money," and that they would be a greater force if they were united.

The aging and disability advocates formed a group called the Louisiana People's Olmstead Planning Group (LaPOP), with the intention of developing a "People's Plan." LaPOP was co-chaired by a representative of the developmental disabilities community and a representative of the aging community. Strong efforts were placed on ensuring that members of the adult disability community and the mental health community were also involved as part of the LaPOP steering committee. This was a very strong and positive collaborative effort. Not only were the developmental disability community and the elderly community working together toward a common goal, but all four disability groups were at the same table and were equal decision makers in the direction of an Olmstead plan for the state of Louisiana.

In January of 2001, the LaPOP group determined that legislation supporting the development of their "People's Plan" would help to ensure effective implementation of the plan. Therefore, LaPOP worked collaboratively with legislators, DHH, the Governor's Office of Disability Affairs, and numerous disability and aging organizations to develop and seek passage of Senate Bill 855. This bill was signed into law by Governor M.J. "Mike" Foster and became Act 1147. Act 1147 creates the Disability Services and Supports System Planning Group (DSSS), which is led by a Consumer Task Force. The DSSS planning group, comprised of numerous aging and disability consumers, family members and advocates, is now the entity responsible for the development of a plan to reform long term care in the state of Louisiana.

Environments for Long-Term Care Change

On a national level, Olmstead, the President's Executive Order, the Systems Change grants, and other federal directives were some of the innovative initial steps in establishing federal and state environments conducive for long term care change. On a state level, implementation of the provisions of the Barthelemy lawsuit will function as a change agent for future reform of long-term care in Louisiana.

There are several other factors, which will force our long-term system to change. The rapid growth in the aging population, including a cohort - namely Baby Boomers - who may not accept institutionalization as a prerequisite for receiving long term supports and services, will create a greater demand for LTC services, including greater demands upon state and federal budgets and upon families. Reduction in birth rates, greater mobility of working Americans, and the increased participation of women in the workforce will decrease the capacity for family members to provide care for family members who are aging or disabled. New, reinvigorated, and politically potent coalitions between aging advocates and disability advocates who have been brought together and fueled by Olmstead. Cross-fertilization between the fields of disability and aging are evolving, such that advocates for the aging will begin demanding the same civil rights, community integration, and consumer directed supports for older adults with disabilities as advocates and self-advocates have been demanding for younger adults with disabilities. Our society is rapidly evolving such that consumers, family members and advocates are no longer buying into the notion of predetermined categories for disability or aging. Instead, they are bannng together and working towards a universal system for ALL people with disabilities, regardless of age.

Mechanisms for Long-Term Care change

One of the most important mechanisms for long-term care change will be the development of partnerships. This includes partnerships between state agencies that provide services, partnerships between state and federal government, public and private partnerships, and most importantly partnerships between states and consumers, family members and advocates. Partnerships with consumers, family members, and advocates should include, but not be limited to: collaboration on grants, policy and procedures development, program development, strategic planning, etc.

Substance of Reform - Short Term

- Change regulations so that family members can be reimbursed for care.
- Flexibility in use of LTC dollars so that family members can do what they are able to do for the family member who is aging or disabled, but they can get the support in the way that they need it most. Costs will be controlled because they are not reimbursed for unnecessary 24 hour care.

- Allow states to bundle Medicare and Medicaid services for a definable population across all age groups, and use the money as a Research and Demonstration waiver to allow more flexibility

- a.) Totally cost neutral for Louisiana

- b.) Neutral to Federal government

- Enhance the federal match rate for Home and Community Based Services, similar to what was done for the Family Opportunity footing by either:

- a.) Removing nursing home care as a required benefit (entitlement) under Medicaid and making LTC services the required benefit so that states have some flexibility in how and where to deliver LTC, or

- b.) Make Home and Community based LTC services a required benefit under Medicaid to be on the same level as nursing homes.

(Another option is to put them on the same footing by passing MiCASSA. MiCASSA would make home and community based care a required benefit.)

- Provide federal dollars to assist poor states with excess institutional capacity to "buy back" certificates of need for surplus nursing home beds. This will produce cost savings in states with too many nursing home beds and should provide nursing homes with resources to re-tool. Bed buy-backs and bed-banking could be used to encourage the retooling of nursing homes to provide home and community-based care.

- Change federal laws and regulations to allow for Cash and Counseling programs.

- Delink eligibility requirements for HCBS from eligibility requirements for institutional care. (Note: It is easier getting into an institution than it is to receive HCBS. Eligibility determination requires that you describe the individual's deficits as opposed to their strengths/assets. This forces an approach of viewing the negatives as opposed to creating a broad array of options. Eligibility is deficit based, therefore the family is forced to describe the person as being as needy as possible to get the minimal amount of care. "Why should we prove that she has the highest level of need to get the lowest level of care....skilled nursing versus active treatment and social opportunity in the community.")

- Enhanced federal match and short-term federal program to buy back nursing home beds in states where there is excess nursing home capacity. This program would be a one time only option. Then nursing homes would enter a competitive market. This would require nursing homes to re-tool and would create incentives for nursing homes to provide other kinds of services and supports.

Substance of Reform - Long-Term

We currently have a long term care system that was built on a model for acute care - namely the hospital - rather than for chronic care. We must rationalize our system of long term care so that "healthcare is incorporated into the context of everyday life" (Kane, Kane, & Ladd, 1998). Normal, everyday life in the community should not have to stop just because a person needs chronic care and long-term support.

Incentives are needed to create equity in states between the public and private sector for Direct Support Professionals (i.e. salaries, benefits, and career ladder). This can be achieved by funding the

recommendation as outlined in the Reauthorization of the Developmental Disabilities Act.

There is a workforce crisis. Studies show that care from family members is a huge unreimbursed service. This is a double dilemma for the Developmental Disabilities population being cared for by aging family members. Of home and community based individuals, 90% of long term care for elders is provided by family members. The services they provide keep individuals out of more costly and restrictive environments, i.e. institutions. However, those caregivers are aging and caregiving takes a toll on the health of the caregivers, impacting women more than men. One way to deal with this is to support family members so that they may provide care for the family member who is aging or has a disability. This will not replace the current workforce but will help build a more comprehensive workforce that is capable of meeting consumer demands.

Overall, we need a comprehensive long term care system that addresses issues such as: flexibility, supporting rather than replacing family caregiving, reimbursement rates, workforce capacity, housing, consumer direction, financial incentives for providers to re-tool in order to meet consumer demand, development of a broad array of options, informed choice, transportation, recreation and social activities. This new system should be guided by a focus on serving all persons with disabilities regardless of whether the disability was acquired by birth, accident/injury, or by the aging process. But most importantly, we should adhere to the concept of "Nothing about me, without me," meaning that services and systems should not be developed unless consumers are meaningfully involved in all aspects of the development of the services that affect their lives.

Appendix A

Barthelemy Case Settlement

Louisiana's Advocacy Center announces agreement to settle a statewide class action lawsuit that will have a dramatic impact on long-term care services in Louisiana. Lois Simpson, Executive Director of the Advocacy Center, says the Barthelemy settlement represents the first crack in the wall that has kept Louisianians with disabilities imprisoned in institutions. "People want change and this settlement will help people with disabilities and seniors achieve the changes they have long been waiting for."

The suit, *Barthelemy v. Louisiana Department of Health and Hospitals*, was filed over a year ago in federal court on behalf of five individuals then living in nursing homes, one individual at risk of nursing home admission and one non profit group that serves people with severe disabilities. Because the suit is a class action, the 36-page agreement potentially covers hundreds - and possibly thousands - of the state's 27,000 nursing-home residents, as well as those in hospitals or living at home but at imminent risk of going into nursing homes.

Home and community based services for adults with disabilities and seniors in Louisiana are generally provided through Medicaid "waiver" programs. Such waiver programs have years-long waiting list for very few spaces. These programs offer personal care, home modification, adult day care, and emergency response systems, and are key to avoiding institutionalization, advocates say.

Key provisions of the settlement are as follows:

- The settlement applies to persons who are in nursing homes or are at "imminent risk" of having to go into a nursing home. "Imminent risk" is defined as having a primary caregiver with a disability or over the age 70, or likely to require admission to a nursing facility, or to face deterioration in condition, within the next 120 days.

- The State will make "all reasonable efforts" to expand capacity to provide home and community based services to class members by seeking necessary approvals from the federal government, and working to increase provider capacity.
- Over the next four years, the State will reduce the existing waiting lists to the point at which class members have to wait no longer than 90 days for waiver services, after they have been found eligible for those services
- The reductions will require minimum increases in the number of waiver slots in 3 different waiver programs, totaling 650 in 2002, 650 in 2003, 250 in 2004, 150 in 2005 and 150 in 2004.
- Information about community services will be made available through a statewide toll free hotline, and through the development of accessible written material disseminated by a variety of organizations, governmental agencies, and providers.
- The State will develop training material about the availability and advantages of community services for employees of medical facilities, case managers, physicians, social workers, and others involved in referring people for post-hospital care or other long-term care. It will train employees of state-operated medical facilities who are involved in that process, and will make training available for other providers.
- The State will advise all nursing home residents of community options for delivery of long term care services, will assure them that receipt of such services will not prejudice their receipt of nursing facility services pending the availability of community services, and will place them on appropriate waiting lists if they so desire.
- The State will amend the State Medicaid plan to include the optional "personal care services" as a Medicaid services, for persons in nursing homes or at imminent risk of nursing home placement, for a maximum of 56 hours per week.
- The State will develop and implement assessment procedures to identify the long-term care service needs and preferences of class members. Consumers, advocates, and providers of community services will participate in the development of these procedures.
- The assessment process will be reviewed by Plaintiffs' counsel following the assessment of a number of individuals in nursing facilities and in the community, with an opportunity for conferring as to proposed changes.
- Class members will be fully informed about the assessment process prior to being assessed. If it is found that community services are appropriate, class members will participate in the development of their comprehensive plans of care and transition plans. Fair hearings will be provided for areas of disagreement about the assessment process or the nature or amount of community service needed.
- The rates of pay of personal care attendants under the waiver programs at issue will be increased to \$12 per hour by January 1, 2002. Case management fees will be increased in the largest waiver program. Caps on services will be removed to allow services to be provided up to the aggregate cost effectiveness limit.
- The State will report on programs in implementing the agreement, including numbers of class members assessed and the results, length of time the assessment process took, length of time to

commencement of services, number of persons admitted to nursing facilities, and the numbers of persons transferred from nursing facilities to community placements.

A team including Philadelphia disability rights attorney Steve Gold, local Advocacy Center attorneys Nell Hahn and Terri Bewig, and Texas attorney, David Kahne represent the class.

For a copy of the settlement, contact the Advocacy Center Lafayette office: 1-800-822-0210.