



INDEPENDENCE  
INCLUSION  
INNOVATION

January 18th, 2011

TO: Mike Kiegerl, Chair, and  
Members of the House Children and Families Committee

FR: Matt Fletcher, Associate Director, InterHab

RE: Waiting List Issues for Kansans with Developmental Disabilities

Thank you Representative Kiegerl, and members of the Committee, for the opportunity to speak with you today regarding the fifteen year legacy of waiting lists for Kansas children and adults with developmental disabilities. These waiting lists are the most visible symptom of the chronic underfunding that plagues the Kansas community developmental disability service system, and threatens the future viability of community-based supports for Kansans with developmental disabilities.

The last time the State of Kansas could boast it had no DD waiting lists was 1996. Since that time, the number of children and adults with developmental disabilities needing help has inched forward to a total of 4,576 today.

The State actually maintains two waiting lists. One for those who receive no services (the 'unserved' waiting list); and one for those who receive some basic level of service, but who have identified need for additional support (the 'underserved' waiting list). The numbers for each of those waiting lists? As of January 7, 2011 – 2,908 children and adults on the unserved waiting list, and 1,668 children and adults on the underserved waiting list. You might hear different numbers from others providing testimony today. The numbers above represent the widest portrait of those waiting for help; that is, all who have been identified as waiting for service.

Over the years, legislators and governors have made attempts to address these waiting lists. However, amounts appropriated have done little more than attempt to balance out the numbers of new individuals who every year are added to the list. In the last legislative session, \$3.3 million SGF was added to the FY 2011 budget in order to remove an estimated 145 individuals from the DD waiting lists. However, in spite of these new dollars the waiting lists are larger than they were this time last year (4,249 individuals in January, 2010). Clearly the approach of the last two administrations has made it impossible for the legislature alone to remedy these unmet needs.

Legislators must begin work on a multi-year plan to eliminate the DD waiting lists.

HOUSE CHILDREN AND  
FAMILIES  
DATE: JANUARY 18, 2011  
ATTACHMENT NO. 4-1

**2006 Legislative Budget Committee Recommendations:**

Your peers have already done the hard work and drawn up a blueprint for eliminating the DD waiting lists. In 2006, the Legislative Budget Committee recommended a three-year plan to both build the needed human service capacity and provide funding to eliminate the waiting lists. We encourage the Legislature to dust off that blueprint and re-commit itself to the recommendations of the report. While the budget numbers would need to be updated, and perhaps even the number of years outlined in the plan modified, the recommendations contained within the report are a solution for ensuring that the Kansas community-based system of supports remains viable for Kansans with developmental disabilities in the future.

**Quality-Based Community Expansion:**

The 2006 Legislative Budget Committee's recommendations were built upon the belief that DD service capacity must be increased in conjunction with efforts to eliminate the waiting lists. The philosophy that these two issues (service capacity and waiting lists) must be addressed in a unified manner that acknowledges the vital interconnectivity of the two was given the name "**Quality-Based Community Expansion**", or "**Q-Base**". The membership of InterHab was instrumental in the development of the philosophical framework of **Q-Base**. I have attached a summary document to my testimony on **Q-Base** that explains the importance of building capacity while addressing the waiting lists.

The membership of InterHab believes in a simple but critical premise – that waiting lists and service capacity must be addressed in tandem if the State and its community partners are to be successful in ending waiting lists for Kansans with developmental disabilities.

Proposing new resources to fund the waiting lists without also providing funding to build up the human resource infrastructure required to serve those new individuals ignores the current reality of the community DD system. Consider the following indicators of a stressed community DD system:

- *In several areas of the State, providers are unable to hire staff to serve new consumers due to low starting wages.*
- *Other providers are without enough supervisory staff, due to turnover, to safely oversee an expansion of services required to address the numbers of individuals on the waiting lists.*
- *Requests that a provider serve a person with challenging behavioral issues may be turned down due to the relative inexperience of existing staff, or*
- *Other requests that a provider serve a person with challenging medical issues may be turned down due to a shortage of persons on staff with adequate training to safely provide the ancillary support tasks of tube feeding or tracheotomy-cleaning.*

To provide increasing amounts of services requires the State/community partnership to expand service capacity and enhance service quality in amounts commensurate with the needs of persons to be served, **ahead** of any increase of service delivery that would be required in ending the waiting lists.

To attempt to increase service delivery without this consideration invites further quality erosion and exacerbates safety risks to all consumers, not just consumers funded by new waiting list dollars.

### **Capacity Expansion:**

Community service providers have few tools with which to develop the human resource capacity needed to serve significant new numbers of persons. These providers find themselves in a constant battle to overcome high turnover and staff shortages that arise as a direct result of low wages for the direct-care workers who are so vital to the community support of Kansans with developmental disabilities.

True capacity building can only result from significant upward adjustments in the HCBS DD Waiver reimbursement rate in order to provide a competitive wage that would reduce the stigmatization of vital direct-care jobs as low-wage, no-advancement jobs. Reducing such stigma removes the initial barrier faced by these providers in attracting staff, i.e. that persons entering the job market routinely do not apply for our jobs because they are known to be hard jobs with low pay.

The State must provide resources adequate to enable service providers to recruit, train, and retain high-quality direct-care staff. Current reimbursement rates are not adequate to make better wages and benefits possible.

We could get a jump start on initiating a new revised version of the Legislative Budget Committee's recommendations, with the Legislature's passage of provider assessment legislation this year. The legislation will enable the State to take advantage of expected changes at the federal level, which would allow additional federal dollars to be drawn down for the HCBS DD Waiver through a provider assessment mechanism. DD providers in Kansas are in favor of the proposal, which has been estimated to bring an additional \$25 million into the DD waiver in its first year of implementation.

Any serious effort to eliminate the waiting lists must first ensure that adequate service capacity exists in the community.

### **Why begin the process of eliminating waiting lists this year?**

I know that, given the current fiscal climate the state faces, legislators may ask "why now?" Compelling arguments can be made to make ending waiting lists a priority for this legislative session:

- ***Kansas taxpayers' investment in the Community Service Model has been allowed to erode*** – Anyone who has owned a home knows that you must continue to invest in the property if you want to **protect** the value of the property. Kansas taxpayers have invested millions of dollars in the belief that supporting a person with a developmental disability in the community is the most cost-effective choice. And it has been. However, the State has not implemented a systemic approach to ensure that the community DD system would receive incremental increases that reflected increased costs of doing business. In fact, in the last 15 years, increases in the HCBS DD Waiver's reimbursement rate to providers have not even kept pace with inflation.
- ***Institutional care costs more*** - If the community network is allowed to erode further, the only other option for persons with developmental disabilities will be institutional care – a model which will continue to be significantly more costly to Kansas taxpayers. FY 2011 annual cost of care at Parsons State Hospital: \$135,415. FY 2011 annual cost of care at KNI: \$169,725. Estimated average annual cost in the community: \$35,663. Further, with Governor Brownback's indication of the intent to close KNI within 23 months, the capability of the institutional system to serve any increase in its population will be severely curtailed. Any attempts to increase that institutional service capacity in the future will require massive investments of State dollars.

- ***“Graduating to the living room” squanders tax dollars*** - Imagine paying for special education services for a child with a developmental disability through two decades of schooling, from pre-school to high school graduation. Now, imagine throwing much of that investment away because supports aren't available to that child once they graduate from school. This example is, in fact, repeated every day in Kansas. To find multiple examples, one can look to the State's DD waiting lists. The skill sets learned through years of special education can be quickly lost, if not reinforced once the child leaves the special education system. With no funding for these ever-growing waiting lists, more and more Kansas children “graduate to the living room” while they wait for services to become available. While they wait, the investment Kansas taxpayers have made in them erodes. It's a shameful thing to do to a human, and it's a shameful waste of Kansas tax dollars.
- ***Making a child or adult with a significant developmental disability wait for help is morally unjustifiable*** - We, as a State, must determine what the primary outcomes of our collective investment in government will be. I would argue that providing help to our most vulnerable citizens should be a primary focus of government.

**Conclusion:**

The members of InterHab stand ready to work with the Kansas Legislature, should it choose to prioritize the formation of a multi-year plan to address the capacity needs of the DD system and eliminate the State's waiting lists. We are excited and encouraged by these hearings, and hope they signal the beginning of a significant recommitment to ensuring the future viability of community-based supports for Kansans with developmental disabilities.

Thank you for the opportunity to speak with you today.

# Legislative Budget Committee

## PUBLIC DEVELOPMENTAL DISABILITIES SYSTEM

### CONCLUSIONS AND RECOMMENDATIONS

The Legislative Budget Committee recommends that the Legislature establish a phased-in effort to accomplish the programmatically linked goals of community capacity expansion and the elimination of the waiting list for services from Home and Community Based Services waiver for persons with Developmental Disabilities (HCBS DD). This effort would consist of the following:

- Expand community capacity through rate adjustments to achieve rates which would more closely reflect a parity between community wages and state institutional wages by adding \$15 million SGF in FY 2008 and \$10 million SGF in FY 2009 and FY 2010; and
- Eliminate the waiting lists for developmental disability (DD) services by adding \$10 million from the State General Fund in both FY 2008 and FY 2009, and \$15 million in FY 2010.

Additionally, the Committee recommends that the Senate Ways and Means and House Appropriations Committees request information during the 2007 Legislative Session on items including but not limited to the following:

- To assure that all programs are designed to meet the intent of the DD Reform Act for greater emphasis on independence, inclusion, integration and productivity;
- To examine, and replicate if appropriate, models in other states which are better designed to assist families of dependent children, rather than relying solely on the current HCBS DD waiver;
- To establish minimum standards for all persons and entities who provide services to persons with DD;
- To assess current capacity planning at the Department of Social and Rehabilitation Services to upgrade the State's ability to provide monitoring and oversight for the expanded numbers of community service providers; and
- To propose ways by which to upgrade employment related services for persons with DD, including providing the Legislature with a fiscal estimate on unbundling supported employment services so as to allow providers of such services to build employment service capacity in the community, and therefore be able to reduce reliance on facility-based employment services.

**Proposed Legislation:** None.

## BACKGROUND

The Legislative Coordinating Council directed the Legislative Budget Committee to study the state's system for serving individuals with developmental disabilities. Specifically, the Committee was directed to review the updated Department of Social and Rehabilitation Services' (SRS) strategic plan and quality assurance and enhancement activities. In addition, the Committee was to examine current and proposed models to meet the demand for community based services.

## COMMITTEE ACTIVITIES

At the September meeting the Committee heard full-day testimony from nearly 20 conferees regarding the developmental disabilities system. Conferees included representatives of state agencies, consumer organizations, Community Developmental Disability Organizations (CDDOs), Community Service Providers (CSPs), provider associations, and other advocacy organizations.

Staff presented an overview of the developmental disabilities system to orient the Committee and lay the foundation for testimony. Following the staff presentation, SRS briefed the Committee on the number of persons served, or waiting for services, and the impact the additional funding approved by the 2006 Legislature is having on waiting lists. In addition, the agency presented information on the Developmental Disabilities (DD) Strategic Plan, quality assurance activities, targeted case management services, and the Federal Deficit Reduction Act.

Although, many comments and suggestions were made by conferees, testimony centered on the following primary themes:

- Closure of remaining state hospitals and private large bed facilities;

- Reduction of the waiting list for Medicaid Home and Community Based Services (HCBS) waiver services and expansion of community based services;
- Increased wages for direct care professionals;
- Improved quality assurance and monitoring;
- Focus on the vision set out in the Developmental Disabilities (DD) Reform Act; and
- Service requirements for individuals with severe, and sometimes violent, behaviors.

The expansion of community based services and the elimination of the waiting list for HCBS waiver services are underlying themes in nearly all of the testimony. However, cautions were expressed regarding the need for capacity expansion, quality oversight, funding and other measures to ensure the expansion is successful. Conferees commented that a quality system of services requires both access for individuals needing services and service providers reimbursed at levels sufficient to recruit and retain employees with the right skills and abilities.

A number of conferees addressed issues with having adequate direct care professionals in the community. The most common comment was regarding the salary of direct care professionals, especially in relation to what staff at the state hospitals are paid. According to testimony, the current state-wide average wage for direct care staff in the community is \$8.83 per hour while the beginning wage for a similar position at a state hospital is \$11.81 per hour. According to testimony, the estimated cost to increase community based staff wages to \$11.81 per hour is \$35 million from the State General Fund. Several conferees commented on the amount of work required

from direct care staff and the difficulty in hiring, training and retaining qualified staff to provide around-the-clock services.

The closure of the remaining two state hospitals and private facilities was discussed by two conferees representing advocacy organizations. According to conferees, institutional services are not the most economical way to serve persons with developmental disabilities. Additionally, federal pressure is building to re-balance funding in favor of community based services. Conferees recommended that all savings generated from closing institutions be directed into the community to fully fund services. The suggestion also was made to set a binding date for closure to facilitate the process. Finally, one conferee suggested the Committee review the report on the closure of Winfield State Hospital and Training Center which reported that individuals moved into the community had better outcomes than when they were in the hospital.

Improving the system for quality assurance and monitoring was cited as a principal of providing quality community services. Conferees indicated that the current system has not kept up with the expanding community system resulting in a concern about whether people are receiving the appropriate services and if state dollars are being spent effectively. Conferees cited the lack of new funding for quality monitoring, both at the state and local level, despite increases in the numbers of consumers, providers and service models. In addition, one conferee commented on the reduction in day-to-day contact that SRS staff have to monitor the provision of services due to staffing reductions and reorganization. Conferees asked for additional resources dedicated to the development of outcome measurements and the establishment of minimum standards for all providers.

A refocusing on the vision of the DD Reform Act, particularly with respect to

adult independence, was a key in a number of presentations. Multiple conferees commented on the need for timely transition of services when youth graduate from high school and move into adult services. According to conferees, these services are critical to moving people into the community and out of the family home where their adult independence may be hampered by overly paternalistic families. Integral to this process and to the provision of better services during school age years, is better communication between SRS and the Department of Education about program requirements and service coordination. Another challenge to adult independence noted by conferees was payments made to families to provide care. According to the testimony, paying family members to provide service may provide a disincentive to those families to move the child out of the home for fear of losing a source of income. The result is a lack of independence for the now adult child to gain independence and integrate into the community.

Another piece of the adult independence theme was testimony about the importance of Supported Employment and Supported Living programs. Testimony was presented that stressed the importance of these two types of services to ensuring adults were integrated into the community. Conferees requested additional support for these programs.

Challenges with dealing with developmentally disabled persons who have severe behavioral issues in the community were addressed by two service providers. According to the testimony, service providers have very little ability to reject clients whose behaviors pose dangers to staff or exceed the providers ability to serve the individual. The providers commented that, particularly in light of the relatively low wages, direct care staff were being put in harms way without sufficient recourse. It was suggested that the state needed to look

at alternatives to deal with persons who exhibit criminal, predatory, violent or other aggressive behaviors.

Other topics presented to the Committee included the value of consumer self-advocacy; gaps in services for children; and the need for Ombudsman services. With regard to consumer self-advocacy, the following three steps were given to ensure consumer rights: consumer participation in quality assurance; increased opportunities for choice and control of services; and increased education and awareness of service delivery options. In addition, more financial support for statewide self-advocacy training was requested. Gaps in services for young children were identified that results from a system designed to serve adults. These gaps include: the lack of HCBS waiver services for persons under age five; in-home supports not designed to meet families' needs; lack of billing system for mental health services; inflexible systems that do not support community collaboration and limited discretionary funds. Finally, one conferee noted the need for Ombudsman services to support and educate persons with developmental disabilities.

#### CONCLUSIONS AND RECOMMENDATIONS

The Legislative Budget Committee recommends that the Legislature establish a phased-in effort to accomplish the programmatically linked goals of community capacity expansion and the elimination of the waiting list for services from Home and Community Based Services waiver for persons with Developmental Disabilities (HCBS DD). This effort would consist of the following:

- Expand community capacity through rate adjustments to achieve rates which would more closely reflect a parity between community wages and state institutional

wages by adding \$15 million SGF in FY 2008 and \$10 million SGF in FY 2009 and FY 2010; and

- Eliminate the waiting lists for developmental disability (DD) services by adding \$10 million from the State General Fund in both FY 2008 and FY 2009, and \$15 million in FY 2010.

Additionally, the Committee recommends that the Senate Ways and Means and House Appropriations Committees request information during the 2007 Legislative Session on items including but not limited to the following:

- To assure that all programs are designed to meet the intent of the DD Reform Act for greater emphasis on independence, inclusion, integration and productivity;
- To examine, and replicate if appropriate, models in other states which are better designed to assist families of dependent children, rather than relying solely on the current HCBS DD waiver;
- To establish minimum standards for all persons and entities who provide services to persons with DD;
- To assess current capacity planning at the Department of Social and Rehabilitation Services to upgrade the State's ability to provide monitoring and oversight for the expanded numbers of community service providers; and
- To propose ways by which to upgrade employment related services for persons with DD, including providing the Legislature with a fiscal estimate on unbundling supported employment services so as to allow providers of such services to build employment service capacity in the community, and therefore be able to reduce reliance on facility-based employment services.





## **Quality-Based Community Expansion - "Q-Base"**

The Kansas Developmental Disabilities (DD) Reform Act (KSA 39-1806), passed in 1995, mandates development of a community network of supports that foster independence, inclusion, integration and productivity for Kansans with developmental disabilities. Significant and sustained efforts must be undertaken by the State of Kansas, in partnership with community providers, in order to build the infrastructure required to carry out this commission.

While small increases in needed resources have been championed by the legislature in recent years, no organized effort has been initiated by policy makers to either address the glaring needs of the community DD system or meet the mandates of the KS DD Reform Act. Strong leadership is now needed to steer the State into a new era of sustained investment in a community-based system of supports for Kansans with developmental disabilities that will finally answer the call of the KS DD Reform Act.

The beginning steps of such a sustained effort must include the elimination of the State's waiting lists for DD services, which now number more than 4,000 children and adults with developmental disabilities.

However, policy makers must understand that in order to end the State's waiting lists, community service capacity must be dramatically enhanced - both programmatically and in terms of human resources infrastructure.

The following is a broad proposal that we believe must be embraced if we are to meet the mandates of the DD Reform Act. This proposal is based on a simple but critical premise, i.e. waiting lists and rate increases must be addressed in combination if the State and its Community partners are to significantly expand community services for persons with developmental disabilities.

Proposing new resources to fund "stand alone items" ignores the reality that waiting list funding alone will not enable community service providers (CSP) to meet the needs of persons on the waiting list, e.g.:

- In several areas of the State CSPs are unable to hire staff to serve new consumers due to low starting wages.
- Other CSPs are without enough supervisory staff, due to turnover, to safely oversee a business expansion.

- Requests that a CSP serve a person with challenging behavioral issues may be turned down due to the relative inexperience of existing staff, or
- Other requests that a CSP serve a person with challenging medical issues may be turned down due to a shortage of persons on staff with adequate training to safely provide the ancillary support tasks of tube feeding or tracheotomy-cleaning.

To provide increasing amounts of services requires the State/Community partnership to expand service capacity and enhance service quality in amounts commensurate with the needs of persons to be served, ahead of the curve of service expansion.

To increase service without this consideration invites quality erosion and exacerbates safety risks to all consumers, not just the consumers funded by new waiting list dollars.

**Only with sufficient rate increases, in combination with creative and flexible program management, can the State/Community partnership insure a quality-based approach to community service expansion.**

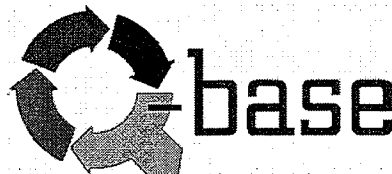
InterHab proposes that any new system dollars – for waiting list reduction and rate increases – be creatively utilized to address four program components:

- Stewardship
- Quality enhancement
- Capacity expansion
- Waiting lists

#### **Community Stewardship:**

Community leadership have long been tasked with combining state/federal resources with local resources to make community DD programs work to the maximum attainment of the statutory and regulatory expectations of the participating funding authorities. To that extent, the following are the stewardship activities that we believe are vital to assure the long term financial sustainability for the coming years:

- State and community efforts must be increased to assure an expanded effort in the community to promote employment and employment related training for persons with developmental disabilities.



- Programs such as 'tiny-k' infant and toddler services which perform vital early intervention for children with disabilities and their families must be enhanced, thereby ensuring a better quality of life for thousands of Kansas children who could be diverted from further need of State-funded assistance.
- State and community efforts must collaboratively develop new family service models that satisfy basic family needs, in order that families are not diverted into the most available funding stream (the current HCBS DD Waiver) but are assisted by options (including the Family Subsidy model, a new Family Services waiver, or other models).
- State and community efforts must be redoubled to increase the maximization of freedom and control that someone can bring to their life.
- State oversight must position its structure, within the philosophical framework of the Developmental Disability Reform Act, to be supportive of community flexibility in adjusting programs, services and staffing to suit the wide spectrum of both proven current needs and possible future needs of populations served.

#### **Quality Enhancement:**

The State and community collaboration of the past, which ushered in a high degree of professionalism and expertise in all areas of the delivery of community services and supports, has taken a back seat to a struggle to maintain 21<sup>st</sup> century quality enhancement momentum with 20<sup>th</sup> century resources. This trend must be reversed.

Further, additional emphasis and resources must be brought to bear on the State's efforts to encourage self-advocacy among Kansans with Developmental Disabilities.

Finally, in order to fill a vital community education and oversight role, the State should pursue creation of a Kansas DD Ombudsman. This ombudsman would provide information to persons served and their families regarding community service and provider options, as well as collect needed data on community provider customer service, quality of service and service access issues.

A significant resource commitment must be made in the following areas of training:

- Training initiatives to assist in the delivery of high-quality services to the increasing numbers of persons with health, behavioral or age-related challenges,
- Training initiatives to upgrade the skill-set of every supervisor of community direct care staff, and



- A comprehensive review must be undertaken to assess the core quality related proficiencies of the current network of service providers.

The expansion of services, the expansion of non-licensed providers, and the lack of adherence to core standards among newly licensed providers – all of these factors give rise to a concern among community leadership that standards of service intended to safeguard the interests of consumers have been sacrificed due to resource shortages. Minimum standards must be established, and reimbursement rate structures must reflect a commitment to such standards.

In the era of increased self-sufficiency among persons receiving service, ensuring the adherence to statutory and departmental quality benchmarks such as the core components of the DDRA (integration, inclusion, independence and productivity) is vital. The State must undertake a development process to implement full oversight of these new service choices, in order to determine that established statutory and departmental outcomes are met.

### **The State's Waiting Lists:**

State and community leaders must better assess and present the characteristics of persons' needs who are waiting for services. Merging the two lists into one list would acknowledge that individuals' needs cannot be arbitrarily prioritized by who is and who isn't currently receiving some services.

State and community leaders must also re-emphasize the generic community supports that do exist, and persons waiting for services, and their advocates, must be assisted in accessing such generic supports. Generic supports can, and often do, mitigate some of the negative effects of waiting for service, and sometimes can become a non-paid alternative to paid services.

### **Capacity Expansion:**

Community service providers have few tools with which to develop the human resource capacity needed to serve significant new numbers of persons, given that the principal energy of human resource professionals in the system is spent in the constant battle to overcome high-turnover and staff shortages that arise as a direct result of low wages.

True capacity building can only result from significant upward adjustments in the wage base to reduce the stigmatization of such jobs as low-wage, no-advancement jobs. Reducing such stigma removes the initial barrier faced by HR staff, i.e. that persons entering the job market routinely do not apply for our jobs because they are known to be hard jobs with low pay.

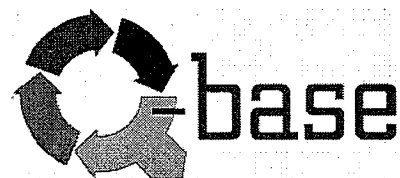
Obviously, the foundation of HR capacity building is the foundation upon which the community service policies rise or fall. It is critical, but still woefully under-addressed, that the State must provide resources adequate to enable service providers to recruit, train, and retain high-quality



direct care staff. Current reimbursement rates are neither adequate nor reasonable to make better wages and benefits possible.

HR capacity building is additionally needed to enable focusing in the following ways:

- To ensure that community developmental disability service providers are reimbursed at a rate which allows them to offer wages and benefits commensurate with attracting and retaining quality direct support staff.
- To utilize higher qualified and/or more experienced staff for the increasing numbers of consumers served whose diagnostic characteristics include (a) significant health needs, (b) increases of the early onset of age-related illness, principally Alzheimer's and other forms of dementia, (c) behavioral challenges of such significance that the failure to provide adequate staff to serve such persons could easily constitute risks to the consumers or the community at large;
- To increase the development of community generic support to help meet individual needs with non-paid services; and,
- To better educate community employers to see workers with DD as a resource to be utilized, and to provide the informal short term assistance to make that happen, as well as the intermittent long-term follow up to assure the viability of those employment experiences.
- To fully-fund supported employment services for persons with developmental disabilities in order to assist them in becoming independent, contributing members of their communities.



THE TOPEKA CAPITAL JOURNAL

# cjonline.com

YOU ARE HERE: [CJOnline](#) » [News](#) » [Education](#)

## Graduating to waiting



Juliet Banks is pictured here with her son, Brandon.

### Students with disabilities age out of public schools and land on a waiting list

BY [BARBARA HOLLINGSWORTH](#)

Created June 6, 2010 at 6:03pm

Updated June 6, 2010 at 10:51pm

Juliet Banks wants the same things most mothers want for their children.

She wants to see her son reach his potential and achieve at least some of his dreams, including working and moving away from home. But 21-year-old Brandon is somewhere in a 4,000-person deep line waiting for services offered to people with developmental disabilities.

Banks, who attended his final days at Highland Park High School last month, is among a growing number of Kansans who at 21 have aged out of the public school system to find nothing waiting on the other end. It is a difficult reality for those with disabilities who can find themselves going from the classroom to the couch, and it is a logistical challenge for families that must make difficult decisions about how to care for children that can't be left home alone. They are decisions that can lead some families to leave jobs, sending them into a financial tailspin.

out there," said Rocky Nichols, executive director of these families who have fought so hard to get special children and fought so hard with Medicaid to get them. They are under 21 now get sucker-punched and not only hit a brick wall, bounce off of it and then find themselves in a 4,000 deep."

For disabled children navigate the system. In those years in advance, she put her son's name down, years in advance. But when funding didn't keep up with the need, she was 21 — the age at which students with special needs graduate.

"My husband and I will probably have to cut back on work during the day," Juliet Banks said.

Services vary depending on the need of the recipient. They could include around-the-clock care, assistance to live independently with roommates or support for working in a job. Some families

are able to pick up the tab for the care — at least for a short time, said Ramona Macek, community developmental disabilities organization director at TARC. Some families face crisis, particularly one-income, single-parent homes. When they are available and able, grandparents can be invaluable, she said.

The Banks are among the families that can count themselves lucky to have two wage earners.

"There are families that have it a lot worse than I do," Juliet Banks said.

Some help is coming, but advocates say it won't be enough. The Legislature restored a 10 percent cut in Medicaid funding that affected both the pay for workers in the field and the quantity of services provided. Lawmakers also added \$6.9 million that will be shared to address the waiting list for the physically and developmentally disabled. Tom Laing, executive director of InterHab called the new money a "drop in the bucket" that might take 150 names off the waiting list.

Lawmakers, Laing said, have years of underfunding to address. Although he said it feels like lawmakers turned a corner this year toward addressing funding, "a hell of a lot of people were ignored."

"It's terribly shortsighted," he said. "The responsibility has been passed on from legislative session to legislative session until the current Legislature was faced with a multiyear challenge. It will take us three or four years at a minimum to whittle down the waiting list until it's manageable again."

In the meantime, many of those children will stay in school longer. Anecdotally, school districts like Shawnee Heights Unified School District 450 say they are seeing greater numbers of children with developmental disabilities stick around until age 21 rather than leave at 18 because they are on the waiting list.

Of Shawnee County residents waiting for services, 81 are between the ages of 18 and 21, Macek said. Some, she said, have waited five years for services.

It is a waste, Laing said, to invest in intensive education services while children make their way through public schools and then leave them with nothing on the other end to help them maximize their abilities.

"When you deny them the one path that exists for them to do that you've not only stolen from their lives but you've thrown your money into the fire, so to speak," he said.

The options are limited. Tonia Martin's oldest son Justin White recently finished up at Washburn Rural High School. While Justin is 21, Tonia Martin can't leave him unsupervised. Cooking would be dangerous. He likely wouldn't make a good choice if a stranger came to the door. As is, Justin receives 15 hours of support services during which he works one day and volunteers another.

Martin believes her son is near the top of the waiting list but is planning to spend time at home with Justin in coming months. A recent graduate in social work from Washburn University, she is going to take some time off before returning to school to work on her master's degree. Until he finds his way off the waiting list, she worries he will lose out on the future he had envisioned, including living away from home.

"Everything we planned for and hoped for, now that his time has come, we're uncertain of what

is going to happen," she said. "It's not fair to them. They deserve the same opportunities that we have."

*Barbara Hollingsworth can be reached at (785) 295-1270 or [barbara.hollingsworth@cjonline.com](mailto:barbara.hollingsworth@cjonline.com) and tweets at [twitter.com/CapJ\\_Barb](https://twitter.com/CapJ_Barb).*

**Make Less Than \$45,000/Year?**

You May Qualify for a Grant to Go Back to School.  
[www.SeeCollegeDegrees.com/Grants](http://www.SeeCollegeDegrees.com/Grants)

**Mortgage Rates Hit 3.54% APR**

Obama Urges Homeowners to Refinance as  
Mortgage Rates Drop Again.  
[www.SeeRefinanceRates.com](http://www.SeeRefinanceRates.com)

**Beat the Credit Card Companies**

See if You Qualify to be Bailed Out of Credit Card  
Debt.  
[www.LowerMyBills.com/Debt](http://www.LowerMyBills.com/Debt)