



# Johnson County

## Developmental Supports

Building Resources for People with Disabilities

January 18, 2011

To: Children and Families Committee

From: Maury L. Thompson, Executive Director  
Johnson County Developmental Supports (JCDS)

RE: Community Developmental Disabilities (DD) Waiting List

Chairman Kiegerl and members of the Committee, I appreciate the opportunity to speak with you today, to provide information regarding the community DD waiting list. Before I begin to address the waiting list, I believe a primer of the community DD system may be helpful in establishing a context for a waiting list discussion.

JCDS is one of twenty-seven (27) designated Community Developmental Disabilities Organizations (CDDOs) in the State of Kansas. These organizations are dually designated by the Kansas Department of Social and Rehabilitation Services (SRS) and county commissioners. CDDOs contract with SRS to perform the duties of a CDDO which are delineated through the DD Reform Act. These duties are to:

- Serve as a single point of application,
- Determine eligibility for services,
- Provide either directly or by referral (subcontract), services to persons with a developmental disability, and
- Ensure the quality of services being provided.

Through this contractual relationship all federal and state funds for community-based DD services are to be allocated to and through the CDDO. By subcontract, CDDOs are to establish a network of Community Service Providers (CSPs). CDDOs are to oversee this network of providers and are responsible for managing the allocation of funds to this network of providers as specified through contract with SRS, although providers of Medicaid services directly bill the State for services provided. In Johnson County this network totals more than 350 providers of service.

CSPs provide some or all of the following three primary community-based services: Day and Employment services, Residential services, including services in the family home, and Case Management services. Case Management services are funded through the Medicaid State Plan. As such there is no wait for Case Management services in Kansas.

Unfortunately, the same cannot be said for Day and Employment and Residential services. These services are primarily funded through the Home and Community-Based Services/MRDD Medicaid waiver. These services are, as the name implies, paid for by Medicaid, a federal-state cost sharing

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program, approximately 40% state, 60% federal. With a waiver the federal government “waives” Medicaid requirements, permitting these funds to be used to purchase community-based services versus traditional, medically-based institutional care, at a much lower cost per person, and in the person’s home community versus a state institution. And unlike Case Management services, under a HCBS waiver, the State can establish a waiting list for these much needed services and supports, which Kansas has done.

This waiting list has now grown to include more than 4,000 plus Kansans! To narrow this list a bit – if we look to only those who needed services by the end of last year – December 31, 2010, the number is reduced to 3,391.

Of these 3,391 individuals, 2,383 are unserved, while 1,008 are underserved.

We define these populations in this manner:

**Unserved:** receiving no waiver services

**Underserved:** receiving at least one service, but needing an additional service  
( One example of being underserved is an adult attending a day employment program while continuing to live at home through adulthood, with parents who have now aged to the point where they can no longer physically care for him or her in the home, and desperately need assistance.)

These 3,391 can be further examined by age: 5-17: 1,413, 18-64: 1,965, 65+: 13

Many individuals on the waiting list have been waiting for service for more than five years.

The cost to remove an individual from the waiting list varies based upon the individual’s needs. However, on average the cost per person is approximately \$40,000 per year, of which the State would contribute 40%.

I can provide a more thorough analysis of the numbers of individuals waiting and the dollars needed to provide these critical services, and would be happy to do so. However there is one number I cannot provide.

The waiting list records the number of individuals with a disability waiting for services, but it does not, and most likely cannot, reflect the “hidden number”. That is, every number on the waiting list represents an individual, who has a family, oftentimes in crisis, because our only response to their need has been to add their name to a list, and hope that someday we’ll be able to meet their needs. There are truly thousands of Kansans impacted by our failure to provide essential services to those in need.

Many of you have heard directly from families impacted by “the wait”. During the interim the Joint Committee on Children’s Issues heard several heart-breaking stories of families struggling under the daily pressure to earn a living for their family, while figuring out how to care for a child with a disability. The Committee heard from some who had been successful – so far – and some who hadn’t.

Families are eager to speak, to share their struggles, and ask for your help. I appear before you today as their representative, to ask for that help.