



# ***Kansas Council on Developmental Disabilities***

SAM BROWNBACK, Governor  
KRISTIN FAIRBANK, Chairperson  
JANE RHYS, Ph. D., Executive Director  
jrhys@kcdd.org

Docking State Off. Bldg., Rm 141,  
915 SW Harrison Topeka, KS 66612  
785/296-2608, FAX 785/296-2861  
http://kcdd.org

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

## **House Committee Children and Families**

January 25, 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.

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

HOUSE CHILDREN AND  
FAMILIES  
DATE: JANUARY 25, 2011  
ATTACHMENT NO. 1-1

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. 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 last 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. We would also like to mention that DD Service providers hire many people in your local communities to care for persons who have a developmental disability so there is an economic benefit to communities in all areas of Kansas through the provision of jobs and services.

Institutional Closure - 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.

Attachment 2 shows the Executive Summary of the closure of Winfield State Hospital and Training Center in the 1990's. The second part of that is a follow-up on some of the former residents that was completed last year to see if the improvements seen during the late 1990's were still being seen. In both cases you can see that the lives of persons who left Winfield continued to get better.

Employment - finally, we support employment of persons with disabilities as seen in Senate Substitute for House Bill 2669, that passed the House last year with only one nay vote. Employment First, the policy described in this Bill, would ask that persons with a disability have the same expectations that everyone has. As children we were often asked: "What do you want to be when you grow up?" As adults we are often asked: "What do you do?" when meeting people. We define ourselves by our employment. Yet too often, people with disabilities are told, or their family members are told, "You cannot work."

We believe that most people can work. Some may have shorter hours or may need some assistance, but almost everyone can work. People with disabilities also want to be part of the workforce, want to earn their own money. Our intention is to get the Bill introduced in the Senate, with no changes from the attached Bill.

Employment First Recommendations are:

- Kansas government and partners must refocus resources and support infrastructure that promotes goal of all people becoming employed
- Kansas Policies must be revised to incorporate Employment 1<sup>st</sup> strategies
- Revise means used to manage disability service systems including funding incentives to encourage expansion of integrated employment as first option – discourage non-work and facility based services
- Analyze policy funding and programs with focus on competitive integrated employment and include a comprehensive cross agency data tracking system
- Invest in on-going training and Technical Assistance with system-wide commitment to quality employment services.

These can be found on the Employment First sheet attached.

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.

Jane Rhys, Ph.D., Executive Director  
Kansas Council on Developmental Disabilities  
Docking State Office Building, Room 141  
915 SW Harrison  
Topeka, KS 66612-1570  
785 296-2608  
jrhys@kcdd.org

## 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*

**Are People Better Off?  
Outcomes of the Closure of Winfield State Hospital**

**Final Report (Number 6)  
Of the Hospital Closure Project  
Required by Substitute House Bill 3047**

**Submitted to:**  
The Kansas Council on Developmental Disabilities  
And  
The Legislative Coordinating Council

**Submitted by:**  
*James W. Conroy, Ph.D.*  
*The Center for Outcome Analysis*  
*1062 East Lancaster Avenue*  
*Suite 15E*  
*Rosemont, PA 19010*  
*610-520-2007, FAX 5271, e-mail jconroycoa@aol.com*

**December, 1998**

# Table of Contents

Overview .....	1
Historical Context .....	3
Methods .....	12
<u>Instruments: The Personal Life Quality Protocol</u> .....	12
<u>Procedures for Data Collection</u> .....	19
<u>Participants</u> .....	20
Results .....	22
References .....	37
Appendix A .....	1
Appendix B .....	2

## Executive Summary

This is the sixth of our seven reports on the closure of Winfield State Hospital and Training Center. It is concerned with scientific, quantitative answers to the questions: "Are the people who moved out of Winfield better off, worse off, or about the same? In what ways? How much?"

To answer these questions, we visited each person living at Winfield when our contract began. We measured dozens of aspects of quality of life and characteristics of service provision for each person. We used questionnaires and scales that have been used in many other studies over a period of 20 years in this and other countries. The reliability and validity of these measures is well established.

Movement of people with developmental disabilities from institution to community has been one of the most successful social movements of the baby boomer generation (Larson & Lakin, 1989, 1991). In contrast, in the field of mental illness, the nation's record in the sixties and seventies was a disgrace (Bassuk & Gerson, 1978).

The Kansas experience of the closure of Winfield has been far more successful than this consulting team predicted. There is good reason for Kansas stakeholders to be gratified. The table below summarizes the measured outcomes of movement of the 88 people for whom we were able to obtain "before and after" data.



## Verbal Summary of Outcomes at Year One

Quality Dimension	Outcome	Direction
Adaptive Behavior Scale	Significant 1.7 point gain (5% up)	V. Positive
Orientation Toward Productive Activities Scale	Large gain 1.7 to 11.5 points	V. Positive
Challenging Behavior	Modest 2.7 point gain (3% improvement)	Positive
# of Services in Individual Plan	Up from 5.2 to 8.2	Positive
Hours of Day Program Services	Up from 4 to 18 hours per week	V. Positive
Hours of Developmental "Programming" in the Home	Down from 10 hours to 6 hours per week	Negative(?)
Integration	Large increase from 3 to 31 outings per month	V. Positive
Choicemaking	Up 50% from 27 to 40	V. Positive
Qualities of Life Ratings	Up from 68 to 78 (Now to Now)	V. Positive
Qualities of Life Perceptions of Changes	Up in every area but one – dental (Then and Now)	V. Positive
Staff Job Satisfaction	Up by 1.2 points out of 10	V. Positive
Staff Like Working With This Person	Up by 1.4 points out of 10	V. Positive
Staff Get Sufficient Support	Up 1 point (3.7 to 4.7, still low)	Positive
Staff Pay Rate	Down \$4000	Mixed
Health Rating	Up from 3.5 to 3.8 out of 4	Positive
Health by Days Ill Past 28	Down from 3.2 to 0.8 days/28	V. Positive
Medications, General	Down from 5.7 to 4.9	Positive
Medications, Psychotropic	Down from 18 people to 6	V. Positive
Doctor Visits Per Year	Down from 22 to 6	Unclear
Dental Visits Per Year	Down from 2.3 to 0.5	Negative
Family Contacts	Up from 7 to 18 contacts per year	V. Positive
Individualized Practices Scale	Up from 47 to 72 points	V. Positive
Physical Quality Scale	Up from 76 to 86 points	Positive
Normalization	Large increase	V. Positive
Subjective Impressions of Visitors	Up on 4 out of 5 dimensions	Positive
Total Public Costs	Down about 15% From \$109,000 to \$91,000	Positive

**Are People Better Off?  
Outcomes of the Closure of Winfield State Hospital  
13 Years Later**

A Follow Up to the Final Report (Number 6) of the Hospital Closure Project  
Issued by Dr. James Conroy in December, 1998

**Submitted to:**  
The Kansas Council on Developmental Disabilities

**Submitted by:**  
*Della Moore*  
*Director of Quality Assurance*  
*Creative Community Living, Inc.*  
*1500 E 8<sup>th</sup> Avenue*  
*Suite 208*  
*Winfield, KS 67156*  
*620-221-9431, FAX 620-221-9336, email [della@cclcel.org](mailto:della@cclcel.org)*

**October, 2010**

1-11  
19

In December of 1998 Dr. James Conroy submitted his final report on the closure of Winfield State Hospital. He referred to the people moving from the hospital as Movers. His report was extensive using a multitude of measures. At that time he stated, "Movers are believed to be better off." (Conroy, p.33)

The logical question is how well Movers are doing today, 13 years later. While we have neither the time nor the resources to replicate Dr. Conroy's work, we believe the 14 quality of life dimensions used by Dr. Conroy offer a strong basis for comparison (Conroy, p. 33). We further believe the parents/guardians of the Movers offer the most reliable information as the Movers do not communicate verbally well or at all. With that in mind we were able to contact 40 parents/guardians of the Movers from 1997. We contacted the parents/guardians via telephone and used the following script to administer the survey.

Script for phone interview:

My name is \_\_\_\_\_ and I work for Creative Community Living. We are collecting information to share in summary form with the Kansas Council on Developmental Disabilities. This information will most likely be used in testimony before legislators as they examine closure of another state hospital. This short survey should only take 5 – 10 minutes of your time. May I proceed? (If answer is "no", ask if there is a more convenient time you can call. If the answer is still "no", thank them and hang up.)

Every parent/guardian we were able to reach participated in the survey.

We anticipated there would be a slight increase in the level of satisfaction with community-based services. We did not anticipate the degree of increase in all dimensions.

Category	State		
	Hospital	Year 1	Year 13
Health	2.6	2.7	4.3
Running his/her own life - making choices	2.2	3.0	4.0
Family Relationships	2.1	2.3	3.9
Seeing friends, socializing	2.3	2.8	4.2
Getting out and getting around	2.3	3.1	4.3
What he/she does all day	2.5	3.1	4.1
Food	2.6	3.5	4.2
Happiness	2.8	3.3	4.3
Comfort	2.9	3.4	4.5
Safety	3.1	3.5	4.3
Treatment by staff	3.4	3.8	4.4
Dental care	2.9	2.4	4.2
Privacy	3.2	3.7	4.3
Overall quality of life	3.0	3.5	4.4

The comments offered by many parents/guardians also supported the increase in degree of satisfaction. Below is a sampling of the positive comments:

- Can tell you in every aspect of their lives things are much better now than at State Hospital.
- As far as her life now is concerned, I really couldn't ask for it to be better.
- I think families are much more comfortable visiting in the community than they were at State Hospital. I've seen a lot of change in my life and that was one of the most positive.
- Life improved dramatically as has health.
- At first I was opposed to closure of State Hospital but I feel she would not have had the opportunities she does now.
- I feel he gets much better care now and has better Quality of Life than when at State Hospital.
- Safety is much better now, more one-to-one care.
- There wasn't as much preventative medical treatment, more reactive. I was one of the last to think this was possible.
- Think whole transition has gone well – better for everyone.

Obviously, there was some dissent although very minimal. Approximately 99% related to staff turnover, but there was consistent praise of the job done by staff today. As one parent phrased it, "There is always someone who cares."

Family relationships showed the least level of increase. The comments relating to those scores referred to declining health and death of family members rather than discontent with community settings. As the comment section shows, many family members found it more convenient and/or comfortable to visit in the community.

Dr. Conroy wrote in 1998, "The Kansas experience of the closure of Winfield has been far more successful than this consulting team predicted." (Conroy, Executive Summary) Thirteen years after the closure the success seems to have kept building.

## References

Conroy, James W. (1998). Are People Better Off? Outcomes of the Closure of Winfield State Hospital, Final Report (Number 6) of the Hospital Closure Project. *Required by Substitute House Bill 3047.*

# EMPLOYMENT



Establishing integrated, competitive employment as the first priority for Kansans with disabilities

## VALUES

- Kansas needs everyone contributing to its economy and cannot afford to have people with disabilities not working. When Kansans with disabilities are employed, we pay taxes, buy goods and services, and support our community rather than relying on our community to support us.
- All Kansans should be as self-sufficient as possible. A lifetime of financial dependency on disability benefit programs is a costly proposition.
- Employment is fundamental to adulthood, quality of life, individual productivity, self-worth, and earning the means to exercise freedoms and choices available to all citizens. Working-age Kansans with any level of disability should enjoy our lives as our non-disabled peers do.
- Kansas must craft an educational and adult service system that expects, supports, and rewards integrated, competitive employment as the first option for every individual with a disability.

## BACKGROUND

Self Advocates with developmental disabilities encouraged the Kansas Department of Social & Rehabilitation Services (SRS) and Community Developmental Disability Organizations (CDDOs) to create an *Employment First* initiative for people with developmental disabilities receiving day services in Kansas. As a result, a task team has been created that is charged with developing a comprehensive employment service delivery evaluation, identify barriers and disincentives for competitive employment and independence, and recommend changes. The work group investigated *Employment First* activities in other states, and studied nationwide best practices for increasing integrated employment outcomes among people with developmental disabilities. While the focus of this particular group was on persons with developmental disabilities, the recommendations apply to individuals with all disabilities.

## RECOMMENDATIONS

- The Kansas government and their partners must refocus resources, and support infrastructure, that promotes the goal of all people becoming employed, regardless of the severity of their disabilities.
- Policies used to guide disability service systems in Kansas must be revised to incorporate *Employment First* strategies, and must include the input of persons with disabilities. Every Person-Centered Plan for people with disabilities of working age should document that *Employment First* options are being presented, identify any barriers, and contain action steps to overcome them.
- Mechanisms used to manage disability service systems in Kansas must be revised, including funding incentives to encourage the expansion of integrated employment opportunities as the first option, and discourage the use of non-work and/or facility based services.
- Analysis of policy, funding, and programs, with a focus on competitive, integrated employment, and a comprehensive cross agency data tracking system, must be initiated.
- The success of the *Employment First* initiative requires an investment in on-going training and technical assistance, with a system-wide commitment to quality employment services.

1-15  
7-11

**The following agencies and organizations support the Values and Recommendations as described on the front of this flyer, and are committed to working together to make *Employment First* a reality in Kansas:**

**Association of Community Mental Health Centers**

**CLASS, LTD**

**Cottonwood, Incorporated**

**CDDO of Butler County**

**Community Supports and Services (CSS), Disability and Behavioral Health Services, SRS**

**Disability Planning Organization of Kansas, Inc. (DPOK)**

**Disability Rights Center of Kansas (DRC)**

**Families Together**

**Governor's Mental Health Services Planning Council's Vocational Subcommittee**

**Interhab**

**Johnson County Developmental Services (JCDS)**

**Kansas APSE**

**Kansas Association of Centers for Independent Living (KACIL)**

**Kansas Commission on Disability Concerns (KCDC)**

**Kansas Council on Developmental Disabilities (KCDD)**

**Kansas Rehabilitation Services (KRS), SRS**

**Kansas State Department of Education**

**Kansas University Center on Developmental Disabilities**

**Kansas Youth Empowerment Academy (KYEA)**

**Keys for Networking, Inc.**

**National Alliance on Mental Illness (NAMI) Kansas**

**Nemaha County Training Center, Inc.**

**OCCK, Inc.**

**TARC, Inc.**

**The Arc of Douglas County**

**Self Advocate Coalition of Kansas (SACK)**

**Statewide Independent Living Council of Kansas (SILCK)**

**Southwest Developmental Services, Inc. (SDSI)**

**Working Healthy, Kansas Health Policy Authority (KHPA)**