



Kansas Council on Developmental Disabilities

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"To ensure the opportunity to make choices regarding participation in society and quality of life for individuals with developmental disabilities"

House Committee on Aging and Long Term Care

January 18, 2011

Mr. Chairman, Members of the Committee, thank you for the opportunity of introducing the Kansas Council on Developmental Disabilities. The Council is federally mandated and funded under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and receives no state funds. The role of the Council is to:

"(1) engage in advocacy, capacity building, and systemic change activities that ... contribute to a system of community services, individualized supports, and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life."

Public Law 106-402

In other words, we work to improve the DD system so that persons who have a developmental disability have access to the same opportunities in life as you and I. The first attachment provides the definition for developmental disabilities found in state law. I provided a more simple explanation and the actual definition found in K.S.A. 39-1801.

The nineteen Council members are appointed by the Governor and include primary consumers, immediate family members, and representatives of the major agencies who provide services for individuals with developmental disabilities. Our members are from different parts of the State and represent many of the different ethnic and racial groups found in Kansas. Attachment 2 lists our members.

HOUSE AGING & LTC

DATE: 01/20/11

ATTACHMENT

#3

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Our mission is to advocate for individuals with developmental disabilities to receive adequate supports to make choices about where they live, work and learn. In that role, you will often see myself and/or other Council staff at hearings, testifying, and providing information to you. We are also available if you need any information. There are DD (Developmental Disabilities) Councils in all fifty states and we can readily obtain info from them regarding their DD systems. We also have expertise and/or know leading experts in the fields of employment, housing, personal care and other services related to persons who have a developmental disability.

We use part of our federal funding to directly improve our State's ability to provide services. For example, we have a grant with Oral Health Care of Kansas to develop and provide training to dentists and other dental care providers on how to provide services to persons who have a developmental disability. We also work extensively in the employment through providing information to consumers and their families on how to get and keep a job. We have also funded many persons with DD to start their own business. Several of the businesses are thriving, even in the current economy, paying Kansas taxes, and their owners are even employing other persons who have a disability, thus contributing to the overall economy and growth of Kansas.

Issues

Waiting Lists - We mentioned that we advocate for persons with DD. The key issue facing persons who have a Developmental Disability is money - money to fund those currently in service and those waiting for services. Attachment 3 shows the growth of the Home and Community Based Services Developmental Disabilities Waiver's Waiting List. As you can see, the list of persons who are *unserved*, who currently receive no Waiver services, has grown from 393 in 1999 to 2,383. The latter number was provided by the Department of Social and Rehabilitation Services this week.

The effect on the individual who receives no services may mean that there is no one to assist them in getting up in the morning, getting dressed and getting breakfast. No one can take them to work, if they have a job, or assist them in buying food, getting and keeping their clothing clean - all basic daily activities most of us take for granted. If they have family members, the effect on the family can also be devastating. Depending upon the severity of their disability, a family member must

quit their job to stay home and care for the person. As family members, especially parents, become older their own health may suffer due to caring for their loved one.

We do not expect this problem to be solved overnight because it is one that has grown over the years. We do ask, and the many persons who are waiting for service and their family members ask, that you carefully study this issue and make plans to reduce the Waiting List numbers. Many Kansans who have this disability can be strong contributing members of our society. They just need assistance.

Institutional Closure - Finally, we support Governor Brownback's proposal to close Kansas Neurological Institute. Winfield State Hospital (WSH) was successfully closed in the mid 1990s and the savings used to bring our DD waiting list to almost nothing. An outside study commissioned by the Legislature and Developmental Disabilities Council showed that overall health and welfare of WSH residents improved after their movement to the community. Closure of another state DD hospital would greatly benefit both persons with Developmental Disabilities and the State. Alaska, Hawaii, Indiana, Kentucky, Maine, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and West Virginia have no state institutions. Illinois recently closed an institution and in the past five years, Louisiana went from nine institutions to three and closed another one last year.

We do appreciate appearing before you today and look forward to working with you in meeting the needs of persons who have a developmental disability. Please feel free to contact me with any questions you may have or if you need any information.

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Attachment 1

What is a Developmental Disability?

Developmental Disabilities are physical or mental impairments that begin before age 22, and alter or substantially inhibit a person's capacity to do at least three of the following:

1. Take care of themselves (dress, bathe, eat, and other daily tasks)
2. Speak and be understood clearly
3. Learn
4. Walk/ Move around
5. Make decisions
6. Live on their own
7. Earn and manage an income

Kansas Definition

(f) "Developmental Disabilities" means:

- (1) Mental retardation; or
- (2) a severe, chronic disability, which:
 - (A) Is attributable to a mental or physical impairment, a combination of mental and physical impairments or a condition which has received a dual diagnosis of mental retardation and mental illness;
 - (B) is manifest before 22 years of age;
 - (C) is likely to continue indefinitely;
 - (D) results, in the case of a person five years of age or older, in a substantial limitation in three or more of the following areas of major life functioning: Self-care, receptive and expressive language development and use, learning and adapting, mobility, self-direction, capacity for independent living and economic self-sufficiency;
 - (E) reflects a need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are lifelong, or extended in duration and are individually planned and coordinated; and
 - (F) does not include individuals who are solely and severely emotionally disturbed or seriously or persistently mentally ill or have disabilities solely as a result of the infirmities of aging.

K.S.A. 39-1801 *et seq*

KANSAS COUNCIL ON DEVELOPMENTAL DISABILITIES

APPOINTED MEMBERS

1/14/11

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¹ person with a developmental disability

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KANSAS COUNCIL ON DEVELOPMENTAL DISABILITIES

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¹ person with a developmental disability

² parent of a person with a developmental disability

Attachment 3

Kansas DD Waiver Waiting List

Kansas Developmental Disabilities System

Kansas has a Medicaid Home and Community Based Services Waiver for persons who have a developmental disability and who meet the State definition. We have had a DD Waiver Waiting List for many years. Unfortunately, it has grown significantly! Below is a spreadsheet showing this growth in both the *unserved* and *underserved* population in chart format. *Unserved* means that the individual receives no DD services. *Underserved* means that they receive some services but need more.

Home and Community Based Services Developmental Disabilities Waiver Waiting Lists

| Year | Number Unserved | Number Underserved | Totals |
|-------------|------------------------|---------------------------|---------------|
| 1999 | 393 | 0 | 393 |
| 2004 | 1,120 | 1,169 | 2,289 |
| 2009 | 1,733 | 1,812 | 3,545 |
| 2010 | 2,182 | 1,957 | 4,139 |
| 2011 | 2,383 | 1,008 | 3,391 |