Approved: January 27, 2011

MINUTES OF THE HOUSE CHILDREN AND FAMILIES COMMITTEE

JANUARY 25, 2011

The meeting was called to order by Chairman Kiegerl at 9 a.m. on January 25, 2011, in Room 142S of the Capitol.

All members were present.

Committee staff present:

Martha Dorsey, Kansas Legislative Research Department
Jay Hall, Intern, Kansas Legislative Research Department
Renae Jefferies, Office of the Revisor of Statutes
June Christensen, Committee Assistant

Others attending: See attached list.

Conferees Appearing before the Committee:

Jane Rhys, Executive Director, Kansas Council on Developmental Disabilities
Jim Leiker, President and CEO, Easter Seals, Capper Foundation
Kathy Lobb, Self Advocate Coalition of Kansas
Matt Fletcher, InterHab

Chairperson Kiegerl reiterated that the purpose of the committee is to help children get off the Developmental Disability (DD) waiting list. He introduced Representative Bill Otto, Kids of Kansas, to present proposed bills.

Mr. Otto reviewed three proposed bills from last year's session: 1) Not to allow children to be removed from the parents' home unless the parents have been convicted of a crime or are mentally incompetent and not to lose permanent rights unless it is voluntary; 2) A proposed bill to not allow those who are temporarily homeless to have their children removed for that reason; 3) A proposed bill that allows judges to use discretion regarding the ability to accept or reject a social worker's recommendation for removal from the home or having alternate placement. He said that often the social worker is a recent college graduate and may not know all the circumstances of the case. There were no objections to allowing these bills to come before the Committee.

Representative Phil Hermanson presented a proposed bill, the *Protective Parent Reform Act,* that would allow more investigation before a child is taken from the home. Kansas removes more children than any other state, and the purpose of the bill would reduce children intake. There were no objections to allow the bill to come before the Committee.

APPROVAL OF MINUTES

Vice chairperson Wolf moved and Representative Rubin seconded a motion to approve the January 13, and January 18, 2011, minutes as presented. The motion carried unanimously.

TESTIMONY

Jane Rhys, Executive Director of Kansas Council on Developmental Disabilities, presented testimony, (Attachment 1) noting that her organization is federally funded and would not be asking for state monies. She invited members to attend the Big Tent Reception that will be held

from 5-7 p.m. tonight. She cited the benefits that would happen for clients if KNI and the Parsons facilities are closed if the funding is used for in-home care. She answered several questions regarding community response, adequate housing, and zoning requirements to place clients in the community.

James Leiker, President and CEO of the Easter Seals Capper Foundation, said Capper Foundation is celebrating its 90-year anniversary this year, having been founded in 1920 by Arthur Capper, United States Senator for 30 years. He presented testimony (Attachment 2) regarding the issues of unfunded services that impact Kansas children and families. He introduced Ms. Debby O'Neill, Vice President of Programs and Services, and Ms. Linda Burgen, Director of Kidlink Childcare and Preschool Program and Director of Autism Services Program. Ms. O'Neill told the story of Sophia, whose disability is not covered under Medicaid, so her services are limited to two hours yearly. Ms. Burgen related Ryan's Story, a young child who was not selected in the Autism Waiver lottery selection, and was unable to receive services. He soon will age-out of the system, and his parents were unable to continue private-pay costs after 33 days. Both children had shown improvement. Both presenters urged the Committee to increase available services so that these children can continue to receive help. Mr. Leiker concluded by saying that services are very inadequate and that the 2007 legislation that was passed is only serving about 45 Kansas children with another 270 on the waiting list.

Kathy Lobb, a representative of the Self Advocate Coalition of Kansas, gave testimony (Attachment 3) urging the Committee to take steps to eliminate the waiting list. She said she is a person with developmental disability and has a part-time job, is a homeowner, a community member, and a taxpayer. She encouraged them to make this possible for others with disabilities.

Matt Fletcher, Associate Director, InterHab, presented additional testimony (Attachment 4) and reviewed its services. He noted that House Substitute Bill 2671 for SB 365 (2008) will provide home- and community-based services at a savings. He reported that the wages of those serving the state as compared with the federal are less and possibly contributed to around a 50 percent turnover in staff. He also encouraged adequate funding to be used from the closure of the two hospitals.

The Case for Inclusion, 2010 An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities, (Attachment 5) was distributed.

The next meeting will be held Thursday, January 27, 2011, at 9 a.m., Room 142S.

The meeting was adjourned at 10:30 a.m.

CHILREN AND FAMILIES COMMITTEE GUEST LIST

DATE: January 25, 2011

NAME (Please Print)	REPRESENTING
MATT FLETCHER	INTERHAB
Debby O'Neill	Easter Seals Capper Foundation
Linda Burgen	Easter Seals Capper Foundation
Bill Otto	Kids of KS
Phil Hermanson	Kids / Parents of KS
Jane Rhys	Ks Council on Dev. Dis.
Kari Presley	Kearney & Associates
[illegible]	Easter Seals Capper Found.
[illegible] Lobb	SRS/L
Steve Solomon	TFI Family Services
Melissa Ness	Shawnee Mission Medical Ctr.
Bruce Linhos	Children's Alliance
Katrina Abraham	Rep. Meigs intern
Hal Schultz	Self Advocate Coalition of Kansas
Craig Knutson	Self Advocate Coalition of Kansas
[illegible]	DD Council
[illegible]	Page, Baldwin, KS
Jacob Richards	Page, Ottawa, KS

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
htpp://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
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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.

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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 1st 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
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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
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Suite 15E
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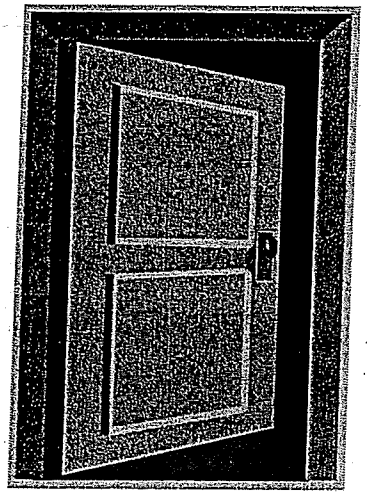
610-520-2007, FAX 5271, e-mail jconroycoa@aol.com

December, 1998

"In 1996, these people were surrounded by walls.
In 1998, they're surrounded by doors."



Citation

The quotation above is from David Loconto, a graduate student at Oklahoma State University. Mr. Loconto was studying the closure of Hissom Memorial Center in Tulsa, an institution that closed in 1994. He personally visited more than 200 Hissom class members in 1995 alone. For this citation, the dates have been changed to fit California's Coffelt years.

Acknowledgements

It is appropriate to recognize the contributions of many stakeholders during the past two years of our work. The staff of Winfield, the staff of the community providers, the leadership of the Developmental Disabilities Council and the Legislative Coordinating Council, relatives of the people who moved, and advocates on all sides, deserve our thanks. The most important acknowledgement, of course, must go to the more than 200 Kansas citizens who moved from Winfield to new homes in regular neighborhoods. These people welcomed our Visitors into their homes, allowed themselves to be interviewed where possible, and we thank them and wish them well.

Table of Contents

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 8th Avenue
Suite 208
Winfield, KS 67156
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October, 2010

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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.*

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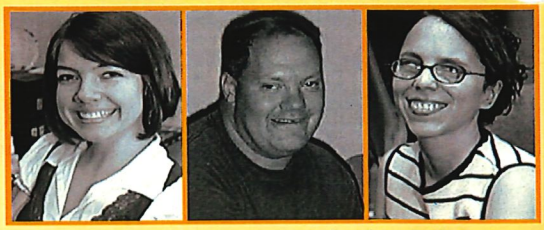
EMPLOYMENT 1st



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 comunity 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 recieving 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 sevice 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 competive, 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.

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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)**

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Easter Seals DISABILITY SERVICES

Capper Foundation

The mission of Easter Seals Capper Foundation is to enhance the independence of people with disabilities, primarily children.

Testimony to the Kansas House Children and Families Committee

January 26, 2011

Good morning Chair Kiegerl and distinguished members of the House Children and Family Committee. I want to thank Chair Kiegerl for taking time from his busy schedule a couple of weeks ago to meet with us about issues impacting children and families in Kansas and for inviting us here this morning.

A special greeting this morning to Representative Melody McCray Miller. Representative Miller and I served together on the Kansas Autism Task Force several years ago.

Thank you for the opportunity to meet with you this morning and share our concerns with the entire committee about issues impacting children and families in Kansas that need serious attention and action.

I would like to introduce my colleagues joining me from Easter Seals Capper Foundation – Ms. Debby O' Neill, Vice President of Programs & Services and Ms. Linda Burgen, Director of our Kidlink Childcare & Preschool Program & Director of our Autism Services Program. My name is Jim Leiker and I am the President & CEO of Easter Seals Capper Foundation.

Our biographies, testimony and related information are included in file folders for each of you to reference.

HOUSE CHILDREN AND FAMILIES
DATE: JANUARY 25, 2011
ATTACHMENT NO. 2-1

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785.272.4060 FAX 785.272.7912
www.capper.easterseals.com
email: abilities@capper.easterseals.com

Sophia's Story:

Sophia is almost two years old, yet she is not yet talking or making attempts to communicate. Most children say their first word around 1 year of age.

Sophia was referred by her pediatrician to the Shawnee County Infant/Toddler Program (also known as Early Childhood Program).

Because of limited state and federal funding for this program, she was scheduled to receive services from a speech therapist for **30 minutes per quarter – only 4 visits per year – only 2 hours per year.**

Sophia's pediatrician referred her for more intense speech therapy services at Easter Seals Capper Foundation.

Kansas Medicaid would not reimburse Easter Seals Capper Foundation for speech therapy services and her parents could not afford to pay for them.

In their letter of denial to Easter Seals Capper Foundation, Kansas Medicaid stated: "We made this decision because the child has developmental language concerns. **There is concern that the services offered through the Infant/Toddler Program are not of sufficient intensity**. However, this does not change the nature of the delay – it is developmental."

If Sophia's language problems had been the result of a head injury suffered after birth, or the result of an illness such as encephalitis suffered at one year of age, Kansas Medicaid would have funded rehabilitation services.

Solutions Needed:

Amend the Kansas Medicaid Policy regarding Therapy Services. (see attached)

It is discriminatory for children with motor and language disabilities due to congenital defects and assumes these children can only maintain their skills rather than make functional gains.

It does not allow families to take advantage of more intensive, medically based rehabilitation which is supported by current clinical research. As stated by Dr. Beverly Ulrich: "That rigorous practice…affects recovery of neuromotor function… within areas of the brain in children and adults, is commonly accepted. Without greater opportunities for early treatment, the costs associated with health care needs in subsequent years will be higher, but the real cost is to those affected with early-onset neuromotor disabilities". (**Opportunities for Early Intervention Based on Theory, Basic Neuroscience, and Clinical Science**. *Physical Therapy*. 2010:20: 1868-1878)

Current Kansas Medicaid Policy regarding Therapy Services:

"All therapy must be prescribed by a physician.
Habilitative therapy is covered only for participants age 0 to under the age of 21. Therapy must be medically necessary. Therapy is covered for any birth defects/developmental delays only when approved and provided by an Early Childhood Intervention (ECI), Head Start or Local Education Agency (LEA) program. Therapy treatments performed in the Local Education Agency (LEA) settings may be habilitative or rehabilitative for disabilities due to birth defects of physical trauma/illness. The purpose of this therapy is to maintain maximum possible functioning for children."

Revision Needed in Kansas Medicaid Policy regarding Therapy Services:

All therapy must be prescribed by a physician. Services must be medically necessary. Rehabilitation services are covered only if they are expected to result in functional improvement. Outpatient rehabilitation for children, whether their disability results from a birth defect or postnatal injury, cannot duplicate what is provided in the Local Education Agency (LEA), Headstart and the Early Childhood Intervention (ECI) program.

Ryan's Story:

- Diagnosed with Autism by age 2.5
- Received Infant Toddler Part C intervention services
- Received Special Education from Public School
- Therapeutic Child Care – Out of pocket expense
- Purchased Therapy that family insurance covered of which parents still paid deductable and copay.
- His name was not selected for the Autism Waiver lottery selection so he did not receive autism services. He will age out soon.
- Autism services were denied through commercial insurance
- Paid out of pocket for 33 days for 30 minutes of Autism Services
- Made documented progress in 4 areas one of which an Occupational Therapist had been trying to make progress on for months. Additional skills were also increased that were not specific to the plan.
- Parents could no longer afford this type of service so it stopped after 33 days.

Solutions Needed:

- Autism Waiver needs to be expanded to more families
- Autism waiver services need to go beyond age 5.
- Autism services are not a duplicated service to school's special education or other therapies such as Occupational Therapy, Physical Therapy, and Speech and Language Therapy.
- Parent or caregiver component is important. We need to develop plans and technologies that can be done by parents in multiple repetitions within the daily routines with professional guidance. We need to increase the involvement in families to help develop functional skills.
- An early aggressive approach is needed which will optimize development and be financially feasible with family involvement. Early intervention is most cost effective as well as proactive in eliminating more severe issues in the future by teaching skills to both the family and child.

Easter Seals
DISABILITY SERVICES

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"Ryan and Kidlink preschool teacher work on fine motor skills with a single-piece insert-puzzle. "

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Issues Adversely Impacting Children & Families in Kansas
That Need Serious Attention & Action

Kansas Medicaid Policy

The current Kansas Medicaid Policy is discriminatory to children with disabilities due to congenital defects. This policy has a detrimental impact on children with developmental disabilities who are unable to access appropriate services based solely on the fact that their injuries occurred at the time of birth.

By limiting access to therapy services for children with birth defects to only those provided by an Early Childhood Intervention (ECI) service provider or Local Education agency (LEA), the Kansas Medicaid Policy denies a child the right to Medicaid services defined by federal law and needed to correct or ameliorate a health concern. Children with disabilities, whether those impairments are from a birth injury/defect or from an illness or accident occurring after birth, should have the same options in selecting an approved provider for medical rehabilitation therapy services. **This policy is unfair and action should be taken to change it immediately.**

State of KS Autism Insurance Coverage Implementation

Autism insurance coverage for children of state employees under age 19 on the state health insurance plan was signed into law in mid-2010, requiring coverage effective January 1. 2011. Despite phone calls, emails from parents and service providers and meetings with the Kansas Health Policy Authority (KHPA) who oversees the state health insurance plan, and health insurance carriers, this autism health insurance coverage has not been implemented and it is uncertain as to when it will be. There has been more than ample time to prepare and implement this Kansas Law requiring autism insurance coverage on January 1, 2011.

This law has autism insurance coverage for children on the state health insurance plan on a one year test track, followed by an analysis of the implementation data and report to the Kansas Legislature. The implementation of this law has been unduly delayed along with cumbersome requirements for eligibility, treatment coverage definitions, benefit provisions and exclusions. This means it will take even more time for children with autism to actually receive covered services. Since the implementation has been delayed, there will be less data to report to the legislature and potential expansion of autism insurance coverage for Kansans with autism spectrum disorders will also be unfairly delayed and adversely impacted. **Action should be taken to implement this state law immediately.**

Kansas Medicaid Autism Waiver &
Critically Important Early Identification & Intervention Services

Kansas has a Medicaid Autism Waiver for children with autism up to age 5. In December 2007, the Report of the Kansas Autism Task Force to the Legislative Planning Committee said, "Current available funding for the Autism Waiver limits its services to 25 children." That is 25 children in the entire state of Kansas! This was an unbelievably minimal number of children covered, which is very embarrassing and dismal at best for our state.

Now, let's fast forward to 2011, 5 years later. My understanding is that currently the Kansas Autism Waiver covers 45 children and 270 children are on a waiting list. Again, this is 45 children in the entire state of Kansas! Again, this is a very minimal number of children covered. This continues to be embarrassing and dismal coverage of young children with autism in Kansas since as many as 1 in every 110 children is diagnosed with some form of autism – for boys it's 1 in every 70 – that's a new diagnosis every 20 minutes.

We recommend that the Kansas Legislature get serious and take action to Make the First Five Count! When kids get the right treatment and therapy they need before the age of 5, they are ready to learn alongside their peers, succeed and achieve their goals and dreams. Early diagnosis and early intervention are critical. Getting the right support at the earliest stage of life can help a child gain the skills he or she needs to be successful.

University of Chicago Distinguished Professor James J .Heckman, a Nobel laureate and expert in the economics of human development makes the case that investing in the first five years of children's lives is a sound and critical investment on our nation's future on the world stage. Professor Heckman reports that "early interventions" have much higher economic returns than later interventions for disadvantaged children. As an economist, James Heckman is an advocate for early education and care and strongly recommends that we "Make greater investments in young children to see greater returns in education, health and productivity."

We agree completely and hopefully a word to the wise in the Kansas Legislature is sufficient to get serious about the critical importance of early identification and intervention services. **It is critically important that your House Children and Families Committee and the entire Kansas Legislature take appropriate action in the 2011 legislative session to increase the number of children on the Kansas Autism Waiver to a reasonable number for a state our size.**

Current Kansas Medicaid Policies Regarding Therapy Services for Children

The Kansas Medical Assistance Professional Services Provider Manual states:

"Habilitative – Therapy is covered for any birth defects/developmental delays only when approved and provided by an Early Childhood Intervention (ECI), Head Start or Local Education Agency (LEA) program. Therapy treatments performed in the LEA settings may be habilitative or rehabilitative for disabilities due to birth defects or physical trauma/illness. Therapy of this type is covered only for participants age 0 to under age 21. Therapy must be medically necessary. The purpose of this therapy is to maintain maximum possible functioning for children.

Rehabilitative – All therapies must be physically rehabilitative. Therapies are covered only when rehabilitative in nature and provided following physical debilitation due to an acute physical trauma or illness."

Kansas Medicaid has established an arbitrary, capricious and unfair policy which prevents access to appropriate therapy by children with disabilities resulting from birth defects or birth injuries. Under the current policy children with congenital/developmental disabilities are unable to receive the medical rehabilitation therapy services they need to correct or ameliorate a health concern. Families of children with disabilities resulting from a birth injury cannot choose a clinic-based therapy provider with specialized training nor can they take advantage of specialized equipment that would only be available in a clinical setting.

The definitions of habilitative and rehabilitative therapy in the Kansas Medicaid Policy are discriminatory and presume that children with impairments resulting from a birth injury or genetic/neurological/orthopedic differences present at birth have a more limited potential than children who suffer a physical trauma or illness after birth. The implied outcome of therapy for children with birth defects/developmental delays is described as "maintaining maximum function" rather than progressing and achieving independence. The Kansas Medical Assistance Program limits therapy options for these children to an ECI, Headstart Program or LEA. These educational agencies are not designed, equipped or staffed to provide the medical rehabilitation services often necessary to help these children achieve independence. These agencies focus on learning opportunities for a child, not on increasing independence through the reduction of disability based on the science of medical rehabilitation.

Kansas Medicaid views therapy services in ECI programs, LEA programs or medical rehabilitation clinics as essentially the same. There are, however, major differences between medically rehabilitation therapy services, educationally based therapy services provided by the local education agency (LEA), and early childhood intervention (ECI) therapy services. These differences include the physical environment, the persons determining the need for service, the goals of the service, the frequency and duration of the service and the techniques and equipment utilized.

Medical rehabilitation services are individualized, hands-on, and derived from the science of medical rehabilitation. They are generally more intense in frequency and shorter in duration than LEA or ECI services and may be provided in periodic "episodes of care" to address specific impairments. Treatment goals are established by the therapist with input from the referring physician's prescription and the parent. Medical rehabilitation services often incorporate technology and modalities such as augmentative communication equipment during speech therapy or electrical stimulation during occupational and physical therapy sessions.

Local Education Agencies (LEA) which provide therapy services are considered a related service. A related service is defined as a supportive service provided to assist a child with a disability to benefit from special education. Physical, occupational and speech therapists working in local education agencies (public schools) do not develop separate goals for physical, occupational and speech therapy. All goals are considered discipline-free and address educational success.

Early Childhood Intervention (ECI) service providers are responsible for consulting with parents and other service providers, participating in multidisciplinary team assessments, and training parents and others to provide those services. Early Childhood Intervention therapists are discouraged from utilizing any "clinic" equipment or materials in the home. ECI programs in Kansas have adopted the coaching model which requires providers to limit hands-on treatment and to serve as consultants in coaching the family in learning opportunities for their child.

In conclusion, the current Kansas Medicaid policy is discriminatory to children with disabilities/developmental delays due to congenital defects. By limiting access to therapy services for children with birth defects to only those provided by an ECI or LEA, the Kansas Medical Assistance Program is denying a child the right to Medicaid services defined by federal law and needed to correct or ameliorate a health concern. Children with disabilities, whether those impairments are from a birth injury/defect or from an illness or accident occurring after birth should have the same options in selecting an approved provider for medical rehabilitation therapy services.

Biographies of Presenters

Jim Leiker
Jim is the President and CEO of Easter Seals Capper Foundation. He earned three Bachelor's degrees from Washburn University of Topeka in 1976 and a Master's Degree in from Wichita State University in 1980.

Jim has proactively led Easter Seals Capper Foundation through significant organizational changes for the past 18 years, expanding services and number of people served. He is actively involved in civic, religious and professional organizations in the Topeka community. In 1989 Jim was named to the Leadership Topeka Class of the Greater Topeka Chamber of Commerce. Jim served as a member of the Kansas Autism Task Force and is currently a member of the Easter Seals National Autism Spokesperson Network.

Jim is the Easter Seals Leadership Association (ESLA) Midwest Regional leader, serves on the ESLA Board and Easter Seals National Planned Giving Team. He serves as a Regional Advocacy Leader for the Kansas Coalition for Autism Legislation (KCAL) and is a member of the Downtown Topeka Rotary Club and Greater Topeka Chamber of Commerce.

Debby O'Neill
Debby is Vice President, Programs and Services at Easter Seals Capper Foundation. She holds a Bachelors Degree in Physical Therapy from the University of Kansas and a Master of Education Degree in Special Education from the University of Washington.

Debby has over 35 years of experience as a pediatric physical therapist working in private practice clinics, hospitals, public schools and university settings. She has held a management position at Capper for over 12 years.

Linda Burgen
Linda is Director of the Kidlink Childcare and Preschool program and Director of Autism Services at Easter Seals Capper Foundation. Linda earned a Bachelors Degree in Human Development and Family Life from the University of Kansas and completed her MS in Early Childhood Special Education from Emporia State University in 1996. Linda is an Autism Specialist and approved provider by Kansas Department of SRS.

Prior to joining the Easter Seals Capper Foundation Team in 2001, Linda taught in the public schools, directed a private community childcare center and served as an educator and coordinator with Parents As Teachers in Wabaunsee county. Linda has been a Field Based Consultant with the Inclusive Network of Kansas Since 1996. She is one of a small group of professionals selected to provide expert consultation to educational teams throughout the state of Kansas. As the Director of the Kidlink program, Linda has led the childcare staff in achieving accreditation through the National Association for the Education of Young Children and has increased enrollment in the program. Linda is one of 53 Early Childhood Specialists selected by Easter Seals to help develop the National Inclusive Child Care Training Modules.

Easter Seals Fact Sheet

www.easterseals.com

- Easter Seals is the leading non-profit provider of services for individuals living with autism, developmental disabilities, physical and intellectual disabilities and other special needs. For more than 90 years, Easter Seals has been offering help, hope and answers to children and adults with disabilities and their families who love them. Through therapy, training, education and support services, Easter Seals creates life-changing solutions so that people with disabilities can live, learn, work and play in their communities.

- Founded 91 years ago in 1919

- First National Society for Crippled Children

- Largest Health Charity in United States

- 1.6 Million People Served

- Top Global Brand

- Over $1 Billion Entity

- 75 Affiliates in U.S.

- Global Partners: Ability First Australia, Easter Seals Canada, CONFE – Mexico

- Primary Services include:

    - Medical Rehabilitation
        - Early Intervention
        - Physical Therapy
        - Occupational Therapy
        - Speech & Hearing Therapy
    - Job Training & Employment
    - Child Care
    - Adult Day Services
    - Camping & Recreation

Professional & Family Training

The Capper Professional and Family Training Program offers continuing education courses designed to enhance clinical decision-making skills, therapy and educational intervention for direct services providers such as therapists, special educators, healthcare professionals, parents, childcare providers and social workers. By enhancing their knowledge and skill, providers ultimately improve and increase the independence of people with disabilities.

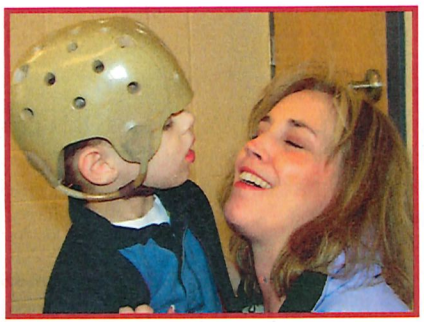
Programs feature a variety of topics and are presented by speakers recognized locally, nationally and internationally. Our on-site conference center provides a professional and comfortable academic atmosphere.

Off-site training opportunities are also available and can be customized to best meet the needs of the audience requesting the training.

Numbers of People Served*

Easter Seals Capper Foundation provided 46,382 hours of services to 2,180 individuals in fiscal year 2010. Individuals from 17 counties and 48 cities in Kansas were served.

**Some individuals were served by more than one program.*



Easter Seals Capper Foundation provides help and hope to families living with disabilities. Your caring support is needed and truly appreciated.

Who & Where

Senior Management

Jim Leiker
President & CEO
Debby O'Neill
Vice President, Programs & Services
Pam Walstrom
Vice President, Development
Sandy Warren
Vice President, Operations

Board of Trustees

Steve Knoll, *Chairman*
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Larry Robbins
Madge Schmank
Marlou Wegener
Terry A. Young, Ex-Officio
Jim Leiker, Ex-Officio

Easter Seals Disability Services
Capper Foundation

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785-272-4060 Fax: 785-272-7912

www.capper.easterseals.com

Easter Seals Disability Services
Capper Foundation
2011

AT A GLANCE

Overview

Mission

Founded in 1920 by Sen. Arthur Capper, the mission of Easter Seals Capper Foundation is to enhance the independence of people with disabilities, primarily children and their families.

Who We Serve

Easter Seals Capper Foundation provides services to infants, children and young adults with developmental and intellectual disabilities. Some of these disabilities include autism, cerebral palsy, sensory processing disorder and other orthopedic and neurological conditions.

Outcomes

We enhance the independence of people with disabilities, primarily children, so they can speak, learn, write, play, be mobile, work, and function as independently as possible.

Strategy

Our staff of pediatric specialists work in collaboration with families, healthcare providers and educational professionals, to creatively adapt and apply therapies, education and equipment. We also provide training for those who live and work with individuals with disabilities. Services are provided at Easter Seals Capper Foundation and in the community.

Funding

Our $2.5 million budget is primarily supported by voluntary contributions. We also receive funding from fees for services and grants.

Staff & Volunteers

There are 34 staff members including pediatric physical, occupational and speech therapists. Last year, 276 volunteers contributed 6,133 rs of volunteer services in a wide variety of ect and indirect service roles.

Programs & Services

Kidlink Childcare and Preschool

Kidlink is a year-round inclusive childcare and preschool program serving children aged two-and-one-half to six years with and without physical disabilities. The curriculum is designed to address all areas of development: cognitive, communication, social/emotional, physical and self-help skills.

Computer assisted learning and swimming in our warm-water therapy pool are favorite activities for both the children and volunteers.

Our staff includes certified special education teachers, teacher assistants, physical, occupational, and speech therapists.

All team members work collaboratively to meet the individual needs of each child. Developmental evaluations and Individual Program Plans are provided for each child.

Physical Therapy

Physical Therapists provide services to increase strength, improve range of motion, coordination and balance with the ultimate goal of empowering the children we serve to be as independent as possible in their functional gross motor abilities. Our physical therapists also assist in the acquisition and modification of adapted mobility equipment, splints/braces and wheelchairs.

Occupational Therapy

Occupational Therapy is the art and science of facilitating the development of skills necessary for daily functions such as fine motor skills, self-care and play/leisure activities. Our occupational therapists treat children with neurological and/or developmental disabilities as well as children with sensory processing disorders.

Speech-Language Therapy

Speech-Language Therapists provide treatment for children with impairments in respiratory function, articulation, voice, fluency and receptive-expressive language skills. Our staff have experience in augmentative and alternative communication (AAC) for individuals with severe physical impairment and communication disorders. AAC includes picture boards, communication devices and communication software for developing written and spoken output.

Ability Awareness Program

Led by our Director of Volunteers, this program is designed to increase understanding, awareness and acceptance of people with disabilities.

The program includes interactive activiti to educate adult and youth participants a East them focus on peoples' abilities, not lim

Self Advocate Coalition of Kansas

Promoting Empowerment
and Independence

2518 Ridge Court
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785-749-5588
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www.sackonline.org

I would like to thank you for the opportunity to talk to you today about the waiting list for people who need developmental disability services in Kansas. My name is Kathy Lobb, and I work for the Self Advocate Coalition of Kansas.

I am a person with a developmental disability and I am a homeowner, an employee, a community member and a taxpayer. I am all of these things because I have received the supports and services I need to be an independent person. I am here to today to ask you to give other people with disabilities the opportunities that I have had by eliminating the waiting list in Kansas.

Currently, there are almost 3,400 people with developmental disabilities waiting for services on Kansas; this means that people have to wait 5 years to get the supports they need. These are five years of a person's life that are wasted, often times just sitting in their parents living room- just waiting.

This is a problem that is easy to solve, we just need to make sure that people get the services that they need. When people get the services that they need, they become more independent. As people become more independent, they enjoy an increased quality of life, they become more involved in the community, and very often, they become transformed from tax consumers into tax payers- like me.

Please do the right thing and eliminate the waiting list. Help people become more independent. It is the right thing to do for the people who are waiting for services. It is the right thing to do for their families. It is the right thing to do for taxpayers. It is the right thing to do for Kansas. It is simply the right thing to do.

Sincerely,

Kathy Lobb

Kathy Lobb

Self Advocate Coalition of Kansas

HOUSE CHILDREN AND
FAMILIES
DATE: JANUARY 25, 2011
ATTACHMENT NO. 3-1

INDEPENDENCE
INCLUSION
INNOVATION

INTERHAB

January 25, 2011

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

FR: Matt Fletcher, Associate Director, InterHab

RE: Kansas HCBS MR/DD Waiver

Chairman Kiegerl, and members of the Committee, thank you for the opportunity today to discuss policy issues surrounding the HCBS MR/DD Waiver and the direct care workers who make community-based services in Kansas possible.

The HCBS MR/DD Waiver:

The majority of funding in the community developmental disability service network comes from the federal government through the Home and Community Based Services (HCBS) MR/DD Waiver. This waiver serves individuals age 5 and over who meet the definition of mental retardation or developmental disability, or are eligible for care in an Intermediate Care Facility for people with Mental Retardation (ICF/MR). The HCBS MR/DD Waiver is funded through a roughly 60% Federal / 40% State match. The waiver's reimbursement rate pays towards the cost of many services, including:

- *Residential Services*
- *Day Services*
- *Medical Alert*
- *Wellness Monitoring*
- *Family/Individual Supports*
- *Environmental/Adaptive Equipment*

HCBS funds account for almost 90% of all community developmental disability funds. The HCBS MR/DD Waiver utilizes a bundled reimbursement for services rendered, meaning providers bill the State's Medicaid billing agent upon completion of the service performed. Much of this reimbursement to providers is utilized in maintaining a workforce which is required to meet the needs of those with disabilities.

No examination of the HCBS MR/DD Waiver's importance to Kansans with developmental disabilities can be complete without acknowledgement of the backbone of the system – the Kansas Direct Support Professional. The Direct Support Professional (or 'direct care worker' as the position is more commonly known) is an indispensible component of HCBS Waiver services to Kansans with developmental disabilities.

HOUSE CHILDREN AND FAMILIES
DATE: JANUARY 25, 2011
ATTACHMENT NO. 4 -1

700 SW JACKSON ST., SUITE 803 TOPEKA, KANSAS 66603 |P|785.235.5103 |F|785.235.0020 WWW.INTERHAB.ORG

Direct Support Professionals – The Core of the Kansas DD System:

Direct Support Professionals are vital in ensuring that Kansans with developmental disabilities can thrive in the community of their choice. They provide support in day and residential settings, often without direct supervision, and must handle demanding tasks such as changing feeding tubes, as well as bathing and clothing persons who need their assistance. These professionals perform a difficult but necessary job, and deserve all the support we can give them.

In many organizations, Direct Support Professionals are also are required to have up to and exceeding 30 hours of training, much of which has to occur within the first three months prior to the professional working independently with consumers. That training includes courses in types of developmental disabilities, working with families, maximizing community resources, counseling skills and more. Training is also required in abuse, neglect and exploitation, bloodborn pathogens, CPR, first aid and non-aggressive restraint techniques.

Kansas community service providers attempt to recruit the best candidates for these positions. Most organizations require that candidates have a high school diploma or equivalent and a good driving record, as well as passing a physical, drug test, adult and child abuse checks and a KBI criminal background check. Still, due to their inability to offer competitive wages, many providers have had to hire applicants with less 'soft' job skills such as a good work ethic, communication skills, the ability to read and write, and personal hygiene.

Take a moment to compare the importance of this position, in terms of its responsibility for the health and safety of a vulnerable person with the following:

$8.78 per hour.

That's the average wage for Direct Support Professionals in Kansas, as reported in a 2009 national study of direct care wages in community DD service settings.

It's no wonder that community providers experience high turnover. In 2004, as part of a grant funded by the Kansas Council on Developmental Disabilities and coordinated by the University of Minnesota and the University of Kansas Center on Developmental Disabilities, data was collected from developmental disability service providers in Kansas regarding challenges in recruiting, retaining adequate direct care staff within the field of community services for persons with developmental disabilities. The grant's summary report found that:

- *"Average annual DSP turnover rates of 57% in 2002 and 53% in 2003."*
- *"The percent of DSPs who quit their jobs within six months of hire was 51% in 2002 and 51% in 2003."*
- *"The percentage of provider organizations that curtailed services due to workforce shortages was 40% in 2002 and 43% in 2003."*

We also know from a 1998 study on direct care staff turnover, conducted by the Kansas State University Institute for Social and Behavioral Research, that the average cost per incident of turnover is $2,094, a significant financial cost to providers. We must act to assist providers in maintaining a quality staff to serve Kansans with developmental disabilities.

Consider the types of job market decisions confronting a person considering a Direct Support Professional position. They could work in a demanding environment requiring physical labor including lifting, moving, bathing and toileting persons who may be physically aggressive, or not capable of communication. Often, they will perform this labor alone, with little supervision.

Or...

They could make more money as a short order cook, a car wash attendant, a grocery store shelf stocker, or any number of positions which pay better, and don't require responsibility for another's life.

Which would you choose?

The State Knows Exactly How Much to Pay Direct Support Professionals:

Currently, the starting wage step for a 'DD Tech 1' position (a directly comparable position to a community Direct Support Professional) in one of the State's institutions is $12.35 per hour. That's almost $4 per hour more than what Direct Support Professionals make in Kansas communities, on average.

The State has previously articulated the reason for increasing institutional direct care wages – turnover.

In the Governor's Budget Report for FY 2006, the Governor stated that:

> *"For a number of years, significant inequalities between the beginning salary ranges for state hospital employees and similar direct care positions in both the state and private sectors have been developing. Such inequalities have led to high employee turnover, which has been costly in terms of training, recruitment, and employee performance."*

It is clear that, years ago, the State concluded that higher wages equal lower turnover. However, the State's application of this remedy stopped at the property lines of its own two institutions.

What would it take to bring parity to the system?

In September of 2006, the Legislative Budget Committee held two days of hearings on the community DD system and received testimony from a wealth of experts both within the community and the State on the status of the system. The Committee took the information they received very seriously, and in January 2007 released recommendations for the community DD system that were unprecedented. The Legislative Budget Committee recommended a three-year funding plan to restore the DD system's ability to pay competitive wages to its workers and eliminate the State's shameful waiting lists (which now total more than 4,500 children and adults with developmental disabilities).

In reviewing the Legislative Budget Committee's report, you'll notice a recommendation for multi-year funding that would build needed capacity in the community to serve persons with developmental disabilities, and eliminate the State's waiting lists. What would such an influx of funding do for the community DD system?

1. ***Increases in reimbursement rates would allow providers to offer wages for Direct Support Professionals that are comparable with what the State pays its own direct care workers.*** The starting wage for direct care workers at the State's two DD institutions is $12.35 per hour. Compare that with the average community wage for direct care workers - $8.78 per hour (as reported by the American Network of Community Options and Resources in 2009). The multi-year plan developed by the Legislative Budget Committee in 2006 called for bridging this parity gap by bringing community direct care wages up to the level of what the State pays its own employees for the same work.

2. ***The State's two waiting lists could be eliminated.*** According to the December, 2010 SRS monthly summary of DD services, 2,908 adults and children wait to receive service in Kansas. Another 1,668 adults and children receive some basic support, but need additional services. The Legislative Budget Committee recommendations could effectively end the DD waiting lists in Kansas – a first for the State in fifteen years. However, without a significant effort to first fortify current service capacity in Kansas communities, as well as build expanded capacity to meet the needs of individuals who may have additional significant behavorial, medical and mental health challenges, the community service system would face severe strain in eliminating these waiting lists. The Legislative Budget Committee acknowledged this by staggering the recommended funding increases – 'frontloading' the funds meant for capacity building and 'backloading' the waiting list funds.

The Legislative Budget Committee has provided you with a thoughtful plan for building a quality future for Kansans with developmental disabilities. They have created a multi-year approach that will fill in current funding gaps as well as address the expanding needs of the DD system.

An Innovative Idea to Help Families and Children:

The membership of InterHab has worked, for several years, on developing a new waiver that would provide in-home support to Kansas families who have a child with a developmental disability. The services offered by this new "Family Support Waiver" would be tailored to specifically meet the needs of families, and could potentially free up needed system resources. Currently, families are often diverted to the HCBS MR/DD Waiver, but many could be better assisted by a model that more effectively met their unique needs. I have attached a copy of testimony from one of the architects of this new concept for your consideration. The testimony from Colin McKenney, Executive Director of Multi-Community Diversified Services, was originally delivered to the Joint Committee on Children's Issues in December, 2010.

This new service concept would provide families flexibility in meeting the service needs of their children, and would provide those services in a more efficient way for families than the HCBS MR/DD Waiver. It is a concept we urge you to take a closer look at.

We respectfully urge you to take action:

The community DD system and the professionals who do this demanding work need the assistance of State policymakers in ensuring that community care for Kansans with developmental disabilities is *quality* care. That begins with ensuring that the community has the resources needed to attract and retain quality staff.

This Committee can be the beginning point in this process. Your recommendations can be the spark that creates a brighter future for all Kansans with developmental disabilities.

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.

ed to Substitute

SOCIAL SERVICES BUDGET COMMITTEE

House Sub. for SB 365

Representative Bob Bethell, Chair

Representative Pat George

Representative Peggy Mast, Vice-Chair

Representative Tom Hawk

Representative Jerry Henry,
Ranking Minority Member

Representative Dick Kelsey

Representative Barbara Ballard

Representative Marc Rhoades

Representative David Crum

The Social Services Budget Committee recommends that the contents of SB 365 be deleted and replaced with the contents of HB 2761, as amended by the Social Services Budget Committee.

The Substitute bill would establish the Home and Community Based Services Oversight Committee, which would be a joint legislative committee comprised of nine members, five from the House of Representative and four from the Senate. Each of the following individuals would appoint a member: Speaker of the House of Representative, Minority Leader of the House of Representative, President of the Senate, Minority Leader of the Senate, Chairperson of the House Appropriations Committee, Ranking Minority Member of the House Appropriations Committee, Chairperson of the Senate Ways and Means Committee, Ranking Minority Member of the Senate Ways and Means Committee, and the Majority Leader of the House of Representative.

The Oversight Committee would meet at least four times per year, with the chairmanship alternating between members of the House of Representatives and the Senate. The chairman for the first year of the Committee would be the member appointed by the Speaker of the House, and alternate each year after. The Committee would review the number of individuals transferred from institutional settings to home and community based settings and the associated funding. The Committee also would review community capacity and ensure adequate progress is occurring for the transfers to occur. The Committee would also review the salaries, benefits, and training of direct care staff. In addition, the Committee would study and determine the possible closure of state long term care facilities based on the success of transfers from institutional settings to home and community based services.

The bill would establish home and community based services savings funds at both the Department of Social and Rehabilitation Services and the Department on Aging, into which all savings resulting from transferring individuals from institutional settings to receiving home and community based services are deposited. These funds would be subject to appropriation. The savings would be the difference between the average cost of institutional care and the cost of providing services to that individual in the community.

The bill would allow the Department on Aging and the Department of Social and Rehabilitation Services to borrow moneys from the Pooled Money Investment Board, at the rate of interest equal to the net earnings rate of the pooled money investment portfolio at the time of the loan. The aggregate of the loans could not exceed the assessed valuation of the state institutions considered for closure by the Oversight Committee. The loan would be payable annually over five years.

The bill would appropriate moneys from the State General Fund for the Department on Aging and the Department of Social and Rehabilitation Services (SRS) in FY 2009, FY 2010, FY 2011 and FY 2012. Funding appropriated in the bill over four years includes:

Department on Aging Home and Community Based Services for the Frail Elderly(HCBS/FE) Waiver:

Addition of $16.0 million, including $4.8 million from the State General Fund, to provide services to individuals on the HCBS/FE waiver waiting list.

Addition of $5.0 million, including $1.5 million from the State General Fund, to increase the HCBS/FE provider rates.

Department of Social and Rehabilitation Services (SRS):

Home and Community Based Services for individuals with developmental disabilities (HCBS/DD) Waiver:

Addition of $97.5 million, including $39.0 million from the State General Fund, to provide services to individuals on the HCBS/DD waiver waiting list.

Addition of $92.5 million, including $37.0 million from the State General Fund, to increase the HCBS/DD provider rates.

Home and Community Based Services for individuals with a physical disability (HCBS/PD) Waiver:

Addition of $43.8 million, including $13.5 million from the State General Fund, to provide services to individuals on the HCBS/PD waiver waiting list.

Addition of $20.0 million, including $8.0 million from the State General Fund, to increase the HCBS/DD provider rates.

Home and Community Based Services for individuals with traumatic brain injury (HCBS/TBI) Waiver:

Addition of $8.0 million, including $2.4 million from the State General Fund, to provide services to individuals on the HCBS/TBI waiver waiting list.

Addition of $2.0 million, including $600,000 from the State General Fund, to increase the HCBS/TBI provider rates.

The total funding included in the bill over four years equals $284.8 million, including $106.8 million from the State General Fund for increases in home and community based services funding.

The Social Services Budget Committee recommends House Sub. for SB 365 be recommended favorably for passage.

MENTAL HEALTH/DEVELOPMENTAL DISABILITY TECHNICIANS

Job Code	Job Title	Pay Grade
5003F2	Mental Health/Developmental Disability Technician Trainee	14
5004F2	Mental Health/Developmental Disability Technician	17
5005F2	Licensed Mental Health Technician	17

OCCUPATIONAL CONCEPT - Provide personal care, active treatment, development, habilitation and/or rehabilitation activities in a state operated facility for the mentally ill or developmentally disabled.

TASKS

- Monitors behavior and reports unusual behavior/activity to management and other relevant staff.
- Provides routine physical, emotional, psychological or rehabilitative care under direction.
- Maintains records of activities, classes, routines, eating habits, medical conditions and/or behavior issues.
- Establishes and supports facility routines.
- Organizes, supervises, and encourages participation in various activities.
- Assists with meals and implement interventions when necessary.
- Intervenes or aid as necessary to prevent injury.
- Gathers and records information upon admission.
- Administers medications if licensed or as authorized by Kansas law.
- Measures vital signs.
- Uses computer to access and update computer-based information and to obtain computer-based training.
- Transports, assists, and/or provides appropriate care within facility.
- Provides a safe and sanitary environment.
- Participates and provides input into the development of person-centered treatment plans.
- Implements interventions as directed by the person-centered treatment plan.
- Promotes independence, productivity and choice making.

LEVELS OF WORK

Mental Health/Developmental Disability Technician Trainee: This is trainee level work where the incumbent is in the process of being trained to perform the procedures required in the active treatment, development, habilitation and or rehabilitation of individuals.

Minimum Requirements: None Required.

Necessary Special Requirements: Requires an approved drug test approved by the Kansas Department of Administration unless promoting, transferring, or demoting from another designated position within the same agency.

Mental Health/Developmental Disability Technician: This is full performance level work planning, directing or coordinating active treatment, developmental, habilitation and rehabilitative

treatment activities and/or programs for individuals or groups of individuals with mental illness or developmental disabilities. Shares leadership responsibility with coworkers in performance of duties to fulfill work responsibilities. Mentors lesser skilled staff by providing individual supports and training. Work may involve supervising staff.

Minimum Requirements: Completion of an established training program approved by Kansas Department of Social and Rehabilitation Services.

Necessary Special Requirements: Requires an approved drug test unless promoting, transferring, or demoting from another designated position within the same agency. Some positions require one year of supervisory/leadership experience; a valid Kansas Drivers License and/or a License to pass medication per Kansas statute.

Licensed Mental Health Technician: This is full performance level work planning, directing or coordinating active treatment, developmental, habilitation and rehabilitative treatment activities and/or programs for individuals or groups of individuals with mental illness or developmental disabilities. Administers medications in a mental health facility. Shares leadership responsibility with coworkers in performance of duties to fulfill work responsibilities. Mentors lesser skilled staff by providing individual supports and training. Work may involve supervising staff.

Minimum Requirements: Kansas license/permit to practice as a Mental Health Technician at time of hire.

Necessary Special Requirements: Some positions require an approved drug test unless promoting, transferring, or demoting from another designated position within the same agency. Some positions require a valid driver's license.

NC: 0605
REV: 08/05

Kansas Civil Service Basic Pay Plan (effective June 13, 2010)
Basic Steps (Hourly Rates)

PG	Step 4	Step 5	Step 6	Step 7	Step 8	Step 9	Step 10	Step 11	Step 12	Step 13	Step 14	Step 15	Step 16	Step 17	Step 18
7	7.56	7.77	7.96	8.18	8.35	8.56	8.76	9.00	9.24	9.44	9.69	9.93	10.15	10.43	10.68
8	7.96	8.18	8.35	8.56	8.76	9.00	9.24	9.44	9.69	9.93	10.15	10.43	10.68	10.92	11.21
9	8.35	8.56	8.76	9.00	9.24	9.44	9.69	9.93	10.15	10.43	10.68	10.92	11.21	11.48	11.79
10	8.76	9.00	9.24	9.44	9.69	9.93	10.15	10.43	10.68	10.92	11.21	11.48	11.79	12.04	12.35
11	9.24	9.44	9.69	9.93	10.15	10.43	10.68	10.92	11.21	11.48	11.79	12.04	12.35	12.66	12.98
12	9.69	9.93	10.15	10.43	10.68	10.92	11.21	11.48	11.79	12.04	12.35	12.66	12.98	13.29	13.61
13	10.15	10.43	10.68	10.92	11.21	11.48	11.79	12.04	12.35	12.66	12.98	13.29	13.61	13.95	14.30
14	10.68	10.92	11.21	11.48	11.79	12.04	12.35	12.66	12.98	13.29	13.61	13.95	14.30	14.66	15.03
15	11.21	11.48	11.79	12.04	12.35	12.66	12.98	13.29	13.61	13.95	14.30	14.66	15.03	15.38	15.75
16	11.79	12.04	12.35	12.66	12.98	13.29	13.61	13.95	14.30	14.66	15.03	15.38	15.75	16.16	16.56
17	12.35	12.66	12.98	13.29	13.61	13.95	14.30	14.66	15.03	15.38	15.75	16.16	16.56	16.94	17.39
18	12.98	13.29	13.61	13.95	14.30	14.66	15.03	15.38	15.75	16.16	16.56	16.94	17.39	17.79	18.26
19	13.61	13.95	14.30	14.66	15.03	15.38	15.75	16.16	16.56	16.94	17.39	17.79	18.26	18.70	19.16
20	14.30	14.66	15.03	15.38	15.75	16.16	16.56	16.94	17.39	17.79	18.26	18.70	19.16	19.65	20.13
21	15.03	15.38	15.75	16.16	16.56	16.94	17.39	17.79	18.26	18.70	19.16	19.65	20.13	20.58	21.13
22	15.75	16.16	16.56	16.94	17.39	17.79	18.26	18.70	19.16	19.65	20.13	20.58	21.13	21.65	22.16
23	16.56	16.94	17.39	17.79	18.26	18.70	19.16	19.65	20.13	20.58	21.13	21.65	22.16	22.72	23.31
24	17.39	17.79	18.26	18.70	19.16	19.65	20.13	20.58	21.13	21.65	22.16	22.72	23.31	23.87	24.48
25	18.26	18.70	19.16	19.65	20.13	20.58	21.13	21.65	22.16	22.72	23.31	23.87	24.48	25.05	25.68
26	19.16	19.65	20.13	20.58	21.13	21.65	22.16	22.72	23.31	23.87	24.48	25.05	25.68	26.29	26.98
27	20.13	20.58	21.13	21.65	22.16	22.72	23.31	23.87	24.48	25.05	25.68	26.29	26.98	27.61	28.31
28	21.13	21.65	22.16	22.72	23.31	23.87	24.48	25.05	25.68	26.29	26.98	27.61	28.31	29.03	29.73
29	22.16	22.72	23.31	23.87	24.48	25.05	25.68	26.29	26.98	27.61	28.31	29.03	29.73	30.46	31.22
30	23.31	23.87	24.48	25.05	25.68	26.29	26.98	27.61	28.31	29.03	29.73	30.46	31.22	31.98	32.78
31	24.48	25.05	25.68	26.29	26.98	27.61	28.31	29.03	29.73	30.46	31.22	31.98	32.78	33.55	34.42
32	25.68	26.29	26.98	27.61	28.31	29.03	29.73	30.46	31.22	31.98	32.78	33.55	34.42	35.25	36.13
33	26.98	27.61	28.31	29.03	29.73	30.46	31.22	31.98	32.78	33.55	34.42	35.25	36.13	37.00	37.95
34	28.31	29.03	29.73	30.46	31.22	31.98	32.78	33.55	34.42	35.25	36.13	37.00	37.95	38.86	39.84
35	29.73	30.46	31.22	31.98	32.78	33.55	34.42	35.25	36.13	37.00	37.95	38.86	39.84	40.83	41.81
36	31.22	31.98	32.78	33.55	34.42	35.25	36.13	37.00	37.95	38.86	39.84	40.83	41.81	42.90	43.91
37	32.78	33.55	34.42	35.25	36.13	37.00	37.95	38.86	39.84	40.83	41.81	42.90	43.91	45.02	46.14
38	34.42	35.25	36.13	37.00	37.95	38.86	39.84	40.83	41.81	42.90	43.91	45.02	46.14	47.29	48.47

JOB DESCRIPTION

Revision Date: July 2007

JOB TITLE: Community Living Trainer - Sleepover
JOB CODE: 1052
SUPERVISOR: Community Living Program Coordinator
RESPONSIBLE TO SUPERVISE: None

JOB SUMMARY: Participate in the planning process. Provide advocacy and empowerment through knowledge about challenges facing persons served and ways to identify and use effective advocacy strategies to overcome those challenges. Assists persons served to build self-esteem and assertiveness and to make choices and decisions. Practice professionalism in the workplace and in the community. Communicate about effective ways to develop supporting relationships with persons served and with the persons served support network. Be aware of the requirements for documentation to fulfill job responsibilities. Promote Health and Safety through the ability to observe and implement action to promote a safe and healthy living environment for persons served. Personal Skill Development by Identifying areas for self-improvement, seeks out training opportunities, actively participates in in-services or training sessions, and share's knowledge with others. Provide Community awareness, involvement, integration through knowledge about formal and natural community supports available to persons served in the community and skilled in assisting persons served to gain access to such supports. Provide Crisis Intervention through knowledge about crisis prevention, intervention, and resolution techniques specific to persons served. Promote Relationships and Supports by matching specific supports and interventions to respond to the unique needs of persons served and recognizes the importance of friends, family, and community relationships. Support the Organization's Values and Vision.

RESPONSIBLE TO: Participate in the planning process by being knowledgeable about assessment practices in order to respond to the needs, desires, and interests of persons served and knowledgeable about developing and implementing PCP's and participating in PCP meetings.

DUTIES:

1. Knows PCP timelines and follows them.
2. Writes Implementation Plans and follows them.
3. Follows Service/Support Plans
4. Knows client restrictions (as documented) and follows them.
5. Knows and follows Activity Plans.
6. Completes Assessments.
7. Knows information contained in Service Guides & CL Program Guides.
8. Follows Psychotropic Medication Plans & actively participates in Med Staffing meetings.

RESPONSIBLE TO: Provide advocacy and empowerment through knowledge about challenges facing persons served and ways to identify and use effective advocacy strategies to overcome those challenges. Assists persons served to build self-esteem and assertiveness and to make choices and decisions.

DUTIES:

1. Utilizes various teaching techniques that enable persons served to do as much for themselves as possible.
2. Teaches persons served about their rights and responsibilities.
3. Practices good stewardship.
4. Assists persons served to make informed choices from options presented.
5. Knowledgeable about barriers getting in the way of persons served and identifies ways to overcome those barriers.
6. Knowledge about the role of a guardian/conservator, payee, parent, family member.
7. Builds self-esteem and confidence of persons served by teaching and supporting the importance of personal appearance
8. Displays problem solving abilities and conflict resolution techniques.
9. Honors and carries out client preferences and choice.
10. Informs CLPC of complaints voiced by persons served, families, and guardians, outside providers, etc., in a timely and respectful manner.

RESPONSIBLE TO: Practice professionalism in the workplace and in the community.

DUTIES:

1. Follows the job description.
2. Is a good role model.
3. Sets appropriate boundaries between work and personal life.
4. Has a positive attitude.
5. Has good morals and ethics.
6. Is punctual and has good attendance.
7. Has good problem solving skills and judgment.
8. Is a team player and flexible.
9. Is responsible, respectful and responsive.
10. Represents and promotes KETCH well.
11. Dresses appropriately.
12. Accurate and thorough.
13. Takes the initiative and is productive.
14. Has common sense.
15. Has self-control.
16. Is person-centered.
17. Seeks assistance as necessary.

RESPONSIBLE TO: Communicates about effective ways to develop supporting relationships with persons served and with the persons served support network.

DUTIES:

1. Communicates with persons served in a respectful and supportive manner.
2. Effectively communicates with persons served and encourages persons served to utilize their communication skills to the best of their ability.
3. Follows through with PCP Communication Plans.
4. Effectively communicates with Supervisor.
5. Effectively, professionally, and respectfully communicates with all team members, parents, guardians, family members, other providers, and co-workers (including communication between shifts and with day staff).

6. Utilizes the chain of contact established in CL.
7. Confidentially communicates about persons served and follows HIPAA policies and procedures.

RESPONSIBLE TO: Complete documentation requirements.
DUTIES:

1. Knowledgable about the importance of daily paperwork and the CLT role in completing it.
2. Meets documentation deadlines.
3. Accurately and consistently uses the electronic timekeeping system to record time worked and follows time-keeping system policies and procedures.
4. Notifies the Assistant Director of CL and CLPC if there are any problems with the timekeeping system or the electronic timecard.
5. Communicates overtime requests to the Assistant Director of CL, Community Living Program Coordinator, and/or CL On-Call (after-hours) before overtime is incurred.
6. Cooperates with the Assistant Director of CL, Community Living Program Coordinator, and CL On-Call (after-hours) regarding scheduling hours of work, leaves of absence, and overtime.
7. Accurately maintains attendance records.
8. Understands and completes PCP documentation (implementation plans, assessments, activity plans, behavior support plans, behavior data, service plans, etc.)
9. Understands documentation contained in Resource Files and Program Files.
10. Completes paperwork that is accurate, legible, and timely.
11. Completes forms as required (ANE, Incident, Accident, Seizure, etc.)
12. Accurately completes daily transportation paperwork including mileage reimbursement forms.
13. Accurately completes medication administration records (MAR's).
14. Accurately completes safety related paperwork (safety drills, safety inspections, fire extinguisher checks, maintenance work orders, etc.)
15. Accurately completes all expenditure records with receipts (resident expenditure, household grocery, and vision card forms).
16. Communicates after hour emergencies that affect the health, welfare, and/or safety of clients or staff to Community Living On-Call.
17. Submits mileage reimbursement forms no later than one month following mileage being accrued.
18. Maintains annual TB Test (within birthday month).

RESPONSIBLE TO: Promote health and safety through the ability to observe and implement action to promote a safe and healthy living environment for persons served.
DUTIES:

1. Maintains home according to KETCH CL Standards (refer to the CL Health and Safety Checklist).
2. Offers healthy food choices to persons served.
3. Meets the dietary needs of persons served.
4. Meets the exercise and wellness needs of persons served.
5. Handles and stores food safely.

6. Keeps outdoor areas clean, neat, tidy, and free of trash and debris.
7. Properly stores cleaning supplies and other household chemicals.
8. Properly administers medications.
9. Properly stores medication.
10. Follows medication reordering procedures.
11. Knowledgable about the basic side effects to medications.
12. Practices emergency drills (fire, tornado, medical emergency, power outage, etc.)
13. Knowledgable about how to respond to seizures.
14. Maintains KETCH vehicles designated for CL use (fueling, cleaning, safety equipment, vehicle logs, etc).
15. Knowledgable about how to operate household equipment in emergency situations (water shut off valves, breaker box location, home alarms, etc.)
16. Safely secures persons who use wheelchairs in vehicles.
17. Uses lifts on vehicles appropriately.
18. Positions individuals safely in chairs and wheelchairs based on their individual support plans.
19. Operates laundry equipment in a safe, responsible manner.
20. Understands smoking policy and assists persons served who smoke to do it in a safe manner.
21. Maintains the home in a secure manner (locking doors, windows, securing alarms, etc.)
22. Documents and reports maintenance and repairs needed in the home.
23. Changes light bulbs when necessary.
24. Utilizes proper infection control procedures and handling BBP.

RESPONSIBLE FOR: Personal skill development by identifying areas for self-improvement, seeks out training opportunities, actively participates in in-services or training sessions, and share's knowledge with others.
DUTIES:

1. Completes required training without lapse in certification.
2. Seeks out additional training beyond minimum requirements.
3. Actively participates in training sessions and in-services.
4. Has the desire, knowledge and skills to mentor and assist new employees to become familiar with persons served and CL operations.
5. Takes the initiative to learn more about persons served and effective ways to support them.
6. Has the desire to self-evaluate and enhance performance.

RESPONSIBLE TO: Provide community awareness, involvement, integration through knowledge about formal and natural community supports available to persons served in the community and skilled in assisting persons served to gain access to such supports.
DUTIES:

1. Utilizes community resources close to home setting.
2. Knowledgable of specific supervision levels of persons served in the community.
3. Knowledge of and uses of low-cost/no-cost activities available to persons served in the community.

4. Assists persons served about how to be a responsible neighbor.
5. Understands community activity preferences of persons served and assists persons to gain access to those activities (church, KSO, family visits, recreation, socialization, etc.)
6. Helps persons served with awareness and safety in the community.
7. Finds ways to coordinate activities with other CL settings.

RESPONSIBLE TO: Provide crisis intervention through knowledge about crisis prevention, intervention, and resolution techniques specific to persons served.
DUTIES:

1. Knowledgable about who to contact in crisis situations.
2. Knowledgable about who to contact if media is involved and what to do.
3. Knowledgable about personal limitations in handling crisis situations and when to seek assistance from others.
4. Appropriately utilizes Mandt principles and techniques.
5. Knowledgable of PRN, all emergency, and ANE protoco.l
6. Knowledgable and properly implements BSP's.
7. Has the ability to disengage from conflict with persons served.
8. Has the desire to learn and know patterns of behavior of persons served and reasons for them.

Responsible to: Promotes relationships and supports by matching specific supports and interventions to respond to the unique needs of persons served and recognizes the importance of friends, family, and community relationships.
DUTIES:

1. Understands and assists persons served to spend time with friends, family, and other important persons in their lives.
2. Assists individuals in purchasing needed items.
3. Purchases groceries based on planned menus, individual preferences, and within budget.
4. Assists individuals to prepare lunches.
5. Feeds individuals as needed and as identified in their individual plans.
6. Notifies supervisor when home supplies are low.
7. Respects the privacy of persons served.
8. Understands KETCH Policy on Sexuality of persons served and how to support persons served to develop healthy relationships.
9. Has a basic understanding of various disability types, especially among those served.
10. Encourages and includes persons served in daily household activities, household chores, and decorating.
11. Offers or suggests reasonable clothing options for persons served, including clothing appropriate for weather conditions.
12. Understands CL Visitation and pet policies.

Responsible to: Support the Organization's Values and Vision
DUTIES:

1. Follows-through with KETCH policies and procedures.

2. Takes ownership for actions.
3. Participates in KETCH functions, meetings, etc.
4. Understands and practices KETCH's Core Values.
5. Provides quality customer service.

1. Essential Functions:
   a) use written materials and devices that you draw or write with
   b) use verbal communications
   c) perform task involving care/treatment of sick or injured
   d) maintain records
   e) use tools or devices for the purpose of transporting or transferring clients
   f) drive cars or trucks
   g) attend to needs of others
   h) contact middle management and supervisors as part of the job
   i) operate in emergency situations-e.g. provide first aid
   j) deal with people in difficult situations
   k) take risks while serving others
   l) perform the same mental and physical task over and over
   m) follow certain set procedures on your job
   n) continually watch out for events that happen rarely on your job but that are important or critical
   o) work under distractions
   p) make efforts equal to lifting up to 50 pounds or ¼ of your body weight
   q) communicate with others to develop a form of action
   r) instruct others in some skill or knowledge
   s) answer questions from others
   t) anticipate the need for materials to accomplish work
   u) clarify goals and tasks for others
   v) compile data for decisions
   w) demonstrate techniques and procedures
   x) prepare plans and schedules
   y) recommend procedures and courses of action
   z) discuss issues and problems with others
   aa) encourage the efforts of others
   bb) dispense medications
   cc) awake supervision
   dd) adjust to new situations
   ee) keep TB Test and First Aid, CPR, Mandt System, and Medications Administration certifications current
   ff) maintain a current valid driver's license with a good driving record

JOB SPECIFICATIONS

EDUCATION/EXPERIENCE:
Requires a high school diploma or GED. Prior experience in a related position working with persons with disabilities is preferred.

HOURS:
Flexible depending upon the needs of the person served and approved shifts. Requires overnight presence in the home during the hours of 10p-6a. Pay for these hours are in accordance with the Federal Wage and Labor guidelines. A signed sleepover agreement must accompany this job description. Private sleep quarters are in accordance with Federal Wage and Labor guidelines.

TRANSPORTATION:
Reliable transportation at the assigned site during each shift, a valid driver's license, and proof of vehicle insurance are conditions of employment for this position. Exceptions are available from the Director of Community Living on an individual basis and are only valid if in writing and for a specified time period.

WORKING CONDITIONS:
The environment is the person's home and the community at large. The home may be an apartment, condominium, 4-plex, or a house.

SKILLS:
Strong verbal and written communication skills, conflict resolution and problem solving ability, organizational and time management skills. Compassionate, patient, reliable, creative and energetic with ability to motivate and teach others. Must have a valid driver's license and a good driving record. Must be able to lift 50 lbs or ¼ of own body weight, whichever is less. Individuals in the position must have knowledge, awareness and understanding of the needs of persons with mental retardation and other developmental disabilities. Individuals must have a visionary and person-centered philosophy of services. Ability to use typical household appliances, medical equipment, and some minor office equipment also required.

CONFIDENTIALITY:
Must be aware of the utmost importance of confidentiality regarding KETCH clients and records. Follow HIPAA guidelines.

SAFETY:
Every KETCH employee is responsible for the safety of staff and persons served under their supervision as well as co-workers and clients.

QUALITY:
Every KETCH employee is responsible for completing quality work in his or her position.

It is the policy and intent of KETCH to comply with all federal and state laws concerning nondiscrimination and equal employment opportunity regardless of race, color, sex religion, natural origin, ancestry, disability, marital status, or age, except where age is a bona fide occupational qualification; and to take affirmative action toward the goals and intentions of the applicable laws.
Furthermore, it is our policy and intent to practice nondiscrimination in regard to the above factors in personnel matters including but not limited to employment, promotion, upgrading, demotion, transfer, recruitment, or recruitment advertising, lay-off or termination, rates of pay or other forms of compensation, and selection for training including apprenticeship. If a staff person feels that a valid grievance exists, he or she can exercise a formal grievance procedure.

Except in cases where undue hardship can be proven, KETCH makes "reasonable accommodations" for the physical and mental limitations of an employee. "Reasonable accommodations" include alteration of job duties, work schedule, physical setting, and the provision of aids.

It is important to note that this job description is NOT an employment contract. KETCH is an employment at will agency. For more detail, refer to the Personnel Policy Manual.

KETCH reserves the right to add or delete duties and responsibilities for this position as business necessitates.

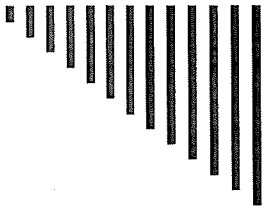
I have read this job description and fully understand that it outlines my duties and responsibilities as an employee of KETCH, Inc.

Employee Signature Date

Supervisor Signature Date

2107 Industrial Drive
McPherson, Kansas 67460

Phone: 620-241-6693
Fax: 620-241-6699
McPherson Industries: 620-241-6797
Fax: 620-241-7610



mcds
Multi Community Diversified Services, Inc.

December 8, 2010

To: Senator Julia Lynn, Chair
Members of Joint Committee on Children's Issues

From: Colin McKenney, President/CEO
Multi Community Diversified Services, Inc.

RE: Developmental Disabilities Support Waiver

Good afternoon, Madam Chair and members of the Committee.

Service options for children through the Medicaid waiver program for people with developmental disabilities are very limited. While a number of options are made available for adults, far less consideration seems to have taken place for school-age children living with their families. Because of this, our system is an example of one size fits all when it comes to support services for children.

Regardless of the type of disability or disabilities a young person has, almost all will be pointed toward in-home support services when they become eligible for the developmental disabilities waiver. In most instances, in-home support services mean funding for an individual to provide support services in a child's home. For some children with disabilities, that type of service creates an opportunity for individualized time to work on acquisition of skills or to provide intensive care if needed. In those instances, having a designated support worker to spend one-on-one time is quite a blessing.

Unfortunately for many children with qualifying disabilities, receiving one-on-one supervision from a support worker in the home is not the primary need. Receiving in-home supports may be one of the needs, but having access to specialized therapies or equipment that are not otherwise funded by Medicaid, a local school district, or the family's insurance may be a far greater need in the effort to minimize the limiting effect a child's disabilities create throughout his or her life.

With that idea in mind, a group of disability stakeholders created and distributed a survey to families of children with developmental disabilities across Kansas. The goal of the survey was to determine if families had opinions about ways the system could be modified to better meet the needs of their

children. With more than 350 responses from all over the state, it became clear that many families do have a strong interest in exploring other service options for their children:

- Of 367 responses, 283 indicated they would strongly consider a new waiver option that allows more flexibility to purchase needed support services, therapies, equipment or supplies.
- The top five priorities families indicated they would like to pursue with available funding included specialized therapies, specialized education, teaching materials, specialized childcare, and transportation services.
- Fifty-six percent of responses indicated a willingness to explore a flexible service option, even if the total annual funding offered for services is less than it would be for the traditional waiver program.

While the level of support decreased when the question referenced the concept of decreasing funding, I believe the number of families who indicated a willingness to consider less funding and more flexibility is remarkable. That question likely came across to many families that completed the survey as an introduction to yet another way to cut funding for programs. Despite that perception, well over half of the responses went out on a limb and agreed to consider the idea.

Although a support waiver would create an opportunity to save funding, that isn't a leading consideration for creating the waiver. The idea is simply to create an option for families to consider that provides a standardized annual allocation amount for them to work with. If the need for hourly support services in the home is not the highest priority, it may very well make more sense to opt for a standardized allocation that offers the flexibility to choose a variety of program options that may cost less than the annual program total offered through the traditional waiver program.

As indicated, the ability to choose the new support waiver would be one option for families. If a family is currently receiving services through the developmental disabilities waiver program and wishes to switch to the new program, that decision would be left up to the family. If a day comes when many families are offered funding for their children who are on the waiting list, a good number of them might opt for the support waiver as an alternative to our current waiver. An additional benefit of the support waiver might be the ability to stretch the dollars to a greater degree to assist more families. The allocation process simply spends the available dollars on service plans until no dollars remain, so more expensive service plans exhaust available dollars quicker. If some families select a service option that costs less than the

current program, it stands to reason that the savings could be made available to the next individual waiting for services.

I hope that you will agree that the concept our committee has been working on for the past few years represents an idea with a great deal of potential. We have explored the feasibility of the program, solicited input from families of children with disabilities, and outlined service categories to meet the needs of as many of them as possible. At this point in the learning process most interested individuals ask what must yet be accomplished to make this service option a reality. The short answer is that most of the technical work remains to be done. Discussion needs to move forward with representatives of Medicaid, which would likely be followed by a significant allocation of the time of state staff members to turn our outline into a detailed Medicaid waiver application.

Because this is a time of reduced staffing in state departments without a correlating reduction in work to be done, finding time to move new programs like this forward becomes a real challenge. Our plan is to continue to make progress as time allows, with a strong hope of having a new program to offer to families and children by the beginning of fiscal 2013.

I would be happy to answer any questions you may have about this concept.

THE CASE FOR Inclusion

2010

An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities

UCP United Cerebral Palsy™

Life without limits for people with disabilities™

Table of Contents

About UCP

United Cerebral Palsy (UCP) is one of the nation's leading organizations serving and advocating for the more than 54 million Americans with disabilities. Most UCP consumers are people with disabilities other than cerebral palsy. Through its nationwide network, United Cerebral Palsy assists more than 176,000 individuals, as well as their families and communities each day, with services such as job training and placement, physical therapy, individual and family support, early intervention, social and recreation programs, community living, state and local referrals, and instruction on how to use technology to perform everyday tasks. For more information, visit www.ucp.org or call (800) 872-5827.

About the Author

Tarren Bragdon has been involved in healthcare policy research and analysis for over a decade. His work has been featured in dozens of newspapers and media outlets nationwide including the *Wall Street Journal, New York Post, New York Sun* and PBS. Past and present clients include United Cerebral Palsy; the MELMAC Education Foundation; the Maine Heritage Policy Center; the Heritage Foundation in Washington, DC; the Manhattan Institute; the Home Care Alliance of Maine; and the National College Access Network. He has testified before the US Senate's Committee on Small Business and Entrepreneurship and presented to numerous legislative committees and physician, hospital, Medicaid, business, social service and policy research organizations. He served two terms in the Maine House of Representatives on the Health and Human Services Committee. He served as chair of the board of directors of Spurwink Services, one of the largest social service providers in Maine with over 850 employees.

Introduction

We release this report in the context of a nation struggling with the worst economic conditions since the Great Depression. States have been challenged to close unprecedented budget deficits over the past two years and are projected to have similar enormous budget deficits for the next two to three years.

Given these factors, this 2010 report needs to be taken in context. Data for this year's report is mostly from state fiscal year 2008 - for most states ending in June 2008 and before the most significant budget deficits. Therefore, this year's report is a look back of where states stood before the current recession and before states received significant boost in federal stimulus funding. The challenge for elected officials, families and advocates is to maintain the progress that has been achieved over the past three decades. We must not let the current economic crisis be an excuse to turn back the clock on Inclusion.

The United Cerebral Palsy (UCP) annual ***Case for Inclusion*** is so important to benchmark states actual performance in improving lives for individuals with intellectual and developmental disabilities. More than how much or how little is being spent, the ***Case for Inclusion*** shows what is being achieved.

As the University of Minnesota's Research and Training Center on Community Living, concisely states: "The promise of access to and support for integrated community lives and roles for persons with [intellectual and developmental disabilities] is clearly expressed in national legislative, judicial, administrative and other sources that make four basic commitments:

- People with disabilities will live in and participate in their communities;
- People with disabilities will have satisfying lives and valued social roles;

- People with disabilities will have sufficient access to needed support, and control over that support so that the assistance they receive contributes to lifestyles they desire; and
- People will be safe and healthy in the environments in which they live.

These commitments have been articulated in a number of legislative, administrative and judicial statements describing national policy."[1]

Medicaid is the safety net program that can assist in supporting individuals with intellectual and developmental disabilities with their acute and long term care service needs. Other state programs can assist in providing other comprehensive supports to individuals. However, some Medicaid long term care policies and state programs can play a negative role by promoting isolation and seclusion.

Beginning in 2006, UCP annually releases rankings of the 50 states and the District of Columbia to show what states are actually achieving. Too often the goals of independence, productivity and community inclusion are at odds with reality. The 2010 rankings use the same methodology and core data sets as the 2007, 2008 and 2009 rankings, allowing readers to appreciate how individual states have improved, regressed or remained the same.

United Cerebral Palsy conducts this holistic analysis to chart each state's ranking and progress in creating a quality, meaningful and community-inclusive life for those Americans with intellectual and developmental disabilities served by that state's Medicaid program.

Nationwide, Medicaid served 608,000 individuals with intellectual and developmental disabilities in 2008, up 72,000 (13.4 percent) from 536,000 in just three years. Medicaid spending rose to $34.3 billion or about $56,400 per person for 2008, up from $29.3 billion in 2005 (17.0 percent increase in 3 years). Although this is a tiny portion of the 58.7 million individuals enrolled in Medicaid and the estimated $339 billion spent in 2008, Americans with intellectual and developmental disabilities are some of the most vulnerable Medicaid recipients. Individuals with intellectual and developmental disabilities make up one percent of all Medicaid recipients, but a generous 10 percent of Medicaid spending.

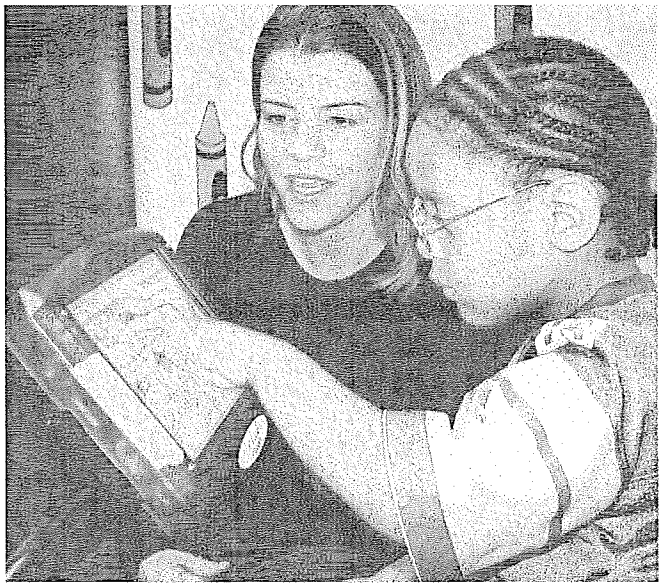
In addition to the noted Medicaid spending, states collectively spend an additional $17.2 billion to support individuals with intellectual and developmental disabilities in the community.

Although this report is a set of statistics, it is a collective summary of the impact and outcomes of Medicaid services to over half a million unique individuals with intellectual and developmental disabilities. Ideally such assessments should not be considered in the aggregate, but at the individual person level.

As always, the state rankings in this report are a snapshot in time. Most data is from 2008, although all data is the most recent available from credible national sources. Unfortunately, the data sourced is only as good as that provided directly by the states to the federal government or in response to surveys.

Although some states rank better than others, every state has room for improvement. The ***Case for Inclusion*** uses data and outcomes to clearly show where states' Medicaid programs are performing well and where improvement is needed.

1 The University of Minnesota Research and Training Center on Community Living. "Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities - Interim Report." September 26, 2005. Page 3. Available at: http://www.cms.hhs.gov/reports/downloads/UnivOfMinn.pdf



What We Don't Know but Should

Unfortunately, some of the most important outcome data is not nationally collected or reported regularly. For example, to more completely assess key outcomes, states should report regularly and be scored on:

- Are services self-directed and how many individuals are participating in self-directed services?
- Are individual budgets used?
- What is the pay and turnover rate of direct support staff?
- What school-to-work transition programming exists for this population?
- What are the detailed results of standard client satisfaction surveys?
- What is each state's long term plan to close large institutions (public and private), if any?

But advocates should always be looking at quality of life for the individual, irrespective of rankings and overall scoring. Aggregate data is important, but the true key to a state's performance is what quality of life each individual is living. The ideal is for outcomes to be reviewed at the individual level.

Hopefully, these *Case for Inclusion* reports, coupled with other advocacy initiatives, will encourage national groups to begin collecting and reporting on the above data measures so that a more complete picture can be presented and scored in future rankings.

Using This Report

This report is intended to help advocates and policymakers understand:

- How their state performs overall in serving individuals with intellectual and developmental disabilities
- What services and outcomes need attention and improvement in their state
- Which states are top performers in key areas, so that advocates and officials in those top performing states can be a resource for those desiring to improve

This report puts into a national context how each individual state is doing. Advocates should use this information to educate other advocates, providers, families and individuals, policymakers and their state administration on key achievements and areas needing improvement within their own state. These facts and figures can support policy reforms and frame debates about resource allocation for this population. Advocates can also use these facts to prioritize those areas that need the most immediate attention. Lastly, advocates can use these facts to support adequate and necessary ongoing funding and increasing resources in order to maintain their high quality outcomes, eliminate waiting lists, and close large institutions.

Elected officials should use this report as a guiding document on what needs time and attention and, possibly, additional resources or more inclusive state policies in order to improve outcomes for individuals with intellectual and developmental disabilities.

Those within federal and state administrations should use this report to put their work and accomplishments in context and to chart the course for the next focus area in the quest for continuous improvement and improved quality of life. The state should replicate this data reporting in more detail at the state and county level to identify areas of excellence and target critical issues needing attention.

What the Rankings Revealed – More Work Needs to Be Done but Improvements Still Being Made over the Past Year

1) All states have room to improve outcomes and services for individuals with intellectual and developmental disabilities and must be particularly vigilant in the current economic climate.

2) Too many Americans with intellectual and developmental disabilities still do not live in the community, although real and notable progress have been made over the last year:

- Now four states (up from two just two years ago) have more than 95 percent of individuals served living in home-like settings (at home, in their family's home or in settings with three or fewer residents) – Arizona, Nevada, New Hampshire and Vermont.
- An impressive 22 states – up three from last year and an increase just 16 states in 2007 - have more than 80 percent of those served living in home-like settings.
- Positively, there are 1,140 fewer Americans living in large state institutions (more than 16 beds). However, there still remain 168 large state institutions (only one closed since last year's report) housing 35,035 Americans. From 2005 to 2008, 4,063 fewer Americans were living in these large state institutions marking real –but unfortunately slow - progress.
- Now 10 states (up from nine last year) report more than 2,000 residents living in large public or private institutions – California, Florida, Illinois, Mississippi, New Jersey, New York, North Carolina, Ohio, Pennsylvania & Texas.
- Overall, the number of Americans with intellectual and developmental disabilities living in large institutions (more than 16 beds, public or private) has decreased an impressive 8,113 from 2005 to 2008, with 57,462 still living in these institutions. Inclusion is still the trend, significantly so in some states, as noted below.
- The number of Americans with intellectual and developmental disabilities served in their own home or in a family home has skyrocketed by about 70,300 (to 704,500 in 2008 from 634,200 three years prior).
- Nine states – Alaska, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont and West Virginia, and the District of Columbia - have no large state institutions. Thirteen states have only one large state facility remaining. No change since last year.

3) Certain states are making substantial progress toward inclusion:

From 2005 to 2008, an impressive 13 states reduced the number of Americans living in large institutions by 20 percent or more – Washington (-91%), Minnesota (-50%), Wisconsin (-46%),

Oregon (-42%), Indiana (-37%), Nevada (-36%), Wyoming (-32%), Kentucky (-29%), Maryland (-29%), Louisiana (-23%), Maine (-22%), West Virginia (-20%) and Delaware (-20%). This is in addition of the 4 states and Washington, D.C. reporting no individuals living in large institutions – Alaska, Hawaii, New Mexico and Vermont.

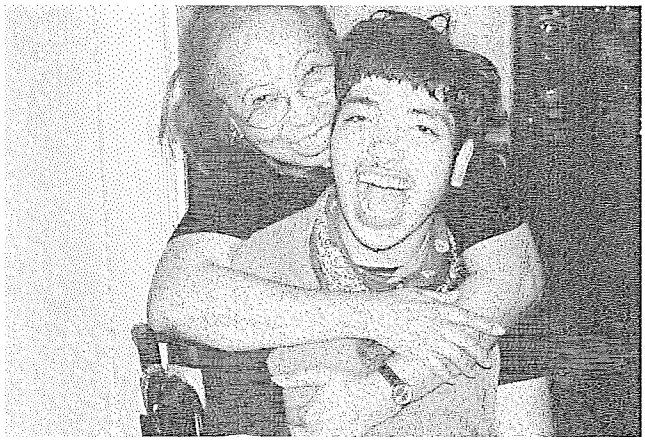
4) Too much money is still spent isolating people in large institutions, with nominal change from last year:

- Nationally, 15.6 percent (down from 19 percent in three years) of those living in institutions consume 36 percent of all Medicaid funding spent on those with intellectual and developmental disabilities.
- Eleven states – Alaska, Arizona, Colorado, Hawaii, Maryland, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, and Vermont– direct more than 90 percent of all related funds to those living in the community rather than in large institutions.
- Nationally, 28 states direct more than 80 percent of all related funding to those living in the community.

5) Waiting list have increased dramatically overall, but performance is quite mixed by state. Most states are not serving all those in need:

- Overall the number of Americans with intellectual and development disabilities on waiting lists for residential services has increased 56 percent from 2005 to 2008 (to 115,000 from 74,000).
- Only seven states – California, D.C., Hawaii, Idaho, Massachusetts, Rhode Island, and Vermont - report maintaining a waiting list with no one waiting for residential services.
- Yet, eighteen states report having a residential services waiting list so large that their programs would have to grow by at least 25 percent to accommodate the need.
- There is a real divide among states – those meeting the need and those documenting the unmet need through a waiting list.

It is important to note that a state may have improved in some specific categories but may drop in the overall ranking. This is primarily due to two factors: 1) A state's performance may have not improved as greatly as the national average and this would cause that state to fall in relation to other states as a whole. 2) A state may improve in one area but decline in another area. The weighted impact of that mixed performance may cause a state to fall in the rankings as well.



How the Rankings Were Developed

These rankings were developed through a broad, data-driven effort. Demographic, cost, utilization, key data elements, and outcomes statistics were assembled for all 50 states and the District of Columbia. Ninety-nine individual data elements from numerous governmental non-profit and advocacy organizations were reviewed. Dozens of Medicaid, disability and intellectual and developmental disability policy experts, were consulted as well as members of national advocacy and research organizations. They were asked to consider the attributes of top performing Medicaid programs and offer opinions and recommendations on the project in general.

To comprehensively determine the top-performing states, a weighted scoring methodology was developed. Twenty key outcome measures and data elements were selected and individually scored in five major categories on a total 100-point scale. If a person is living in the community, it is a key indicator of inclusion; therefore the "Promoting Independence" category received a majority of the points, as noted in the table on page 10.

In general, the top-performing state for each measure was assigned the highest possible score in that category. The worst-performing state was assigned a zero score in that category. All other states were apportioned accordingly based on their outcome between the top and worst-performing.

As noted, most data is from 2008, but all data is the most recent available from credible national sources. Therefore, these state rankings are a snapshot in time. Changes and reforms enacted or beginning in 2009 or later have not been considered. When reviewing an individual state's ranking, it is important to consider action taken since 2008, if any, to accurately understand both where that state was and where it is presently. Also, it is important to note that not all individuals with disabilities were considered. To limit the scope of the effort and to focus subsequent initiatives on meaningful, achievable improvement, only individuals with intellectual and developmental disabilities served were considered.

A note of caution: Although over 60 points separate the top performing state from the poorest performing state, less than 12 points separate the top ten states, about 19 points separate the top 25 states but only 10 points separate the 25 states in the middle. Therefore, minor changes in state policy or outcomes could significantly affect how a state ranks on future or past ***Case for Inclusion*** reports.

Movers and Shakers

More than the change from year to year, it is important to look at trends over time. Twenty-one states shifted at least six places in the rankings from 2007 to 2010 Case for Inclusion rankings. As previously noted, the variation in scoring among most states is very small. Therefore, small changes in outcomes can mean a significant change in rankings.

In total, 21 states had a sizable change in rankings over last four years. These states include:

State	2010	2009	2008	2007	Change from 2007 to 2010 (positive=improved)
Alaska	27	3	3	2	-25
Delaware	30	13	14	14	-16
Florida	37	18	16	18	-19
Georgia	17	31	32	30	13
Idaho	16	15	18	25	9
Indiana	44	42	41	37	-7
Iowa	33	39	39	39	6
Kentucky	31	38	38	40	9
Maryland	18	32	33	33	15
Missouri	25	29	28	41	16
Nevada	13	34	34	27	14
New Hampshire	3	4	9	11	8
Oklahoma	41	30	36	35	-6
Pennsylvania	15	16	15	29	14
Rhode Island	38	19	27	28	-10
South Carolina	35	17	17	15	-20
Utah	46	37	37	36	-10
Washington	4	25	20	20	16
West Virginia	22	23	24	16	-6
Wisconsin	20	22	23	31	11
Wyoming	29	28	25	17	-12

Why? The answer is different for each state.

Alaska- dropped so dramatically due to the number of people being served in a family home was previously estimated (by the state) at over 3,000 but for this year was reported as actually being just 79. This dramatic change illustrates the problems with using estimated data compared with hard facts.
Delaware – dropped primarily due to the state no longer participating in a national quality assurance effort. Delaware in the past participated in the National Core Indicators quality assurance program.
Florida – similar to Delaware, Florida dropped as a result on no longer participating in a national quality assurance effort. Florida in the past participated in the Council on Quality and Leadership program.
Georgia – improved almost in most areas by serving more individual in home-like settings and directed more resources to the community. Georgia also added a Medicaid Buy-in program.
Idaho - directed more people and resources to the community. Idaho also added a Medicaid Buy-in program.
Indiana – dropped due to the large increase in the number of individuals served in residential setting with 7-15 individuals and a large reduction in the number served in settings with fewer than 7 residents. Also, the percent of individuals in competitive employment dropped by more than half – to 22% in 2006 from 48% in 2004.
Iowa – improved due to its participation in a national quality assurance effort, the Council on Quality and Leadership program for numerous Iowa agencies.
Kentucky – improved performance in almost every measure – dramatically increased the portion of residents served in home-like settings to 90% from 83% and added a Medicaid Buy-in program.
Maryland – improved dramatically due to serving more people in the community and directing more resources to the community, began having private agencies participating in the Council on Quality and Leadership quality assurance program, and added a Medicaid Buy-in program.
Missouri – improved dramatically as a result of a striking increase in the portion of resources being directed at community services (to 82% in 2008 from 50% in 2005) and beginning to participate in a noteworthy quality assurance program, the National Core Indicators.
Nevada – improved as a result of an impressive increase in the portion of resources being directly at community services (to 86% in 2008 from 68% in 2005) and having providers begin to participate in a noteworthy quality assurance program, the Council on Quality and Leadership.
New Hampshire – improved due to beginning to participate in a noteworthy quality assurance program, the National Core Indicators, and a drop in the number of individuals served having a reported abuse complaint
Oklahoma – dropped as a result of serving fewer people in home-like settings (from 75% of those served in 2005 to just 68% in 2008) and an increase of 2,700 people on their waiting list
Pennsylvania – improved dramatically due to substantial improvement in several areas including a significant increase in the number of individuals served (to 55,000 from less than 30,000), a substantial shift in more individual in community settings (less than 7 residents per setting, to 92% from 85%), a drop in population in large settings of 350, the closure of one state institution, and a reduction in its waiting lists
Rhode Island – dropped as a result of no longer participating in a quality assurance program, the National Core Indicators, but, positively, did add a Medicaid Buy-in program
South Carolina – dropped as a result of no longer participating in a quality assurance program, the National Core Indicators, but, positively, are directing more resources to the community (to 73% in 2008 from 55% in 2005)
Utah – dropped as a result of no longer participating in a quality assurance program, the Council on Quality and Research
Washington – improved in the rankings as started reporting the size of their waiting list and its being relatively small
West Virginia – dropped in rankings mostly due to not keeping pace with the rest of the country
Wisconsin – improved in rankings due to a substantial increase in the number and overall portion of individuals served in the community and a higher share of spending directed toward community services.
Wyoming – dropped in ranking as a result of modest change in overall score among a group of tightly clustered states.

UCP United Cerebral Palsy
Life without limits for people with disabilities

Subrankings of States in Four Key Outcomes And Data Elements

Allocating Resources to Those in the Community (Non-ICF-MR)

% of ID/DD Expenditures on non-ICF-MR		Rank
100%	Alaska	1
99%	Vermont	2
99%	New Hampshire	3
99%	Michigan	4
98%	Oregon	5
98%	Arizona	6
97%	Rhode Island	7
95%	Colorado	8
94%	Hawaii	9
94%	New Mexico	10
93%	Maryland	11
90%	Minnesota	12
90%	Montana	13
89%	Alabama	14
88%	California	15
87%	Kansas	16
86%	Nevada	17
86%	Wisconsin	18
86%	Wyoming	19
84%	Maine	20
84%	Georgia	21
84%	South Dakota	22
83%	West Virginia	23
82%	Missouri	24
82%	Connecticut	25
82%	Massachusetts	26
82%	Washington	27
82%	Delaware	28
80%	Florida	29
78%	Pennsylvania	30
78%	Idaho	31
75%	Ohio	32
75%	Nebraska	33
75%	Oklahoma	34
75%	Tennessee	35
74%	Dist. of Columbia	36
73%	Indiana	37
73%	South Carolina	38
72%	Utah	39
70%	Kentucky	40
70%	New York	41
70%	Virginia	42
70%	North Carolina	43
66%	North Dakota	44
66%	Arkansas	45
63%	Iowa	46
61%	Illinois	47
61%	New Jersey	48
59%	Texas	49
53%	Louisiana	50
30%	Mississippi	51
77%	US Average	

Supporting Individuals in the Community and Home-like Settings

% Living in Settings with 1-3 Residents		Rank
93%	Nevada	1
93%	Vermont	2
95%	Arizona	3
95%	New Hampshire	4
93%	Idaho	5
90%	California	6
90%	Kentucky	7
89%	Washington	8
89%	New Mexico	9
89%	Alaska	10
88%	Hawaii	11
87%	Georgia	12
85%	West Virginia	13
85%	Colorado	14
81%	Delaware	15
81%	New Jersey	16
81%	Florida	17
81%	Ohio	18
80%	South Carolina	19
80%	Maryland	20
80%	Tennessee	21
80%	Montana	22
79%	Alabama	23
79%	Oregon	24
79%	Virginia	25
78%	North Carolina	26
78%	Michigan	27
78%	Massachusetts	28
77%	Missouri	29
76%	Iowa	30
76%	Utah	31
74%	Connecticut	32
73%	Maine	33
73%	New York	34
72%	Kansas	35
71%	Louisiana	36
71%	Indiana	37
69%	Pennsylvania	38
68%	Oklahoma	39
67%	North Dakota	40
67%	Nebraska	41
66%	Wisconsin	42
66%	Dist. of Columbia	43
65%	South Dakota	44
65%	Minnesota	45
63%	Texas	46
62%	Rhode Island	47
59%	Wyoming	48
54%	Arkansas	49
50%	Illinois	50
44%	Mississippi	51
81%	US Average	

Keeping Families Together through Family Support

Families Supported with Family Support per 100k of Population		Rank
537	New Mexico	1
348	New Hampshire	2
309	Arizona	3
308	Montana	4
261	South Dakota	5
228	Alaska	6
228	New Jersey	6
227	Connecticut	8
224	California	9
216	Massachusetts	10
216	New York	10
214	Vermont	12
213	Hawaii	13
211	South Carolina	14
206	Delaware	15
199	Wisconsin	16
199	Wyoming	16
185	Pennsylvania	18
181	Louisiana	19
157	Minnesota	20
139	Maryland	21
139	Mississippi	21
131	Oklahoma	23
129	Kansas	24
129	Missouri	24
123	West Virginia	26
117	Washington	27
113	Florida	28
113	Michigan	28
105	Ohio	30
105	Tennessee	30
103	Nevada	32
100	Texas	33
95	North Dakota	34
87	Illinois	35
76	Georgia	36
74	Colorado	37
69	Rhode Island	38
67	Iowa	39
66	Indiana	40
62	Alabama	41
52	Utah	42
50	Idaho	43
49	North Carolina	44
42	Kentucky	45
41	Maine	46
38	Virginia	47
35	Oregon	48
32	Nebraska	49
28	Arkansas	50
0	Dist. of Columbia	51
144	US Average	

Supporting Meaningful Work

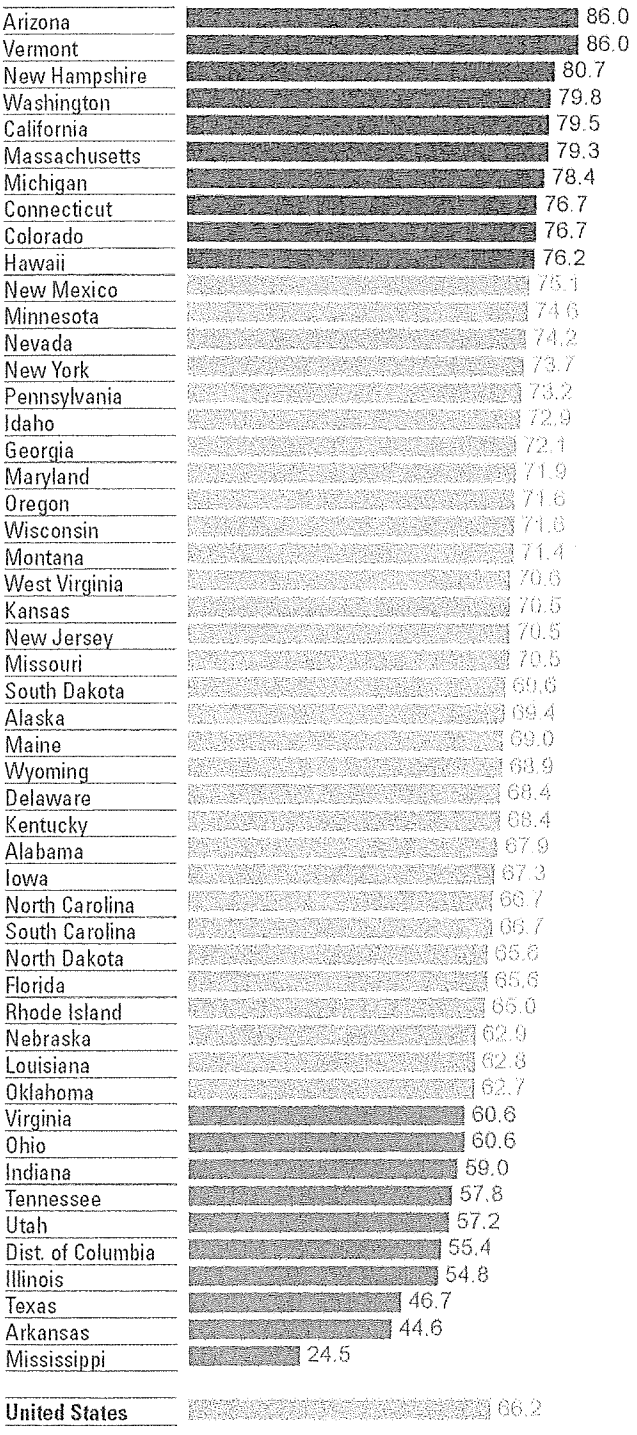
% in Supportive or Competitive Employment		Rank
77%	Oklahoma	1
61%	Washington	2
51%	Connecticut	3
48%	Vermont	4
45%	Louisiana	5
44%	Massachusetts	6
38%	Maryland	7
38%	Pennsylvania	7
35%	Alaska	9
35%	Colorado	9
34%	New Mexico	11
34%	Oregon	11
32%	Utah	13
30%	South Dakota	14
29%	Nebraska	15
29%	New Hampshire	15
28%	Iowa	17
26%	Delaware	18
26%	Georgia	18
24%	Michigan	20
23%	Virginia	21
22%	Florida	22
22%	Indiana	22
22%	Ohio	22
21%	Kentucky	25
21%	Maine	25
21%	Wyoming	25
20%	Rhode Island	28
20%	Tennessee	28
20%	Texas	28
19%	North Carolina	31
16%	Nevada	32
16%	Wisconsin	32
15%	Idaho	34
15%	Minnesota	34
15%	Mississippi	34
15%	North Dakota	34
14%	Arizona	38
14%	Montana	38
14%	New Jersey	38
13%	California	41
13%	Illinois	41
12%	New York	43
12%	South Carolina	43
11%	West Virginia	45
10%	Dist. of Columbia	46
10%	Kansas	46
9%	Missouri	48
8%	Hawaii	49
5%	Alabama	50
2%	Arkansas	51
21%	US Average	

States' Ranking of Medicaid for Americans with Intellectual and Developmental Disabilities

Best performing state ranks #1

State	*2010*	*2009*	*2008*	*2007*
Alabama	32	33	31	32
Alaska	27	3	3	2
Arizona	1	2	1	1
Arkansas	50	50	46	46
California	5	7	5	5
Colorado	9	9	7	8
Connecticut	8	10	10	6
Delaware	30	12	14	14
Dist. of Columbia	47	48	48	49
Florida	37	18	16	18
Georgia	17	31	32	30
Hawaii	10	8	8	12
Idaho	16	15	18	25
Illinois	48	47	49	47
Indiana	44	42	41	37
Iowa	33	39	39	39
Kansas	23	24	23	22
Kentucky	31	38	38	40
Louisiana	40	46	45	44
Maine	28	35	30	24
Maryland	18	32	33	33
Massachusetts	6	5	4	4
Michigan	7	6	6	9
Minnesota	12	13	12	7
Mississippi	51	51	51	51
Missouri	25	29	28	41
Montana	21	27	26	19
Nebraska	39	44	42	43
Nevada	13	34	34	27
New Hampshire	3	4	9	11
New Jersey	24	21	22	23
New Mexico	11	11	11	13
New York	14	14	13	10
North Carolina	34	36	35	34
North Dakota	36	40	43	38
Ohio	43	45	44	48
Oklahoma	41	30	36	35
Oregon	19	20	19	21
Pennsylvania	15	16	15	29
Rhode Island	38	19	27	28
South Carolina	35	17	17	15
South Dakota	26	26	29	26
Tennessee	45	43	40	42
Texas	49	49	50	50
Utah	46	37	37	36
Vermont	2	1	2	3
Virginia	42	41	47	45
Washington	4	25	21	20
West Virginia	22	23	20	16
Wisconsin	20	22	24	31
Wyoming	29	28	25	17

Scoring of States



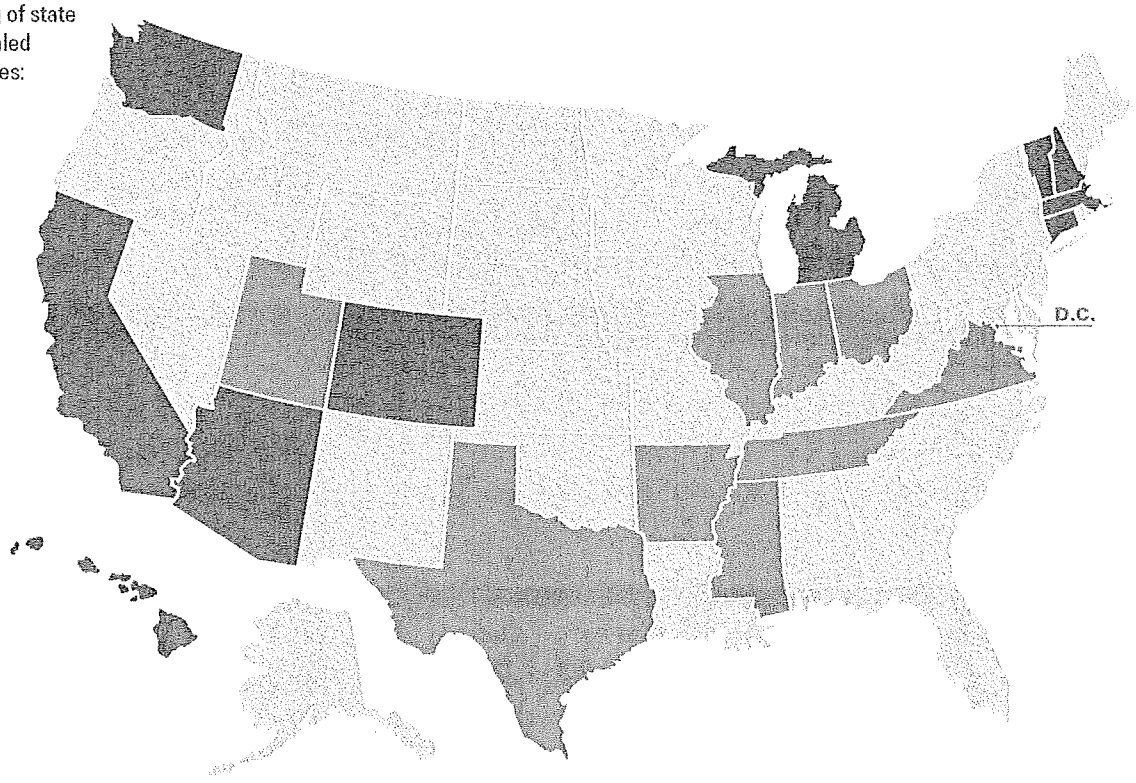
Map of Best and Worst Performing States

The results of this scoring of state Medicaid programs revealed the following Top Ten states:

1. **Arizona**
2. **Vermont**
3. **New Hampshire**
4. **Washington**
5. **California**
6. **Massachusetts**
7. **Michigan**
8. **Connecticut**
9. **Colorado**
10. **Hawaii**

...and Bottom Ten:

42. Virginia
43. Ohio
44. Indiana
45. Tennessee
46. Utah
47. Dist. of Columbia
48. Illinois
49. Texas
50. Arkansas
51. Mississippi



Facts about the Top Ten States

Further examining the top 10 states shows that a state does not need to look a certain way in order to best serve individuals with intellectual and developmental disabilities through Medicaid.

What matters is how a state acts and what is achieved.

In fact, the top 10 states are quite diversified. Consider these facts about the top ten states:

Large and Small Population

- Includes the most populous - California (#1), and Michigan (#8) – as well as the least populous states –Hawaii (#42), New Hampshire (#41) and Vermont (#49)

Rich and Poor

- Includes some of the wealthiest states in median household income –Connecticut (#4), Hawaii (#5), Massachusetts (#9) and New Hampshire (#1)– and less affluent states – Arizona (#33) and Michigan (#25)

High and Low Tax

- Includes high tax burden states – Connecticut (#9), Hawaii (#7), and Vermont (#1) – and low tax burden states –Arizona (#32), Colorado (#31), Massachusetts (#29), and New Hampshire (#50)

High and Low Spenders (spending per individual with intellectual and developmental disabilities served)

- Includes states with some of the highest spending per person served by the HCBS waiver – Connecticut (#10), Massachusetts (#10), and Vermont (#13)– as well as some that spend considerably less –Arizona (#45), California (#50), Colorado (#31), Hawaii (#33) and Washington (#38)

Ranking Methodology

Major Category	*Data Element*		*Weight*	*Total Weight of all Measures in the Category*
Promoting Independence	Community-based	Percent of recipients with ID/DD on HCBS	9	24
		Percent of ID/DD expenditures on HCBS	7	
		Percent of ID/DD expenditures on non-ICF-MR	8	
	Residential services in the community (includes all types)	Percent living in 1-3 residents settings	13	24
		Percent living in 1-6 residents settings	11	
		Percent living in 16+ residents settings (negative)	-4	
		Percent living in large state facilities (negative)	-3	
	Waivers promoting self-determination		2	2
Tracking Quality and Safety	Noted quality assurance program		6	12
	Percent of clients with abuse or protection report		6	
Keeping Families Together	Family support per 100,000 of population		6	12
	Percent served living in a family home		6	
Promoting Productivity	Medicaid buy-in program operating		2	10
	Percent in supported or competitive employment		6.5	
	Vocational rehab	per 100k of population	1	
		Percent VR wages to state average	.25	
		Mean weekly hours worked	.25	
Reaching Those in Need	Average percent growth of program for residential and HCBS waiting list		9	16
	Individuals with ID/DD served per 100,000 of population		3	
	Ratio of prevalence to individuals served		4	
TOTAL	20 measures			100

Appendix I

Key Data on States' Medicaid Programs for Those with Intellectual and Developmental Disabilities

ABBR	State	Promoting Independence													
		Community-based			Residential										
		% of Recipients with ID/DD on HCBS	% of ID/DD Expenditures on HCBS	% of ID/DD Expenditures on non-ICF-MR	Own Home	Family Home	Family Foster Care				Congregate Care (includes ICF-MR)					
					1	1	1-3	4-6	7-15	Total	1-3	4-6	7-15	16+	Total	
AL	Alabama	96%	88%	89%	205	3,497	223	8	0	231	1,631	413	2,044	826	198	5,068
AK	Alaska	100%	100%	100%	427	79	201	0	0	201	*171*	*104*	275	10	0	285
AZ	Arizona	99%	98%	98%	465	25,425	971	0	0	971	1,315	1,190	2,505	40	169	2,714
AR	Arkansas	68%	40%	66%	650	1,476	419	16	48	483	196	21	217	801	1,420	2,441
CA	California	89%	34%	88%	19,955	128,748	3,933	0	0	3,933	*12366*	*12,365*	24,731	1,293	4,724	30,748
CO	Colorado	98%	93%	95%	778	6,313	0	0	0	0	5	652	657	543	105	1,305
CT	Connecticut	88%	67%	82%	1631	7,088	399	0	0	399	1105	2,570	3,675	388	760	4,823
DE	Delaware	86%	74%	82%	16	2,062	162	0	0	162	268	436	704	0	138	842
DC	Dist. of Columbia	69%	46%	74%	46	675	49	0	0	49	524	529	1053	151	0	1,204
FL	Florida	91%	74%	80%	5,020	36,139	0	0	0	0	294	5,371	5,665	1,186	3,125	9,976
GA	Georgia	92%	79%	84%	712	11,263	557	0	0	557	1,655	963	2,618	0	1,970	4,588
HI	Hawaii	97%	92%	94%	155	2,183	542	226	0	768	3	166	169	15	0	184
ID	Idaho	81%	52%	78%	1,321	12,980	1,594	0	0	1,594	0	169	169	507	483	1,159
IL	Illinois	62%	41%	61%	4,172	12,516	181	28	0	209	183	3,635	3,818	7,179	6,041	17,038
IN	Indiana	71%	59%	73%	5,980	4,592	283	0	0	283	2029	1,456	3,485	2576	464	6,525
IA	Iowa	86%	51%	63%	5,585	5,156	7	0	0	7	*0*	*391*	391	1,070	1,851	3,312
KS	Kansas	93%	81%	87%	2,493	2,656	153	0	0	155	639	1,478	2,117	476	412	3,005
KY	Kentucky	86%	67%	70%	481	2,406	630	0	0	630	2,151	36	2,187	112	499	2,798
LA	Louisiana	58%	40%	53%	2,053	10,262	55	0	0	55	66	1,878	1,944	1,275	1,906	5,125
ME	Maine	93%	79%	84%	443	529	550	59	0	609	1278	721	1,999	192	38	2,229
MD	Maryland	98%	90%	93%	1,700	2,350	214	0	0	214	3,545	1,380	4,925	257	279	5,461
MA	Massachusetts	93%	71%	82%	823	21,226	1541	0	0	1541	1,301	5,043	6,344	1,134	929	8,407
MI	Michigan	99%	96%	99%	5,202	17,263	739	0	0	739	*464*	*3,621*	5,085	1412	666	7,163
MN	Minnesota	89%	84%	90%	2,020	13,093	976	325	0	1,301	951	8,001	8,952	569	415	9,936
MS	Mississippi	43%	12%	30%	87	1,666	0	0	0	0	421	81	502	714	2,025	3,241
MO	Missouri	99%	75%	82%	2,824	8,294	23	0	0	23	352	1140	1,492	1,131	1,195	3,818
MT	Montana	98%	86%	90%	621	3,386	209	12	0	221	214	371	585	402	67	1054
NE	Nebraska	88%	66%	75%	764	471	415	0	0	415	831	615	1,446	100	501	2,047
NV	Nevada	94%	78%	86%	1,412	3,120	79	7	0	86	0	36	36	0	69	105
NH	New Hampshire	99%	98%	99%	484	551	917	9	0	926	275	76	351	19	25	395
NJ	New Jersey	78%	44%	61%	895	26,915	1,276	0	0	1,276	1,381	3,273	4,762	855	2,971	8,588
NM	New Mexico	95%	92%	94%	536	1303	594	12	0	606	777	267	1044	121	0	1,165
NY	New York	88%	59%	70%	7,651	78,542	1,302	895	7	2,704	3,247	10,541	13,788	18,665	3,132	35,585
NC	North Carolina	70%	56%	70%	1,695	14,525	888	*0*	*171*	1059	*2549*	*2,549*	5,098	528	2,201	7,827
ND	North Dakota	86%	52%	66%	1,093	715	29	0	0	29	0	219	219	501	468	888
OH	Ohio	74%	54%	75%	11,733	19,322	726	0	0	726	*1140*	*1,140*	2,280	2,445	4,233	8,958
OK	Oklahoma	79%	68%	75%	1,594	2,725	441	0	0	441	0	750	750	597	1,046	2,193
OR	Oregon	100%	97%	98%	795	6,382	*2309*	*0*	*0*	2,309	230	2,113	2,343	331	83	2,757
PA	Pennsylvania	80%	68%	78%	5,541	30,488	*1,710*	0	0	1,710	286	*12,779*	*13,065*	*1,286*	*2,871*	17,232
RI	Rhode Island	99%	97%	97%	696	875	96	4	0	100	251	969	1,220	182	23	1,425
SC	South Carolina	79%	56%	73%	660	13,631	144	0	0	144	441	1,875	2,316	865	841	4,043
SD	South Dakota	95%	80%	84%	539	807	7	0	0	7	664	349	1013	559	166	1,738
TN	Tennessee	86%	70%	75%	5,079	3,668	506	0	0	506	216	555	771	781	656	2,008
TX	Texas	62%	44%	59%	3,056	5,026	5,976	*0*	*0*	5,976	*4256*	*4,257*	8,854	625	6,041	15,520
UT	Utah	84%	63%	72%	257	2,015	241	0	0	241	837	319	1,156	139	779	2,076
VT	Vermont	100%	99%	99%	215	1,527	1143	0	0	1143	49	72	121	0	0	121
VA	Virginia	83%	62%	70%	1,569	9,594	739	0	0	739	1136	1449	2585	564	1420	4569
WA	Washington	92%	70%	82%	3,759	13,461	136	0	0	136	122	1,877	1,999	178	113	2,290
WV	West Virginia	89%	75%	83%	753	2,714	258	0	0	258	218	171	389	500	47	936
WI	Wisconsin	93%	80%	86%	2,607	7,958	1,372	0	0	1,372	0	3,370	3,370	1,768	946	6,084
WY	Wyoming	96%	84%	86%	195	701	209	0	0	209	161	716	877	97	82	1056
	United States	85%	65%	77%	115,873	588,594	24,964	1,601	226	26,791	31,529	72,112	144,879	52,745	54,513	271,137
	United States - Est.				115,873	588,594	35,742	2,294	226	38,262	48,819	111,658	160,477	55,198	57,462	271,137
	Source	Research and Training Center on Community Living		Coleman Institute	Research and Training Center on Community Living											
	Table/Page	T. 3.9, P. 108		Calculated	T. 2.8, P. 76	T. 2.9, P. 77	T. 2.7, P. 75				T. 2.6, P. 74					
	Year of Data	2008			2008	2008	2008				2008					

Appendix I *Continued*

State	Promoting Independence															
	All Individuals by Size of Residence									Large State Facilities						
	Totals (includes own home, family home, family foster care and congregate care)									% in Large State Facilities	Residents in Large State Facilities per 100,000 population	Number of Large State Facilities	Residents at Large State Facilities	FY2008 Aver per diem		Persons with ID/DD in Non-specialized Nursing Facilities
	1-3	%	4-6	1-6	%	7-15	16+	%	Total	16+						
Alabama	5,556	79%	421	5,977	85%	826	198	3%	7,001	2.8%	4.2	1	198	$	467	998
Alaska	878	89%	104	982	99%	10	0	0%	992	0.0%	0	0	0	NA		5
Arizona	27,874	95%	1,199	29,064	99%	90	169	1%	29,273	0.4%	1.9	1	126	$	329	47
Arkansas	2,741	54%	37	2,778	55%	852	1,420	28%	5,050	21.4%	37.9	6	1,082	$	279	155
California	165,002	90%	12,365	177,367	97%	1,293	4,724	3%	183,384	1.4%	6.9	7	2,330	$	772	1,393
Colorado	7,096	85%	652	7,748	92%	543	105	1%	8,396	1.3%	2.1	2	105	$	529	180
Connecticut	10,823	74%	2,570	13,393	92%	388	760	5%	14,541	5.2%	21.7	7	760	$	920	420
Delaware	2,508	81%	436	2,944	96%	0	138	4%	3,082	2.6%	9	1	79	$	834	48
Dist. of Colombia	1,294	66%	529	1,823	92%	151	0	0%	1,974	0.0%	0	0	0	NA		7
Florida	41,453	81%	5,371	46,824	92%	1,186	3,125	6%	51,135	2.2%	6.1	6	1,169	$	401	297
Georgia	14,187	87%	963	15,150	93%	0	1,070	7%	16,220	5.9%	9.9	3	960	$	514	1,561
Hawaii	2,883	88%	392	3,275	100%	15	0	0%	3,290	0.0%	0	0	0	NA		86
Idaho	14,995	93%	169	15,164	94%	507	485	3%	16,154	0.5%	3.5	1	94	$	318	109
Illinois	17,052	50%	3,663	20,715	61%	7,179	6,041	18%	33,935	7.1%	18.6	9	2,403	$	349	1629
Indiana	10,894	71%	1,436	12,330	80%	2,576	464	3%	15,280	0.9%	2.3	4	145	$	636	1,641
Iowa	10,748	76%	391	11,139	79%	1,070	1,851	13%	14,060	3.9%	18.2	2	547	$	514	592
Kansas	5,941	72%	1,478	7,419	89%	476	412	5%	8,307	4.3%	12.8	2	359	$	415	0
Kentucky	5,668	90%	36	5,704	90%	112	499	8%	6,315	2.7%	4.1	2	173	$	718	500
Louisiana	12,436	71%	1,878	14,314	82%	1,275	1,906	11%	17,495	6.8%	27.1	7	1,127	$	460	399
Maine	2,800	73%	780	3,580	94%	192	38	1%	3,810	0.0%	0	0	0	NA		105
Maryland	7,849	80%	1,360	9,229	95%	257	279	3%	9,765	2.9%	5	1	279	$	478	385
Massachusetts	24,885	78%	5,043	29,928	94%	1,134	929	3%	31,991	2.9%	14.3	6	929	$	728	818
Michigan	23,679	78%	4,621	28,300	93%	1,412	666	2%	30,378	0.4%	1.2	1	118	$	791	393
Minnesota	17,040	65%	8,326	25,366	96%	569	415	2%	26,350	0.2%	0.8	1	41	$	906	245
Mississippi	2,173	44%	81	2,255	45%	714	2,025	41%	4,994	26.3%	34.7	5	1,314	$	516	140
Missouri	11,493	77%	1,140	12,633	84%	1,131	1,195	8%	14,959	5.9%	14.9	7	882	$	338	524
Montana	3,430	80%	383	3,813	89%	402	67	2%	4,282	1.6%	6.9	1	67	$	668	204
Nebraska	2,481	67%	615	3,096	84%	100	501	14%	3,697	7.2%	15	1	267	$	389	178
Nevada	4,611	98%	43	4,654	99%	0	69	1%	4,723	1.1%	2	2	51	$	342	87
New Hampshire	2,227	93%	85	2,312	98%	19	25	1%	2,356	0.0%	0	0	0	NA		89
New Jersey	30,570	81%	3,278	33,848	90%	855	2,971	8%	37,674	7.7%	33.4	7	2,897	$	641	952
New Mexico	3,210	89%	279	3,489	97%	121	0	0%	3,610	0.0%	0	0	0	NA		101
New York	91,042	73%	11,436	102,478	82%	18,672	3,132	3%	124,282	1.7%	10.9	10	2,119	$	861	1,123
North Carolina	19,637	78%	2,549	22,206	88%	699	2,201	9%	25,106	6.6%	18.1	5	1,666	$	481	400
North Dakota	1,857	67%	219	2,056	75%	504	165	6%	2,725	1.4%	18.7	1	126	$	476	112
Ohio	32,921	81%	1,140	34,061	84%	2,445	4,233	10%	40,739	3.7%	13.2	10	1,521	$	413	DNP
Oklahoma	4,700	68%	750	5,510	79%	397	1,046	15%	6,953	4.2%	8.1	2	294	$	525	492
Oregon	9,626	79%	2,113	11,739	97%	331	83	1%	12,153	0.3%	0.8	1	32	$	906	28
Pennsylvania	39,023	69%	12,779	50,894	92%	1,296	2,871	5%	54,971	2.3%	10.2	5	1,275	$	550	1685
Rhode Island	1,918	62%	973	2,891	93%	182	23	1%	3,096	0.0%	0	0	0	NA		93
South Carolina	14,876	80%	1,978	16,754	91%	885	841	5%	18,480	4.6%	18.8	3	841	$	320	165
South Dakota	2,017	65%	349	2,366	77%	559	166	5%	3,091	4.9%	18.7	1	159	$	447	158
Tennessee	7,269	80%	355	7,624	84%	781	656	7%	9,061	5.7%	8.2	3	512	$	262	930
Texas	18,314	63%	4,257	22,571	77%	625	6,041	21%	29,237	16.4%	19.7	13	4,789	$	288	DNP
Utah	3,950	76%	319	4,269	82%	150	770	15%	5,189	5.5%	8.6	1	235	$	433	121
Vermont	2,934	98%	72	3,006	100%	0	0	0%	3,006	0.0%	0	0	0	NA		25
Virginia	13,038	79%	1,449	14,487	88%	564	1,920	9%	16,471	7.9%	16.8	5	1,304	$	478	2523
Washington	17,478	89%	1,877	19,355	99%	178	113	1%	19,646	4.8%	14.3	5	938	$	551	383
West Virginia	3,943	85%	171	4,114	88%	500	47	1%	4,661	0.0%	0	0	0	NA		469
Wisconsin	11,937	66%	3,370	15,307	85%	1,768	946	5%	18,021	2.5%	8.1	2	455	$	677	223
Wyoming	1,269	59%	716	1,985	92%	97	82	4%	2,164	3.8%	15.4	1	62	$	618	45
United States	760,960	81%	73,713	834,673	89%	52,971	54,513	6%	942,157	3.7%	11.5	168	35,035	$	514	23,500
United States - Est.	789,028	78%	113,952	902,980	89%	53,424	57,462	6%	1,013,866							26,080

Source: Research and Training Center on Community Living

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Year of Data: 2008 | 2008 | 2008 | 2008 | 2008

State	Promoting Independence			Ensuring Community Involvement and Safety				
	Waivers that Can Promote Self-Determination			Quality Assurance			Abuse	
	Independence Plus Waivers	Other Self-Directed - 1115 or 1915(c) Waiver for ID/DD	Money Follows the Person - Award or Apply	Council on Quality and Leadership	National Core Indicators (HSRI)	Noteworthy State QA Initiatives	Protection and Advocacy Clients	% of all those served
Alabama				Yes	Yes		58	1%
Alaska						Yes	117	12%
Arizona		Yes			Yes		34	0%
Arkansas		Yes	Yes		Yes		734	15%
California	Yes	Yes	Yes		Yes	Yes	1,517	1%
Colorado	Yes	Yes		Yes		Yes	60	1%
Connecticut	Yes		Yes		Yes	Yes	15	0%
Delaware	Yes		Yes				26	1%
Dist. of Columbia			Yes				78	4%
Florida	Yes	Yes					180	0%
Georgia	Yes		Yes	Yes	Yes		96	1%
Hawaii			Yes		Yes		183	6%
Idaho	Yes						85	1%
Illinois			Yes	Yes	Yes		105	0%
Indiana			Yes	Yes	Yes		92	1%
Iowa			Yes	Yes			114	1%
Kansas			Yes	Yes			30	0%
Kentucky			Yes	Yes	Yes		69	1%
Louisiana	Yes	Yes	Yes	Yes	Yes		105	1%
Maine	Yes				Yes		166	4%
Maryland	Yes	Yes	Yes	Yes			73	1%
Massachusetts	Yes				Yes		136	0%
Michigan	Yes	Yes				Yes	59	0%
Minnesota		Yes		Yes		Yes	349	1%
Mississippi							162	3%
Missouri	Yes		Yes	Yes	Yes		143	1%
Montana	Yes						35	1%
Nebraska			Yes	Yes			91	2%
Nevada				Yes			117	2%
New Hampshire		Yes			Yes	Yes	48	2%
New Jersey	Yes	Yes	Yes	Yes	Yes		130	0%
New Mexico				Yes	Yes	Yes	259	7%
New York		Yes	Yes	Yes	Yes	Yes	38	0%
North Carolina	Yes		Yes	Yes	Yes		84	0%
North Dakota	Yes	Yes	Yes	Yes			40	1%
Ohio	Yes		Yes	Yes	Yes		640	1%
Oklahoma			Yes		Yes		533	5%
Oregon		Yes	Yes				51	0%
Pennsylvania			Yes	Yes	Yes	Yes	1,132	2%
Rhode Island							43	1%
South Carolina	Yes						74	0%
South Dakota				Yes	Yes		63	2%
Tennessee							76	1%
Texas			Yes	Yes	Yes		579	2%
Utah							270	3%
Vermont		Yes			Yes	Yes	68	2%
Virginia			Yes				86	1%
Washington			Yes		Yes		46	0%
West Virginia					Yes		156	3%
Wisconsin			Yes	Yes		Yes	88	0%
Wyoming					Yes	Yes	111	5%
United States	19	15	28	24	28	13	10,386	1%
United States - Est.								
Source	CMS	PAS Center	CMS & Mathematica	Council on Quality and Leadership	Human Services Research Institute	QualityMall.org	Administration on Developmental Disabilities	
Table/Page			MRDD	Orgs in ST		QA & QI	Outcomes	
Year of Data	2006	Nov-06	2007	2010	Jul-09	2010	2008	

Appendix I *Continued*

State	Keeping Families Together								
	Family Support				Cash Subsidy		Other Family Subsidy		
	Families	Spending	Spending per Family	Families Supported per 100k of Population	Families	Spending per Family	Families	Spending per Family	% Individuals Living in Family Home
Alabama	2,360	$ 648,389	$ 232	62	0	N/A	2,360	$ 232	56%
Alaska	1,516	$ 4,668,000	$ 3,079	228	1,516	$ 3,080	8	$ 15,000	8%
Arizona	18,361	$ 213,935,759	$ 11,652	309	573	$ 1,626	17,788	$ 11,968	86%
Arkansas	790	$ 578,107	$ 732	28	92	$ 1,555	698	$ 623	29%
California	81,096	$ 437,010,818	$ 5,389	224	0	N/A	81,096	$ 5,389	70%
Colorado	3,432	$ 6,235,187	$ 1,817	74	0	N/A	3,432	$ 1,817	75%
Connecticut	7,984	$ 45,121,284	$ 5,651	227	3,525	$ 951	4,459	$ 9,384	53%
Delaware	1,735	$ 1,667,775	$ 955	206	126	$ 1,856	1,735	$ 821	67%
Dist. of Columbia	0	$ -	$		0	N/A	0	N/A	34%
Florida	20,035	$ 321,925,639	$ 16,068	113	210	$ 2,255	19,825	$ 16,214	71%
Georgia	6,801	$ 23,243,497	$ 3,418	76	0	N/A	6,801	$ 3,418	69%
Hawaii	2,739	$ 31,276,613	$ 11,419	213	0	N/A	2,739	$ 11,419	66%
Idaho	709	$ 302,722	$ 427	50	0	N/A	709	$ 427	75%
Illinois	11,114	$ 62,531,939	$ 5,626	87	2,611	$ 13,815	8,503	$ 3,112	37%
Indiana	4,139	$ 28,515,681	$ 6,905	66	0	N/A	4,139	$ 6,905	30%
Iowa	2,002	$ 30,565,329	$ 15,267	67	378	$ 4,239	1,624	$ 17,834	37%
Kansas	3,549	$ 43,293,821	$ 12,198	123	1,418	$ 2,402	2,131	$ 18,712	32%
Kentucky	1,735	$ 3,324,247	$ 1,916	42	0	N/A	1,735	$ 1,916	38%
Louisiana	8,211	$ 118,768,849	$ 14,465	181	1,705	$ 2,738	6,506	$ 17,543	59%
Maine	545	$ 1,100,000	$ 2,018	41	545	$ 1,101	545	$ 917	14%
Maryland	7,846	$ 38,235,667	$ 4,873	139	0	N/A	7,846	$ 4,873	24%
Massachusetts	14,114	$ 38,711,810	$ 2,743	216	0	N/A	14,114	$ 2,743	66%
Michigan	11,539	$ 54,108,014	$ 4,689	113	6,722	$ 2,629	4,817	$ 7,576	57%
Minnesota	8,183	$ 182,768,481	$ 22,335	157	2,346	$ 5,709	5,837	$ 29,018	50%
Mississippi	3,052	$ 20,643,970	$ 5,095	139	0	N/A	3,052	$ 5,095	33%
Missouri	7,463	$ 13,534,785	$ 1,814	129	0	N/A	7,463	$ 1,814	55%
Montana	2,885	$ 11,066,985	$ 3,836	306	0	N/A	2,885	$ 3,836	56%
Nebraska	566	$ 4,634,959	$ 8,189	32	0	N/A	566	$ 8,189	13%
Nevada	2,451	$ 6,640,537	$ 2,709	103	454	$ 4,136	1,997	$ 2,385	66%
New Hampshire	4,605	$ 6,881,345	$ 1,494	348	0	N/A	4,605	$ 1,494	23%
New Jersey	20,013	$ 59,123,973	$ 2,954	228	7,851	$ 1,529	12,162	$ 3,874	71%
New Mexico	10,262	$ 34,058,910	$ 3,319	537	164	$ 3,468	10,098	$ 3,317	36%
New York	41,571	$ 56,317,890	$ 1,355	216	0	N/A	41,571	$ 1,355	63%
North Carolina	4,255	$ 27,304,416	$ 6,417	49	0	N/A	4,255	$ 6,417	58%
North Dakota	601	$ 5,607,743	$ 9,282	95	142	$ 4,279	462	$ 10,823	26%
Ohio	12,067	$ 10,482,428	$ 869	105	0	N/A	12,067	$ 869	47%
Oklahoma	4,615	$ 43,682,678	$ 9,465	131	2,077	$ 2,394	2,538	$ 15,252	39%
Oregon	1,275	$ 4,554,818	$ 3,572	35	0	N/A	1,275	$ 3,572	53%
Pennsylvania	22,990	$ 64,982,837	$ 2,827	185	0	N/A	22,990	$ 2,827	55%
Rhode Island	753	$ 10,343,464	$ 13,736	69	50	$ 3,402	703	$ 14,471	28%
South Carolina	8,959	$ 34,006,902	$ 3,850	211	1,151	$ 2,867	7,838	$ 4,003	74%
South Dakota	2,019	$ 3,161,365	$ 1,566	261	0	N/A	2,019	$ 1,566	26%
Tennessee	6,283	$ 11,565,100	$ 1,840	105	2,018	N/A	4,265	$ 1,796	40%
Texas	22,980	$ 50,174,833	$ 2,183	100	2,674	$ 1,870	20,306	$ 2,225	17%
Utah	1,268	$ 14,546,828	$ 11,474	52	5	$ 5,181	1,263	$ 11,507	39%
Vermont	1,354	$ 15,819,422	$ 11,683	214	0	N/A	1,354	$ 11,737	51%
Virginia	2,917	$ 2,480,413	$ 850	38	0	N/A	2,917	$ 850	58%
Washington	7,292	$ 48,177,202	$ 6,607	117	2,513	$ 2,019	6,392	$ 6,743	69%
West Virginia	2,232	$ 20,057,784	$ 8,986	123	0	N/A	2,232	$ 8,986	59%
Wisconsin	11,064	$ 23,235,497	$ 2,100	199	0	N/A	11,064	$ 2,100	44%
Wyoming	1,010	$ 13,037,112	$ 12,908	199	0	N/A	1,010	$ 12,908	33%
United States	428,803	$ 2,305,149,428	$ 5,376	144	40,866	$ 3,046	389,684	$ 5,596	62%
United States - Est.									

Source: Coleman Institute

Table/Page: T. 12, P. 47

Year of Data: 2006

State	Promoting Productivity											
	Medicaid Buy-In		Supported or Competitive Employment				Voc Rehab					
	Has?	Enrollment - 12/08	Participants	Utilization	Spending	%	Total Number in Competitive Employment	per 100K of population	% VR Wages to State Aver	Mean Weekly Hours Worked
Alabama			245	5	$ 2,104,982	5%	7,554	163	50%	34
Alaska	Yes	239	316	48	$ 3,812,415	35%	568	86	65%	33
Arizona	Yes	1044	1,158	19	$ 5,738,045	14%	1,925	30	56%	33
Arkansas	Yes	117	130	5	$ 368,882	2%	2,447	87	64%	36
California	Yes	4,103	8,505	25	$ 62,219,630	13%	13,886	38	49%	32
Colorado			1,982	43	DNF	35%	2,617	54	51%	31
Connecticut	Yes	4,940	4,061	116	$ 61,035,054	51%	1,345	42	67%	31
Delaware			373	44	$ 4,461,605	26%	905	105	43%	33
Dist. of Columbia			161	28	$ 3,009,473	10%	576	98	33%	38
Florida			3,456	20	$ 9,009,717	22%	12,411	69	63%	34
Georgia	Yes		3,202	36	$ 13,897,915	26%	4,668	49	50%	34
Hawaii			114	9	$ 496,800	8%	589	48	62%	31
Idaho	Yes		898	63	$ 3,356,575	15%	2,083	138	62%	32
Illinois	Yes	647	3,518	28	$ 19,662,872	13%	5,640	45	42%	30
Indiana	Yes	4,609	2,317	37	$ 13,062,679	22%	4,393	70	56%	32
Iowa	Yes	12,376	2,825	95	$ 5,617,855	28%	2,146	72	64%	32
Kansas	Yes	1680	408	15	$ 1,963,000	10%	1,645	61	51%	30
Kentucky	Yes		1,164	28	$ 2,883,581	21%	4,949	117	60%	34
Louisiana	Yes	1932	1,641	56	$ 8,144,698	35%	2,315	64	82%	36
Maine	Yes	850	1,004	76	$ 5,442,378	21%	730	56	64%	28
Maryland	Yes	539	3,564	63	$ 47,167,713	39%	2,290	41	45%	31
Massachusetts	Yes	10,476	5,769	88	$ 76,990,892	44%	3,446	54	46%	28
Michigan	Yes	1141	4,554	44	$ 25,120,550	24%	7,543	76	52%	32
Minnesota	Yes	7,205	2,946	57	$ 13,161,136	15%	2,620	51	49%	29
Mississippi	Yes		400	14	$ 1,968,841	15%	4,353	157	73%	36
Missouri	Yes		368	6	$ 1,917,241	9%	4,365	75	51%	31
Montana	Yes		235	25	$ 1,744,979	14%	913	96	66%	30
Nebraska	Yes	169	1,018	58	$ 7,625,561	29%	1,543	88	57%	33
Nevada	Yes	29	286	12	$ 2,874,686	16%	1,060	41	53%	34
New Hampshire	Yes	1,591	324	25	$ 4,507,016	29%	1,219	93	54%	29
New Jersey	Yes	3,232	1,363	16	$ 10,643,132	14%	4,385	51	44%	32
New Mexico	Yes	819	1,224	64	$ 8,533,696	34%	1,692	87	64%	32
New York	Yes		8,263	43	$ 45,547,000	12%	13,256	69	36%	31
North Carolina	Yes	50	1,853	21	$ 9,209,328	19%	6,442	70	48%	32
North Dakota	Yes	526	306	38	$ 2,121,796	15%	903	146	66%	35
Ohio	Yes	0	9,528	83	$ 32,846,005	22%	9,656	85	66%	33
Oklahoma			3,029	86	$ 25,908,414	77%	2,246	64	61%	36
Oregon	Yes	1069	1,264	35	$ 15,388,300	34%	2,604	69	58%	31
Pennsylvania	Yes	9,002	9,418	75	$ 34,587,914	38%	9,221	75	56%	33
Rhode Island	Yes	27	622	57	$ 3,749,529	20%	750	72	52%	28
South Carolina	Yes		447	20	$ 5,852,903	12%	8,663	196	59%	36
South Dakota	Yes	104	675	87	$ 4,827,779	30%	861	109	56%	29
Tennessee			4,211	29	$ 7,443,860	20%	2,484	41	55%	33
Texas	Yes	51	2,956	13	$ 14,440,392	20%	11,724	49	49%	35
Utah	Yes	639	735	30	$ 5,196,124	32%	3,310	122	64%	35
Vermont	Yes	624	831	1M	$ 7,212,384	48%	1,523	249	58%	29
Virginia	Yes	32	2,460	32	$ 21,670,027	23%	4,912	63	42%	33
Washington	Yes	1290	4,130	66	$ 26,376,608	61%	2,357	36	50%	28
West Virginia	Yes	503	417	23	$ 1,912,397	11%	1,773	98	68%	35
Wisconsin	Yes	13,150	2,736	49	$ 16,450,726	16%	3,641	66	59%	29
Wyoming	Yes	107	250	39	$ 2,125,280	21%	699	134	58%	32
United States	43	83,424	110,539	37	$ 708,872,399	21%	195,626	65	56%	
United States - Est.		160,000								
Source	National Consortium for Health Systems Development		Coleman Institute				US Dept of Education, Office of Special Education and Rehabilitation Services			
Table/Page			T. 11, P. 41							
Year of Data	Dec-08		2006				2008		2005	

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Appendix I *Continued*

State	Reaching Those in Need								
	Waiting Lists					Prevalence		Individuals with ID/DD served per 100k of population	Ratio of Prevalence to Individuals Served
	Waiting List for Residential Services	% Growth in Residential Services Required to Meet Waiting List	Waiting List - ID/DD HCBS - Kaiser	% Growth in HCBS Services Required to Meet Waiting List	Waiting List - Average	% Children with Mental Disability	% Adults with Mental Disability		
Alabama	439	12%	NA	NA	12%	6.1%	6.8%	151	2%
Alaska	618	68%	1,500	145%	106%	4.3%	5.2%	150	3%
Arizona	80	2%	NA	NA	2%	4.6%	4.8%	454	10%
Arkansas	870	24%	876	26%	25%	7.6%	7.3%	180	2%
California	0	0%	NA	NA	0%	3.6%	4.1%	504	12%
Colorado	1,390	30%	NA	NA	30%	3.8%	4.0%	172	4%
Connecticut	560	8%	1,730	22%	15%	4.4%	3.7%	422	11%
Delaware	180	18%	NA	NA	18%	6.0%	4.3%	358	8%
Dist. of Columbia	0	0%	NA	NA	0%	6.8%	4.5%	337	8%
Florida	4,683	31%	22,639	73%	52%	5.0%	4.6%	284	6%
Georgia	6,392	129%	10,364	101%	115%	4.3%	4.7%	171	4%
Hawaii	0	0%	NA	NA	0%	3.3%	3.5%	266	8%
Idaho	0	0%	NA	NA	0%	5.0%	5.1%	1,074	21%
Illinois	10,446	49%	NA	NA	49%	4.6%	3.7%	268	7%
Indiana	17,919	168%	33,753	334%	251%	5.5%	4.9%	244	5%
Iowa	99	1%	1,646	13%	7%	5.5%	4.8%	472	10%
Kansas	1,163	21%	1,631	22%	22%	5.1%	4.5%	307	7%
Kentucky	293	7%	2,753	89%	48%	7.0%	7.5%	149	2%
Louisiana	DNF	DNF	9,151	133%	133%	6.6%	6.5%	411	7%
Maine	69	2%	98	3%	3%	8.7%	6.8%	291	4%
Maryland	10,741	146%	NA	NA	146%	5.2%	3.7%	376	5%
Massachusetts	0	0%	NA	NA	0%	5.8%	4.4%	502	11%
Michigan	45	0%	NA	NA	0%	6.4%	5.6%	308	5%
Minnesota	2,641	26%	NA	NA	26%	4.9%	4.0%	312	13%
Mississippi	DNF	DNF	NA	NA	DNF	6.1	7.5%	173	2%
Missouri	469	7%	NA	NA	7%	5.9%	5.8%	257	4%
Montana	499	26%	1,372	61%	43%	5.5%	5.4%	149	8%
Nebraska	1,914	59%	NA	NA	59%	5.1%	3.8%	210	6%
Nevada	541	33%	540	36%	35%	3.2%	3.4%	184	5%
New Hampshire	35	2%	NA	NA	2%	6.5%	4.5%	181	4%
New Jersey	4,639	40%	NA	NA	40%	4.2%	3.3%	442	13%
New Mexico	4,350	198%	1,141	30%	169%	4.5%	5.6%	185	3%
New York	4,291	9%	NA	NA	9%	4.8%	4.1%	648	16%
North Carolina	1,355	13%	NA	NA	13%	5.8%	5.3%	275	5%
North Dakota	DNF	DNF	NA	NA	0%	5.2%	3.8%	141	12%
Ohio	DNF	DNF	30,670	294%	294%	6.4%	5.4%	360	7%
Oklahoma	4,660	96%	12,350	225%	160%	5.7%	6.4%	197	3%
Oregon	3,260	36%	3,528	33%	45%	5.7%	5.5%	321	6%
Pennsylvania	2,974	8%	20,460	73%	41%	6.1%	5.0%	449	9%
Rhode Island	0	0%	NA	NA	0%	6.6%	5.4%	298	6%
South Carolina	1,954	46%	1,296	24%	32%	4.9%	5.7%	418	7%
South Dakota	3	0%	23	1%	0%	4.1%	4.3%	391	9%
Tennessee	1,572	29%	2,516	31%	30%	5.9%	6.7%	148	2%
Texas	DNF	DNF	38,449	337%	337%	5.1%	4.5%	122	3%
Utah	190	6%	1,054	31%	23%	3.7%	4.3%	192	4%
Vermont	0	0%	NA	NA	0%	7.6%	5.6%	491	9%
Virginia	5,976	74%	8,334	107%	90%	5.2%	5.2%	216	6%
Washington	DNF	DNF	829	9%	9%	5.6%	5.6%	304	5%
West Virginia	137	7%	303	8%	7%	9.5%	8.5%	260	3%
Wisconsin	3,632	36%	3,930	30%	33%	5.6%	4.2%	327	8%
Wyoming	55	4%	170	5%	5%	5.6%	5.2%	416	8%
United States	98,622	23%	253,306	49%	36%	5.1%	4.8%	343	7%
United States - Est.	114,916	26%							

Source	Research and Training Center on Community Living	Kaiser Family Foundation		US Census Bureau, ACS		
Table/Page	T. 2.5, P. 71	Waiting List		T. B18005		Calculated
Year of Data	2008	2008		2005-2007		

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State	Serving at a Reasonable Cost											
	ICF-MR			HCBS			Other I/DD Community Spending			Overall Spending		
	Total Expenditures-2008	Aver. Residents	Aver. Cost per Resident	Total Expenditures-2008	Aver. Residents	Aver. Cost per Resident	Total Community - 2006	Total Non-HCBS Community Expenditures (2006 total community-2006 HCBS)	% of total HD/DD Spending	HD/DD Spending per 1k personal income	HD/DD Spending per capita
Alabama	$ 36,179,938	240	$ 150,750	$ 267,362,504	5,350	$ 49,967	$ 267,716,930	$ 18,621,983	6%	$ 2.13	$ 69
Alaska	$ -	0	$ -	$ 76,806,107	1036	$ 74,137	$ 95,262,803	$ 28,379,700	27%	$ 3.79	$ 160
Arizona	$ 15,370,880	197	$ 78,025	$ 649,467,289	19,610	$ 31,589	$ 611,738,095	$ 134,974,195	18%	$ 3.36	$ 129
Arkansas	$ 147,860,176	1,609	$ 91,924	$ 97,104,703	3,351	$ 28,978	$ 276,787,397	$ 195,656,620	44%	$ 5.23	$ 156
California	$ 610,506,432	9,489	$ 64,342	$ 1,709,987,080	74,446	$ 22,966	$ 4,090,348,336	$ 2,752,106,336	34%	$ 3.48	$ 139
Colorado	$ 22,289,078	127	$ 176,198	$ 311,354,728	7,212	$ 43,175	$ 412,706,622	$ 159,613,942	32%	$ 2.37	$ 101
Connecticut	$ 236,997,479	1,132	$ 209,362	$ 475,540,000	7,099	$ 66,978	$ 1,040,106,923	$ 619,642,504	47%	$ 7.66	$ 386
Delaware	$ 29,814,083	140	$ 213,864	$ 83,576,384	803	$ 104,145	$ 117,237,222	$ 48,323,645	30%	$ 4.47	$ 188
Dist. of Columbia	$ 82,083,747	587	$ 139,955	$ 54,469,781	1147	$ 47,510	$ 199,270,454	$ 181,737,921	57%	$ 6.14	$ 343
Florida	$ 338,699,599	3,167	$ 106,947	$ 945,063,427	31,182	$ 30,308	$ 1,166,409,741	$ 405,018,018	24%	$ 2.19	$ 94
Georgia	$ 103,532,026	1,009	$ 102,609	$ 581,689,903	10,235	$ 57,256	$ 398,712,442	$ 144,127,891	23%	$ 1.96	$ 66
Hawaii	$ 9,027,307	82	$ 110,089	$ 104,462,436	2,566	$ 41,685	$ 133,115,676	$ 48,115,676	30%	$ 2.93	$ 131
Idaho	$ 62,099,912	539	$ 115,046	$ 68,119,607	2,124	$ 32,071	$ 284,256,401	$ 181,869,359	54%	$ 5.40	$ 187
Illinois	$ 659,781,238	9,118	$ 72,360	$ 461,700,080	13,648	$ 33,829	$ 972,605,586	$ 571,181,456	34%	$ 3.17	$ 134
Indiana	$ 304,804,854	4,056	$ 75,158	$ 443,949,814	10,112	$ 43,905	$ 778,788,798	$ 385,252,718	34%	$ 4.41	$ 181
Iowa	$ 288,092,999	2,129	$ 135,350	$ 303,613,019	12,978	$ 23,394	$ 438,579,354	$ 182,597,950	24%	$ 6.84	$ 260
Kansas	$ 63,193,291	592	$ 106,836	$ 274,843,524	5,281	$ 37,732	$ 361,951,956	$ 132,328,712	28%	$ 4.43	$ 174
Kentucky	$ 111,177,567	581	$ 191,520	$ 226,531,475	3,097	$ 73,145	$ 208,170,944	$ 35,548,307	10%	$ 2.80	$ 88
Louisiana	$ 180,641,734	6,190	$ 93,657	$ 322,451,576	9,875	$ 46,906	$ 472,558,648	$ 228,227,046	22%	$ 6.61	$ 242
Maine	$ 65,103,906	266	$ 244,748	$ 248,956,942	2,824	$ 88,158	$ 525,504,979	$ 104,387,141	25%	$ 8.00	$ 319
Maryland	$ 55,146,161	308	$ 179,344	$ 517,577,519	10,563	$ 49,001	$ 629,823,463	$ 180,187,051	25%	$ 2.93	$ 136
Massachusetts	$ 234,838,072	927	$ 253,468	$ 583,547,891	11,672	$ 49,998	$ 1,160,808,876	$ 489,721,617	37%	$ 4.78	$ 205
Michigan	$ 16,728,240	116	$ 144,209	$ 381,731,216	7,851	$ 48,625	$ 1,126,603,882	$ 781,183,032	66%	$ 3.53	$ 120
Minnesota	$ 178,358,058	2,173	$ 82,098	$ 925,198,681	14,578	$ 63,465	$ 1,308,592,108	$ 659,499,082	37%	$ 6.91	$ 342
Mississippi	$ 285,877,979	2,612	$ 109,448	$ 38,013,037	1,977	$ 19,233	$ 120,778,501	$ 85,319,563	21%	$ 4.31	$ 141
Missouri	$ 129,144,915	993	$ 130,121	$ 392,751,282	8,563	$ 45,869	$ 525,709,812	$ 215,142,724	29%	$ 3.67	$ 127
Montana	$ 13,044,028	55	$ 239,340	$ 78,291,028	2,255	$ 34,714	$ 98,938,286	$ 35,951,550	28%	$ 4.01	$ 133
Nebraska	$ 68,217,464	546	$ 124,940	$ 147,500,141	3,447	$ 42,797	$ 188,013,079	$ 61,087,283	22%	$ 4.29	$ 157
Nevada	$ 18,993,803	112	$ 170,348	$ 65,416,000	1,382	$ 33,156	$ 106,449,850	$ 54,976,552	39%	$ 1.34	$ 54
New Hampshire	$ 3,805,371	25	$ 120,215	$ 155,729,108	3,460	$ 45,015	$ 185,205,628	$ 53,435,496	25%	$ 3.72	$ 163
New Jersey	$ 633,129,543	2,921	$ 216,785	$ 595,859,000	9,986	$ 59,661	$ 906,522,206	$ 470,012,206	29%	$ 3.85	$ 189
New Mexico	$ 23,171,893	182	$ 127,669	$ 267,982,051	3,744	$ 71,576	$ 318,088,292	$ 74,389,457	20%	$ 5.67	$ 187
New York	$ 2,675,893,359	7,874	$ 339,746	$ 3,825,876,515	57,481	$ 66,560	$ 5,647,227,656	$ 2,459,350,904	27%	$ 7.93	$ 467
North Carolina	$ 461,931,336	4,150	$ 111,309	$ 457,750,000	9,505	$ 48,161	$ 879,328,436	$ 609,861,502	40%	$ 4.36	$ 167
North Dakota	$ 70,722,378	589	$ 120,073	$ 77,570,212	3,590	$ 21,571	$ 126,553,829	$ 61,925,098	29%	$ 7.30	$ 340
Ohio	$ 691,974,985	6,543	$ 105,766	$ 813,795,687	17,234	$ 47,220	$ 1,908,330,121	$ 1,307,626,250	46%	$ 6.22	$ 248
Oklahoma	$ 126,915,256	1,558	$ 81,462	$ 267,877,651	5,428	$ 49,351	$ 347,960,715	$ 119,019,862	23%	$ 4.03	$ 146
Oregon	$ 12,240,527	37	$ 335,357	$ 438,537,585	10,583	$ 41,438	$ 532,097,917	$ 167,578,806	27%	$ 4.65	$ 164
Pennsylvania	$ 578,710,845	3,845	$ 150,569	$ 1,224,627,946	27,938	$ 43,803	$ 1,981,698,388	$ 878,527,134	33%	$ 5.51	$ 219
Rhode Island	$ 8,737,809	41	$ 215,748	$ 251,288,605	3,172	$ 79,233	$ 275,358,295	$ 44,543,957	15%	$ 7.15	$ 293
South Carolina	$ 154,255,458	1,546	$ 99,777	$ 215,293,000	5,319	$ 39,343	$ 369,031,116	$ 199,031,118	35%	$ 5.81	$ 128
South Dakota	$ 22,366,350	154	$ 145,237	$ 86,921,676	2,671	$ 32,543	$ 103,274,098	$ 26,659,683	20%	$ 5.00	$ 172
Tennessee	$ 241,018,741	1,202	$ 200,598	$ 553,899,151	7,356	$ 75,304	$ 621,831,279	$ 159,925,405	17%	$ 4.35	$ 156
Texas	$ 890,443,032	11,312	$ 78,717	$ 698,358,386	17,355	$ 40,240	$ 1,030,757,221	$ 559,206,601	26%	$ 2.02	$ 90
Utah	$ 69,802,718	796	$ 87,747	$ 126,595,282	4,033	$ 31,394	$ 188,616,950	$ 54,183,560	22%	$ 2.09	$ 93
Vermont	$ 979,009	6	$ 163,167	$ 121,270,835	2,235	$ 54,260	$ 120,115,919	$ 17,870,416	13%	$ 5.72	$ 229
Virginia	$ 273,332,795	1,656	$ 165,100	$ 443,732,702	7,815	$ 56,783	$ 530,976,174	$ 196,089,359	21%	$ 2.58	$ 120
Washington	$ 150,434,481	764	$ 197,033	$ 352,580,599	9,261	$ 38,068	$ 614,982,233	$ 315,380,011	39%	$ 3.33	$ 127
West Virginia	$ 60,128,913	477	$ 126,056	$ 222,697,603	3,872	$ 57,512	$ 234,281,003	$ 66,938,619	19%	$ 4.86	$ 195
Wisconsin	$ 128,508,098	1,003	$ 128,188	$ 504,234,866	12,955	$ 38,924	$ 765,173,254	$ 293,841,157	32%	$ 5.12	$ 168
Wyoming	$ 18,312,242	88	$ 207,285	$ 93,970,241	2,081	$ 45,167	$ 95,093,143	$ 15,858,077	12%	$ 5.81	$ 240
United States	$ 11,962,854,423	94,846	$ 126,130	$ 22,310,392,935	513,301	$ 43,464	$ 35,592,522,143	$ 17,220,293,554	33%	$ 4.12	$ 171
United States - Est.											
Source	Research and Training Center on Community Living						Coleman Institute				
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Year of Data	2008						2006			2006	

Report Data Sources

Organization	Link for Data Referenced
Council on Quality and Leadership	map.c-q-l.org/about
Research and Training Center on Community Living	rtc.umn.edu/misc/pubcount.asp?publicationid=186
Administration on Children and Families	www.acf.hhs.gov/programs/add/reports/Clients06.html
Centers for Medicare and Medicaid Services	www.cms.hhs.gov
Coleman Institute	www.colemaninstitute.org/
Department of Education	www.ed.gov/rschstat/eval/rehab/2005-tables
Human Services Research Institute	www.hsri.org/nci/
PAS Center	www.pascenter.org/demo_waivers/demoWaiverTable_2006.php
Kaiser Family Foundation	www.statehealthfacts.org
US Census Bureau	www.Census.gov
Quality Mall	www.QualityMall.org

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