



INDEPENDENCE
INCLUSION
INNOVATION

September 12, 2012

TO: Senator Carolyn McGinn, Chair; Representative Marc Rhoades, Vice Chair and
Members, Legislative Budget Committee

FR: Tom Laing, Executive Director,
InterHab

RE: Waiting lists for HCBS services and supports for persons with intellectual/developmental
disabilities.

We appreciate the committee choosing this topic for interim consideration. We know you have all heard testimony or received letters regarding the consequences of the unfunded waiting lists – from the erosion of hard earned skills for young people leaving special education with no services for employment or independent living skill building, to the emotional and financial toll on moms and dads who cannot get service.

We appreciate that the Kansas Legislature has always provided opportunities for comments from families and advocates, and will do so in the future,; therefore today, this will be a very brief run-down on current concerns regarding the lists.

I. The Intellectual/Developmental Disability Waiting List:

The I/DD waiting list is an ironic symbol of the success of Kansas community services for persons with intellectual/developmental disabilities (I/DD). It is truly ironic because the response to the success of the home and community based services model (illustrated by long waiting lists) is the State's reluctance to allocate sufficient funds to shorten the lists. Despite that, families continue to embrace the long term hope of services for their sons and daughters with I/DD.

Joint Legislative Budget Committee
September 12 and 13, 2012
Attachment: 7

The lists represent both the unmet needs and the undiminished hopes of Kansas families. The growth of the waiting lists represents the insufficient State response to those hopes and needs.

We urge the legislature to renew its historic leadership role in this matter to plan and finance a long term commitment to end the waiting lists for Kansans with intellectual/developmental disabilities. We know it is not easy, and that it takes time, but the effort must begin.

Recommendation: That this committee update the 2005 Legislative Budget Committee report which, among other recommendations, proposed a three-year phased-in approach to (1) eliminate the I/DD waiting lists, and (2) upgrade reimbursement rates for I/DD service providers to enable community capacity to expand to meet the increased demands.

II. The status of the DD waiting lists today:

The numbers have grown almost every year for the past decade.

The most recently reported number of persons waiting for services, whose requested service date has passed, is 4043, according to the State's posted July information.

This number includes those with no services (un-served), and those with partial services who need additional services (under-served), but this number only includes those whose requested date of service had come and gone, on the date the information was posted, in July of this year.

Based on this information and absent information which was previously posted (see below) we do not know exactly how many more are also in line, with a start-date later than July 2012, but based on prior history, we can estimate it roughly to be in excess of 800 persons.

III. How waiting list numbers should be reported:

The State had long maintained the practice of monthly reporting of all persons in two general categories who had applied and were determined eligible for services:

- Eligible persons unserved, and
- Persons receiving limited services but eligible for and in need of additional services (the underserved).

The practice had included those who were eligible applicants but whose start-date had not yet arrived. Previous and current administration officials had often objected to our use of those numbers, because they believed that others have said in the past, that complete numbers do not reflect an accurate number of persons waiting for service. Their reasoning is that since some have "start dates" in the future, then they are not yet technically "waiting" for service.

So now, the new information being reported on the KDADS website no longer shows the numbers of persons whose start date has not yet arrived.

The downside to this approach is that the posted information no longer fully describes the depth of need that exists in the immediate future; but Legislative decisions are all about the future and it is counterproductive to an effective legislature to be deprived of information about the future, when such information (as in this case) is known and easy to report.

The information formerly posted on the State's web site gave a clearer picture of the future, and such information should be made available once again. This type of transparency should be practiced.

We know there is a high degree of sensitivity relating to large waiting lists. We know that federal questions have been raised, and so on. All of us agree that shorter waiting lists (and ultimately no waiting lists) would be good.

To move in that direction, however, we suggest that resources be appropriated to meet the needs of persons on the list. Pretending the numbers don't exist is not the right approach.

Recommendation: That the committee request KDADS to renew the practice of posting on its website the "DD Monthly Summary" and the reports it had historically contained. The "Summary" has been a valuable tool for those who want to track the progress made by the State and its Community partners in serving the needs of Kansans with I/DD.